



# IMPACT OF REHABILITATION CARE ON THE SOCIAL INCLUSION OF PEOPLE WITH DISABILITIES IN TOGO:

**Survey of 30 lower limb amputees** 











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The statements in this report reflect the views and perceptions of the respondents and should be considered as such.

Although the author is working in the rehabilitation field and has a very good professional relationship with the entire staff of CNAO-RF, he has tried to be objective and to express the views of the respondents in an impartial way.

## **CONTENTS**

ABBREVIATIONS AND ACRONYMS	4
1-INTRODUCTION	8
2- CONCEPTUAL FRAMEWORK	8
2.1- OPENING QUESTION	
3- PROTOCOL OF THE STUDY	
3.1- PEOPLE SURVEYED 3.2- AREA OF THE SURVEY 3.1.1- Inclusion Criteria 3.1.2- Exclusion criteria 3.2- DATA COLLECTION TOOLS 3.2.1- Interview guide 3.2.2- Social status assessment grid 3.3- DATA COLLECTION METHOD	
4. THE RESULTS	15
4.1- The ELIGIBILITY RATE 4.2- CAUSES OF AMPUTATION	
CNAO-RF	
6- DISCUSSIONS	27
7- PROPOSALS	29
CONCLUSION	30
8- APPENDICES	31
8.1: Interview guide	32
BTBI TOGRAPHY	38

## **Abbreviations and Acronyms**

**CNAO-RF**: National Orthopaedic and Physical Disability Rehabilitation Centre **CRAO-RF**: Regional Orthopaedic and Physical Disability Rehabilitation Centre

**DCP**: Disability Creation Process

**FETAPH**: Togolese Federation of Disabled People's Organizations

HI: Handicap International

**NGO:** Non-Governmental Organization

RIPPH: Réseau International sur le processus de production du handicap

(International Network on the Disability Creation Process)

TA: Traffic Accident

**UNO**: United Nations Organization

WB: World Bank

#### **Préface**

Pour n'importe quel être humain, l'intégration sociale est au cœur de nos efforts individuels et collectifs pour améliorer constamment notre bien-être et vivre avec dignité dans nos communautés.

Cette étude sur l'impact de la réadaptation fonctionnelle contribuant à l'inclusion sociale des personnes handicapées au Togo est une des premières qui utilise le Processus de Production du Handicap (PPH) comme base conceptuelle dans le contexte Ouest Africain. Le Processus de Production du Handicap est un modèle qui présente le handicap comme un processus dynamique et complexe avec lequel ce ne sont pas seulement les incapacités qui définissent le handicap d'un individu. À ce titre, la réadaptation concernant la santé joue un rôle important, mais non unique, dans l'inclusion sociale de la personne. L'étude utilise une méthodologie scientifique rigoureuse pour recueillir des renseignements précieux sur les obstacles et les facilitateurs que rencontrent les personnes handicapées. Ainsi cette méthodologie pourrait être utilisée dans divers contextes de développement pour produire des preuves comparables et utilisables pour mesurer l'impact, planifier des programmes et mobiliser les ressources.

Le point d'entrée, la réadaptation fonctionnelle, a une importance particulière pour les équipes de Handicap International et leurs partenaires. C'est, en effet, incontestablement une de nos contributions les plus significatives pour surmonter les barrières de l'insertion sociale des personnes handicapées dans les pays où nous travaillons.

Susan Girois - Directrice de la Division des Ressources Techniques - HI

#### **Preface**

For any human being, social inclusion is at the heart of our individual and collective endeavours to constantly improve our well-being and to live with dignity in our communities.

This study on the impact of health-related rehabilitation as a contributor to social inclusion for people with disabilities in Togo is among the first of its kind to use the Disability Creation Process as a conceptual basis in the West African context. The Disability Creation Process is a model which represents disability as a dynamic and complex process whereby an individual's impairments alone do not define his/her disability. As such, health-related rehabilitation plays an important, but not singular, role in the person's social inclusion. The study uses a rigorous scientific methodology to collect valuable information on the obstacles and facilitators faced by people with disabilities. As such, this methodology could be used in a broad range of development contexts to generate comparable evidence for use in measuring impact, programme planning and resources mobilisation.

The entry point, health-related rehabilitation, is of particular importance to Handicap International teams and partners, as this is undeniably one of our most significant contributions to overcome barriers to social inclusion for people with disabilities in countries where we work.

Susan Girois - Director, Technical Resources Division, HI, Lyon, France.

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- ❖ Messrs. Franck Flachenberg, Patrick Jullien, and Agnès Pierre at HI Lyon
- The staff of HI Togo
- The staff of CNAO-RF
- Mrs. Rozenn Botokro, West Africa Rehabilitation Advisor, HI
- Dr. Christian Mésenge, Director of the Health Department, Senghor University

Finally, we express our gratitude to all those fitted with orthopaedic devices who warmly welcomed us into their homes and gave up some of their valuable time for the interviews.

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# IMPACT OF REHABILITATION CARE ON THE SOCIAL INCLUSION OF PEOPLE WITH DISABILITIES IN TOGO:

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Study report presented by

TUBLU Yawovi Enyonam Melagbe

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2009

#### 1-Introduction

Nearly 20% of the poor in the world are persons with disabilities [1]. To them, poverty is both a cause and a consequence of their marginalization and exclusion.

The exclusion and the stigmatizing of persons with disabilities is not a new problem. In ancient times, disability was seen as a curse, and in the seventeenth century it was categorized as pathological and abnormal [2]. Of course, nowadays these representations are no longer so blatant, but ignorance and superstition are still barriers that isolate people with disabilities. The caricature of Charles Gadou [3] reflects the situation faced by people with disabilities in our societies: "Neither outsiders nor insiders. Neither found guilty nor treated as innocent, because they are embarrassing and responsible for disturbing the tranquillity of a society that dreams of men and women without defects. Neither slaves nor full citizens neither entirely subjugated nor free".

These sociocultural constraints constitute obstacles to the self-fulfilment of people with disabilities. In awareness of this situation, national and international organizations have campaigned for the greater social participation of persons with disabilities. From the International Year of Disabled Persons (1981) to the signing of the Convention on the Rights of Persons with Disabilities (2007), many efforts would appear to have been made.

In Togo, Handicap International (HI), a non-governmental organization, and the Togolese Federation of Disabled People's Organizations (FETAPH) are working alongside the government for the well-being of persons with disabilities. The dignity of people resides in their social participation, in their pride in being full members of the community, and disability can diminish such participation. The goal of rehabilitation is to help restore the dignity and worth of people with disabilities by enhancing their social participation.

The aim of this study is to evaluate the impact of rehabilitation on the social inclusion of persons with disabilities in Togo by analyzing the services provided with regard to their effects on the beneficiaries.

## 2- Conceptual framework

## 2.1- Opening question

Thanks to the financial support, equipment and technology that HI provides to the various rehabilitation centres in Togo, more than 4,000 people have been fitted with orthopaedic devices and rehabilitated from 2003 to 2007 to improve their social participation.

After ten years<sup>2</sup> of experience, can we say that rehabilitation has improved the socioeconomic inclusion of the beneficiaries? We shall try to answer this question by analyzing the situation of lower limb amputees.

2

<sup>&</sup>lt;sup>2</sup> HI has been working in Togo since 1997

## 2.2-Concept definitions and purpose of the study

## 2.2.1- Concept definitions

#### 2.2.1.1-Disability and the disability creation process

Under the French law of 11 February 2005, disability is "any limitation on activity or restriction on social participation that a person suffers in their environment due to a substantial, lasting or definitive alteration of their physical, sensory, mental, cognitive or psychological functions, a multiple disability or an incapacitating health condition". [4].

The approach to disability that we find to be the most comprehensive, and which will serve as a framework for this study, is that of P. Fougeyrollas *et al.* [5], according to whom disability is a complex and multi-facetted phenomenon resulting from the interaction of the following factors:

#### ❖ Risks factors

These are elements forming part of the individual or originating from their environment which are likely to cause illness, injury, physical harm, or affect their personal development. Risk factors are called "causes" when they give rise to concrete effects (e.g. the presence of unexploded ordinances which leads to an accident causing an amputation).

#### ❖ Personal factors

These are the characteristics of the person, such as age, gender, sociocultural identity, physiological systems (all of components of the body which strive towards a common function) and skills and capacities (possibility for a person to perform a physical or mental activity).

#### ❖ Environmental factors

These are all of the physical and social factors that determine how a society is organised and the environment which if offers: access to buildings, dispositions for making tasks accessible, access to rehabilitation care and vocational training and the availability of jobs.

#### Life habits / social participation

These are common activities or social roles valued by the person or their sociocultural environment in terms of characteristics such as age, gender and sociocultural identity. They ensure the survival and self-fulfilment of the individual in their society throughout their life.

The extent to which an individual achieves their desired life habits is an indicator of their degree of social participation.

A situation of disability involves a reduced ability to achieve a desired lifestyle and is the result of the interacting personal and environmental factors (Fig. 1).

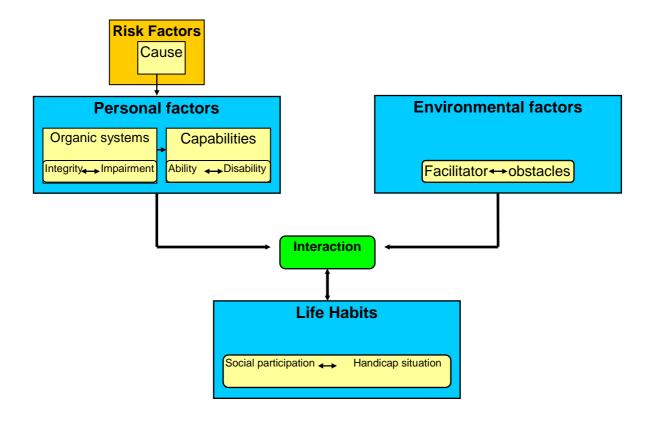


Fig.1: P. Fougeyrollas et al, DCP, RIPPH, 1998

#### 2.2.1.2- Health related rehabilitation of amputees

According to Zribri & G. D. Poupée-Fontaine [4], "physical disability rehabilitation is the use of various techniques to achieve a threefold result:

- preventive action to cope with accidents or disabling illnesses
- functional or health-related rehabilitation to eliminate or reduce a functional disability
- compensatory action in the event that total recovery is impossible. This involves a range of orthopaedic technologies: prosthetics and orthoses, assistive devices"

As part of our study, all the amputees have received a prosthetic device and physiotherapy sessions (muscle strengthening exercises, training in walking with prosthetic devices) for an optimal use of their device.

## 2.2.2- Objectives and purpose of the study

The study had two specific objectives:

to identify how people fitted with prosthetic devices perceive the care they receive (how they are attended to and their needs taken into account, staff availability, quality of devices). ❖ to identify the obstacles to optimal social participation of persons with disabilities and to explore solutions for better socioeconomic inclusion.

The purpose of the study is to explore the links between functional rehabilitation and social inclusion and to examine the extent to which functional rehabilitation has improved, or failed to improve, the social participation of persons with disabilities. In concrete terms the purpose it twofold:

- ❖ First, it will provide some epidemiological data. In a country where information on disability is almost non-existent, this study will contribute to a better knowledge of the situation of people with disabilities
- ❖ Then it will analyze the extent to which people with disabilities are satisfied with the care received and will consider solutions for better care

## 2.3. Subject and hypothesis of the study

The prerequisite for the social inclusion of persons with disabilities is autonomy. Contrary to what people have always believed, autonomy does not depend only on the capacity of the disabled person, but also on other environmental factors such as access to care and employment.

We advance the hypothesis that effective functional rehabilitation, which addresses both personal and environmental factors, will positively influence the achievement of the desired social participation, thus contributing to the inclusion of people fitted with orthopaedic devices.

To test this hypothesis, a qualitative survey by way of interviews was conducted from June  $1^{st}$  –  $30^{th}$  with persons that had been fitted at the National Orthopaedic and Physical Disability Rehabilitation Centre (CNAO-RF) of Lomé.

## 2.4- Analysis model

The phenomena to be studied are rehabilitation and inclusion and we are seeking to link the two through a hypothesis. The analysis of rehabilitation care at CNAO-RF will have three focuses (performance of the administrative department, orthoprosthesis services, and physiotherapy services). The indicators that will enable us to make the link between rehabilitation and social inclusion are the satisfaction expressed by the beneficiaries and the impact of care on personal factors, life habits and environmental factors (figure 2).

The interviews therefore focused on the person's life before and after rehabilitation in order to identify the changes that have occurred in their everyday life.

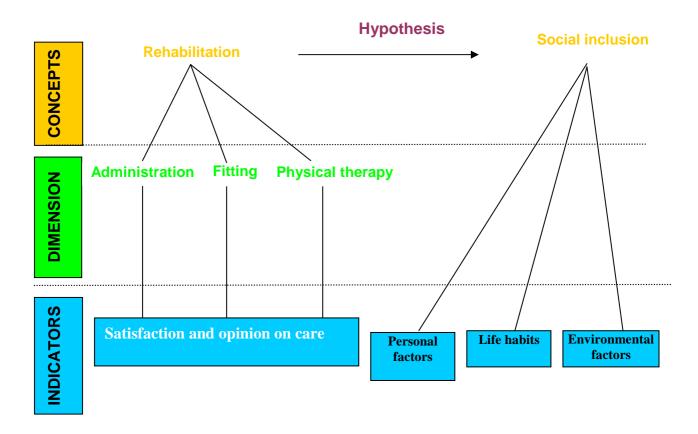


Figure 2: Analysis model

## 2.5- Analysis method

In order to better assess the social participation of people fitted with orthopaedic devices, we opted for a method based on qualitative interview analyses. We therefore interviewed lower limb amputees fitted with devices to explore and describe their daily experiences after rehabilitation. According to Miles & Huberman [6], qualitative data are "the best strategy for discovering and exploring a new field." The method used will allow us to:

- identify barriers to their social participation
- assess satisfaction regarding the care received
- suggest improvements to the various services of CNAO-RF
- have guidelines for better socio-economic inclusion

## 3- Protocol of the study

## 3.1- People surveyed

The study focused on patients who have undergone trans-tibial or trans-femoral amputation and have received functional rehabilitation care between 2003 and 2008 (orthopaedic fitting and physiotherapy sessions) at CNAO-RF in Lomé.

## 3.2- Area of the survey

The survey covered the Maritime region. This is an area in southern Togo. It comprises five prefectures and the town of Lomé (the capital). The population is estimated at 2,265,000 or 43% of the total population, with a density of 371 inhabitants/km², compared to 70 inhabitants/km², 37 inhabitants/ km², 56 inhabitants/ km² and 71 inhabitants/ km² respectively for the Plateaux region, the Central region, the Kara region and the Savannah region (the other regions of Togo). CNAO-RF is based in the town of Lomé. To reach CNAO-RF, patients in the Maritime region must travel a maximum distance of around 60km.

#### 3.1.1- Inclusion Criteria

The following people have been included in the study:

- persons fitted with orthopaedic devices of both sexes over the age of 5 who have received functional rehabilitation for at least 3 months
- at the time of the study, patients living in the Maritime region.

#### 3.1.2- Exclusion criteria

The following people have been excluded from the study:

persons fitted with orthopaedic devices who do not have an address or telephone number in their patient file via which we could contact them.

#### 3.2- Data collection tools

#### 3.2.1- Interview guide

The interviews were conducted on the basis of an interview guide inspired by the life habits measure, MHAVIE, and the environmental quality measure, MQE, [7, 8] which are in turn based on the model of disability creation process presented above.

Thus the whole architecture of the interview guide is based on the disability creation process nomenclature; the only difference, introduced to facilitate contact between the interviewer and the interviewee, is that the interview begins with the personal factors. The choice of risk factors (the causes, in our survey) that are specific to the context of Togo has been done on the basis of an international directory of impairment causes used by Handicap International.

#### 3.2.1.1- Life habits measure (MHAVIE)

MHAVIE is a tool for gathering information of the impact on daily life habits (at home, at work or in the neighbourhood) based on the DCP model. The original questionnaire consists of 240 items covering the following areas: nutrition, physical state, personal care, communication, mobility, home, responsibilities,

interpersonal relationships, community life, education, work and leisure. As part of our study, 10 activities requiring the use of lower limbs were selected (appendix 8.1).

The assessment consisted of asking the people fitted with orthopaedic devices if they performed the activity or not and asking them to express their satisfaction in four ways (dissatisfied, not very satisfied, satisfied, very satisfied). If the person has doubts concerning the accomplishment of an activity, we consider it as not accomplished.

#### 3.2.1.2- Measure of the quality of the Environment (MQE)

MQE is used to assess the influence of the environment on the accomplishment of common activities. It is also based on the DCP model. MQE has 109 original items dealing with situations relating to the social attitudes of the person's entourage, the labour market, sources of income, social and health services and accessibility. In relation to the objectives of our study, 11 open questions were put to people with disabilities to see whether these situations have an impact (positive, negative) or not on their lives (appendix 8.1).

This assessment allowed us to get two pictures (before and after rehabilitation) of the life of people fitted with orthopaedic devices. These two pictures were then compared to measure the changes arising from functional rehabilitation.

#### 3.2.2- Social status assessment grid

For an assessment of social status, a grid was designed on the basis of indicators such as income-generating activities, housing, possessions and food. Each indicator has assessment procedures and is marked from 0 to 18 points. Thus people fitted with orthopaedic devices who have a score between 0 and 6 are considered as poor, those with a score between 7 and 12 are considered as part of the middle class, and those who have between 13 and 18 points are considered as belonging to the wealthy classes (appendix 8.1).

#### 3.3- Data collection method

The survey took place from 1 to 30 June, 2008. Contacted by telephone, 30 people fitted with orthopaedic devices were approached and interviewed at home by a single investigator using a semi- structured guide.

A research schedule was developed based on the availability of each patient and a breakdown by area. The exact time of the interview was decided at the discretion of the researcher in order to better ascertain whether the device was actually being worn or not.

In order to enable the people surveyed to express themselves freely and to get objective answers, 2 steps were taken:

1. the people surveyed did not know the name of the sponsor of the survey, nor did they know of the relationship between the researcher and CNAO-RF.

2. the researchers, although they were in fact working in the rehabilitation field, introduced themselves as students doing educational research as part of a professional project.

Some aspects of our methodology might have imposed limitations on our study. A discussion of their possible impact on the quality of the study can be found in the discussion section.

## 4. The results

## 4.1- The eligibility rate

The objective of the study was to carry out 30 to 50 interviews. With the help of the patient records collected from CNAO-RF, 61 people fitted with orthopaedic devices were selected, but only 35 (58%) were eligible according to the inclusion criteria. One person refused to participate in the study and five people were involved in the pre-survey.

The following results therefore concern thirty (30) people. Of these twelve (40%) were interviewed in a national language (Ewé or Kabyé) and eighteen (60%) in French.

The same interview guide was used for adults and children. In the case of the children, the parents participated in the interview; certain indicators (social class, family situation) were provided by the family head.

## 4.2- Causes of amputation

In general, traffic accidents (30%) and diabetic foot (27%) are the main causes of amputation in our sample (Table 1).

Most of the interviewees (7/9) are victims of traffic accidents involving the *Zemidjan* (motorcycle taxi) and are adults under the age of 45 five men and two women. In contrast, all diabetic amputees (five men and three women) are elderly persons (between 54 and 74 years old).

Among the five amputations as a result of poorly treated injuries, two were due to a poorly treated fracture that led to gangrene and required amputation. These two people expressed their dissatisfaction with what they consider to be "serious professional malpractice".

Causes	Number	Percentage

Total		30	100
	Total	14	47
	Other <sup>3</sup>	5	17
	Congenital malformation	1	3
Disease/malformation	Diabetes	8	27
	Total	16	53
	Seriously injured in traffic accident	9	30
Trauma	Complication from injection/ transfusion	2	6
	Poorly treated wound	5	17

Table 1: Various causes of lower limb amputation at CNAO-RF from 2003 to 2008

#### 4.3- Personal factors

## 4.3.1- Age and Gender

The age of the respondents varies between 5 and 74. The average age of the sample is 43. We have 4 (13%) children (below 18 years old) and 26 (87%) adults. More than half (17/30) of the respondents are aged between 18 and 55. Approximately 1 in 3 is over 55 years and only a minority (4/30) is under 18.

Although ages are declared without producing a birth certificate, we can trust the declarations for two reasons: first, on the ground, we did not observe much hesitation among respondents when they gave their age, and the analysis did not show any grouping around decimal ages.

About 2/3 (19/30) of those surveyed are men, and 1/3 (11) are women. The gender ratio of 63% of disabled men against 37% of disabled women is somewhat unbalanced compared to the gender ratio of disabled people in the general population, where there are 57.8% of men with disabilities compared to 42.2% of women with disabilities [14]. The under-representation of women may be due to the eligibility criteria that included a telephone contact.

## 4.3.2- Family situation

For all respondents, the family situation did not change after the fitting. These people all lived in a family, with a husband or wife, or with parents. No one lived alone. The majority of adults were married and lived with their spouse before the amputation.

Regarding family relations, almost all respondents reported having noticed no positive or negative change after the rehabilitation. There was just one 27 year-

<sup>&</sup>lt;sup>3</sup> Complications of vascular diseases (thrombophlebitis, ischemia) without any specific cause.

old young woman living with her uncle who expressed her desire to leave the family home. According to her, disagreements with her uncle arose after the rehabilitation. She believes that her uncle, with whom she lived before her rehabilitation, had difficulties adapting to her new life as somebody who "moves more". "With the fitting, I move more, I go to worship and I'm learning a trade, and my uncle says I am always away from home. My uncle is too strict with me", she said.

On the whole, we see that in our sample rehabilitation had no influence on the family situation. But is the case of this young woman not also a symbol of the difficulties in achieving emancipation and freedom experienced by people with disabilities in their families and in society in general?

#### 4.3.3- Economic and social status

#### 4.3.3.1- Social status

People fitted with orthopaedic devices are from all social classes, though the middle class is not strongly represented (Figure 3). With this division into 3 classes, it is difficult to compare the poverty rate of 33% of our sample with what is expected in the Maritime region, but if we consider the middle class as poor, we have a rate of 74%, which is reasonably close to the expected rate of  $70\%^4$ .

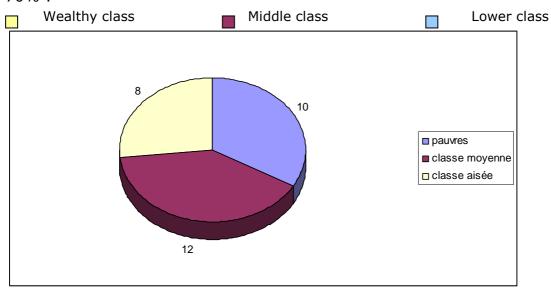


Figure 3: Breakdown by class of lower limb amputees from the sample

#### 4.3.3.2- Economic status

A third of the respondents had no income-generating activity (figure 2); most of them became unemployed when after becoming disabled. Some lost their jobs (mostly in the informal sector). Others (traders and sellers for the most part) were ruined by the cost of hospital care and the purchase of prosthetic devices). There were 4 men and 6 women, with an overall male/female ratio of 63/37.

<sup>4</sup> Intermediary Strategy Paper for Poverty Reduction in Togo, 2007 [unpublished], available on the UNDP Togo website: <a href="http://www.tg.undp.org/undptogo/index.htm">http://www.tg.undp.org/undptogo/index.htm</a>, consulted on 21/08/2008

They told us they were able to eat "thanks to the resourcefulness and solidarity of parents and friends who give" them "food or money".

What is encouraging is that we have noticed that all those unemployed are determined to start a business if they find the means. They considered that their mobility allowed them to undertake income-generating activities. They are not currently undertaking any income-generating activities due to lack of means.

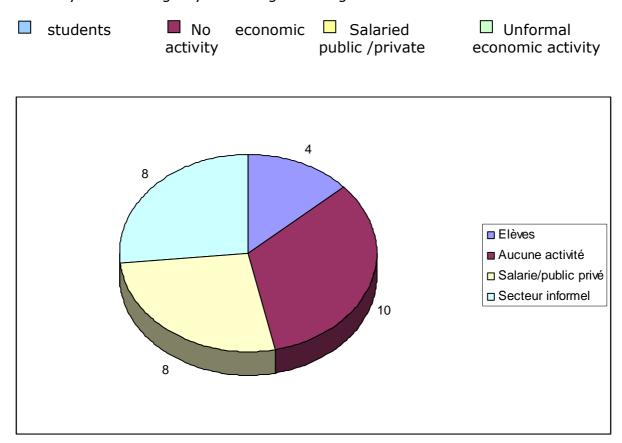


Figure 4: Economic status of lower limb amputees from the sample

## 4.3.4- Wearing the devices

17 people out of 30 were wearing their prosthetic device when the researcher arrived. The average time between the date of amputation and date of the making of the device was 20 months. The shortest period was 3 months and the longest 9 years.

The wearing of prosthetic devices was influenced by the following factors:

#### 1. The delay between the amputation and the making of the device

The longer the delay, the less the device was used. (t = -0.013; f = 95). This is illustrated by the case of a 30 year-old young man who was fitted nine years after his amputation. He does not use the device. He declared that despite the rehabilitation sessions, he could not get used to his prosthetic device. He preferred to use crutches because "they allowed him to move faster than with the prosthesis".

#### 2. The age of the person fitted

The older the person, the less the device was used (t=-1.81; f=90%). Most of those who used their device (11/17) were under 45 years old. In contrast, more than half of those who did not use their device were elderly people (54 to 74 years old). They only used their device when they were going out of their neighbourhood.

#### 3. The quality of the devices

The case of 2 women aged 39 and 46, who are trans-femoral amputees, is quite illustrative. They said they did not use their devices at all because they found them very uncomfortable (see section 4.5.2.2 on the assessment of care). After several unsuccessful attempts to find a satisfactory solution with the orthoprosthesis technicians, they decided to abandon their prostheses. They move about using crutches, which they find more.

In conclusion, we can say that, for more effective rehabilitation care:

- we could consider a policy that gives priority to children and young persons if resources are insufficient
- we need to make patients aware of the importance of having a fitting quickly; the rehabilitation centres should make efforts to deliver the devices to the patients quickly.

## 4.4- Impacts on lifestyle

When asked the question "Does the fitting and the physiotherapy enable you to carry out domestic activities and to move around in a way that you could not before?", three categories of response were given:

#### Those who greatly benefited from the rehabilitation care

24/30 spontaneously stated: "I can move better," "get on with my work", "see friends" or simply "have a walk".

# Those who benefited to a moderate extent from rehabilitation care

There are 4 people in this category. Rehabilitation only helps them move within a limited area: "going to the toilet", "walking around the neighbourhood", "going to worship".

"Thanks to my prosthesis, I can take a little walk in the neighbourhood. But I admit that I feel embarrassed, I am ashamed, and I no longer visit my friends. I lost my job and I spend most of my time sleeping" a young lady told us.

#### \* Those who do not use their devices at all

This is the case of two women aged 38 and 39. They said that their devices were of no use. One of them said: ""I do not even use the device; I do not even go out any more. For me, this was a waste of money. I cannot even go and sell things at the market. I am obliged to seek the support of people. If I had known, I would have invested the money for the prosthesis in a small business".

#### 4.4.1- Personal care and housework

For personal care, specifically dressing in a standing position:

- ❖ 7 out of 30 fail to do so. They are all older people (54-74ans) who reported having becomed used to dressing entirely in a sitting position.
- ❖ 21 out of 30 could do it, but only half of them are very satisfied with the level of accomplishment. The others spoke of back pain, sores or swelling caused by the stump, and they were sometimes obliged to dress in a sitting position.

Regarding housework (the question was put mainly to women, given the cultural division of work in Africa) they were all able to sweep the courtyard and do the laundry.

However, they cannot fetch water from the fountain with their prosthesis. This can be attributed to three main factors, namely:

- the advanced age of the patients (the average age of our sample is 43)
- the relative difficulty of this task for a fperson with a fitting
- the quality of the prosthesis. (see 4.5.2.2)

## 4.4.2- Mobility

#### Walking without crutches

17 out of 30 respondents move around without crutches. They are mostly younger adults and children. The 13 others, who are mostly elderly persons, said they continue to use the crutches because they were afraid of falling due to the state of the physical environment (cracked, muddy or sandy roads) and to their difficulties in crossing the roads. The crutches are for them a sign of their disability, forcing road users to facilitate their crossing.

In general, the majority of those who do not use crutches are not very satisfied. They complained about their restricted walking range and therefore their restricted social participation (see 4.5.2.2).

#### Going up and down steps

Two thirds of people in the sample are able to walk up steps. But they are not satisfied because they face enormous difficulties in going down steps. This is due to the lack of a handrail on the stairs in some buildings.

#### Walking on uneven ground

About 2/3 can walk on uneven ground. The fear of falling leads others to avoid uneven ground. Some said they no longer dare to go out after rain because of previous falls due to slippery ground. All those who do walk on uneven ground said they are dissatisfied. The reason cited was the state of the physical environment.

#### Using public transport

All the respondents use public transport wearing their devices. The most used means of public transport is the taxi-bus. Two of them told us they are able to drive their own vehicles (motorcycle and car). Another person told us that she eagerly wished to do the same but cannot manage it. She believed that it is because of the quality of her device. She said: "I know a man whose limb is amputated at the same level as mine and who is also older than me. But he drives his car with his prosthesis. My prosthesis was poorly made. They (the technicians) have promised to correct it. If they fail, I will have another prosthesis made in Ghana".

Nevertheless, the majority of people are not satisfied with the way they have to use public transport, because the prostheses oblige them to ask the driver to adjust the seat in order for them to be comfortable.

The majority no longer use the Zemidjan "because of the risk it represents", they told us.

It is therefore clear that apart from the difficulties related to the physical environment (cracked, muddy or sandy roads, lack of handrails on the stairs) the devices greatly improved the mobility of persons with disabilities.

## 4.4.3- Community life

The majority (27/30) of the respondents reported having a more or less normal community life. They all said that their prostheses helped them participate in social activities. This essentially involves religious activities for the elderly and for women, and sports and recreational activities for children and young people.

A young woman of 27, who is a trans-femoral amputee, told us: "Thanks to my prosthesis, I have joined the youth choir of my church. I dance and I participate in all the activities like the others and I'm happy about that".

A young boy of 10 in the sixth year of primary school told us: "Thanks to my prosthetic device, I can go to school with the other pupils and even play football with them. I do everything the same way as them".

## 4.5- Impact of environmental factors

#### 4.5.1- The attitudes of the entourage

Everyone said they have been supported and encouraged by their friends and parents since the fitting. Their relatives were "surprised and full of admiration" to see them "walk on two feet again".

One man even told us that he had become the "subject of admiration" in his neighbourhood. "Seeing me walking was a topic of conversation for people in the neighbourhood who knew that I had been amputated and who had seen me walking with crutches. One couple even had the courage to come and ask me if I had really been amputated, and if so, what miracle had allowed me to walk again".

A young man also told us that his friends had exclaimed when they saw him walking with his prosthesis: "You can walk like before, white people are clever!"

It should be noted that the expression "white people are clever" is often used in everyday language to express admiration for techniques that go beyond the comprehension of the speaker. It is believed, whether rightly or wrongly, that only white people possess such techniques, which are worthy of admiration. In this particular case, the prosthesis allows a lower limb amputee to stand up and to walk normally. This phrase is not just a praise of the Western technology that led to the making of the prosthesis but also a tribute to the staff of CNAO-RF, which in the popular consciousness, is the organization that actually puts the technology into practice.

Regarding the impact of rehabilitation on their love life, only 2 of the 26 persons to whom the question was asked said that changes had taken place after their rehabilitation. They are 2 young women aged 25 and 27.

The first found that the prosthesis made her "feel more like a woman" and that young men in her entourage were more considerate towards her. "But I do not feel ready for amorous adventures and especially not for marriage. I always wonder if I could fulfil the obligations of a housewife", she said.

As to the second, she said she had noticed that after being fitted, her lover and her admirers, who had cast her aside are, are trying to come back into her life, having found out that she is "walking again".

There is also this important testimony from a woman of 38, who has been using a device since her childhood: "I have been wearing my prosthesis for years. Without it, I could not have studied nor could I have found a man. Today, I am married, I have a child, and I assume my duties as a housewife. I owe all this to my prosthesis and I thank my dad for having had me fitted".

Regarding the impact of rehabilitation on love life, it is possible that the answers given by the respondents do not reflect the real situation. It must be recognized that such an intrusion into privacy is a sensitive issue and we are not sure that

the answers given by respondents are completely true, especially as in the case of most of the married people, the spouse was present at the interview.

### 4.5.2- The social and health system

### 4.5.2.1- The quality of the welcome at CNAO-RF

#### **❖** At the level of the administrative department

Four out of 30 people claimed to have been poorly welcomed at the reception of the CNAO-RF. These people criticized the receptionist for:

- responding timidly to their greeting (barely audible response),
- being stony-faced, with no trace of a smile,
- not inviting them to sit down, either in the lobby or at her desk
- giving information that was too vague

Some say that the information about the exact hours of consultations was not very accurate. "They just said that consultations were on Tuesday and Thursday afternoons, but when I arrived on Tuesday at 4 pm I was surprised to learn that the consultation was over" one woman told us.

Another person expressed her dissatisfaction with regard to the order in which patients were received for the consultation: "The order is respected, people jump the queue and sometimes there is favouritism", she said.

But for the majority (26/30) of those surveyed, the welcome was impeccable. "The receptionist is very nice; she welcomes you with a smile as if she already knew you." All these people consider that the information on the services was provided correctly. "Everything is arranged to satisfy your needs. You always get appointments. But if you happen to miss an appointment or if the centre cannot keep an appointment, they let you know you by phone", one woman said.

It should be noted that all the respondents had a good opinion of the Director of CNAO-RF. One of the interviewees summed up what all the respondents think of here: "She welcomes you personally in her office, listens to you and does everything to calm you down and encourage you. She motivates you and shows you pictures of people who have already been fitted and have resumed their lives without difficulties; she is a nice and very welcoming person".

#### **❖** At the level of the orthoprosthesis technicians

Eight out of thirty people have found that the welcome at the level of the orthopaedic technicians was not good. They blamed them for a lack of technical information on the characteristics of their devices (prior information on the type of device) and especially on how the material used withstands water. Not knowing what would happen to the device if it got wet, many people dared not go outside when it rained for fear that they would damage their device. For them, this lack of information was an obstacle to their mobility.

One man accused his orthopaedic technician of greed. "He does not do small repairs promptly, and you have to give him a little tip for him to do them. I hate this behaviour. After the job, I could give him something, but making the job dependent on tips is a bad thing". He also accused technicians of not listening: "They do not want to listen to your complaints and repair your device accordingly. They think they are always right. If you complain about your device, they do not want to listen to you. They just refer to theories and tell you that your device is fine, but I'm the one who's wearing it and I'm the one who feels uncomfortable. I'm tired of saving the same thing every time. I have decided not to visit them any longer, I do the small repairs myself", he said I did indeed notice that this gentleman had put on two socks before wearing his prosthesis and that he had bandaged his knee. "With these personal repairs, I feel more comfortable" he added. The same is true of a man who, to cope with the fact that his prosthesis was short compared to the other limb, put a strip of sandal leather in the shoe for the foot with the prosthesis. "The technicians did not want to listen when I told them that the prosthesis is too short, I have worked out this solution myself and now I feel good in my prosthesis", he said.

For the other 22 persons, the welcome from the orthoprosthesis technicians was good. According to these people, the technicians were attentive and welcoming, and they consider that they received proper attention. Several said that, given the economic difficulties they were experiencing, the technicians often gave them money for food or to pay for the taxi.

With regard to respecting their privacy in the fitting centre, almost all respondents said that the work environment (moulding and fitting room) protected their privacy. Except for one woman who said that her privacy was intruded upon one day in a fitting booth by another patient. According to her, it would be better if men and women used separate changing rooms and booths.

#### \* At the level of the physiotherapists

Almost all (29/30) of the respondents said they were well received by the physiotherapists, who they said were "very nice". "They clearly explain the exercises to do and encourage you to do them", said one man. They said the physiotherapy unit was well organized (properly arranged appointments and available to see you even if you arrived late for your appointment). Respondents said there was often a cheerful atmosphere in the physiotherapy unit which "encourages you to come back for further treatment".

However, one man spoke of a disagreement between himself and his therapist, who believed he "lacked the commitment and seriousness to do the exercises properly". He got angry and stopped the treatment. "But he came back to me about ten minutes later to encourage me".

For all the respondents, the facilities at the physiotherapy department made them comfortable and protected their privacy: booths with curtains for activities that require the patient to undress.

#### 4.5.2.2- Assessment of the care

#### Impressions of the quality of the devices

The majority (24/30) of the respondents expressed their dissatisfaction regarding their prosthesis. A total of 31 complaints, which can be classified into eight categories, were recorded (Figure 5). In their opinion, the discomfort is mainly due to the quality of the device and is an obstacle to a truly fulfilling lifestyle.

#### Impressions of the quality of the physiotherapy

Almost all the respondents (28/30) were satisfied with the care provided. In their view, the exercises were interesting and progressed at an appropriate pace. This allowed them to quickly recover their autonomy. Only two of the thirty people found that the sessions were sometimes painful, but not to the extent that they wanted to stop.

The majority of the respondents still remembered the name of their physiotherapist and said they had a very good relationship with them. "Thanks to my young physiotherapist, with whom I still have a good relationship, I am able to go up stairs; I am waiting for the end of my medical convalescence to return to work. I am aware that I cannot climb the cranes like before, but with the progress I have made, I will remain with the company and do other tasks ".

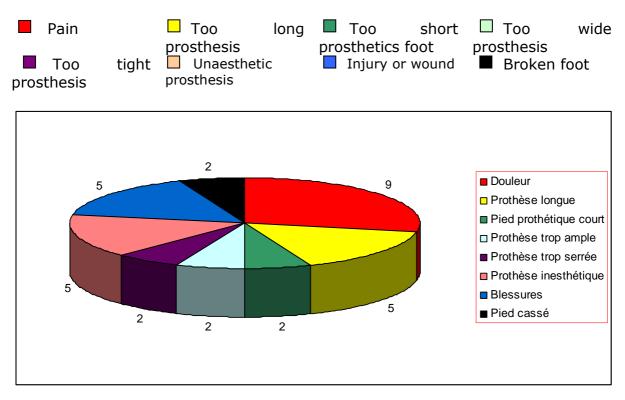


Figure 5: Frequency of complaints from lower limb amputees of the sample

#### Impressions of the cost of the care

Four people in 30 have no idea of the price of their prosthesis, which was fully paid for NGOs. For the other 26 (including those who were granted discounts by the Social Affairs Services), the devices were too expensive.

However, only three of the 30 people reported difficulties paying for the physiotherapy sessions. They had to abandon the sessions prematurely. Two were widows aged around and one was in his fifties - none of them had any source of income.

## 4.6- Impact on sources of incomes

For 14 people out of thirty, the rehabilitation had no economic impact:

- seven people who have not yet resumed their economic activity or found new employment following their rehabilitation. They have no source of income and are fully reliant on third parties.
- seven employees who are on medical leave or are retired and who are receiving pension or sickness allowances.

Sixteen persons have been able to resume an existing or new activity which has had, or will have, economic impact:

- nine people who experienced a direct economic impact thanks to the fitting. They have been able to resume their former activities without any difficulties. They are salesmen and craftsmen for the most part. This has allowed them to have financial autonomy. It is true that some of these people, particularly the traders and shoemakers can carry out their activities using crutches, but that would be more difficult than with prosthetic devices, which afford more autonomy, and would have negative consequences in terms of income
- ❖ seven people for whom there has been an indirect economic impact. The use of the prosthesis has allowed 3 people to become autonomous and to do without the services of a housekeeper (or `servant', as they are commonly called in Togo) to do the housework or to take the burden off a family member who had previously had to assist them. The other four are students who have started or resumed school thanks to the rehabilitation

# 5- Geographical origin of patients and their familiarity with the CNAO-RF

More than 2/3 of the respondents live relatively far from the centre (see Figure 2). They live outside the Tokoin district where CNAO-RF is located. This shows the wide coverage of the centre. The channels through which people found out about the centre confirm this wide coverage: sixteen people were referred by their doctors, and 14 learned about the centre from other people (parents, friends and the media).

Patient from the Patient from Lomé, Patient from the Maritime region (more than (between 5 – 20 km away) district (less than 5 km 20 km away)

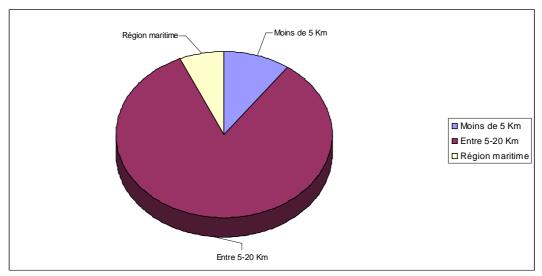


Figure 6: Geographic origin of lower limb amputees of the sample

## 6- Discussions

The study identified two main causes of amputations: traffic accidents and diabetes, which reduce the physical capabilities of those affected. These results are similar to those found elsewhere in the world, where accidents and injuries account for 16% of disabilities and non-infectious diseases for 20% [9].

Regarding the actual impact of rehabilitation on the social inclusion of people fitted with devices, an analysis of the interviews shows that rehabilitation has introduced positive changes in the lifestyles of the respondents in the sense that it allows better social participation. In general, rehabilitation gives better mobility to people fitted with devices. The fact that many people were considered to be incapable of getting dressed in a standing position is due to the interpretation of the data, since all those who said that they had never tried getting dressed (out of personal choice) were considered to be incapable of doing so.. The devices also made their community life easier (for some at school and for leisure activities, for others for worship and professional occupations). Only a few difficulties related to the environment remain (the quality of the roads, the lack of handrails).

But as regards the economic impact, only just over 50% (16/30) of the respondents were able to truly begin or resume an activity. Many of those who were economically inactive have difficulty regarding food and housing. Although efforts have been made to provide rehabilitation care (the existence of regional centres where devices are available and an increase in the number of care

providers), much remains to be done concerning access to employment for the disabled. Work is highly valued and inclusion in the workplace is essential for social inclusion. However, "the very low economic growth leads to unemployment that affects [...] low-skilled jobs, and the disabled are the first victims" [10]. Efforts to provide more employment opportunities for disabled people would therefore improve their social inclusion. This could take the form of incomegenerating activities for unqualified people and legal provisions to promote and secure employment both in the public and private sectors for people with disabilities. These provisions would help people with disabilities to "avoid social exclusion [11] and break the vicious circle of poverty and disability" [1].

In terms of access to rehabilitation care, thanks to the actions of the government and non-governmental organizations, all social classes have access to functional rehabilitation. But efforts still have to be made to improve both in the way in which patients are taken in charge and in terms of the quality of the devices. About 1/3 of the respondents have criticized the way they were treated by the orthopaedic technicians and more than 2/3 have complained about the quality of the devices. This has a negative impact on the social participation of people fitted with devices. These results are in line with those of a study in 2007 by Handicap International in Togo as part of the evaluation of its "promotion of the right to rehabilitation for disabled persons in Togo", where 50% of people with disabilities complained about the quality of the devices and 15% about indifference to their needs and the quality of the information provided by the staff in the care centres.

However, there are certain methodological issues which require us to treat the results of this study with caution:

- the representativeness of our sample. The study focused only on the Maritime region, which is the richest in the country. Its socioeconomic profile cannot be applied to the country as a whole.
- the possession of a telephone as a criterion may have resulted in the under-representation of the poor in the sample, given a telephone has an appreciable cost.
- the grid used for assessing economic status is not a standard tool. Created to reflect the current realities of the country, it may not give an accurate picture of the situation

But these methodological limitations do not affect the quality of the information provided by the respondents. Based on this information, we have made the following proposals with a view to greater social participation on the part of people with disabilities.

## 7- Proposals

These proposals are directed at HI, which has sponsored the study, and also to CNAO-RF. They concern the preliminary work needed for the endorsement of the results and for exploring their possible implications.

#### 1. A bi-partite discussion of the study results

It would be desirable for Handicap International to meet with the staff of CNAO-RF to establish whether they agree with the results of this study. If endorsed, the two partners can explore together the practical implications.

#### 2. Implications for Handicap International

The study highlighted the difficulties in integrating economically which are faced by the persons interviewed. HI might examine what measures can be taken to improve the economic inclusion of people with disabilities in Togo. These could be centred on two main lines of action:

- The implementation of micro-projects for people with disabilities. This could involve projects carried out within organizations for disabled people. Particular emphasis should be placed on women, who are the most affected.
- ❖ Lobbying various partners to strengthen the legal framework in Togo regarding the promotion of employment opportunities and social protection for disabled persons. To date, there is only Act No. 2004-005 on the social protection of disabled persons, which has still not been passed into law.

#### 3. Implications for CNAO-RF

To improve the quality of the services provided, it would be appropriate to introduce quality initiatives in the rehabilitation centre that incorporate two main components: listening to the patients and taking into account their expectations and projects.

Good listening benefits both the patient and the professional. According to B. Choteau [12], "respectful and non-selective listening helps the patient to negotiate their way through their suffering. This essential exchange [...] helps the professional to act more effectively [...] to know ourselves betters and to be aware of our limitations, our own emotions and our own values so that we can give others the space which they require. This exchange can then lead us along a path of shared humanity and mutual growth.

In addition, a discussion with the patient about their projects in life will make it possible to address their real concerns and to know whether they really need a device, or whether the person has resorted to care because their entourage or rehabilitation professionals have pushed them into it.

This approach with the focus on quality will greatly reduce complaints about the devices and thus reduce the number of people who, as we observed in course of the field study, have ceased to wear them.

## **Conclusion**

This study has allowed us to highlight the changes that rehabilitation care as physiotherapy and prosthetics devices introduce into the daily lives of amputees. It is clear that rehabilitation is a new opportunity for amputees to enjoy greater social participation and a more fulfilled lifestyle.

This study help to reinforce the Evidence based Practice in physiotherapy and prosthetics and orthotics science.

The efforts made by partners working with the State in particular Disabled People Organisations (DPO) and Non Governmental Organisations (NGO) like Handicap International on behalf of the well-being of persons with disabilities should therefore be continued and strengthened through measures to restore the financial autonomy of people in a state of disability.

With a methodological point of view, a questionnaire based on the Disability Creation Process (DCP) was created and piloted. This tool is now available and usable in similar contexts. It is very cheap to implement.

The assessment of the impact of interventions done in a given context is always very difficult. But, with this questionnaire and the method of this study, it is possible to think that a part of the response is offer to someone who wants to evaluate the impact of rehabilitation care in developing country.

To have a better picture of the situation and to work out better policies for persons with disabilities, we need to complement this study with a nationwide study or studies in other countries in the region.

## 8- Appendices

## 8.1: Interview guide

Identification	N	Name of the district	Date of the interview	
		I- Personal factor	rs (1)	
1- Age:	<b>2-</b> Sex: □ <sub>1</sub> Male	□ <sub>2</sub> Female		
2- Type of amputation	$\Box_1$ trans-tibial $\Box_2$ trans-fe	emoral		
<b>3</b> -Date of amputation				
<b>4</b> -Date of fitting				
<b>5-</b> Family situation				
		1	A.C. C**	
	Before fitting		After fitting	
Alone	Before fitting	Alone	After fitting	
	Before fitting  spouse □ <sub>2</sub> without a spouse		After fitting $: \Box_1 \text{ with a spouse } \Box_2 \text{ without a spouse}$	
			: $\Box_1$ with a spouse $\Box_2$ without a spouse	
With family : $\Box_1$ with a		With family	: $\Box_1$ with a spouse $\Box_2$ without a spouse	
With family : $\Box_1$ with a Other (specify)		With family	: $\Box_1$ with a spouse $\Box_2$ without a spouse	
With family : $\Box_1$ with a Other (specify)	spouse □ <sub>2</sub> without a spouse  Before fitting	With family	: □₁ with a spouse □₂ without a spouse fy)	

## II- Personal factors (2)

**8**-Social status:  $\square_1$  Poor = [0; 6]  $\square_2$  Middle class = [7; 12]  $\square_3$  Rich = [13; 18]

<b>6-</b> Social status. $\Box_1 \cap OOI = [0, O]$ $\Box_2 \cap OOI = [0, O]$	$\square_2$ White class $= [7, 12]$ $\square_3$ Kich $= [13]$		, 10]	
Indicators	Scale	Grid	Grade	
Income-generating activity	<b>0</b> =no activity; <b>1</b> = occasional activity; <b>2</b> = regular informal activity <b>3</b> = salaried in public/private sector; <b>4</b> = salaried with health insurance	0 to 4	/4	
Housing:				
<b>Possession</b> : $\square_1$ Housed by someone ; $\square_1$ Tenant, $\square_3$ Owner	$\Box_1 = 0 ; \Box_2 = 1 \Box_3 = 3$	0 to 3	/3	
Quality: Electricity, drinking water, latrine/toilet with septic tank	1 point for each available facility	0 to 3	/ 3	
Property: TV set, fridge, motorcycle, car	1 point for each property, except for a car that is worth 2 points	0 to 5	/5	
Food: Number of daily meals	1 for each daily meal	0 to 3	/ 3	
Total		0 to 18	/18	

## **II- Risk factors**

## **1-**Causes of amputation

Trauma	Illness
Small wound that has been neglected $\square_{1 \text{ Yes}}  \square_{2 \text{ No}}$	Diabetes □ <sub>1 Yes</sub> □ <sub>2 No</sub>
Complication due to an injection/transfusion $\square_{1 \text{ Yes}} \square_{2 \text{ No}}$	Infection/parasitic disease (specify if Buruli Ulcer) □ <sub>1 Yes</sub> □ <sub>2 No</sub>
Seriously injured in traffic accident 1 Yes □2 No 1	Osteonecrosis (related to drepanocytose) $\square_{1 \text{ Yes}}  \square_{2 \text{ No}}$
	Congenital malformations of the limbs□ <sub>1 Yes</sub> □ <sub>2 No</sub>
Other (specify)	Other (specify)

## III- Life habits

Do fitting and physical therapy allow you to do domestic work and move in a way that was impossible before?			

Life habits	Fulfilled or not 1 Yes 2 No	Level of satisfaction  1 very satisfied, 2 satisfied, 3 little satisfaction, 4 not satisfied
Personal care		
1- Dressing in a standing position	$\square_1$ $\square_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
Mobility		
2- Walking without crutches	$\Box_1$ $\Box_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
<b>3</b> - Going upstairs	$\Box_1$ $\Box_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
4- Walking on unstable ground	$\square_1$ $\square_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
5- Using public transport (bus, taxi)	$\Box_1$ $\Box_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
Housework		
<b>6</b> - Sweeping	$\Box_1$ $\Box_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
<b>7</b> - Fetching water	$\Box_1$ $\Box_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
<b>8</b> - Doing the laundry	$\Box_1$ $\Box_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
Financial and family responsibilities		
<b>9</b> - Doing an income-generating activity	$\Box_1$ $\Box_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
10- Taking care of others (children, spouse,		$\square_1$ $\square_2$ $\square_3$ $\square_4$
parents)	$\Box_1$ $\Box_2$	
Community life		
11- Taking part in	$\Box_1$ $\Box_2$	$\square_1$ $\square_2$ $\square_3$ $\square_4$
association/religious/sporting/leisure activities		

## **IV- Environmental factors (1)**

Environmental factors	Impact on t	the life of the fitted	l person
	Positive impact (list them)	No impact (check the box)	Negative impact (list them)
Attitude of the entourage			
1- Impact of rehabilitation on your love life (having a boyfriend/girlfriend, getting married)			
<b>2</b> -Attitude of the entourage after your fitting (rejection, pity, support, admiration, acceptation)			
Social and health systems			
<b>4-</b> Have you been well received by the administrative unit? (smiling, greeting, eye contact, inviting you to sit down, explanations, referral)			
5- Have you been well received by the orthoprosthesis technician? (smiling, greeting, privacy, explaining the process, presentation of the device, appointment)			
<b>6-</b> Have you been well received by the physical therapist? (smiling, greeting, privacy, explaining the exercises and expected results, appointment)			

## V- Environmental factors (2)

<b>Environmental factors</b>	Impact on the life of the fitted person		
	Negative impact (list them)	No impact (check the box)	Positive impact (list them)
Social and health systems			
7- What is you assessment of the device? (comfortable, too long, too short, pain, blotches, duration of use, aesthetic quality, cost)			
<b>8-</b> What is you assessment of the physical therapy? (painful, boring, reasonable duration, improvement of the condition, relation with the therapist, cost)			
Source of income			
<b>9</b> - Impact of the fitting on your economic situation (going back to work, finding a new job, better performance)			

<b>10-</b> How did you hear of CNAO-RF: $\Box_1$ from your doctor	$\Box_2$ from someone else	$\square_3$ Other (specify)	
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**<sup>11</sup>**-Geographical accessibility of CNAO-RF:  $\Box_1$  patient from the district, less than 5 km away,  $\Box_2$  patient from Lomé, less than 20 km away,  $\Box_3$  patient from the maritime region (more than 20 km awa

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