

Teaching Materials and Services

IILEP: Guidelines for the social and economic rehabilitation of people affected by leprosy

This is a 61-page publication, strongly bound A4 format, published by the *International Federation of Anti-Leprosy Associations* (IILEP) in 1999, having been commissioned by the Medico-Social Commission in response to requests from IILEP members. The main chapter headings are: Understanding Social and Economic Rehabilitation; Managing Social and Economic Rehabilitation; Managing and Supporting Field Activities; Field Experience; Assessing Impact; Case Studies, Discussion Material and Getting Started.

This invaluable document should surely be studied by all who work with people affected by leprosy and the authors are to be congratulated on the production of a clearly written and definitive account of an aspect of this disease which, unfortunately, is still in need of greater attention. The *References and Resources* in the final pages read as follow:

References

- ¹ Arole M and Arole R, *Jamkhed: A Comprehensive Rural Health Project*, Bombay, 1994.
- ² Chambers R, *Whose Reality Counts? Putting the First Last*, Intermediate Technology Publications, London, 1997.
- ³ Mikkelsen B, *Methods for Development Work and Research: A Guide for Practitioners*, Sage Publications, London, 1995.
- ⁴ Gosling L, *Toolkits, Save the Children UK*, London, 1995. (Chapter 5 describes the Log Frame planning method, and there is a great deal of other relevant material.)
- ⁵ Intrac, *A Tool for Project Management and People-driven Development: Proceedings of a Workshop on LFA and OOIP*, Intrac, 1994.
- ⁶ Eade D, Williams S, *Oxfam Handbook of Development and Relief*, Oxfam, UK, 1995.
- ⁷ IDEA, *Quest for Dignity: Personal Victories Over Leprosy/Hansen's Disease*, IDEA, Franklin Press, USA, 1997.
- ⁸ Chambers R, *Rural Development: Putting the Last First*, Longman, UK, 1983.
- ⁹ Moris J and Copestake J, *Qualitative Enquiry for Rural Development: A Review*, Intermediate Technology Publications, London, 1993.
- ¹⁰ Grandin B, *Wealth Ranking in Smallholder Communities: A Field Manual*, Intermediate Technology Publications, London, 1988.

Recommended reading

The social aspects of leprosy

Devadas Jayaraj T. and Saleem H. M. (eds), *Social Work in Leprosy Eradication*, Indian Leprosy Foundation (4 Gajapathy Street, Shenoyanagar, Madras 600 030, Tamil Nadu, India), 1990.

Frist T, "Don't Treat Me Like I Have Leprosy!" *A Guide to Overcoming Prejudice and Segregation*, TALMILEP, London, 1996.

Kaufmann A, Senkenesh GM and Neville J, *The Social Dimension of Leprosy*, TALMILEP, London, 1992.

Challenging stigma

- Allred N, Benbow C, Currie H, Nash J, Ransom B, Saunderson P (eds), *The End to Isolation: A Handbook for the Social and Economic Reintegration of Persons Affected by Leprosy*, ALERT and ILO, Ethiopia, 1999.
- Coleridge P, *Disability, Liberation and Development*, Oxfam, UK, 1993.
- Gokhale SD and Sohoni N (eds), *The Human Face of Leprosy*, Ameya Prakashan, Pune, India, 1999.
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Health care and rehabilitation for people with disabilities

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- Healthlink Worldwide, *Key Organisations Working in Primary Health Care and Rehabilitation*, UK, 1996.
- Healthlink Worldwide, *Essential CBR Information Resources, an international listing of publications in CBR published by Healthlink Worldwide*, UK, 1996.
- Healthlink Worldwide, *CBR News*, an international newsletter on CBR and the concerns of people with disabilities, published three times a year.
- ILO, *Listen to the People: A Guide for Planners of Disability Programmes*, Geneva, 1994.
- ILO, UNESCO and WHO, *Community-based Rehabilitation for and with People with Disabilities*, Joint position paper, 1994.
- O'Toole B and McConkey R (eds), *Innovations in Developing Countries for People with Disabilities*, AIFO and Lisieux Hall (Whittle-le-Woods, Chorley, Lancashire PR6 7DX, UK), 1995.
- WHO, *Towards a Common Language for Disablements: ICIDH*, Geneva, 1998.
- WHO, *Disability Prevention and Rehabilitation in Primary Health Care: A Guide for District Health and Rehabilitation Managers*, WHO, Geneva, 1995.

Development issues

- Chambers R, *Rural Development: Putting the Last First*, Longman, UK, 1983.
- Feuerstein MT, *Partners in Evaluation*, Macmillan, London, 1986.
- Freire, P, *Pedagogy of the Oppressed*, Seabury Press, New York, 1970.
- Hope A, Timmel S, *Training for Transformation: A Handbook for Community Workers*, Mambo Press, Zimbabwe, revised 1995.
- Most Significant Changes in People's Participatory Rural Development Programme, Christian Community for Development in Bangladesh (PO Box 367, Dhaka, Bangladesh), 1996.

Gender

- Moser C, *Gender Planning and Development*, Routledge, UK, 1993.
- Williams S (ed), Seed J, Mwau A, *The Oxfam Gender Training Manual*, Oxfam, UK, 1995. (Many other publications on gender are also available from Oxfam.)

Management

- Gosling L, Tookits, *Save the Children UK*, London, 1995. (Chapter 5 describes the Log Frame planning method, and there is a great deal of other relevant material.)
- Intrac, *A Tool for Project Management and People-driven Development: Proceedings of a Workshop on LFA and OOIP*, Intrac, 1994.

Special needs of children

- Werner D, *Disabled Village Children*, Hesperian Foundation, US, 1994.
- Werner, D, *Nothing About Us Without Us*, Hesperian Foundation, US, 1998.

Methodology

- Eade D, Williams S, *Oxfam Handbook of Development and Relief*, Oxfam, UK, 1995.

- Grandin B, *Wealth Ranking in Smallholder Communities: A Field Manual*, Intermediate Technology Publications, London, 1988.
- Marsden D and Oakley P, *Evaluating Social Development Projects, Oxfam Development Guidelines No 5*, Oxfam, UK, 1990.
- Pratt B and Loizos P, *Choosing Research Methods: Data Collection for Development Workers, Oxfam Development Guidelines No 7*, Oxfam, UK, 1992.
- Rubin F, *A Basic Guide to Evaluation for Development Workers*, Oxfam, UK, 1995.
- Strauss B and Corbin J, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, Sage Publications, London, 1990.

Income generation

- Hurley D, *Income Generation for the Urban Poor, Development Guidelines No 4*, Oxfam, UK, 1990.
- Karlsson L, *How to Start a Small Business: A Manual for Community Workers Assisting People with Disabilities, Vocational Rehabilitation Branch*, ILO, Geneva, 1992.

Resources

The following publishers and organizations produce materials relevant to SER.

Leprosy organizations

ILEP—the International Federation of Anti-Leprosy Associations supplies and produces useful materials through its Medico-Social Commission and through TALMILEP. The Federation also co-ordinates the work of major NGOs working in leprosy and related areas. ILEP, 234 Blythe Road, London W14 0HJ, UK.

e-mail: ilep@ilep.org.uk. Website: <http://www.ilep.org.uk>

INFOLEP—a service supported by Netherlands Leprosy Relief offers an information service on printed materials on leprosy and manages a database of available materials—this is accessible on the Internet. Infolep, Postbus 95005, NL – 1090 HA Amsterdam, The Netherlands. e-mail: infolep@antenna.nl, Web site: <http://infolep.antenna.nl>

TLM International (Partners magazine for paramedical workers in leprosy) 80 Windmill Road, Brentford, Middlesex TW8 0QH, UK.

Social Science and Leprosy Network—a Web-based discussion group; to join the group e-mail Jeanette.Hyland@utas.edu.au

General health and development

Healthlink Worldwide (formerly AHRTAG) is committed to strengthening primary health care and community-based rehabilitation in the South; Cityside, 1st Floor, 40 Adler St, London E1 1EE.

e-mail: info@healthlink.org.uk, Web site: <http://www.healthlink.org.uk>

Intermediate Technology Publications Ltd, 103–105 Southampton Row, London WC1B 4HH, UK.

Oxfam Publishing, 274 Banbury Road, Oxford OX2 7DZ, UK.

World Health Organisation Publications, 1211 Geneva 27, Switzerland. Web site: <http://www.who.int>

TALC – Teaching-aids at Low Cost, PO Box 49, St Albans, Hertfordshire AL1 4AX, UK e-mail: talcuk@btinternet.com

Action Aid India (quarterly newsletter Disability News), Web site: <http://www.actionaidindia.com>

Tearfund (Footsteps, a quarterly publication on health and development issues), 100 Church Road, Teddington, Middx TW11 8QE, UK.

The Institute of Child Health, CBR Resource Centre, London. Web site: <http://www.ich.ucl.ac.uk/library/cbr.htm>

Advocacy organizations for people affected by leprosy

Associations for people affected by leprosy have been formed in several countries and take a variety of forms. In some organizations, membership is limited to people affected by leprosy; in others, it is open to people with other disabilities and other interested members of the community at large.

IDEA – the International Association for Integration, Dignity and Economic Advancement

This is an international organization for people affected by leprosy. There are branches in several countries providing an international network of support. Membership of IDEA is open to all interested persons. Contact addresses for IDEA representatives are as follows:

Dr P. K. Gopal, President, International Relations, IDEA, 58 Selvam Nagar, PO Box 912, Collectorate PO, Erode, 638 011, India. e-mail: ideaind@vsnl.com

Ms Anwei Law, International Project Co-ordinator, IDEA, PO Box 133, Oak Hill, WV 25901, USA. email: ideausa@inetone.net

National organizations for people with disabilities exist in Japan, Ethiopia, Brazil, Nigeria and elsewhere. Contact details are available from IDEA.

The International Leprosy Union—ILU is a union of non-governmental organizations and individuals. The Union supports field projects and also works in advocacy. Contact: Dr S. D. Gokhale, International Leprosy Union, Gurutrayeri Building, 1779–1784, Sadashiv Peth, Pune 411 030, India.

Training centres

The following organizations and centres offer training courses in SER or related subjects:

International Nepal Fellowship/Release, Nepal, c/o Mr Siegfried Beecken, SER Co-ordinator, INF Release Project, PO Box 28, Pokhara, Nepal. e-mail: pfr@inf.wlink.com.np

German Leprosy Relief Association (GLRA), India, c/o Mr Srinivasan, Co-ordinator, GLRA, 4 Gajapathy Street, Shenoyanagar, Chennai, 600 030, South India. e-mail: glra@md2.vsnl.net.in

Danish Bangladesh Leprosy Mission (DBLM), PO Box 3, Nilphamari, Bangladesh.

St Francis Leprosy Centre, Buluba, PO Box 1059, Jinja, Uganda.

Action Aid India, Web site: <http://www.actionaidindia.com>

COMBRA, PO Box 9744, Kampala, Uganda.

Marie Adelaide Leprosy Centre, PO Box 8666, Karachi 74400, Pakistan.

ILEP produces an annual Catalogue of Training Courses some of which offer training in SER.

Further enquiries: ILEP, 234 Blythe Road, London W14 0MJ, United Kingdom.

Fax: +44 (0)20 7371 1621.

E-mail: ilep@ilep.org.uk

Web: www.ilep.org.uk

The International Leprosy Association Global Project on the History of Leprosy: appointment of a Research Officer based in the Wellcome Unit for the History of Medicine, University of Oxford, UK

Dr Jo Robertson (Brisbane, Australia) was appointed as Research Officer for the project period of 20 months, starting in October 2001. Dr Robertson's research has included leprosy in terms of imperial

and colonial relations in Queensland history and her thesis for the degree of Doctor of Philosophy in the University of Queensland in 1999 dealt with leprosy both as disease and metaphor in Europe and the British Empire and the implications for the colony of Queensland at the turn of the last century.

The Research Officer, under the supervision of the Acting Director of the Wellcome Unit, Dr Mark Harrison, will be responsible for the creation of a database of historical collections relating to leprosy throughout the world. Collections may relate to any period, but the main focus will be on the modern era, from 1830 onwards. Additional input will include 1) encouraging leprosy organizations and projects to do all possible to preserve their records and archives and 2) building a network of academics interested in historical research into leprosy.

This project first started in September 1999 as an initiative of the *International Leprosy Association*, the scientific society of doctors, researchers and others working leprosy. It is supported by the Nippon Foundation, Japan and has professional links with colleagues in the World Health Organisation. A Steering Group for the project, created by the *International Leprosy Association*, will meet once or twice a year and the Research Officer will have support from Mr Paul Sommerfeld, past General Secretary of the *International Federation of Anti-leprosy Associations* and Dr A. Colin McDougall, previously Department of Dermatology, Oxford.

Exchange: a networking and learning programme on health communication for development, London, UK

Exchange is a networking and learning programme on health communication for development, which aims to encourage the sharing of lessons learned about what works and what doesn't in health and disability communication. In particular, *Exchange* aims to support organizations in developing countries to document more fully their own organizational learning, evaluation experience and the impact of this on their work. Though our main focus is on health communication, we are keen to identify where links can be made and lessons shared across the range of organizations in different sectors, contexts and places (see separate sheet), as well as to identify any gaps in health and disability communication work which need support or development. The geographical spread is in UK, USA and developing countries.

Aim of work

- Improving access of health workers in developing countries to information.
- Increasing awareness and understanding of health issues among the public.
- Encouraging individual and social behavioural change.
- Organizations promoting sharing/networking.

Medium

- Radio
- Television
- News media
- Edutainment
- Printed materials
- Computing and Internet
- Telephone and fax
- Personal contact
- Community action

- Film and Video
- Theatre

Organization type

- Broad health, disability and development organizations
- Organizations with a selective focus on aspects of health or disability
- Organizations working with partners or particular communities
- Public Health organizations
- Private Sector organizations
- Training organizations
- Consultants
- Academic/Research institutions
- Community-based organizations
- Government Departments/Ministries
- Media

Communication emphasis

- Participatory approaches
- Social mobilization
- Advocacy/Promoting access
- Health promotion/education
- Repackaging information
- Information management/building knowledge base
- Organizational learning/personal development
- Training
- Evaluation/Needs assessment
- Communication theories/approaches

Further information: Learning Co-ordinator, **Exchange**

A networking and learning programme on health communication for development. c/o Healthlink Worldwide, Cityside, 40 Adler Street, London E1 1EE, UK

Tel: +44 (0) 20 7539 1575 (direct), Fax: +44 (0) 20 7539 1580

E-mail: vincent.r@healthlink.org.uk Internet: <http://www.healthcomms.org>

Healthlink Worldwide. Free international newsletters on health and development

This is the title of a 59-page publication, A4 format, by Healthlink, recording a vast amount of valuable information about newsletters and journals on a wide range of subjects relevant to health and development, regionally and internationally.

The *Introduction* reads as follows:

This fourth edition of *Free international newsletters on health and development and recommended journals on subscription* gives details of 145 newsletters, magazines and journals relating to health and disability issues which are available free or at low cost to readers in developing countries. Also listed are 22 recommended newsletters and journals available on subscription.

This resource list has been used as a valuable networking tool to learn about the activities of other organizations working regionally and internationally. It also provides a rich source of core materials to build up resource centres and provide up-to-date health information at little extra cost.

This list has been compiled by Healthlink Worldwide from information provided by the publishers. The titles appear in alphabetical order. They are indexed by subject, geographic focus (by World Health Organization region) and language. You will find the index at the back of the publication.

Electronic access

As more and more newsletters and journals are now available electronically on the Internet or by e-mail, the most recent website and e-mail address of electronic titles has been given (please note however, website and e-mail addresses do sometimes change).

These titles are marked with a symbol in the left-hand margin, as follows:



available over e-mail



available over the Internet

This resource list is also available as a database on the Healthlink website: <http://www.healthlink.org.uk>

The UK address is healthlink Worldwide, Cityside, 40 Adler Street, London E1 1EE.

Fax: +44 20 7539 1580. E-mail: info@healthlink.org.uk

WHO and top publishers announce breakthrough on developing countries' access to leading biomedical journals. WHP Press Release (WHO/32), 9th July 2001

The World Health Organisation and the world's six biggest medical journal publishers today announce a new initiative which will enable close to 100 developing countries to gain access to vital scientific information that they otherwise could not afford. The arrangement agreed to by the six publishers would allow almost 1000 of the world's leading medical and scientific journals to become available through the Internet to medical schools and research institutions in developing countries for free or at deeply-reduced rates.

Overseeing the signing of the Statement of Intent by senior executives of the publishers, Dr Gro Harlem Brundtland, Director-General of WHO, said: 'As a direct consequence of this arrangement, many thousands of doctors, researchers and health policy-makers among others will be able to use the best-available scientific evidence to an unprecedented degree to help them improve the health of their populations. It is perhaps the biggest step ever taken towards reducing the health information gap between rich and poor countries.' Until now, biomedical journal subscriptions, both electronic and print, have been priced uniformly for medical schools, research centres and similar institutions irrespective of geographical location. Annual subscription prices cost on average several hundred dollars per title. Many key titles cost more than \$1500 per year. This has made it all but impossible for the large majority of health and research institutions in the poorest countries to access critical scientific information.

Scheduled to start in January 2002, the initiative is expected to last for at least 3 years while being monitored for progress. It will benefit bona fide academic and research institutions, which depend on timely access to biomedical journals. Between now and the end of this year, these institutions will be identified individually and the process put in place so that they can receive and use access authentication. All parties—the publishers and the participating institutions will learn from this experience. Decisions about how to proceed after the initiative will grow from the precedents it sets, and will be informed by the working relationships, which have developed among the partners.

The initiative is an important step in the establishment of the Health InterNetwork, a project introduced by United Nations' Secretary-General Kofi Annan at the UN Millennium Summit last year. Led by WHO, the Health InterNetwork aims to strengthen public health services by providing public health workers, researchers and policy makers access to high-quality, relevant and timely health information through an Internet portal. It further aims to improve communication and networking. As key

components, the project will provide training as well as information and communication technology applications for public health.

Working with the British Medical Journal and the Open Society Institute of the Soros foundation network, WHO approached the 6 biggest medical journal publishers, Blackwell, Elsevier Science, the Harcourt Worldwide STM Group, Wolters Kluwer International Health & Science, Springer Verlag and John Wiley, with the aim of bringing them together with the countries concerned to seek a more affordable pricing structure for online access to their international biomedical journals.

The outcome is a tiered-pricing model developed by the publishers that will make nearly 1000 of the 1240 top international biomedical journals available to institutions in the 100 poorest countries free of charge or at significantly reduced rates.

For further information, journalists can contact Mr Gregory Hartl, WHO Spokesperson, WHO, Geneva. Telephone (+44 22) 791 4458; Fax (+41 22) 791 4858; Email: hartlg@who.int. All WHO Press Releases, Fact Sheets and Features as well as other information on this subject can be obtained on Internet on the WHO home page: <http://www.who.int/>

Postgraduate study in Epidemiology: Principles and Practice, Health Systems Management and Infectious Diseases, London, UK

With sub-heading 'Lead college: London School of Hygiene and Tropical Medicine', this is the title of a 25-page publication describing the numerous courses available, entrance requirements and method of application. The main headings include: The University of London, studying at a distance, London School of Hygiene and Tropical Medicine, study materials, epidemiology: principles and practice, health systems management, infectious diseases, staff, unit outlines entrance requirements, registration and fees.

Copies are available free of charge from The External Programme, The Information Centre, Senate House, University of London WC1E 7HU, United Kingdom. E-mail: enquiries@external.lon.ac.uk
Web site: <http://www.lon.ac.uk/external/>

International Review of Clinical Dermatology and Dermatocosmetics

We are grateful to Sanidad y Ediciones (SANED, S.L.), C/Capitan Haya 60, 28020, Madrid, Spain for copies of this publication, which carries, in Spanish, selected articles from the *International Journal of Dermatology* (the official publication of the *International Society of Dermatology*). The Editors acknowledge Blackwell Science Limited, Oxford, UK for allowing translation and publication of selected articles in Spanish.

Each issue (8 per year) has a section on leprology, coordinated by Dr Terencio de las Aguas, together with reviews and abstracts of publications. A recent issue carried an article by Dr Terencio on Buruli ulcer, including a discussion on differential diagnosis and numerous high quality pictures of this dreadfully disabling disease, which has increased markedly in the past decade and is still difficult to treat and control.

SANED SL: tel 91 749 95 06. Fax 91 749 95 07
E-mail: saned@medynet.com

Knowledge and Research Programme on Disability and Healthcare Technology

From the *Asia Pacific Disability Rehabilitation Journal*, Vol 1, No 2, 2001, page 148:

Identifying and making better use of appropriate technologies that will improve the lives of poor people worldwide is the focus of this programme to encourage the development and use of appropriate

disability and healthcare technologies. It is managed by a unique partnership between a management consulting firm—GIC Ltd—and a UK-based health, development and disability communications charity—Healthlink Worldwide. Funding for the programme is being provided by the Department for International Development (DFID). The KaR Programme on Disability and Healthcare Technologies will make a total of £1.2 million available over the next 2 years to support a range of projects under the themes of: Improving healthcare technologies and infrastructure for poor people, and Minimizing the detrimental effects of disability on the lives of poor people. The Programme sees technologies as including processes and management practices, organizational and supportive systems and dissemination practices that make them more accessible. The Programme will support projects that fall within one of three broad indicative categories: Development of a new technology, Adoption of a newly developed technology and Contribution to the wider use of a successful technology. An annual competition will be used to select the projects that will be awarded funding. Projects can be awarded funding for up to 100 per cent of their costs. Full details of the application process are available on the Programme's website.

Further information from: Roger Drew, KaR Programme Director, Healthlink Worldwide, Tel: +44 20 7539 1577; Fax: +44 20 7539 1580; e-mail: drewr@healthlink.org.uk

Aron Cronin, KaR Programme Manager, GIC Ltd. Tel: +44 20 7253 7000; Fax: +44 20 7251 3100; e-mail: kar@giclimited.com; Website: www.kar-dht.org