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LESSONS FROM EXPERIENCE:
KNOW-HOW ANALYSIS

Diabetes prevention and control projects in countries with limited resources



**HANDICAP
INTERNATIONAL**

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Learning from Handicap International's experience in diabetes control

HANDICAP INTERNATIONAL'S APPROACH TO THE PREVENTION AND CONTROL OF DIABETES

Handicap International – the organisation

Handicap International is an independent international aid and development organisation working among poor and marginalized people and in situations of conflict and disaster. In both word and deed, it works with persons with disabilities and other vulnerable groups to meet their basic needs, improve their living conditions and promote respect for their dignity and fundamental rights.

Its commitment to fighting diabetes

If diabetes is not properly controlled, the common symptoms and potential complications of this disease (cardiovascular disease, kidney failure, erectile dysfunction, chronic wounds in the feet that could lead to amputation) are potentially extremely invalidating.

Handicap International's actions on diabetes are aimed at preventing disabilities related to the disease, ensuring the offer of prevention, treatment and rehabilitation services is available, adapted and affordable, building capacity and promoting social participation and the application and exercising of the rights of persons living with diabetes.

In concrete terms, this translates into providing support to local partners (associations of persons with diabetes, health professionals and health authorities) in the following areas:

▶ Strengthening the capacities of associations

Our organisation also works in contexts of reconstruction or development among people living with disabling diseases, diseases that can lead to irreversible physical, sensory and mental impairments.

Handicap International is careful not to replace local actors in its work, but seeks to build capacities and help local partners towards autonomy.

of diabetic patients in the fields of advocacy, psychosocial support, awareness-raising and therapeutic peer education,

- ▶ Conducting awareness-raising campaigns on diabetes,
- ▶ Identifying cases of diabetes within the community and referring them to care facilities,
- ▶ Training health professionals,
- ▶ Renovating and equipping care and rehabilitation facilities,
- ▶ Setting up new care units in accordance with health authority planning,
- ▶ Making recommendations for clinical practice and care protocol,
- ▶ Carrying out epidemiological studies,
- ▶ Advocating for the improvement of accessibility and the quality of services provided to persons with diabetes.

Its desire to share its experience

The purpose of the learning-from-experience work presented in this paper is to share the know-how acquired by Handicap International during the first 3-year project cycle. We do not attempt here to describe all the activities implemented and all the results achieved, but have

chosen to focus on selected activities that we feel are particularly worth sharing.

This paper will provide guidance to our project teams in five countries (Nicaragua, Philippines, Kenya, Burundi, and Tanzania) in initiating a new 4-year project cycle starting 2010.

A PRODUCT OF THE LEARNING-FROM-EXPERIENCE PROCESS

This paper is the outcome of the learning-from-experience process in which Handicap International diabetes project teams were engaged from November 2009 to January 2010. The learning-from-experience work was carried out to prepare for and facilitate experience-sharing between the different diabetes projects at a

seminar for project managers and local partners held from 7th to 11th December in Nairobi.

There are **two clear phases** to this learning-from-experience process: a learning-from-experience activity carried out by each team before the seminar, and the sharing of experience during the seminar.

The learning-from-experience process before the seminar

Each of the five diabetes project teams, together with the technical advisor on disabling diseases, chose a subject on which to capitalise and separately carried out a learning-from-experience activity. Know-how analysis sheets

were drawn up using detailed learning-from-experience methodology¹, coupled with remote technical support or direct on-site support, depending on the team.

Experience-sharing during the seminar

During the seminar each team made an oral presentation of its learning-from-experience activity. Each presentation was followed by an exchange of experiences during which the teams compared the different strategies and

know-how used according to the different contexts.

These discussions helped clarify and enhance the know-how analysis sheets produced by the teams and presented in this document.

1. This methodology is based on the CIEDEL methodology (GRAUGNARD Gilbert ; QUIBLIER Véronique. *Note de synthèse du module de formation : « Introduction à la capitalisation d'expériences »*. Lyon : Ciedel, 2006.- 24 p. URL: <http://evaluation.francophonie.org/IMG/pdf/download.pdf>).

Mobilizing stakeholders to organise a symbolic event

GENERAL ISSUE

Our wish was to use World Diabetes Day (WDD) as a means of fostering cooperation between **the different stakeholders** engaged in diabetes control in Burundi: persons with diabetes, health workers, health authorities, international inter-governmental organizations and Non Governmental Organizations.

World Diabetes Day (WDD), held on 14th November every year, is a vast awareness-raising campaign involving diabetes stakeholders throughout the world. The initiative was first launched by the International Diabetes Federation and World Health Organization in 1991 and since the adoption in 2007 of Resolution 61/255, has become a United Nations International Day. The aim of a UN international day is to draw attention to crucial international issues. In the case of diabetes, the day

provides a yearly opportunity to communicate widely on this chronic disease which, although increasingly wide-spread, does not usually attract media attention because it does not produce the sort of spectacular crisis caused by epidemics. The purpose of World Diabetes Day, therefore, is to **raise awareness** and educate people on diabetes as a disease and on the ways in which it can be prevented.

An international day is a symbolic event in that it offers an opportunity to present an abstract notion in concrete terms. Although the main objective of an international day is to raise awareness, it can also be used to **encourage stakeholders to work together**. This then was the subject that we decided to **share our know-how**, as this type of cooperation is often vital to the success of a project.



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Association partners, trainers and the Handicap International project team in Burundi.

PROJECT AND CONTEXT

PROJECT IDENTITY CARD

Project: Developing cooperation between stakeholders so that they join hands in the fight against diabetes in Burundi through activities aimed at raising the awareness of the general population.

Country: Burundi

Period: June - December 2008

Expected outcomes:

- ▶ Capacities of the associations of diabetic persons are reinforced.
- ▶ An information day on diabetes and its complications is held on World Diabetes Day (14 November 2008).

The population and public authorities in Burundi know very little about diabetes. Health professionals themselves are not adequately trained on this disease. Following advocacy by NGOs and with the support of the World Health Organization, the Integrated National Program on

Non-Communicable Chronic Diseases was launched by the Ministry of Public Health in early 2009. However, there is still scant awareness of the scale of the public health problem caused by this disease in Burundi. It has now become essential to mobilize people on this issue through different awareness-raising activities such as the World Diabetes Day.

Associations of people with diabetes are crucial stakeholders owing to their experience with the disease and their potential for relaying awareness-raising messages to the population. However, they seem to enjoy little legitimacy among health professionals and their capacity to take part in such events is still limited. Full participation by these associations in the organisation of the World Diabetes Day requires capacity-building.

PROJECT INTERVENTION LOGIC

We felt it was crucial for the role of involving the different diabetes control stakeholders in preparations for World Diabetes Day to be played by the Ministry of Public Health. We therefore began by convincing the Ministry of the importance of organising an awareness-raising day. Having agreed to our proposals, we then worked jointly with the Ministry in determining the membership of the technical organisation committee, ensuring all the different diabetes-control stakeholders were included.

The committee members were representatives of the Ministry of Public Health, international and national NGOs, associations of persons with diabetes and health professionals. Via this committee, we were able to jointly identify awareness-raising activities, select the venues for the World Diabetes Day celebrations and produce awareness-raising materials approved by the Ministry of Public Health's Department of Information, Education and Communication.

ANALYSIS OF KNOW-HOW: MOBILIZING STAKEHOLDERS TO ORGANISE A SYMBOLIC EVENT

Advocating for the event to become a national public policy priority

Ensure support from the Ministry of Public Health's focal point: A few months before 2008 World Diabetes Day, we met with the focal point for diabetes at the Ministry of Public Health with a view to enquiring about activities planned by the Ministry for World Diabetes Day.

In the course of this meeting we realized that no activities had been planned due to lack of a budget and social interest. The focal point said he totally agreed with our proposal to

organize the day together with other stakeholders. To resolve the problem of a lack of human resources assigned to diabetes within the Ministry of Public Health, we suggested that the stakeholders we had met during the exploratory mission be involved in organizing the day. To obtain more funds for the activities, we got the Ministry of Public Health to contact organisations such as WHO and the Lion's CLUB, contacts which bore fruit.

Identifying which types of stakeholder to involve in organizing the event

Determine who to involve in organising World Diabetes Day: The exploratory mission carried out at the project development stage provided us with an analysis of local diabetes-control stakeholders. We decided to seek the help of these same stakeholders in organising the day, in order to build on the dynamics developed during the exploratory mission.

As far as the composition of the exploratory mission's technical committee is concerned, we had sought to form a multi-disciplinary group

of three to eight members, including diabetes stakeholders interested in setting up a diabetes control project in the selected pilot zone, including:

- ▶ one member of an association of persons with diabetes
- ▶ one health professional
- ▶ one health sector decision-maker
- ▶ one social stakeholder
- ▶ one NGO member

Observe and analyse the group dynamics

We noticed that participation was unbalanced with discussions dominated by the professionals due to cultural barriers related partly to gender and partly to levels of education. We

learnt that in order to optimize participation by women and persons with diabetes it was imperative to carry out capacity building prior to the meetings.

Motivating stakeholders to get involved in the project

Convince stakeholders to take part in the organization meeting: We contacted all those we had met during the exploratory mission by telephone. We convinced those we talked to of

the importance of the awareness-raising day by pointing out that the Ministry of Public Health would be taking part.

Convincing stakeholders of the importance of an inclusive approach

Convince the different types of stakeholders of the importance of working together: When we contacted the different stakeholders, we noticed that health professionals were clearly uncomfortable about the idea of associations of persons with diabetes being involved in the organization of World Diabetes Day. To resolve this problem, we met with the most influen-

tial health professionals and impressed upon them the need to involve the associations, arguing that the associations were closest to the communities (diabetic and non diabetic persons) and hence had a key role to play in delivering awareness-raising messages to the communities.

Determining the meeting's agenda and each party's role beforehand

Organise the meeting beforehand: Handicap International's team, in partnership with the Ministry of Public Health, decided on the agenda and objective of the meeting to which all the stakeholders were invited. The aim of this meeting was to set up a small technical committee for organising the 2008 World Diabetes Day. Roles in preparing for and facili-

tating the meeting were attributed beforehand: the Ministry of Public Health would chair the meeting and take care of the logistics, while Handicap International would act as secretary. It was also Handicap International's job to contact stakeholders by telephone to invite them to this meeting.

Promoting participation by all the stakeholders

Conduct the meeting in a manner that encourages everyone to participate: At the beginning of the meeting, there was a recap of the history to and importance of World Diabetes

Day, an event officially recognized by Burundi. We then went round the table to gather the twenty or so participants' proposals on activities to be carried out on the day. Then, we

examined each of the proposals in light of the available budget. To ensure that decisions were made jointly, every proposal was first discussed and then voted on, and every member of the

committee had equal decision-making powers. We thus managed to jointly select the activities to be carried out on the 2008 World Diabetes Day.

Creating a body recognized by all

Create a small technical organisation committee recognized by all types of stakeholder: As there were a lot of participants, at the end of the meeting we decided to set up a representative technical organisation committee

comprising a representative from the Ministry of Public Health, the NGOs, the associations of persons with diabetes, the Burundi Association of Medical Students and the WHO, and each group chose its own representative.

Offering proper methodological support to partner associations

Offer methodological support to associations of persons with diabetes to enable them to design projects and raise funds: We held discussions with representatives of associations of persons with diabetes on the role they had been assigned on World Diabetes Day.

Since these associations have limited experience in organising such awareness-raising events, we held a two-day training workshop for them on proposal writing, applying for funding and event organisation. This training was preceded by a training needs assessment.

Encouraging our partners to write and submit proposals

Motivate the associations of persons with diabetes to submit proposals to us for World Diabetes Day: Thanks to the competencies acquired during the training, the associations were able to write proposals on the activities they wished to carry out on 2008 World Diabetes Day and submit them to us for funding. We then reviewed the proposals with each association before making any necessary adjustments to their content. For each proposal approved,

Handicap International awarded a mini grant with which to implement the activities. After World Diabetes Day, we helped each association write a narrative and financial report on the activities carried out.

This process enabled the associations to gain confidence and realize that they were now capable of applying for funding from donors on their own.

Helping partner associations carry out their activities

Help partner associations of persons with diabetes carry out their activities: We were present throughout the preparations of all the activities planned for 2008 World Diabetes Day and were available to help the associations before the activities (booking premises, paying

deposits), during the activities (welcoming the participants, setting up the public address system, etc.) and after the activities (justifying the various budgets, writing a narrative and financial report).

Writer: Candide Kayonde, Charles Barutwanayo

Bringing services closer to communities

GENERAL ISSUE

Supporting the Ministry of Health in scaling up its services in diabetes care consists in implementing actions that enable the Ministry of Health to develop its competence to be able to offer more accessible and better care to diabetic patients.

As supporting Ministry of Health in scaling up its services is a common objective in many of the projects on disabling diseases implemented by Handicap International, it is therefore well worth sharing the know-how developed on this theme and strategies used to collaborate with health authorities.



Children with diabetes, together with the nurse and the Association of people with diabetes in Kitale, Kenya.

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PROJECT AND CONTEXT

PROJECT IDENTITY CARD

Project: Diabetes in East Africa Region: strengthening the health systems and empowering people with diabetes.

Country: Kenya, Trans-Nzoia West, East and Kwanza Districts, Kitale.

Period: January 2009 - December 2012.

Objectives:

- ▶ General objective: To improve the quality of life of people with diabetes within East Africa Region.
- ▶ Specific objective: To reduce the incidence of disabling complications from diabetes within East Africa Region.

Expected outcomes:

- ▶ The local health system has the capacity to provide quality diabetes care and rehabilitation services to the population in pilot zones.
- ▶ Local capacities to empower the general population to prevent the onset of diabetes through changes in lifestyle are promoted and reinforced.

- ▶ People with diabetes are empowered to access quality diabetes care, advocate for their rights, sustain their lives and alleviate social and economic impact of diabetes.

- ▶ Local and regional expertise networks are developed among stakeholders on diabetes in East Africa region.

Main activities:

- ▶ Support the Ministry of Health in scaling up its services in diabetes management.
- ▶ Support in organizing awareness and prevention campaigns.
- ▶ Capacity building of diabetes associations.
- ▶ Establishment and promotion of networking, dialogue and exchange of expertise between diabetes stakeholders at national and regional levels.

The minimal recommendation for diabetes care delivery in resource limited countries is “to organize care around the person living with diabetes, using an appropriately trained health-care professional to deliver the diverse aspects of that care”³. In Kenya, this recommendation has been applied by creating “diabetes clinics” within district hospitals. New districts were recently created to bring services closer to communities. The new districts already have district hospitals and are seeing diabetes

patients, although their capacity to manage these patients is limited. The opening of two new diabetes clinics (a diabetes clinic is a “one-stop shop” within the hospital where diabetes patients can get comprehensive care from a multidisciplinary team) has strengthened health services, reduced the social economic impact of diabetes on the patients and relieved congestion at the main District Hospital in the area thereby ensuring quality care for patients.

PROJECT INTERVENTION LOGIC

In order to strengthen the health systems, four main areas of action were selected to be implemented in partnership with Ministry of Health and the Kenya Diabetes Association.

- ▶ **Training of Ministry of Health health workers** on diabetes care and management at the primary, secondary and tertiary care levels and subsequently and sending them for a clinical practicum in a tertiary level hospital.
- ▶ **Opening of two new diabetes clinics** and initiation of service delivery (in Endeless and Kapsara district hospitals).

- ▶ **Procurement of proper medical and laboratory equipment** for the care centers based on the gaps identified by the Ministry of Health.
- ▶ **Upgrading or renovation of three care centers.**
- ▶ **Strengthening the health information system** in light to diabetes data.
- ▶ **Empowering community health workers in diabetes management**, so as to raise awareness at community level in order to prevent the onset of diabetes and reduce the impact of diabetes.

ANALYSIS OF KNOW-HOW: BRINGING SERVICES CLOSER TO COMMUNITIES

Specifying the role we wish to play

Defining our roles together with institutional partners: Through a series of meetings with the hospital management team and Handicap International, the roles of each party were clearly set out and minutes taken. These minutes, recognized both by Handicap International and Ministry of Health representatives as an accurate account, formed the basis of the Memorandum of Understanding. It was stated that Handicap International is not a health service provider but will support the Ministry of

Health in scaling up its diabetes management services. It was therefore agreed that Handicap International would not build a new building but renovate and adapt an existing room to become a diabetes clinic. Handicap International will also provide support in procuring medical and laboratory equipment which will be used in the diabetes clinics. The Ministry of Health is to provide the space and the staff to run the clinics and ensure their smooth running.

Involving the health authorities in project implementation

Specifying together with the Ministry of Health the criteria for selecting clinic staff: The hospital management team together with Handicap International had a consultative

meeting at which it was agreed that there was a need to have both full-time staff working in the clinic (nurses) and other (Clinical Officer, Lab. Technician, Nutritionist etc.) staff members

3. IDF Clinical Guidelines Task Force. Global guideline for Type 2 diabetes. Brussels: International Diabetes Federation, 2005

available when called upon, to ensure the clinic is operational throughout the week, bearing in mind the Ministry of Health's staff shortages. The guidelines for identifying the staff were further discussed and the following agreed upon: each clinic staff member should have previous experience in diabetes care, the ability

to communicate effectively, a positive attitude and have received training on diabetes management. The hospital management team had a one day meeting to identify staff members who could work in the clinic with regard to the guidelines discussed at the previous meetings.

Ensuring the Ministry of Health follows through on its roles and responsibilities in terms of project implementation

Encouraging the Ministry of Health to identify a room for the diabetic clinic: It is the Ministry of Health's own policy that all diabetes patients be seen in a "one-stop" area. Handicap International came in to support the Ministry of Health to achieve this goal. Identifying a room was one of the Ministry of Health's

first responsibilities. After several formal and informal meetings between the Ministry of Health representatives and Handicap International, they reached a mutual agreement upon a room in the outpatient department which was not fully utilized.

Holding a forum to exchange ideas between all stakeholders

Setting aside a day to initiate service delivery with all stakeholders: There was a meeting with involved stakeholders (Ministry of Health, Kitale Diabetes Association and Handicap International) and beneficiaries to discuss the need to initiate services in the two new districts. It was evident in this meeting that beneficiaries wanted the services to be initiated as soon as possible in order to use them immediately.

The Ministry of Health was to take a lead role in this activity since it was to be implemented within its facilities, but with the support of Kitale Diabetes Association and Handicap International. Together with the Ministry of Health and Kitale Diabetes Association members, a suitable day was agreed upon based on their calendar of activities to initiate service delivery in the new district hospitals.

Sharing responsibilities between stakeholders

Specifying all together the role of each stakeholder for the diabetic clinic opening day: At the same meeting, the roles and responsibilities of each party (Handicap International, Kitale Diabetes Association, Ministry of Health and the beneficiaries) were discussed and agreed upon. The beneficiaries (community members) took a lead role in mobilizing the community. The Ministry of Health was to clean the room,

put IEC (Information, Education, Communication) materials up on the wall, host the members during the opening and provide blood testing services. Handicap International was to renovate the room, equip it with all medical equipment needed, provide lunch for the participants and support the community members in their mobilization activities.



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Walk organized by the Association of people with diabetes for the World Diabetes Day on 14th November 2009 in Kitale, Kenya.

Involving beneficiaries and policy makers in the implementation of project activities

Mobilizing public authorities and community members for the opening: Community health workers, Ministry of Health representatives and Kitale Diabetes Association members visited schools, churches, homes and offices to invite people to attend and witness the initiation of service delivery. Handicap International coor-

inated these activities between the Ministry of Health and Kitale Diabetes Association in the two districts and supported KDA (Kitale Diabetes Association) and the Ministry of Health in mobilizing the community by facilitating transportation.

Ensuring communities feel as if they have reaped benefits of their commitment

Providing a free blood sugar test to mark the beginning of service delivery in the clinics: Having being involved from the beginning, the community members and diabetes patients were happy to be attended to at the clinics. The nurse immediately started providing diabetes education and the clinical officer provided treatment. Ninety-five community members

benefited from free blood sugar testing, including fifty-four known diabetics and six newly diagnosed cases. The patients appreciated the move and were grateful to all those who ensured successful implementation of the activity which may well directly reduce the socio-economic impact of the disease.

Writer: Elizabeth Bonareri

Supporting the decentralization of diabetes care

GENERAL ISSUE

The minimal recommendation for diabetes care delivery in resource limited countries is “to organize care around the person living with diabetes, using an appropriately trained health-care professional to deliver the diverse aspects of that care”⁴. In the Philippines, this recommendation has been applied in a pilot project for decentralizing care to public primary health care centers, through “Diabetes Day”.

“Diabetes Day” is a day dedicated to diabetes care, when health services are delivered through a multidisciplinary team, including diabetes consultation (doctor), diet counseling (nutritionist) and diabetes education (nurse). It is a first in the Filipino public health system, implemented on a weekly or monthly basis, and only in pilot health centers. It increases geographical access to diabetes care services, which were previously only available on the tertiary care level and from private institutions. Support for local stakeholders in initiating

Diabetes Day goes beyond looking at their technical capacities or human resources. It requires the participation of a variety of community stakeholders (in the health care team, local government, civil society organizations) working together to address the various needs of persons with diabetes that go beyond the remits of the healthcare team. Providing diabetes services in public primary health care centers is a culmination of various parallel efforts focused on the same goal.

Increasing access to health care services through the decentralization of care is a key concern for Handicap International’s diabetes projects. This is especially challenging since the diabetes projects are piloted in various low-resource settings.

This approach for supporting local stakeholders in the decentralization of diabetes care may be useful for other countries with similar health care systems.



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A nutritionist conducting a dietetic counseling session for people with diabetes, in the Philippines.

4. IDF Clinical Guidelines Task Force. Global guideline for Type 2 diabetes. Brussels: International Diabetes Federation, 2005

PROJECT AND CONTEXT

PROJECT IDENTITY CARD

Project: Project for the Prevention of Disabilities Linked to Diabetes.

Country: Davao City, Philippines

Period: January 2007 - December 2009

Specific objectives:

Methods for the prevention of disabling situations brought on by diabetes are understood and assimilated by key players in the health and rehabilitation sector in Davao.

Expected outcomes:

- ▶ The at-risk public is aware that they can avoid developing the disease by leading a healthy lifestyle.
- ▶ People suffering from diabetes can control their disease and prevent further complications.
- ▶ The disabling situations brought on by complications from diabetes are under control, there are services in place to deal with them and these services are well-coordinated.
- ▶ A system for monitoring diabetes-related data is set up and used by the stakeholders concerned to identify problems and define the most appropriate strategies.

Diabetes care is still not sufficiently integrated into the Philippines' public health system. The programs most strongly supported by non-

governmental organizations are mainly focused on the prevention and control of communicable diseases. There is a National Cardiovascular Disease Prevention and Control Program with primary prevention as the priority strategy (behavioral change and lifestyle modification) and a related program, "Healthy Lifestyle to the Max", a national healthy lifestyle campaign aiming to prevent non-communicable diseases (mainly cardiovascular diseases, cancer, chronic respiratory diseases and diabetes). This program however has not completely filtered down to most of the communities and does not include adequate provision for the strengthening of diabetes care services, as it is really entirely focused on prevention.

In the context of the Philippines, with a decentralized health system, basic health service delivery is in the hands of the local government units. The extent of provision largely depends on the importance the local government gives to healthcare. It is therefore preferable that pilot projects first work with the city or provincial health offices. Even the smallest unit of government, the Barangay, has a certain degree of autonomy in implementing health programs. The strategies then will have to be unique to each community.

PROJECT INTERVENTION LOGIC

Initiating and sustaining diabetes care services in public health centers requires many actions directed at different target populations:

- ▶ **Capacity building of primary health care teams** (public health doctors, nurses, nutritionists, midwives and community health workers) to improve their knowledge and skills through training and mentoring.
- ▶ **Providing an enabling environment for service provision through:**
 - **Materials and tools for the health care team** (education materials, foot care kits, practice guidelines, record forms and registries, glucose meters).
 - **Setting up a referral network.**
 - **Working on the demand for diabetes care by**

educating the community to avail of the health services available.

- **Advocating** for the availability of medicines and diagnostics.
- **Working with the local government** to provide logistical and legislative support.

The know-how presented hereafter results from a learning-from-experience process focusing on four key moments in the project: definition of the project strategy (May-July 2007), 2nd Consultative Group Meeting for Clinical Practice Recommendations (December 2007), Barangay Lapu-Lapu Health Committee Meeting (March 6, 2008) and Handicap International courtesy call Lapu-Lapu Barangay Captain (August 15, 2009).



© Melanie Ruiz, 2008

People with diabetes waiting for their medical examination sessions (blood pressure test, weight control, foot care, etc.) conducted by healthcare officers in the Philippines.

ANALYSIS OF KNOW-HOW: BUILDING THE CAPACITY OF HANDICAP INTERNATIONAL'S PROJECT TEAM

Acquiring a team vision of the project

Analyzing the goals and objectives of the project as a team: As the project team was recruited after the needs assessment they had not taken part in the proposal writing, and therefore had to work to take the project on as their own. The team therefore had a series

of meetings and workshops to better understand the project. First we reviewed the project proposal, analyzed the logical framework and classified the activities according to the objectives.

Taking time to discuss all possible implementation strategies

Based on initial needs assessment in the communities, we classed the project goals into realistic and unrealistic goals. We tried to turn those that were unattainable into realistic goals

bearing in mind the project's overall objectives. We then agreed on the different implementation strategies on how to reach the goals.

Resolving to work as a team as early as possible

Defining the role of each member of the project team: Once the subsequent steps had been made clear to the team, the next sessions focused on the role of each project team member to achieve the defined goals. The first questions answered were: What is your dream for the project? How do you see your role in attaining that dream? What do you need to do to attain that dream? After summarizing the answers, the role of each team member was

defined. Each team member was also put in charge of interfacing with a project partner: the project manager with the local government unit, the medical coordinator with the health care team, and the community nutritionist with the persons with diabetes. This interface role consisted in regularly communicating with and updating the partner and ensuring that the approaches of each team member and each partner were consistent.

Building the team's capacities to get better results

Determining the strengths and weaknesses of each team member with regards to his role and coming up with a capacity building plan to work on each member's weaknesses:

After role identification, individual and then team SWOT (Strength, Weaknesses, Opportunities and Threats) analyses were carried out. Focusing the weaknesses and threats we came

up with individual and team capacity building plans so that each team member will be able to perform his role effectively. We had to execute this capacity building plan immediately and within the shortest possible timeframe in order to keep to the project schedule. The immediate need then was for the team to acquire sufficient knowledge of diabetes and to develop training skills. Each team member came up with a study schedule and set time for reading and

research. The Medical Coordinator was tasked with simplifying diabetes topics and lecturing to the Field Administrator and Logistician. We also searched for training offered by recognized professional training organizations so we could be certified and recognized as professional diabetes educators. The team was certified as diabetes educators by the Philippine Center for Diabetes Education Foundation (PCDEF) on August 2007.

Coming up with a consensus on key messages for communication on the project

The next step was to formulate key messages for each project partner and the general public, and to define strategies to deliver these key messages. Around this time, the team had also the opportunity to attend a training course on health communication scheduled in Davao City, the project site, conducted by professors of the University of the Philippines College of Public Health. It appears that immediate concern at this time was to have the project accepted by the local stakeholders specifically in order to: make Handicap International known amongst the project partners and the communities, ensure the project partners understand the objectives and strategies of the diabetes

project, present the benefits the project may produce, clarify the role of Handicap International in the diabetes project and clarify the roles of the project partners. Messages were developed to start with a positive statement. An example of the key messages: Handicap International works with different stakeholders to improve their capacity to provide care services. Handicap International does not give free medicines and does not directly conduct free medical consultations or free blood testing. This is because handing out medicines will not produce long term benefits and is not sustainable.

ANALYSIS OF KNOW-HOW: USING A PARTICIPATORY APPROACH WITH THE LOCAL PARTNERS TO IMPROVE HEALTH SERVICE DELIVERY

Requiring participation since the beginning

Even if it takes time, it is very important to us that the participatory approach is used from

the very beginning of an activity.

Defining the project strategy jointly with local authorities

In a participatory approach, it appears essential to work in collaboration with the local authori-

ties to define the strategy of the project.

Ensuring the stakeholders' ownership of the project

The project objectives called for the development of protocols and guidelines for the management of diabetes for use in Davao City. After much discussion regarding the strategy, the team decided to create a consultative group to define the most appropriate clinical practice recommendations for the local setting. Such a consultative group appears to be the best way

for stakeholders to claim ownership of this part of the project, ownership which is the key to facilitating the implementation of the guidelines later on. Furthermore, the consultative group defined the role of each member of the public health care team when it comes to diabetes management.

Building a advocacy group with various types of stakeholders

Building a multi-stakeholder advocacy group with public-private partnership and participation of diabetes care services users:

After receiving training on diabetes, the community health workers of Barangay Lapu-Lapu asked the Barangay Councilor for Health to set up a diabetes day every Thursday, mainly for diabetes screening and blood sugar monitoring. The Barangay Council (local government unit) regretfully acknowledged a lack of funds for subsidizing the blood sugar testing strips. While the presence of one representative from a drug company selling anti-diabetic medicines offering free monthly fasting blood sugar has been greatly appreciated, he could not cater for more than fifty patients. Collecting payment for the strips was one option considered in order to continue with the planned diabetes day. Implementing this scheme, however, would have required a resolution from the Barangay and should first be put to the people with diabetes themselves. Thus, the Barangay health committee chairperson

called for a stakeholder meeting after the trial run for the diabetes day to discuss this, as well as other concerns, such as implementation of the diabetes program in the Barangay. The stakeholders include the people with diabetes, Barangay health center staff (Community Health Workers and Midwife), district health center staff (doctor, nurse and nutritionist), the pharmaceutical firm representative, the members of Barangay Lapu-Lapu health committee (composed of three Barangay councilors) and Handicap International. The patients consulted during the meeting agreed to pay PhP 30.00 for every blood sugar test. The district health staff also committed to providing monthly diabetes consultations (doctor), diet counseling (nutritionist), and diabetes education (nurse). The chairperson of the health committee would also be lead an exercise group every weekend. Handicap International's role would be to facilitate the formation of the local diabetes support group and continue with capacity building for the health care team.

Advocating as often as possible to the local authorities

Keeping the stakeholders informed, creating opportunities for voicing advocacy:

During the project team's strategic planning, it was agreed that one of our key messages to the local government unit is that they should try to find ways to **increase access to essential drugs** for persons with diabetes. This key message was delivered through the Lapu-Lapu Health Club, the local diabetes support group (LDSG). Their President approached the Barangay Captain (local chief executive) to make Glibenclamide available at the Barangay pharmacy as Metformin was already available. An opportunity presented itself to the Handicap International team to personally follow up the club's request when it paid a courtesy call to the

Lapu-Lapu Barangay Captain. The aim of the courtesy call was to introduce Handicap International and the project to the newly elected Captain because the project started under his predecessor's leadership. During this time we made the rounds updating those who were reelected and orienting those who were newly elected. The new Captain enquired about the local diabetes support group's request and asked the price of one box of Glibenclamide tablets. Right then and there, the chief executive gave funds to the health center to buy the drugs.

Writers: Ivy Boyose-Nolasco, Jenny Lyn Hernandez

Strengthening “clubs” of people with diabetes

GENERAL ISSUE

Within the framework of a national program on non-communicable diseases, the public health system in Nicaragua has been promoting the setting up of «Chronic Diseases Clubs». The objective is to provide space for experience sharing and learning how to live with the disease, as well as carrying out educational activities intended to improve the patients' quality of life. Family involvement in the activities is encouraged.

The clubs are non profit-making organizations, membership is voluntary and the members do not pay any fees. The funds are raised from voluntary collection in order to implement one-off activities. Although the Ministry of Health provides some guidance on the functioning and organization of these clubs, they are run directly by the members. These clubs do not develop to the same level their growth depends on the level of members' involvement and the leadership provided by their management committee.

Handicap International aims to support existing groups and promote new ones.

The experience of supporting the clubs in the department of Estelí was based on the outcomes of a participatory needs assessment carried out in all six municipalities of the department. The main weaknesses identified were the following: out of the six municipalities, only three had an operational management committee; their members did not fully understand their role; 33% of the patients managed in the health centers were not registered as club members; family support was very limited. Furthermore, the meeting identified the lack of technical assistance within the clubs.

The collaborative work undertaken by Handicap International with the clubs in the department of Estelí, has enabled people living with diabetes to understand their health rights, advocate for improvements in medical care at local level (healthcare staff, local decision makers) and actively participate in awareness raising activities like walks on International Diabetes Day. Another salient point is the enhancement of internal management by the club leaders and the health authorities.



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Walk organized by people with diabetes in Nicaragua on the World Diabetes Day in 2007.

PROJECT AND CONTEXT

PROJECT IDENTITY CARD

Project: Prevention and reduction of diabetes complications in the department of Estelí.

Country: Nicaragua

Period: August 2007 - December 2009.

Expected outcomes:

- ▶ The health service users know and detect in time diabetes risk factors.
- ▶ The department of Estelí proposes higher quality medical services to a large number of people living with diabetes and their families through operational capacity building in the framework of the National Diabetes Program.
- ▶ People with diabetes understand the disease and its possible complications, and they take the necessary measures to control its development.

The department of Estelí is 140 km away from the capital city. It is made up of six municipalities. The health system in Nicaragua is in the process of restructuring with the implementation of a new health model known as the Family and Community Healthcare Model, which brings healthcare services closer to the community. In this process of care decentralization, new primary health care units have been set up. Each unit has a medical doctor and two nurses and targets around 2,500 people. The healthcare system in the province of Estelí now encompasses one reference Health Center with some beds and fifty-seven health units, one in each new administrative unit. The clubs of people living with chronic diseases and among them the clubs of people living with diabetes were reorganized according to this process of care decentralization.

PROJECT INTERVENTION LOGIC

In order to strengthen the setting up of clubs for people with diabetes, the following actions were implemented:

▶ **Needs assessment of clubs for people with diabetes in the six municipalities of Estelí**

Before initiating the intervention activities, it was necessary to understand the prevailing situation in the clubs. In this regard, six municipalities were visited in Estelí and meetings were planned with people living with diabetes in each health unit. A SWOT (Strength, Weaknesses, Opportunities and Threats) analysis was carried out in order to assess the strengths and weaknesses.

▶ **Setting up management committees in the clubs of people with diabetes in the six municipalities**

Once we understood the situation of people with diabetes, we started by reorganizing the existing management committees that were not functioning correctly and we put in place new ones where they did not exist.

▶ **Strengthening the leadership capacity of the clubs' management committees**

The Methodological Guide on the Organization and Functioning of Clubs, developed by

the National Program on Chronic Diseases, was used.

▶ **Empowering the members of clubs for people with chronic diseases**

After the first step to strengthen leadership capacity, the members of the clubs were empowered using the Methodological Guide on the Organization and Functioning of Clubs; this document contains details on the need for organizing a club and how to make it functional.

▶ **Using a joint planning, monitoring and evaluation methodology**

This methodology was used in order to improve the performance of the clubs. In this regard, the health staff members of the club met with the management committees of clubs for people with diabetes in each municipality. Together, they developed action plans. Later on, the six action plans were consolidated in order to integrate all the activities. The consolidated plan was validated by the club management committees, the healthcare personnel and Handicap International. They agreed to carry out quarterly assessments of the plan. Thereby, the management committees were able to self-assess their

own activities; they could identify problems and find solutions.

► **Experience sharing among clubs for people with diabetes**

In this regard, meetings were planned at the departmental level to bring together all the management committees in order to share experiences, testimonies and reactions with a view to making improvements to the activities.

The know-how presented hereafter results from a learning-from-experience process focusing on four key moments in the project: SWOT analysis with the groups of people living with diabetes in each of the six municipalities of Estelí; training of management committees in

the clubs for people with diabetes; experience sharing among clubs.



Leisure activities organized by a club for people with diabetes and their circle, Nicaragua.

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ANALYSIS OF KNOW-HOW: ASSESSING THE ROLE OF PEOPLE WITH DIABETES IN THE HEALTHCARE SYSTEM

Being recognized as a stakeholder in the fight against diabetes

Presenting Handicap International's actions against diabetes: In each municipality the Handicap International Team explained why the association is involved in the fight against

diabetes, and presented the project activities to healthcare staff, people living with diabetes and community leaders.

Identifying people with diabetes involved in primary health care

Getting in contact with groups of people with diabetes involved in primary health care in each municipality: The physicians in charge of

diabetes healthcare in each municipality helped us to contact people with diabetes in order to share information on the clubs.

Promoting the role of people with diabetes in the healthcare system

Encouraging the groups of diabetics to join the clubs: The Health Educators visited people with diabetes to invite them to attend a meeting organized in the health centers of various municipalities. At these meetings, Handicap International project objectives and activities and

United Nations resolutions were presented. Above all, the focus was on the need for organization in associations or clubs. The meeting was organized so that people with diabetes could have a diabetes consultation on the same day.

Defining the capacity building strategy of the local associations based on a needs assessment

Identifying the strengths and weaknesses of groups of people with diabetes in order to build a strategy to support them: During the meeting, we split into working groups in order to carry out, for each group in each municipality, a needs assessment of their organization.

Each group had to identify its strengths and weaknesses. From the outcomes of the analysis carried out in each municipality, the Handicap International team proposed a strategy to support the clubs. This strategy was presented to the Department of Health who validated it.

ANALYSIS OF KNOW-HOW: BUILDING THE CAPACITIES OF CLUBS OF PEOPLE WITH DIABETES

Revitalizing club leadership

Encouraging the management committees to revitalize: In active clubs of diabetics, some management committee members were no longer able to assume their function for personal reasons. In order to replace them, new members were elected. The previously elected members who wished to continue their activity

were confirmed in their positions. For the municipalities whose clubs were inactive, a meeting with the groups of people with diabetes was organized. They elected amongst themselves the management committee members for the municipality's diabetics club.

Facilitating benchmarking

Facilitating benchmarking: The management committees of the active clubs met to reflect

on the way they were working and on the work they were accomplishing.

Using existing tools for capacity building in the clubs

Encouraging reflection on the role of the management committee and its members: The management committee members were

empowered on running a club. As reference material, they used the guide developed by the National Program on Chronic Diseases.

Involving health professionals in the activities of the diabetic clubs

At the request of the management committees, the municipal health authorities involved a

member of the healthcare team in all the activities of clubs.

Supporting clubs to develop their activities

Providing technical, methodological and financial support to clubs for their annual plans: Handicap International, together with the municipal health authorities, supported

the clubs to develop their annual action plans. Every club defined its annual work plan according to the needs and weaknesses of each municipality.

Empowering clubs in the monitoring of their activities

Providing methodological support to the clubs in order to monitor their activities: The clubs were assisted on how to monitor the acti-

vities carried out. This support enabled them to learn the methodology of producing quarterly progress reports.

ANALYSIS OF KNOW-HOW: EMPOWERING THE CLUBS THROUGH EXPERIENCE SHARING

Promoting experience sharing

Coordinating the experience sharing meetings with the clubs and municipal health authorities: The meeting, attended by the municipal health directors, management committees, the Handicap International

team and the department personnel in charge of following-up on chronic diseases, aimed to develop the activities to be carried out within the framework of information sharing among the various clubs.

Promoting the replication of success stories

Promoting the integration of successful actions carried out by other clubs into work plans: The management committees made presentations of their experiences in organizing and success stories they developed in order to

encourage the weaker clubs to develop similar activities. After sharing experiences, each club included, in their work plans, success stories that that they would replicate in their municipalities.

Empowering clubs in their lobbying action

Supporting clubs on how to present the problems they face in terms of healthcare services: The management committees were

assisted on how to speak tactfully about the problems faced in healthcare services.

Promoting mutual knowledge between people with diabetes and healthcare staff

Encouraging the healthcare staff to understand and support the clubs' actions: By attending inter-club meetings and monthly meetings,

primary healthcare staff were made aware of the challenges faced by people with diabetes.

Writer: Dr Brenda Tapia

Supporting associations of persons with diabetes in implementing adapted physical activities

GENERAL ISSUE

It is recommended to advise and encourage persons with diabetes to take part in regular physical activity⁵. Physical activity enables people suffering from Type 2 diabetes to achieve average blood sugar levels (reducing HbA1c by 0.66%, irrespective of changes in weight), as well as a long-term reduction of morbidity and mortality and an increase in insulin sensitivity. In addition to these physical benefits to health, physical activity can have an impact on mental and social wellbeing. It can help boost self esteem, which is usually low among people living with a chronic disease, and if practised collectively, can create links between people who may otherwise be isolated or lack the courage to undertake physical activity because of their state of health. The term « physical activity » refers to everyday physical activity (housework, gardening, errands, work, walking, going up and down the stairs, travelling, etc), leisure-based sports and physical activities.

By taking part in adapted physical activity (APA), persons with diabetes are able to take exercise under medical supervision, thereby limiting the risks of high blood sugar, high blood pressure and foot injuries.

The diabetes project supported, on a pilot basis, the implementation of sports and physical activities by Bamako associations of persons with diabetes. For maximum public health impact, these adapted physical activities were also extended to people without diabetes but who were at risk of becoming diabetic, such as obese or overweight people.

The interest in capitalising upon this experience is that it is a pilot project that has called for the development of special know-how. This experience could benefit other stakeholders from associations of persons with diabetes or persons living with chronic disabling diseases in other parts of the country or in other countries.



A diabetic woman exercising on a stationary bicycle in Mali.

PROJECT AND CONTEXT

PROJECT IDENTITY CARD

Project: Improvement of diabetes prevention, care and one of the main complications: amputation of the diabetic foot

Country: Mali

Period: January 2008 - December 2009

Consortium:

- ▶ **Santé Diabète Mali** (SDM, France), NGO « Development Support, head of the project in Mali»: in charge of medical activities, information, education and sensitization on the project.
- ▶ **International Insulin Foundation** (IIF, United Kingdom): in charge of distribution of registers, data collection, drafting protocols, carrying out the survey, analysis and publishing results.
- ▶ **Handicap International** (HI, France): in charge of building staff capacity on rehabilitation of HI intervention areas, taking care of equipment and supporting diabetic patients in need of equipment, support to association.

Specific goal of the project:

Morbidity, development of complications and mortality related to sugar diabetes are reduced in Bamako district, Tombouctou, Sikasso, Mopti, Ségou, Kayes regions and Douentza area.

Expected outcomes:

- ▶ Statistical data represent morbidity and mortality related to diabetes are known.
- ▶ The level of knowledge on diabetes, its risk factors and its consequences is enhanced.
- ▶ The level of competence of the care staff in detection and diabetes care as well as the prevention of its complications, including the diabetic foot, is enhanced.
- ▶ Diabetic persons have access to quality care at all levels of care.
- ▶ Amputees following diabetic complications get support and follow-up with a view to equipping them and the rehabilitation.
- ▶ The capacity of patients and civil society to intervene through patients' associations is enhanced.

Bamako, the capital city of Mali, is an urban centre that is not conducive to walking, running or cycling due to the relative danger involved and the lack of adapted urban amenities, as well as for cultural and climatic reasons. Physical activity is therefore essentially leisure-based or sports. Some segments of the population, such as young people and privileged social categories, regularly practice a sport, the most popular being football, basketball and martial

arts. However, persons with diabetes have few opportunities to practise sports, owing mainly to limited available and adapted choices, as well as cultural and financial obstacles that limit access to these activities. Associations of persons with diabetes, through their psychosocial support role, would seem to provide an appropriate framework for the implementation of adapted physical activity.

PROJECT INTERVENTION LOGIC

This pilot project aims to promote sports and physical activities with training regimes made adapted for persons with diabetes and persons free from diabetes but who are at risk of becoming diabetic. These adapted physical activities are reserved for association members and include adapted training regimes, an initial medical check-up, and supervision by trained facilitators. Successive stages were involved in the implementation of this project:

- ▶ **Drafting of adapted physical activity guidelines** by a multi-disciplinary group

of stakeholders involved in sports and diabetes in Mali and elsewhere. These guidelines for associations of persons with diabetes outline the strategy for implementing adapted physical activities for persons with diabetes.

- ▶ **Validation and ownership of the guidelines** by means of a workshop involving partners, health professionals and the Handicap International project team.
- ▶ **Call for proposals from associations of persons with diabetes in the district of**

Bamako: the associations received prior training on proposal writing and project management. The proposals submitted by these associations included the context, the intervention logic, the implementation process, the logical framework, the timeline and the budget.

- ▶ **Identifying those persons with diabetes physically capable of undertaking APAs:** the medical examination is done by doctors specialised in diabetes selected during the guidelines validation workshop. Three of the six doctors from Bamako's referral health facilities were selected. The selection was based on the attendance rates and availability of appropriate medical equipment at their health centres.
- ▶ **Additional check-ups** are done and a medical certificate issued to anyone whose physical condition enables them to undertake the APA.
- ▶ **Training of the APA sports facilitator** from each municipality by the diabetes doctor of the selected municipalities.
- ▶ **Identification of sports halls** by the associations.
- ▶ **Purchase of adapted material** for physical activity: indoor exercise bicycle, treadmill, balls (basketball, volleyball) and bowls.
- ▶ **APA practice by association members:** three times a week in sports halls. The

activities are practised collectively under medical supervision. Blood pressure, blood sugar levels and weight are checked before and after the activity.

▶ **Project evaluation.**

The know-how described in the paragraph below is derived from an analysis of two key moments in the project: **the drafting of the guidelines**, which produced a reference document for the implementation of activities with diabetes and sports professionals, and **the workshop in which these guidelines were validated and rendered operational** by the stakeholders involved, who at the same time were able to appropriate them.



A medical doctor interviews a diabetic woman attending adapted physical activity sessions in Mali. The small bag containing sport goods allows her to go to physical activities without drawing people's attention.

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ANALYSIS OF KNOW-HOW: DRAFTING A REFERENCE DOCUMENT

Identifying the need for a reference document

Identify the need to develop guidelines on implementing adapted physical activity in collaboration with our partner: The implementation of adapted physical activities for persons with diabetes was a relatively long and laborious process. This was due to the fact that the project document contained no explanation of how to go about launching adapted physical

activities, nor were there any reference documents available on adapting such activities for implementation in Mali. During the consultations between Handicap International's team and the local NGO partner, Santé Diabète Mali, it was therefore decided to produce guidelines outlining strategies for implementing adapted physical activities in Mali.

Seeking adapted technical support

Identify and seek external expertise: After carrying out some bibliographical research and looking into the existing medical networks, various resource persons were identified and

asked to contribute towards the drafting of the guidelines. The help offered informally and free of charge by a doctor in diabetology with considerable experience in the therapeutic educa-

tion and multi-disciplinary care-management of persons with diabetes proved to be crucial. By phone and e-mail, we were able to discuss the

medical aspects of the project with this specialist, who was able to answer most of the questions that arose.

Identifying stakeholders to work on drafting the document

Identify technical partners, partner associations and professionals to work on drafting the guidelines: During the drafting of the guidelines, a “Sports and Diabetes” working group was set up. This multidisciplinary team was made up of:

- Locally: several members of the Handicap International team (namely those in charge of strengthening rehabilitation services, the Cultural, Leisure and Sports Activity Project;

and strengthening associations of persons with diabetes), a malian diabetes doctor, the director of the local partner NGO Santé Diabète Mali and two local associations of persons with diabetes.

- From abroad: professional technical advisors on disabling diseases and on sports based in France and an international expert based in Switzerland.

Defining the method to be used for drafting the document and the role of the various people involved

Define modalities for developing the guidelines and everyone’s role at each stage: Once the “Sports and Diabetes” working group was set up, it began considering the methodological approach to adopt for jointly developing a guideline. Each member of the working group’s contribution was defined according to their

skills profile. It was thus decided to entrust the drafting of the first version of the guidelines to sports and diabetes specialists and then hold a workshop involving the partner associations and beneficiaries to look at the operational aspects and ensure the guidelines are suited to the context.

Ensuring the scientific quality of the document

Entrust the drafting of the initial version to professionals and experts: The document was drawn up by diabetes and sports specialists. Those unable to physically attend the work sessions because of the distances involved took part by e-mail or telephone. These diabetes and sports professionals submitted technical and specific recommendations for adapted physical activity. Some of these recommendations concerned international medical scientific standards to be adhered to in carrying out APAs. It was decided, amongst other things, that checks should be carried out to ascertain each patient’s weight/height ratio (weight and

height: BMI <34), blood pressure at rest (BP) (<17/10) and blood pressure immediately after an effort (<200/110), pulse rate (<160/minute), the absence of wounds to the feet, the absence of acetone in the urine and random blood sugar levels (<2g/l). Once the scientific quality of the document had been assured by the professionals, the other stakeholders focused on recommendations for ensuring the document was adapted to the realities on the ground and the feasibility of the activity for the future beneficiaries (members of associations of persons with diabetes).

Obtaining external professional support

Involve an expert in therapeutic patient education for persons with diabetes: Professor Assal, who is based in Switzerland, assisted with the drafting of the document from a distance since his travel and work commitments made it difficult for him to come to

Bamako. He therefore contributed to the work of the “Sports and Diabetes” working group by communicating through a single medical contact at Handicap International. His invaluable expertise was offered free of charge.

Considering sustainability issues at document-drafting stage

Seek to reduce costs and the complexity of implementing APA: To ensure that the adapted physical activities can continue once the project comes to an end, the drafting team made sure they included recommendations in the guidelines that would make it possible to carry out low-cost activities and simplify their implementation as much as possible. For example, the diabetes specialists confirmed that patients

on glibenclamide and gliclaside could practice APA without any major risk, and that it was not absolutely necessary to check the blood sugar levels before and after every session for patients making regular follow-up visits to their doctor. The reason for including such advice in the guidelines was to ensure the sustainability of the activities, which might otherwise be too costly to continue after the end of the project.

ANALYSIS OF KNOW-HOW: VALIDATING THE WORKING TOOLS WITH ALL THE STAKEHOLDERS INVOLVED

Adopting a strategy that ensures everyone's ownership of the tools

Get the guidelines approved by the project partners: Drafting the first version of the guidelines was a long and complex undertaking carried out by diabetes and sports specialists. This initial version already outlined the roles of the different stakeholders whose input would be required in implementing the adapted physical activity (APA) project: Handicap International, diabetes doctors and associations of persons with diabetes in the district of Bamako. However, although the requirements and guide-

lines to follow during APA sessions were based on the concrete experience of the drafting team members, they remained theoretical. It was therefore decided to organise a guidelines validation workshop that would bring together all the partners and all the stakeholders mentioned in the guidelines (except the APA facilitator, who had not yet been identified) in order to share with them and hear their proposals for making them operational.

Establishing criteria for selecting the facilitator

Choose the right person to facilitate the guideline validation workshop: The choice of the guideline validation workshop facilitator was fundamental and had to be done with care. Professor Sidibé Assa Traoré was approached for several reasons. First, she had participated in the whole drafting process, including the final meeting to approve the recommendations in October 2008. She was therefore fully

familiar with the content of the document, as well as with all the people involved in the drafting process. The project team also needed a diabetes specialist to present the desired outcome of the adapted physical activity and to personally endorse the simplified medical follow-up proposal for participants in the adapted physical activities.

Adopting a facilitation method that allows everyone to participate

Set objectives and adopt a facilitation method to ensure doctors and association leaders fully participate: The project team presented the facilitator with a draft version of the terms of reference for the workshop, which contained, among other things, the project objectives with regard to adapted physical activity and the expected outcomes of the workshop. It was crucial to adopt a coherent

and efficient facilitation method with Professor Sidibé Assa Traoré so as to ensure the diabetes doctors and association leaders could participate fully in validating the guidelines. We therefore prepared a detailed programme, for the workshop which included a presentation on diabetes, a presentation of the guidelines and the results of the group work and then a general summary.

Seeking the participation of institutional partners

Invite diabetes doctors from the referral hospitals and health centres in the municipalities within the district of Bamako:

Getting diabetes doctors involved in the project was a priority right from the start. Their help was sought in setting up the associations of persons with diabetes and also in training these associations. We also wanted them to take

part in the guideline validation workshop. We therefore sent them individual invitation letters through their referral health centres before speaking to them personally to convince them that their participation in validating the guidelines was vital as the document was part of the tools which would be used in implementing the APAs.

Seeking to involve association partners

Invite leaders of Bamako's associations of persons with diabetes:

This guidelines validation workshop was an excellent opportunity for bringing together leaders of associations of persons with diabetes from every municipality in the district of Bamako. Furthermore, these guidelines defined their role in implementing the adapted physical activities and it was crucial to

inform them all at the same time so that they could all actively participate in the validation process. To ensure the associations' participation, we first informed them of the objectives of the workshop before contacting them again to stress the importance to them of implementing these activities, as they are both stakeholders in and beneficiaries of the project.

Providing stakeholders with sound knowledge of the subject

Begin the workshop with an introduction to diabetes and the importance of physical activity in the care-management of persons with diabetes:

The workshop facilitator, Professor Sidibé Assa Traoré began with an introduction to diabetes: risk factors, causes, clinical symptoms and the most frequent complications and consequences. This presentation was much appreciated by members of the associations of persons with diabetes, who said it provided them with new information, especially with regard to

managing diabetes. The presentation particularly emphasized the role of adapted physical activities in the prevention of diabetes and the care-management of persons with diabetes. This provided an opportunity for explaining the relevance of adapted physical activities in the diabetes project and highlighting the ways in which they are complementary to the other activities that Handicap International is implementing within the associations of persons with diabetes.

Present the content of the document to partners

Share the guidelines with the participants:

Each of the participants (diabetes doctors, leaders of associations of persons with diabetes), who did not know about the guidelines before the workshop, were given 15 minutes to read the document before sharing their reflections with the rest of the group. Then Professor Sidibé Assa Traoré answered any

questions. The project team then went on to explain the desired outcome of this project that Handicap International was implementing on pilot basis. Thus we were able to hold discussions with the association leaders on the issues involved, the success and risk factors, as well as the importance of empowering them as project beneficiaries.

Defining a facilitation method adapted to the objectives

Organize group work to ensure the recommendations for putting the activities into operation are applicable in all the municipalities:

The objective of the workshop was to gather concrete proposals on how to make the guidelines operational and ensure that the

adapted physical activities are kept as simple as possible while guaranteeing the required and necessary medical follow-up. To do this we formed working groups. All these groups included a doctor and people with diabetes who did not reside in the same municipality as

the doctor's practice. The aim was to come up with a system that would be applicable to all the municipalities. The instructions for each group were to design a concrete APA implementation plan from beginning to end, including the choice of venue, the types of activities, the number of sessions per week, prior medical check-ups,

issuance of medical aptitude certificates and the length of validity of these certificates, the duration of each session, etc. This was also a way for participants to meet members of other municipalities and share information on the improvement of diabetes healthcare services.

Drafting recommendations using a participatory approach

Summarise the outcomes of the group work collectively: Each group presented its work to the others, explaining the thinking behind each proposed recommendation. The recommendation was then accepted or rejected by a raising of hands. The summarized outcome of the group work was therefore the sum of the collective recommendations. The next steps were determined in this way: identifying APA participants, the types of physical activities,

organizing medical visits, the choice of APA facilitators, the number of sessions per week, the possible time-table, etc. These aspects complied with all the compulsory aspects of the guidelines, such as the inclusion criteria, the type of medical visits, the type of checks (blood sugar, blood pressure, weight checks) before and after each session, the obligation to have an emergency kit available during each session, etc.

Producing a working tool via the collaboration of all the participants

Make the workshop report a working tool to be used by all participants: Given the importance of the workshop and its expected outcome, a report was prepared based on notes taken during the workshop. The report was approved by the facilitator. This report gave Handicap International a clear vision of the support needed by the associations for implementing adapted physical activities (APA),

especially with drafting APA project documents. This report was then distributed to the workshop participants. For the association leaders, this validation workshop report became an annex to the guidelines, while for the diabetes doctors, it became a tool for ensuring that the APAs are correctly implemented in each municipality in the district of Bamako.

Writer: Dr Fatouma Dicko

Carrying out a study for a disabling disease project

GENERAL ISSUE

Handicap International frequently carries out studies for its projects in order to further assess a situation or evaluate an activity that has been carried out.

Carrying out a study is an activity of **great importance** in terms of **quality** of our activities, on the one hand, as they are better assessed or better adapted to needs, and in terms of **visibility** of Handicap International on the international scene, on the other hand, as studies often present an opportunity for talking about a project. The findings of a study often **determine activities planned thereafter**, like campaigns to create awareness within a population about a disease or policy advocacy activities. However, we should admit that a study is **an undertaking full of perils** as it is difficult to organize and carry out. If the quality criteria are not met, there is a great **danger** of obtaining useless data. Therefore, there is need to take specific precautions in order to **increase the chances of success**.

Handicap International has a long experience in carrying out frequent studies in all its areas of intervention.

For all these reasons, exchanging what has been learnt from experience by carrying out studies therefore seems of particular interest and aims to **promote methodological culture**, which is at times removed from the operational culture of the project teams and their local partners.

What is more particularly of interest to us in this case is the implemented know-how so that we are able to include the requirement to write an article as a deliverable in the terms of reference of various studies.

This document was written from the point of view of the technical advisor whose role includes providing technical support, both from abroad and during missions, to those we work with in the areas of intervention and assure quality of the implemented projects.

PROJECT AND CONTEXT

STUDIES IDENTITY CARD

Types of studies:

- ▶ Nutrition studies.
- ▶ Knowledge, attitude and practice studies.
- ▶ Studies on professional practices in care and the state of health of the patients before and after implementation of the project.

Subject: Diabetes, Lymphatic Filariasis, Buruli ulcer

Countries: Madagascar, Burkina Faso, Togo, Philippines, Nicaragua

Study period: 2006 - 2010

Study objectives:

- ▶ Better awareness of knowledge and perception of diabetes by the general public as well as people's dietary habits.
- ▶ Studying the people's dietary habits.

- ▶ Studying communication channels within a community in relation to lymphatic filariasis.
- ▶ Improving the quality of activities for early detection of suspect cases of the Buruli ulcer within the community.
- ▶ Assessing the effectiveness of projects aimed at enhancing medical care services for diabetes.

Expected outcomes :

- ▶ Recommendations for adopting a project implementation strategy (education and sensitization on a given disease, early detection of cases) or for reviewing the implementation strategy.
- ▶ Writing of reports and articles for dissemination within the scientific community to carry out advocacy among health workers and health authorities for the improvement of the quality of healthcare.

Unique aspects of the intervention context

The unique aspects of the intervention context are closely related to the fact that **resources are limited**, and consequently, data collection often proves to be **complex**, even for relatively simple data like weight and height.

However, the **methodological approach**, and to a larger extent, the culture of **clinical research** or **evaluation**, is **not widespread** among health workers, as compared to the practice in developed countries. In addition, **free access to data obtained through biomedical or public health research** in developing countries is rather recent and the habit of referring to this data has **not yet** been

adopted in many countries. This failure to refer to study findings can also be explained by the fact that **few studies** have been carried out within a context of limited resources and therefore the findings of most studies are not applicable in such a context. Finally, project teams have **skills** in project management and in the relevant technical areas, but **rarely in research methodology**.

All these unique aspects point to the choice of studies with non innovative methodologies but are simple and well adapted to the locally available resources.

INTERVENTION LOGIC

In keeping with the positioning and practices of Handicap International, we have tried to **call as much as possible upon local resources** to carry out the study. Depending on the contexts, these local resources were public research agencies or consultants, with generally a lot of linkages within these circles. The expression of **demand** and **follow-up** of the study were both done by the **project team**.

The activities were implemented following a series of successive stages:

- ▶ Determining our expectations of the study and drafting the terms of reference
- ▶ Recruiting the consultant
- ▶ Discussing the technical offer with the consultant
- ▶ Having commissioned the study, supervising the study as carried out by the consultant
- ▶ Discussing with the consultant the submitted report on the study
- ▶ Approval of the final report by our team
- ▶ Handover of the study findings by the consultant

- ▶ Using the study findings
- ▶ Internal communication of the study findings
- ▶ Publishing an article in a professional journal

Publishing an article in a professional journal is essential as it makes it possible to disseminate the study findings within professional circles, thereby influencing practices. There are more chances of successfully publishing in a professional journal if there was planning well in advance during the drafting of the terms of reference for the study. Indeed, the final report of a study cannot be used directly for the purposes of professional publication as the format is not suitable. The report needs to be transformed into an article, which requires a lot of work. Writing an article should therefore be explicitly required of the consultant during the initial commissioning.

In this document, we have focused our know-how analysis on this special key moment: including the writing of a scientific article among the deliverables of a study.

Évaluation de l'état de santé des patients diabétiques en ambulatoire dans les centres de soins primaires. 2008 - Estelí, Nicaragua, Amérique centrale. Étude transversale.

Introduction



Le diabète est une cause majeure de handicap à travers le monde. On estime que la prévalence du diabète atteignait 9 % au Nicaragua en 2003¹. En partenariat avec le ministère de la Santé, Handicap International (organisation non gouvernementale internationale) a mis en œuvre un projet de prévention et de réduction du taux de complications du diabète dans le département d'Estelí, Nicaragua. Dans le cadre de ce projet, une étude épidémiologique préliminaire a été réalisée en 2008 afin d'évaluer l'état de santé des patients diabétiques en ambulatoire.

Objectif

Déterminer le niveau de régulation glycémique, le taux de complications et les facteurs de risque cardiovasculaire chez les patients diabétiques en ambulatoire dans les centres de soins primaires de la région d'Estelí, Nicaragua

Méthode

Une étude transversale a été réalisée en 2008 auprès de 313 patients diabétiques en ambulatoire, choisis au hasard sur la liste des patients des centres de soins primaires. Les personnes sélectionnées devaient justifier de quatre consultations au cours de l'année précédente, témoignant d'un suivi médical régulier. Chaque patient a répondu à un questionnaire avant de subir un examen médical et des analyses biologiques, notamment un examen ophtalmologique, neurologique et podologique, un dosage de l'HbA1c, un bilan lipidique, un test de glycémie à jeun, un test de glycémie postprandiale, une mesure de la créatininémie et une recherche de microalbuminurie.



Résultats

CARACTÉRISTIQUES DE LA POPULATION PRINCIPALE (2008)

Femmes	66,0 %	[61-71]
Plus de 40 ans	90,0 %	[87-93]
Diabète de type 2	91,0 %	[88-93]
Plus de 10 ans	73,0 %	[68-78]

FACTEURS DE RISQUE CARDIOVASCULAIRE (2008)

HbA1c supérieur à 7 %	76,0 %	[71 - 81]
HTA	60,0 %	[55 - 65]
Crise cardiaque	4,0 %	[2 - 7]
Surpoids 25 - 29	17,0 %	[16 - 24]
Obésité 30 - 99	55,0 %	[53 - 64]
Hypercholestérolémie	31,0 %	[28 - 36]
Tabagisme	7,0 %	[4 - 10]
Angine de poitrine	4,8 %	[2 - 7]

COMPLICATIONS CHRONIQUES DU DIABÈTE (2008)

COMPLICATIONS	POURCENTAGES
Rétinopathie	39,2 % [34 - 45]
Cataracte	29,0 % [24 - 34]
Glaucome	20,0 % [16 - 24]
Angine de poitrine	4,8 % [2 - 7]
AVC	1,0 % [0 - 2]
Neuropathie des membres inférieurs	58,6 % [53 - 64]
Claudication intermittente	39,2 % [34 - 45]
Ulcère chronique du pied	12,4 % [9 - 16]
Amputation	5,1 % [3 - 8]

Conclusion

La prévalence des complications chroniques identifiées dans le cadre de cette étude est globalement comparable à celle des autres études cliniques². Nous avons cependant remarqué que le taux d'amputation était supérieur aux données de la FID (4,8 %) ³. La prévalence élevée d'une régulation inadéquate de la glycémie (24 % de HbA1c > 11 %) laisse prévoir de nouvelles complications au sein de ce groupe de patients. Il faut améliorer la qualité de prise en charge du diabète dans les centres de soins primaires, notamment les soins ophtalmologiques et la prise en charge du pied diabétique



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† Ministère de la Santé, 2007

³ 2006. FID. Atlas du diabète

Crédits photo : © Ana Martinez/ Handicap International



Poster presenting survey results of health condition for people with diabetes carried out in Nicaragua in 2008, displayed during the World Diabetes Congress in Montreal, in 2009.

ANALYSIS OF KNOW-HOW: CLEARLY STATING THE STUDY DELIVERABLES

Collectively analysing the working approaches

Discussing with colleagues (people who do the same work): As a technical advisor, whenever I had to help project teams prepare for their studies, I held frequent discussions with other technical advisors who had had similar experiences to seek advice and solutions to problems I faced. Simply talking about a situation often improves one's appreciation of it. Thus the questions my peers asked me helped to better analyse what had happened in retrospect and the reasons why some previous publi-

cation projects did not succeed. These discussions were often informal in nature (talking face to face, e-mails) and at times formal in nature (meetings, writing documents). The informal discussions within small committees are sometimes conducive for analysing practices due to the atmosphere of trust that prevails in them. Later on, putting this analysis in writing helps to clarify the working approaches. Writing is also fundamental as it creates institutional memory.

Learning from previous experiences

Analysing the reasons for failure or success of past studies helped us to become aware of the areas that require caution. The assumption in learning from experience is that the mistakes that are sometimes made are accepted and the causes of these mistakes analysed. For success, this approach should be considered as a formative evaluation, aimed at improving

everyone's performance and not apportioning blame. Although it is sometimes painful to make actors relive events considered as failure, analysis can also be a source of relief and optimism when it helps to identify solutions that will ensure that failure does not recur. Presentation of success is also vital and raises a number of new aspects of understanding.

Anticipating and constantly keeping the ultimate goal of a project in mind

Identifying aspects that can be used in a publication well before carrying out the study: Carrying out a literature review helps to identify similar articles on the same disease based on the same methodology, or even

concerning the same geographical area. This aspect of research helps to identify aspects that are potentially innovative and which stand a greater chance of being published.

Mobilizing various contributors as soon as preparations for the study begin

Follow a joint process in the drafting of the terms of reference for the study: Preparing a study requires various skills. This involves calling upon several contributors. To many, drafting the terms of reference is complex and requires both a proper division of roles and joint planning of the collaboration. It is important to think of the role of every professional involved, depending on everyone's duties and skills. If it is thus properly understood, contributions are

not limited to critical re-reading but to contribution of additional elements. It is also essential right from the start that the writer who initiates the drafting of the terms of reference adopts an attitude of co-constructing a document and not of simply approving a half-baked document. Indeed, at an advanced stage of writing it is often difficult to reverse the basic choices that have already been made.

Sharing an understanding of the issues

Discussing the impact of publishing findings of a study as a team: The issues in a study are different depending on the level at which every member of the team works. Therefore, at the local level, operational issues, such as the

impact of the study on implementation, come first, while the predominant issue at the macroscopic level is to contribute to the development of professional approaches in the prevention and control of disabling diseases. Discussion

between various members of the project team enables everyone to look at the issues in a professional publication as a whole and thereby buy into the idea of an article. It also helps to

identify an external problem of contributing to the development of the professional field in addition to the problem of improving the quality of our interventions

Being clear on the expected format

Giving the consultant a model to follow and recommendations for writing the article: Now we add a model article as well as recommendations to authors of a recognized journal⁶ as an appendix to the terms of reference for the study. This serves as an example for the consultant,

who will thus clearly understand our expectations. The recommendations to the authors are often very demanding and therefore play a role of quality standard for the expected article. This serves as a methodological guidance well before the work.

Writer: Dr Pauline Guimet

6. The practice in biomedical journals is to provide the authors with recommendations for writing the articles.

For further information on Handicap International's diabetes activities, consult:

- ▶ CORRE Gilles. **Diabetes, a developing disease**. Paris: Sanofi-aventis, 2009.- 40 min.
Video available in short version, in English:
<http://www.sanofi-aventis.tv/thechannels/diabetes-prevention-first/s84-277-en>
Video available in short version, in French:
<http://www.sanofi-aventis.tv/leschaines/le-diabete-une-maladie-en-developpement/s83-276-fr>

- ▶ GUIMET Pauline. **Le diabète : une maladie peu connue et mal comprise**, in Bulletin de Medicus Mundi Suisse, n°115, February 2010
<http://www.medicusmundi.ch/mms-fr/services/bulletin>

- ▶ PASQUIER Estelle, GUIMET Pauline. **Needs assessment to develop diabetes control and prevention projects: a guide for international non-governmental organisations**. Lyon: Handicap International, 2009.- 73 p.
Available in English:
<http://www.handicap-international.fr/fileadmin/documents/publications/GuideDiabetEN.pdf>
Available in French:
<http://www.handicap-international.fr/fileadmin/documents/publications/GuideDiabete.pdf>
Available in Spanish:
<http://www.handicap-international.fr/fileadmin/documents/publications/GuideDiabeteES.pdf>

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What this paper is about...

This analysis paper presents the know-how used by Handicap International in its diabetes prevention and control projects. Its purpose is to serve as a source of inspiration for other diabetes projects and is mainly intended for teams in the field.

A number of the organisation's diabetes project teams have been engaged in a process of learning from experience and they met to share this experience at a seminar organised in Nairobi in December 2009. This paper is the outcome of the learning-from experience work carried out prior to the seminar, enhanced by the exchanges and discussions that took place during the seminar.

In terms of contents, after a presentation of Handicap International, its diabetes-control activities and the learning-from-experience process, you will find six know-how analysis sheets based on the themes selected by the teams:

- ▶ Mobilizing stakeholders to organise a symbolic event (Burundi)
- ▶ Bringing services closer to communities (Kenya)
- ▶ Supporting the decentralization of diabetes care (Philippines)
- ▶ Strengthening "clubs" of people with diabetes (Nicaragua)
- ▶ Supporting associations of persons with diabetes in implementing adapted physical activities (Mali)
- ▶ Carrying out a study for a disabling disease project

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