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Fighting against epilepsy in Rwanda: An efficient patient-centred experience

From the Rwanda experience 2008-2012



Handicap International

“Handicap International is an independent and impartial international aid organisation working in situations of poverty and exclusion, conflict and disaster.

Working alongside persons with disabilities and other vulnerable groups, our action and testimony are focused on responding to their essential needs, improving their living conditions and promoting respect for their dignity and their fundamental rights.”

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Key figures

WHO

50 millions people worldwide have epilepsy

90% cases in developing countries

70% could be successfully treated

90% cases in Africa remain untreated

WHO's recommended treatment cost

5\$ per year

70% cases can stop treatment after 5 years

1,5% epilepsy prevalence in Sub-Saharan Africa

4,9% epilepsy prevalence in Rwanda

This brief aims to summarize a learning-from-experience process.

It was lead on the Rwanda project of care access and integration of epileptic people in 2012. Handicap International has identified this pilot project as efficient and wishes to highlight the key elements of success to enable its sustainability and its replication possibilities. The result of this process is fully developed in the document of the same name.

It is intended for the different stakeholders involved in the fight against epilepsy: government structures, national and international associations and NGOs.

In Rwanda, it is meant to support the continuation and standardisation of the intervention on a national scale. By sustaining the know-how and best practices developed during the project, while taking into account the lessons learned.

Epilepsy is fully part of Handicap International scope of activity.

It is a public health problem, as a disabling disease causing mental, intellectual and physical deficiencies. It is a stigmatizing condition denying the patient access to education, social and economic opportunities.

Epilepsy is the name for a group of brain disorders characterized by seizures. It is the most common serious neurological disorder, and can affect anyone. The majority of people with epilepsy under treatment can be seizure-free. Discrimination and stigmatization affecting people suffering from epileptic disorder in the whole world are often more difficult to overcome than the seizures.

Causes: mostly from brain damage due to infections, trauma, stroke, brain tumour or development abnormalities. In many individuals it remains unknown.

Why a project on epilepsy? Following the WHO survey stating the epilepsy prevalence at 1.5% in Sub-Saharan Africa, Rwanda carried out a national survey with the support of WHO and Coopération Technique Belge. It revealed a 4.9% prevalence. The Ministry of Health organised a conference to raise international partners awareness. Handicap international, present in the country for over 17 years, proposed the project and obtained fund from the European Union.





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Project Datasheet

Name

Promotion of access to medical care and education, family and community inclusion of children with epilepsy in Rwanda

Country

Rwanda - Rusizi, Gisagara, Ngoma and Rutsiro districts

Project duration

Jan. 2008 - Feb. 2012

Objective

People with epilepsy get appropriate medical care and are included in their families and communities.

Total Budget of the project and main donors

895 584 €: 75% European Commission
7% Handicap International
18% Foundation Symphasis

Stakeholders Datasheet

HI Team 1 project manager, 1 mental health nurse, 1 management 1 psychosocial 1 advocacy and 1 technical advisors.

Partners 2 already active Rwandese associations Institutional Ministry of Health, Camerwa, District and sector authorities

Professionals from Health facilities, schools

Community CHW, beneficiaries and entourage, pupils and parents, influencers (religious leaders, healers, opinion leaders, etc.)

Project results:

- 6 338 person identified
- 4 390 are under medical treatment in 16 districts
- Over 460 trained health professionals
- 415 traditional healers and 563 religious leaders educated on epilepsy
- Over 4 500 Community Health Workers (CHW) mobilised, trained
- 75 psycho-educational groups are created and operational
- Camerwa/ pharmacies/ health institutions provided with antiepileptic drugs
- 931 epileptic pupils are integrated into regular primary schools
- 6 hospitals are supervising the 85 health centres
- Advocacy actions are taken into consideration through mass media and official events
- Rwandan League against epilepsy is created and operational

Strategy and Intervention methods

Handicap International has adopted an **inclusive, multidisciplinary and community-based global approach**.

Empowering the local stakeholders thus ensuring the sustainability of the interventions.

5 intervention methods:

Developing capacities of health professionals working in reference facilities and primary health centres to ensure that epilepsy is integrated in primary health care.

↳ By a serie of cascade trainings.

Ensuring access to antiepileptic drugs, especially since drugs solution exists and can be distributed at an affordable price (phenobarbital = 1st category drug according to WHO).

↳ By funding the first batch and starting a sustainable supply process.

Raising awareness within the community by relying on available resources in order to educate people with epilepsy, their entourage and the whole community, to improve medical care provided and to fight against stigma.

↳ Through all the project stakeholders and IEC techniques.

Ensuring top level political commitment in order to ensure that epilepsy remains among the priorities and to ensure that drug supplies will continue over time.

↳ By involving them every step of the way.

Encouraging politicians to develop and to implement programmes that fight against epilepsy through **the civil society mobilisation and advocacy initiatives**.

↳ By supporting the creation of a National League Against Epilepsy



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Focus: The Community-Based Approach



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The team relies on existing resources of the community to improve patients' care and fight against the stigma. **Attitudes must be changed, starting with the patient and his environment.**

The goal is not to replace but to reinforce medical services through the involvement of Community Health Workers, community influencers, the patient and his entourage in providing basic prevention support and medical care. Thus, reducing social and economic consequences.

Objectives

To change the perception and the attitude of the community towards epilepsy and epileptic people and thereby overcome stigma

To change the perception of epileptic people on the disease: self esteem, treatment compliance, inclusion (at all the levels: school, social, cultural, economic, etc.)

Challenges encountered in the community

- Stigma over the disease and the patient
- Lack of will among the stakeholders
- Lack of knowledge
- Inadequate medical care
- Extreme poverty

Solutions and Know-how developed

Building a sustainable community-based dynamics

By training volunteers within the community to identify and refer suspected cases of epilepsy

Addressing the root causes of stigma

By raising community influencers' awareness

Providing psychological and education support to the beneficiaries and their entourage

By implementing psycho-educational groups.

Bringing an effective response to beneficiaries and volunteers economic inclusion

By training CHW cooperatives and psycho-educational groups to Income Generating Activities

The community-based approach strengthens the action by considering the patient's environment. It addresses people needs on a larger scale, ensures their participation and inclusion in society, and improves their quality of life. Through psychosocial support, therapeutic education, empowerment of epileptic people's associations, advocacy for access to services etc.



Perception key figures

From the 2005 Rwanda, OMS and CTB study *

Perception

- 53% believe that epilepsy is a possession of evil spirits
- 32 % believe that epilepsy comes from a curse or a spell
- 87 % are afraid of a person with epilepsy.
- 51 % cannot live under the same roof than an epileptic person

Treatment

- 25 % believe that only traditional healers can cure epilepsy.
- 52 % do not believe in modern treatment using antiepileptic drugs.

Social and occupational inclusion

- 66% believe that an epileptic person should not get married.
- 69 % believe that an epileptic person should not appear in public places.
- 73 % believe that there are specific tasks epileptic persons should not perform.
- 66% believe that epileptic persons cannot go to school.

*« Prévalence de l'épilepsie au Rwanda : connaissance, perception et attitudes de la population et des professionnels de la santé »
F. SEBERA et H. NYIRAMAZAIRE, 2006, Ministère de la Santé, OMS et Coopération technique Belge (CTB)

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Stories around the project

“An epileptic seizure is very impressive, people are scared and run away. Nowadays, when they see traditional healers or CHW hurrying to assist someone, they understand that epilepsy is not contagious. They are no longer afraid.”

“We have created a committee for home-visits, we advocate in administrative meetings about the efficiency of the treatment. We also visit teachers who refuse to welcome epileptic children.”

Rebecca, Group Pdt in Rustiro

“I was not considered as a human being before but now, some colleagues do not even know that I suffer from epileptic disorder. And people respect us from the mere fact of meetings”

Anastase, Group Pdt in Ngoma

«Epilepsy is a unique-need disorder: medical and family care. It is above all a community-based action, it does not require hospitalisation or major surgery. The most important thing is to strengthen the community knowledge.»

Dr Ntilivamunda, Director of Murunda hospital, Rutsiro district.

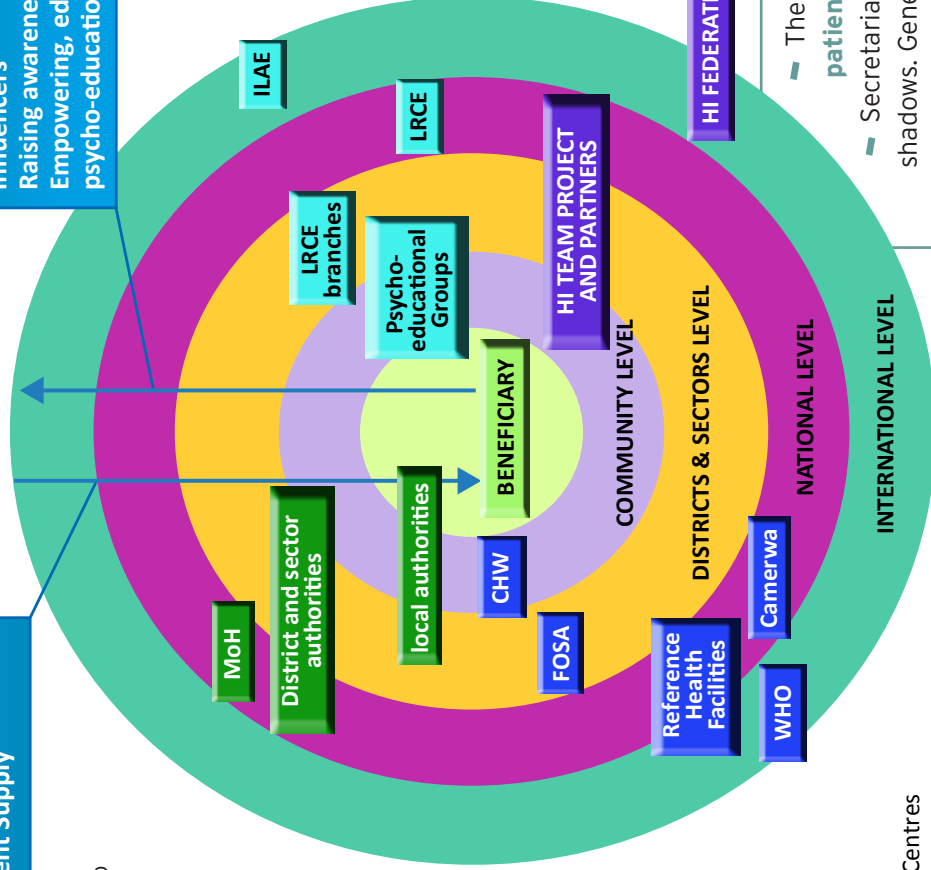
« This community-based approach, starting from and around the person, is extremely interesting. It mobilises people from their home to the care level, goes up instead of only imposing from top down. Promoting knowledge and understanding is very positive and meaningful.»

Claire Nancy Misago,

Head of « Social mobilisation and community intervention» division in MoH

Bottom-up :
COMMUNITY-BASED APPROACH
 Mobilising Civil Society and influencers
 Raising awareness - IEC
 Empowering, educating through psycho-educational groups

Top-down :
 Involvement of Authorities
 Capacity building (trainings)
 Treatment Supply



To learn more

- The full document **Fighting against epilepsy in Rwanda: An efficient patient-centred experience**
- Secretariat of ILAE/IBE/WHO. Global Campaign Against Epilepsy out of the shadows. Geneva, World Health Organization 2003.
- WHO factsheet on Epilepsy: www.who.int/mediacentre/factsheets/fs999/fr/index.html#
- « Prévalence de l'épilepsie au Rwanda : connaissance, perception et attitudes de la population et des professionnels de la santé » F. SEBERA et H. NYIRAMAZAIRE, 2006, Ministère de la Santé, OMS et Coopération technique Belge (CTB)
- A larger bibliography is provided in the complete version of the document.

- CIVIL SOCIETY**
- MEDICAL**
- POLITIC**
- HI**

FOSA= Hospitals and Health Centres
 CHW = Community Health Workers
 WHO = World Health Organisation
 LRCE = Ligue Rwandaise Contre l'Epilepsie
 ILAE = International League Against Epilepsy
 MoH = Ministry of Health

Including Divisions: Mental Health, Pharmacy, Community-based Health