

SEMINAR PROCEEDINGS

Nairobi, Kenya, 7-11 December 2009

March 2010

From disease specific toward comprehensive and integrated management of disabling diseases: diabetes, lymphatic filariasis and Buruli ulcer



*Disabling Diseases Seminar Participants
Handicap International, Nairobi, 7-11 December 2009*

**HANDICAP
INTERNATIONAL**

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This document reports on the disabling diseases seminar organised in Nairobi from 7th to 11th December 2009 by Handicap International.

47 participants from 22 countries gathered to exchange state-of-the-art knowledge in the field of disabling diseases: diabetes, lymphatic filariasis and Buruli ulcer.

After three days of disease specific workshops field officers from non governmental organisations, political leaders from developing countries, and international experts

were gathered for a two days joint workshop on comprehensive and integrated approach of disabling diseases. An innovative perspective on integrated chronic wound and lymphoedema care at community level was discussed during the workshop.

At the same time it provided a forum for exchange among field project officers.

This is following the previous edition of 2008 in Bamako, who brought together stakeholders on disabling diseases to give food for thought on footwear for high risk foot.

HANDICAP INTERNATIONAL'S SCOPE OF ACTIVITY

Handicap International is an independent international aid organisation working in situations of poverty and exclusion, conflict and disaster. Working alongside persons with disabilities and other vulnerable groups, our action and testimony are focused on responding to their essential needs, improving their

living conditions and promoting respect for their dignity and their fundamental rights.

One of our target populations are persons living with chronic disabling diseases, diseases which may result in irreversible physical, sensorial or mental deficiencies.

HANDICAP INTERNATIONAL'S ACTION IN THE FIELD OF DISABLING DISEASES

Handicap International's action in the field of disabling diseases aims to achieve the following goals:

- To prevent invalidity, impairment and disability linked to disabling diseases,
- To ensure the service of prevention, care

and rehabilitation are available, adapted and accessible,

- To strengthen capacities, to promote social participation of people living with a disabling disease and the application and exercising of their rights.

Proceedings from the diabetes workshop

There were 20 participants in the diabetes workshop run by Dr. Pauline Guimet, technical adviser on disabling diseases for Handicap International. This workshop was divided into three parts: learning from experience, training, and reflection on the diabetes framework document.

LEARNING FROM EXPERIENCE

The objective of this part of the workshop, held over three half-days, was to share experience on specific subjects. Each team gave an oral presentation of lessons learned from a particular experience. Time was then allowed for experience-sharing between the teams, giving participants an opportunity to compare the different strategies adopted and the know-how used in each setting.

The subjects chosen for experience-sharing were varied:

- ▶ The Kenya project team presented the know-how that was used for bringing services closer to communities by supporting the Ministry of Health in introducing consultations for persons with diabetes.
- ▶ The project team from the Philippines then went on to analyse the know-how used in supporting the decentralization of care services for persons with diabetes, first by strengthening the project team's own capacities and then by using a participatory approach with local partners.

- ▶ The technical adviser on disabling diseases shared her experience of carrying out studies within disabling disease-control projects, stressing the need to determine exactly what is expected of the study in the initial terms of reference.
- ▶ The Mali project team explained how it supported associations of persons with diabetes in running adapted physical activities, notably by drawing up a guide using a participatory approach.
- ▶ Also on the subject of local partner involvement, the project team from Burundi presented the know-how it used for getting stakeholders to take part in the organisation of World Diabetes Day 2008.
- ▶ Lastly, the Nicaragua project team shared its experience of strengthening diabetes clubs.

In the first half of 2010 these workings will be published in a document of lessons learned from experience acquired by Handicap International via its diabetes prevention and control projects in resource-poor countries.

TRAINING: MANAGEMENT AND PREVENTION OF THE DIABETIC FOOT

A 90-minute training session on the management and prevention of the diabetic foot was organised for the project teams and local partners.

This training was designed to give participants general knowledge of the management and prevention of the diabetic foot that would be useful to them in their roles as project managers. The session was based on international recommendations on this subject¹.

Dr. Pauline Guimet, technical adviser on disabling diseases for Handicap International, gave a presentation of the medical case-management aspects, and Frederic Joyeux, technical

adviser on orthopaedics, then gave a presentation on footwear, orthoses and prostheses for persons with diabetes.

These oral presentations were followed by discussion between participants, notably on the difference between the international recommendations and current practice, and the reasons for this difference. The conclusion was that the use of total contact plaster casts, the reference method in the treatment of chronic diabetic ulcers, should be generalised in the countries in which we work. The project teams undertook to promote this method and assist with its implementation in the field.

THEMATIC FRAMEWORK DOCUMENT: REFLECTION WORKSHOP

A reflection workshop on the thematic framework document entitled *Handicap International and Diabetes* was held over two one-hour work sessions.

Handicap International's thematic framework documents are guidance documents on a specific subject for use by its projects teams. They define the subject, explain where and how it fits into Handicap International's mandate, the target populations, intervention strategies (standard expected outcomes, standard activities), monitoring and evaluation indicators, the type of partnership to be envisaged, the human resources needed, and essential reading. Produced every three years, the *Handicap*

International and diabetes framework document needs to be enhanced with experience acquired by project teams.

Three groups were formed and each focused on a different subject area: primary prevention, case-management, orthosis and prosthesis. One of the instructions was to define the target population for each type of activity so as to be able to broaden this population by moving towards a global and integrated approach. Each group produced a written paper for inclusion in the policy paper and gave a short oral report on its conclusion to the other workshop participants.

1. Practical guidelines on the management and prevention of the diabetic foot, International Working Group on the Diabetic Foot, 2007

Proceedings of the workshop on the integrated approach to chronic wound and lymphoedema management

Forty-seven participants attended the workshop on the comprehensive and integrated approach to chronic wound and lymphoedema management, facilitated by Dr. Pierre Brantus, consultant on lymphatic filariasis for Handicap International.

BRAINSTORMING ON THE CONCEPT OF INTEGRATED APPROACH

Dr. Brantus began the day by conducting a brainstorming exercise with all the participants present on the definition and concept of integration. The outcomes were relevant and critical, with useful input from the participants. The main conclusions were as follows:

- Integration involves developing and imple-

PLANNING OF INTEGRATED ACTIVITIES

The rest of the day focused on basic public health principles and the planning of integrated activities for identifying patients, awareness-raising and health education, and lymphoedema and wound management.

Four groups were formed, each group including people involved in controlling each of the three diseases concerned.

The groups addressed the following questions on the different steps to programme planning:

- What are the key points to be considered during the situation analysis?
- What are the objectives (general and specific)?
- What are the key points when it comes to implementing the activity?
- What are the key points for implementing patient follow-up and the referral system?

Group work was carried out on all these questions and the outcomes of each group were presented and discussed in a plenary session. The final outcomes can be found in Appendix III. These outcomes could serve as a basis for planning integrated activities for wound and lymphoedema management in diabetes, Buruli ulcer, lymphatic filariasis and leprosy.

menting common activities for managing several diseases,

- Integration should be factored into each level of programme planning,
- Integration also requires the pooling of logistical, human and financial resources.

The main points discussed were:

- With regard to detection and identification, should the criteria be very specific or should they be kept very general to heighten sensibility (example of tuberculosis using the very general criteria of “coughing over the last two weeks”). It was agreed that visual aids are the best means of detection.
- For awareness-raising / education, integrated messages should focus on one message at a time and be based on existing messages from specific national programmes on diabetes, Buruli ulcer, lymphatic filariasis and leprosy so as to increase ownership of the concept by these programmes.
- A chronic wound is a wound that has not healed within three weeks. Special attention should be given to assessing the level of stigmatization of patients. The wound management strategy should focus on self-care.
- With regard to lymphoedema management, when the use of compression is being considered, the cause of the lymphoedema must be known in order to avoid any contraindications. Compression should not be used in diabetes patients suffering from arteriopathy. For all other types of care, the cause does need to be known and an integrated approach can be used.

MONITORING AND EVALUATION OF INTEGRATED ACTIVITIES

A disease-specific workshop session had been carried out beforehand in which each group had drawn up a list of specific indicators for each disease. The lists of indicators established for diabetes, Buruli ulcer and lymphatic filariasis during these earlier workshops were compared here in order to establish common monitoring

and evaluation indicators. The outcomes of these work sessions are given in Appendix IV.

The following is a consolidated list of integrated indicators for monitoring and evaluating integrated activities for wound and lymphoedema management at each level of intervention:

At community level	<ul style="list-style-type: none"> - Rate of patients detected at an early stage (need to define «early stage» for each disease) - Rate of confirmed diagnoses - Number of cases - Rate of patient follow-up - Presence of chronic wound - Rate of patients with limitation in movement - Rate of referral in case of problem/complications - Rate of cases referred to a higher level
At district level	<ul style="list-style-type: none"> - Rate of patient follow-up - Rate of patients detected at an early stage (need to define «early stage» for each disease) - Rate of confirmed diagnoses - Number of cases - Presence of chronic wound - Rate of patients with limitation of movement - Rate of referral in case of problem/complications - Rate of cases referred to a higher level - Rate of amputation
At national level	<ul style="list-style-type: none"> - Quality of life

Some indicators still need to be discussed:

- ▶ Number of patients under treatment (diabetes, leprosy, BU)
- ▶ Percentage of patients needing shoes / wearing appropriate footwear

CONCLUSIONS AND RECOMMENDATIONS

Dr. Brantus presented a summary of recommendations made throughout the two days of workshops:

- ▶ The integrated management of chronic wounds and lymphoedema related to diabetes, Buruli ulcer, lymphatic filariasis and leprosy seems realistic and workable. In some countries, experience is already being gathered.
- ▶ The outcomes of the work sessions on the planning of integrated programmes for wound and lymphoedema management could serve as basis for future activities. The results obtained during the previous workshop on footwear in 2008 could be included to ensure a comprehensive approach.
- ▶ The outcomes from the work sessions on integrated indicators could serve as basis for the work of the World Alliance on Wound and Lymphoedema Care.
- ▶ A lot remains to be done on these basic principles for integration.

DAY 1 - Joint introduction		
9:00-10:30	Welcome and Introduction Program Objectives / Handouts Introduction of Participants Overview of Partnerships in Disability Prevention (LF, Leprosy, Diabetic Foot, BU) WHO Integration Paradigm	Dr. Brantus Dr. Brantus / Dr. Guimet Dr. Brantus / Dr. Guimet NGDOs
11:00-12:30	Burden of problem Global Initiative for Wound and Lymphoedema Care Footwear workshop: update	Dr. Brantus Dr. Macdonald Dr. Geyer
DAY 1 - Diabetes specific workshop		
2:00-3:00	Lessons learned: Implementation of diabetes clinics, Kenya	Elizabeth Bonareri
4:00-5:00	Lessons learned: Decentralization of diabetes care, Philippines	Dr. Boyose-Nolasco
DAY 2 - Diabetes specific workshop		
8:30-9:30	Lessons learned on epidemiological studies	Dr. Guimet
9:30-10:30	Lessons learned on adapted physical activity for people with diabetes in Mali	Dr. Dicko
11:00-12:30	Lessons learned on the World Diabetes Day celebration in Burundi	Candide Kayonde
2:30-5:30	Workshops on Framework Document <i>Handicap International and Diabetes</i> <ul style="list-style-type: none"> • group 1: footwear, orthoses and prostheses • group 2: strengthening the capacity of health system • group 3: prevention of non communicable diseases 	Frédéric Joyeux Dr. Curti Athanase Ntampuhwe
DAY 3 - Diabetes specific workshop		
8:30-9:30	Lessons learned: strengthening the capacities of clubs for people with diabetes, Nicaragua	Dr. Tapia
9:30-10:30	Training: management and prevention of diabetic foot: an overview	Dr. Guimet
11:00-12:30	Training: management and prevention of diabetic foot: A focus on orthotics and prosthetics	Frédéric Joyeux
2:30-5:30	Workshops: Monitoring and Evaluation of diabetes projects	Dr. Guimet

DAY 4 – Joint Workshop on integrated approach to chronic wounds and lymphoedema

8:30-9:30	Introduction Definition of integration: brainstorming	Dr. Brantus
9:30-10:30	NGOs experiences: Reggio Terzo Mondo (RTM), Handicap International	Dr. Jaona Andrianarimisa Eliezera
11:00-12:30	Public health basic principles and planning: working groups <ul style="list-style-type: none"> • Identification of patients • Management: wound, lymphoedema, footwear, other activities 	Dr. Brantus / Antony Vautier / Dr. Guimet / Dr. Geyer / Dr. Macdonald
2:30-3:30	Public health basic principles and planning: working groups (continued)	Dr. Brantus / Antony Vautier / Dr. Guimet / Dr. Geyer / Dr. Macdonald
4:00-5:30	Public health basic principles and planning: working groups (continued) Restitution Summary of the day	Dr. Brantus / Antony Vautier / Dr. Guimet / Dr. Geyer / Dr. Macdonald

DAY 5 - Joint Workshop on integrated approach to chronic wounds and lymphoedema

8:30-10:30	Monitoring and evaluation indicators of comprehensive and integrated projects Presentation of specific indicators related to each disease Working groups Restitution Discussion	Dr. Brantus / Dr. Geyer Groupes
11:00-12:30	Monitoring and evaluation indicators of comprehensive and integrated projects Conclusions and recommendations	Dr. Brantus / Dr. Geyer Groupes

Appendix

List of participants

Name of participant	Organization	Country of work	Diseases	Email adress
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Appendix

Summary of the evaluation of the seminar

THE MAJORITY OF PARTICIPANTS WERE VERY SATISFIED:

- ▶ Diabetes workshop: 13 out the 14 participants who attended this workshop were very or extremely satisfied,
- ▶ Workshop on the integrated approach to disabling diseases: 31 out the 33 participants who attended this workshop were very or extremely satisfied.

MOST FREQUENTLY-MADE COMMENTS:

Areas of satisfaction:

- ▶ Quality of experience-sharing with participants from different countries (mentioned 7 times), in a relaxed working atmosphere and with a certain freedom of expression
- ▶ The subject of the integrated approach (6)
- ▶ Quality of the discussions (3)
- ▶ Joint exercise in listing common indicators for the monitoring and evaluation of programmes focusing on different diseases (4)

Areas for improvement:

- ▶ Preparation for the seminar to be improved (send out the invitations early enough, give more time and more instructions to the contributors, send out the programme earlier) (5)
- ▶ Language barrier (3)
- ▶ Instructions for group work not clear enough (2)
- ▶ Facilitation of group work to be improved (2)

WITH REGARD TO THE LOGISTICS OF THE SEMINAR, 31 OUT THE 33 PARTICIPANTS WHO ATTENDED WERE VERY OR EXTREMELY SATISFIED:

- ▶ Some people found the food to salty or too frequent. Next time, the caterers should be sent recommendations on producing properly-balanced meals.
- ▶ The relatively flexible time-management irritated some, but was appreciated by others as it allowed time for in-depth discussion.

FEW CITATIONS FROM EVALUATION FORMS:

« Feeding at short interval »

« Facilitators need some training to stick with topic, encourage participation and minimize disruptive members of groups disconnect between group discussions and presentation »

« Les objectifs du séminaire étaient importants à traiter en termes d'efficience et très clairs ; Les débats étaient très riches, beaucoup d'idées partagées ; On arrive à une synthèse et des recommandations qui devraient être partagées par tous ; Cadre agréable mais éloigné de la ville. BRAVO ! »

« Le fait d'oser proposer des indicateurs communs pour différentes maladies »

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