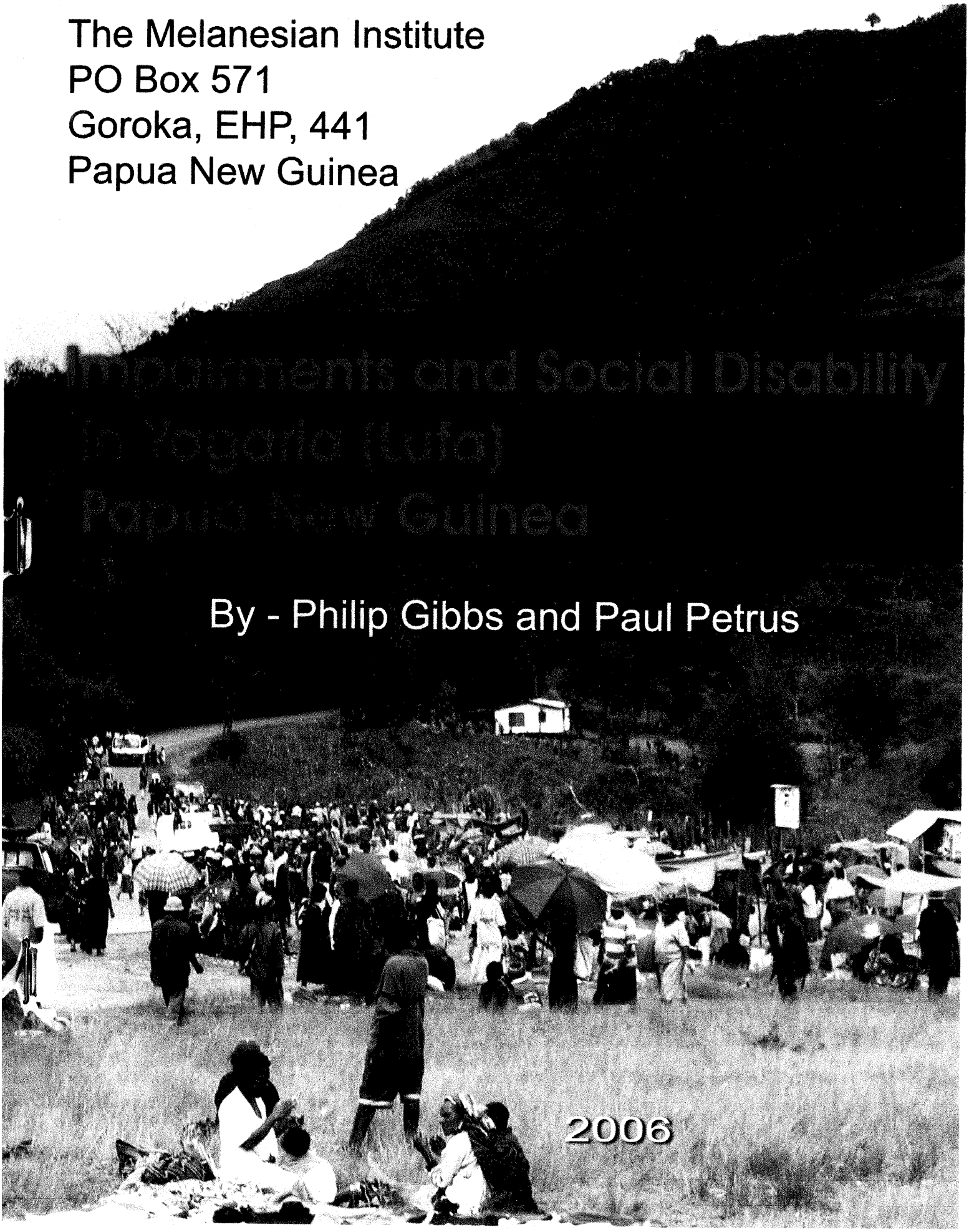
The Melanesian Institute
PO Box 571
Goroka, EHP, 441
Papua New Guinea



# Impairments and Social Disability in Yogera (Tufa) Papua New Guinea

By - Philip Gibbs and Paul Petrus

2006

Contents

Appendices



Maps



Tables



**Acknowledgment:**
We would like to thank all those people who contributed to this study, by agreeing to be interviewed, assisting us in arranging interviews, providing us with food and accommodation and helping us in many other ways including assistance in planning and in suggestions during the analysis and writing. We hope that this report will contribute to the quality of life for the Yagaria people.

# Impairments and Social Disability in Yagaria (Lufa), Papua New Guinea

Philip Gibbs and Paul Petrus - Melanesian Institute

## 1. Introduction and Aim

This work has been done in conjunction with a study being conducted by Ms Patricia Thornton (VSO) and sponsored by Callan Services for Disabled persons. That study involves a survey of Disability in selected rural (Yagaria - Lufa) and urban (Goroka town) areas of the Eastern Highlands Province, Papua New Guinea (PNG). It is a pilot research project, planned prior to further studies in other provinces of PNG.

Our study, sponsored by the Melanesian Institute benefits from the Survey of Disability, but focuses on social disability -- which prevents a person from living a normal social and working life.

Disability is commonly thought of in bio-psychological terms, such as problems with seeing, hearing, moving, or the effects of some incapacitating illness. However a concept such as "disability" will surely be influenced by beliefs, attitudes and values within any particular cultural context. The understanding of the relationship between impairments and disability may well be culturally defined.

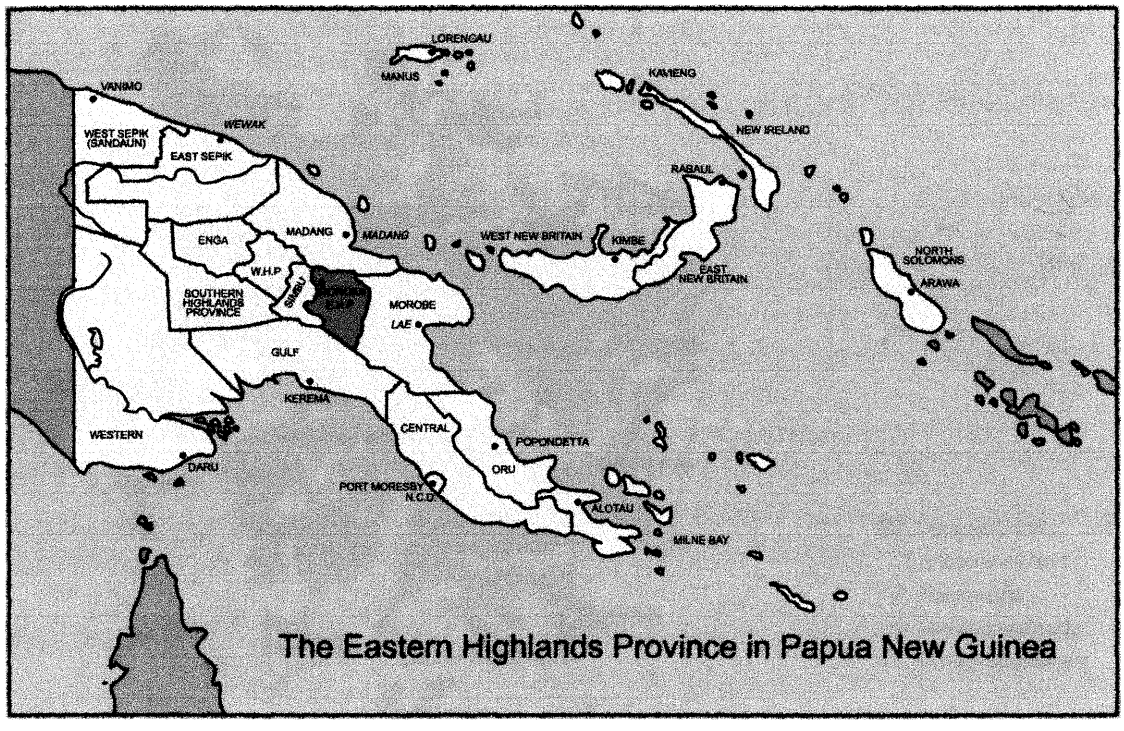
In Papua New Guinea, where communal values dominate, particularly in rural areas, physical, sensory and mental impairments may have different social meanings from modern urban contexts. In the introduction to the book *Disability and Culture*, Whyte and Insgstad note, "Studies of disability require us to move away from the clinic toward the community, where individuals and families live with deficits" (Whyte and Ingstad, 4). Following their line of thought, in this study we consider not simply disability per se, but the issue of "social" disability with concerns such as personhood, dependence, and the capacity to live up to the expectations of the social norms in the given context. Are people with impairments social impaired in the sense that their difficulty limits their active participation in the community? Byford and Veenstra have noted how a "social" model (in contrast to a "medical" model) understands disability "as being created by the social environment" (Byford and Veenstra, 166). If one follows this model, the primary focus becomes the integration of individuals into society, rather than the provision of medical care.

The purpose of our research is to gain a better understanding of how physical, sensory and mental impairments can have social consequences. We try to respond to three basic questions:

1. To what extent do physical, sensory and mental impairments translate into social disabilities?
2. How is social disability related to perceived causes of impairments?
3. What factors influence the way a person with impairments or their family seek help?

The Disability Survey conducted by Mr Thornton began in the latter part of 2005. A survey using a questionnaire was conducted in 3 wards of the Yagaria-speaking part of the Lufa district, and another survey in a ward of Goroka town. The Lufa survey

helped provide a sampling frame for our work, which started in February 2006. Our study concentrates on social and cultural issues in the context of the Yagaria-speaking part of the Lufa district of the Eastern Highlands Province, Papua New Guinea.




Map 1. Papua New Guinea

## 2. Lufa

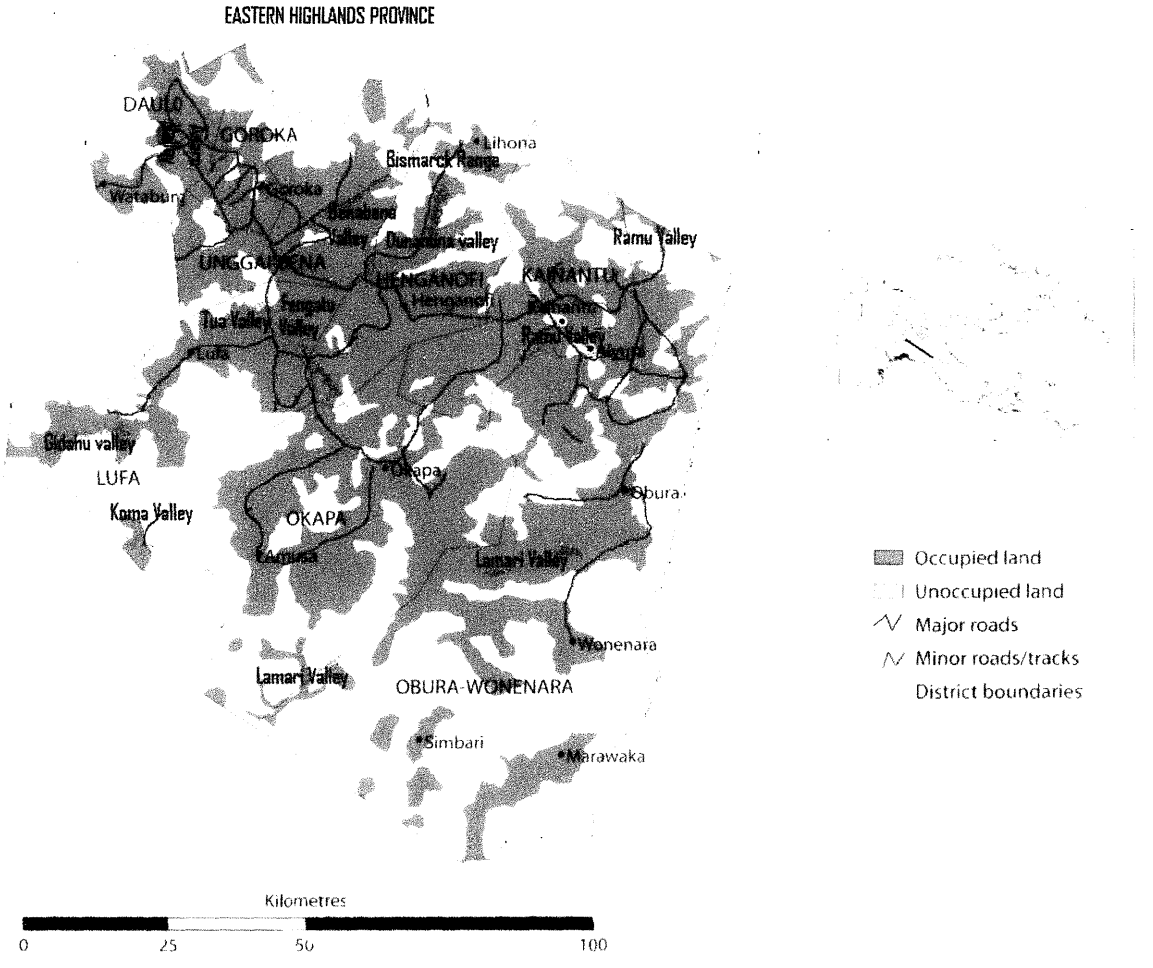
Lufa, situated southwest of the provincial capital Goroka, one of eight districts in the Eastern Highlands Province of Papua New Guinea, (See Maps 1 and 2).

Topographically, Lufa is a land of mountains, hills, and river valleys, with forests, savannah grassland and cultivated patches of garden land and coffee plots. According to the national census (2000), Lufa District had a total population of 45,868 people. Politically the District is divided into three census divisions. This study concentrated on the Yagaria census division where the majority of people speak the Yagaria language. There are eight distinct dialects in Yagaria (Renck 17). Most of our work was with people speaking the Kami-Kuluka and Oliguti dialects (See Map 3).

## 3. The People

According to the year 2000 census there were 25,388 people in the Lufa Rural Census Division The majority of people in this census division are Yagaria speakers, and people in neighbouring districts refer to those in the Lufa Rural Census Division as the "Yagaria" people. We worked mostly with people in wards 23 (Oliguti, population 2,223) and 24 (Kami, population 1,831), with a few people from ward 25 (Folapi No 1, population 1,664) and ward 32 (Napuru, population 2,784). The Yagaria people are mostly subsistence farmers with sweet potato being their staple food. The kinship ideology is patrilineal, with people divided into clans made up of patrilineages. The patrilineage or "lain" consists of men and women tracing descent through males

to a common remembered male ancestor. The patrilineage is the the exogamous unit. A man may not marry his "sister."

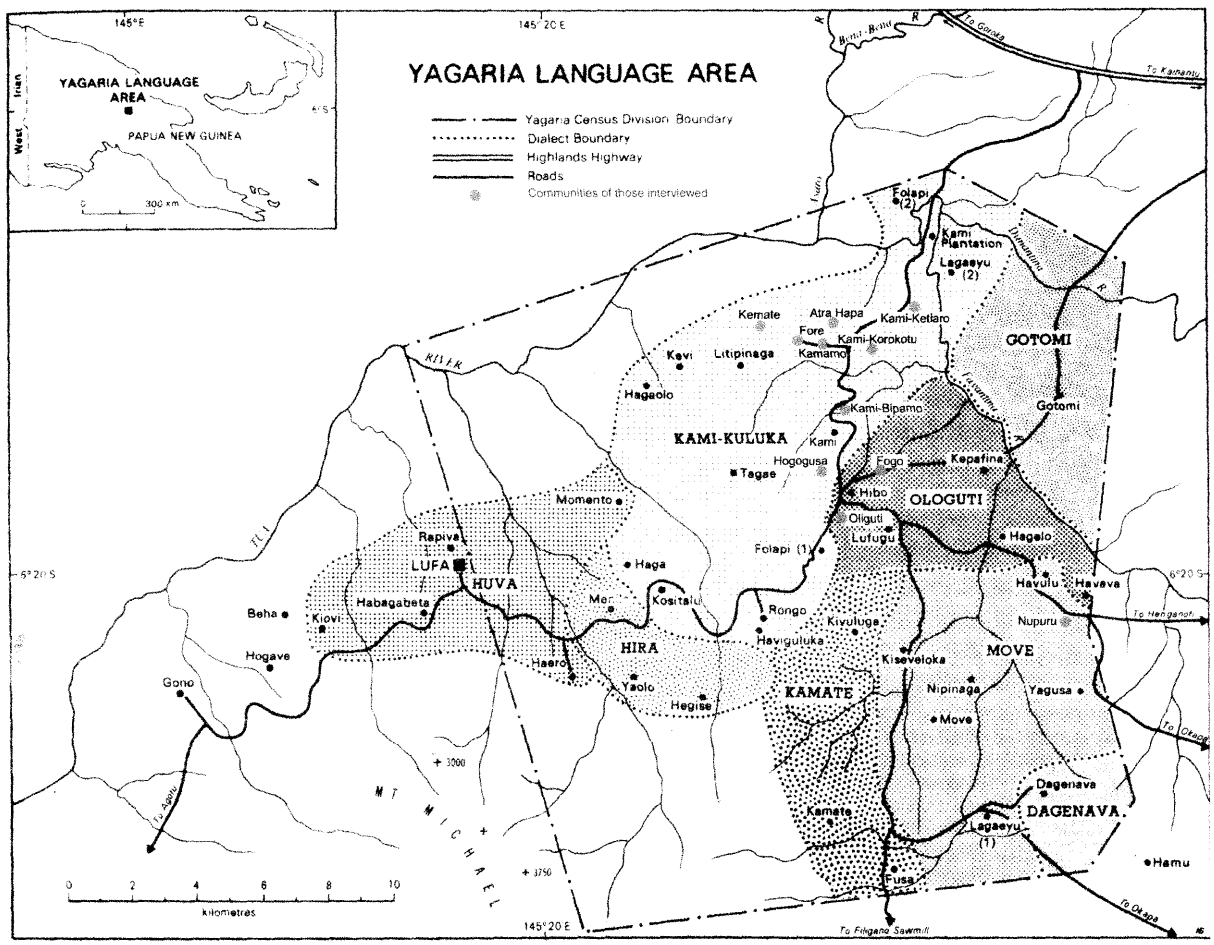



Map 2. Eastern Highlands Province

Road construction during the 1950s opened up the area to the outside world. Changes came rapidly with the establishment of schools, people going to work in the towns or as contract labourers to the coast, and the introduction of cash crops such as coffee. Christian mission activity has resulted in the establishment of at least seven denominations: Lutheran, New Tribes, Four Square, Faith Fellowship, Seventh Day Adventist, Revival, and Baptist. Most people profess to be Christian, yet traditional belief in ghosts and spirit beings continue to influence the thinking and behaviour of many people.

There are no published ethnographies of the Yagaria people. Studies with some anthropological insight have been conducted by Robert Smith (1981) and Anna Meigs (1984). Günter Renck has published several works on the Yagaria language (1977, 1990). Renck notes how among the Yagaria, as in many parts of Papua New Guinea, a person's status is not so much determined by him or her as an individual, but rather by being part of society. "Everything he does is determined by the society, and is looked at and judged by the society" (Renck 1990: 25). He goes on to demonstrate through an analysis of personal pronouns and verb forms how there is

no true distinction between the speaker and the group to which the speaker belongs. Within the clan people have obligations over and to each other. Older persons are obliged to help the younger ones, such as contributing to paying bride wealth. Younger ones show their appreciation by returning goods and helping their benefactors when they are able to do so. Ideally leaders too use their wealth and power to benefit the community, not just themselves.




Map 3: Yagaria Language Area (Map from Renck 1977)

The Yagaria share many cultural characteristics with their neighbours, the Bena (Langness 1965, 1967), Gahuka (Read 1965), Siane (Salisbury 1965), Auyana (Robbins 1982) and Kamano, Usurufa, Jate, Fore (Berndt 1962, 1972). Robbins refers to "mud beings" that live in swampy areas. If their habitat is disturbed, such as when their "homes" are destroyed by gardening, these mud men have the ability to make small children sick (Robbins 22). As will be seen further in this study, the Yagaria have a similar belief which they call *degi*. Robbins also describes forms of sorcery which he terms soul assassination, one form of which (*nai*) causes accidents and illnesses. He comments, "... as it was a labor-intensive economy, status was to a large extent dependent on physical well-being and so 'physical' bad breaks very quickly become 'social' bad breaks" (Robbins 29). We will see similar attitudes reflected in this study. Some "cures" too are similar. For instance, bleeding painful parts of the body by shooting them with a toy bow and arrow (Robbins 36). A similar form of treatment is illustrated in the photos at the end of this study. Berndt says that belief in sorcery "is common to the whole region under review" (Berndt 1962, 208).

This applies also to areas in the vicinity of the region Berndt refers to such as Yagaria. Many of the forms of sorcery described by Berndt appear similar to those encountered in our study. However, sorcery as described by Berndt usually leads to death, whereas in our study we came across a number of cases where it was said to lead to long-term impairments that do not necessarily lead to the death of the victim.

While many underlying beliefs and values remain, exposure to modernisation and the global economy means that people's life style in the Eastern Highlands has changed a great deal since those cultural studies were conducted.

Ethnographic studies in the Eastern Highlands do not deal with disabilities. Studies from other parts of PNG include Byford and Veenstra 2004, and Gibbs 2003. Gibbs reports that in the Wosera area of the East Sepik Province disabled people are generally well accepted in their communities. There were cases discovered though where social stigma and fear discouraged people from seeking help (Gibbs, 172-4.) Blyford and Veenstra found that in the Middle Ramu district of the Madang Province cultural beliefs play a significant role in determining the participation restrictions associated with certain impairments (Byford and Veenstra, 167). This study will treat issues such as social stigma, fear and other culturally related beliefs that translate into social disabilities or influence the way persons with impairments or their family seek help. Both the Wosera and the Middle Ramu studies found that supernatural causes (such as spirits or sorcery or breaking taboos) were a significant factor in explaining the causes of disabilities. This study will also investigate whether such factors are significant in Yagaria area of the Eastern Highlands.

**4. Disabilities and Terminology**

The International Classification of Functioning, Disabilities and Health (ICF) includes the following three dimensions in its umbrella definition of "disability":

- impairment
- activity limitation
- restriction in participation

*Impairments* are problems in body function or structure
*Activity limitation* refers to the execution of a task or action such as seeing, hearing or moving.
*Participation restrictions* affect a person's involvement in a life situation, such as education, work, community, or social and civic life.

While problems in bodily or mental functioning are fundamental to this definition, it also takes account of the extent a person can participate in the life of the community. Our study will follow the ICF terminology, and focus on social disability, which prevents a person from living a normal social and working life.

**5. Method**

Our study uses qualitative methods sensitive to the social context, principally observation, in-depth individual interviews, focus groups and discussion groups. Selection of people for interviews was a challenge. We heard that there were at least four "lists" of disabled persons in the Yagaria area:

List #1 of 25 "clients" held by a Community Based Rehabilitation (CBR) co-ordinator.[1]
List #2 of 75 clients held by another CBR co-ordinator.[2]
List #3 of 553 people identified in advance for the Disabilities Survey.
List #4 of 495 persons with difficulties interviewed in the Disabilities Survey.
The lists do not all correspond well.[3] For example in the Disabilities Survey (#4) only half the people listed in (#3) were interviewed and a further 235 not on list #3 were recruited during fieldwork.

We began interviews for our study with people drawn from respondents to the Lufa District Disability Survey (list #4) begun late 2005. That study had classed people with difficulties into groups according to the extent of their reported difficulties. We received a list of those who had reported at least one activity that they could not do at all. With the logistic help of some CBR volunteers, interviewees were chosen from the list in a way that we would include a range of types of activity limitation expected to result from impairments. We also tried to include both male and female, and young and old. The local contacts helping to set up appointments included Arkson Apatove a CBR volunteer co-ordinator, and Sena Jowapo, assistant CBR Co-ordinator for the EHP, employed at Mount Sion Resource Centre for Disabled Persons near Goroka. No one received payment for assisting us and it was made clear from the beginning that work with us would be on a voluntary basis.

Part way into our study we realised the limitations of sampling using the Survey list. It became apparent to us that:
- the people listed in advance (list #3) but not interviewed are a significant group.
- We were told that some did not give their names for the initial listing (#3) because they knew their names were already on the lists #1 and #2, held by the CBR volunteers.
- Some of the 235 people recruited during fieldwork saw it as an opportunity to have their name listed in the hope there might be an (unspecified) advantage for them in that.
- At the time of our interviews, some of those listed as having the greatest difficulty, did not report such great difficulty at all.

So, part-way through our study we allowed the possibility of interviewing people whose names do not appear on the list provided from the Survey, and consequently interviewed 21 people from the Survey list and 11 people not in that category. We did 6 follow-up interviews with persons we had interviewed previously, making a total of 38 personal interviews of people experiencing difficulties or their carers.

We began in February 2006 and conducted fieldwork over an eight month period through to September. Either one or both of the researchers visited Lufa 17 times, sometimes for one day, often staying several days at a time. Interviews were conducted in or near the homes of the interviewees, because we wanted to observe

[1] List provided by Sena Jowapo. It includes 5 classed as "hearing impaired," 12 "physical," 1 "intellectual," 1 "cerebral palsy," 2 "deaf," 3 "spina bifida," and 1 "deaf and blind."
[2] List provided by Arkson Apatove. As well as those on the list in footnote no. 1 above, it includes 22 with "epilepsy," 17 with "vision problems," and 11 "not yet interviewed." Source: Lufa Kewo Club Annual Report for 2005.
[3] Arkson Apatove says that lists #1 and #2 are much smaller than lists #3 and #4 because different criteria were used in compiling the list. He says that lists #1 and #2 contain names of people who the CBR volunteers considered to have severe difficulties in need of rehabilitation.

the living situation of the person, and for their own convenience. A drawback of this strategy is having less control over interested on-lookers. Interviews were conducted in Melanesian Pidgin except for 7 cases in which the interviewee was not a pidgin speaker and we had a CBR volunteer translate from Yagaria into Pidgin.

We also interviewed three people knowledgeable about healing rituals, and near the end of the study we participated in two focus group meetings and one discussion group meeting.[4] Focus group meetings were designed to have people experiencing difficulties and/or their carers concentrate on issues directly related to the three questions listed in the aim of our study. For example, the first focus group comprised only women who were experiencing difficulties, plus the two researchers and a male CBR volunteer (Aaron Abraham). The second focus group comprised CBR volunteers invited by the volunteer CBR co-ordinator Arkson Apatove. (Our plans for a focus group with only men did not eventuate.) Discussion group meetings were more like open forums where we announced to the community that anyone interested could attend (which meant at least one came who was well under the influence of alcohol!). Also the topics of conversation in the discussion group were more wide-ranging than those in the focus groups. Both interviews and focus group meetings were semi-structured with a list of topics to guide our discussion. Discussion groups also started with a set of topics, opening into a more open-ended conversation.

We also conducted interviews with 14 persons, not because they were experiencing difficulties, but because of their knowledge of the local situation – people like nurses or pastors. With permission of the interviewees or their guardians/carers, the 38 interviews and the focus group meetings were recorded and transcribed.

A summary of details on the 32 people experiencing difficulties or their carers who we interviewed appears in Table 5 in Appendix 1.

Transcribed interviews were discussed in group meetings at the Melanesian Institute. Data in the interviews was coded and analysed manually using annotated transcripts and colour coding for selected themes.[5] Only near the end did we have the assistance of the NVivo7 computer program for qualitative data analysis.

Drafts of the report were then circulated to stake holders such as the Melanesian Institute faculty, Ms Elizabeth Thornton and the CBR co-ordinators. Their comments were taken into account in preparing the revised version of this report.

---

[4] The first focus group comprised women experiencing various seeing, hearing and movement difficulties: Aitave Kotani, Nare Urupa, Hawa Pose, Hugo Benaeve, Koge Sevety. The second focus group comprised CBR volunteers: Arkson Apatove, Justin, Charlie Kamis, Jacob, Grace and Sevako Anamo. The discussion group meeting held at Kamamo on 11 July divided into two groups for discussion. Group 1: Paul Petrus, Jerry Hekere, Dick Kelefu, Alfred Nupade, Joe Namagato, Jacob Tom, Charlie Kamis, Faki'e Edward, Willie Hekere, Akemasi Keksi, Imalta Alfred, Bill Keneku, Kimo Tufa, Sena Jowapo. Group 2: Philip Gibbs, Philemon Kitene, Stephen Kovokovo, Vavo Nunu, Waisa Rex, Arkson Apatove.

[5] We found helpful the coding and analysis methods as set out in Jane Richie and Jane Lewis (eds.) *Qualitative Research Practice* (London: Sage, 2004).

## 6. Speaking about Impairment and Disability

To understand how people in Lufa understand disability one needs first to consider their approach to illness and the terms they use to refer to persons with physical, sensory or mental impairments.

There is no commonly used general term for "sickness" in Yagaria. The reference is usually to different ways of being afflicted (Renck 1990, 51). Sometimes people are said to be *gei hei* (literally: got sickness). This expression applies to maladies such as malaria, typhoid, or the flu, which last for some time but which people recover from either naturally or with the help of medication. People with physical or mental impairments generally are not called "sick". Rather they are covered by the general terms *kevo*, meaning non-functioning limbs, paralysed, or *degi*, meaning dumb, deaf, crazy, unknowing. Occasionally they will be referred to as *tau veka*, meaning someone to be pitied. Generally people refer to their specific difficulty such as their blindness or their malfunctioning leg (see Table 1 below).

### 6.1 Local terms found in the fieldwork

(The terms are taken from the kami-kuluka dialect, where the study was based. Each of the eight of Yagaria dialects might have a slightly different orthography or pronunciation)

**Table 1: Terms used for body functions and impairments**

| Kami-kuluka | English | Tok pisin | Comments |
|---|---|---|---|
| *Degi* | In term *degi* does not refer directly to physical impairments. It has a wide variety of meanings depending on the context used. It is a derogatory term normally indicating that someone is stupid or crazy. | Longlong, hapsens, are the closest tok pisin terms for a *degi* person. | Those with hearing difficulties who cannot speak are called a *degi.* People with mental disorders or persons with epilepsy are called *degi.* People use the term *degi* after a person's name to identify them as *degi, eg.* John *Degi.* A "normal" person who does something wrong can also be called *degi* meaning that the person is very foolish. |
| *Kevo* | Non-functioning limbs | Lek, han i bagarap tru na i no inap mekim wok | *Kevo* is a general term referring to a state of lack of function in a person. It can be used for both mental and physical difficulties |
| *kemo* | Speech | tok | [Si] in *Ke'asima* is the negative marker imbedded in the expression "to be unable" to do something. A person unable to speak properly is spoken of as a *degi* person with a mental problem. "Em longlong man" (He/she is mentally deficient) |
| *Ke'asima degi* | Unable to talk | Longlong na i no toktok | |
| *Bobo'baba' degi* | Speech difficulty | I no tok klia | |
| *Kegetamo havio* | Know, Understand | Tingim na harim | The term *havio* is linked with *kegetamo* (he thinks) using a hearing image for understanding through one's "inner ear." |

| | | | |
|---|---|---|---|
| *degi kana tie* | Mental illness | longlong | *Degi kana tie* means "long long [*degi*] taim *[kana*] bilong en kamap" (someone who goes "off" occasionally.) |
| *Ketamo la'amo* | Anxiety | Wari planti | *Keta/ketamo* (thoughts), *la'a* (much), *havite* (inner feelings), *namabo* (something), *lina* (does), *faipa* (ruin), *haie* (person marker) |
| *Keta la'a havite namabo lina faipa haie* | Anxiety and worry | Tingting planti na em bagarapim em | |
| *Ketamo no havie* | Remembering | Tingim samting | *Ketamo* (thinking) *no* (still) *havie* (hears)<br>*Buki vitabo* (all the time), *ke* (thinking) *no* (still) *kinie* (loses) |
| *Buki vitabo kenokinie* | Short memory | Em i lusim tingting kwik | |
| *Havio* | Hearing | Harim | A person with severe hearing problems is called *degi*, for instance, *degi de* (a deaf man). In the expression *Keta kinite*, *Kinite* means blockage and can also be used to describe the physical blockage, for example, a landslide blocking road. |
| *Keta kinite* | Deaf | Yau pas | |
| *Kavubo kie* | It hurts | Em pen | In the paralysis of the body parts the term used *filite/filie* (dead) is often used.<br>Body parts may also be said to be "bad" or "no good" - *hoasi*: *keta hoasi* (ear no good), *amota* (hand no good), *aia hoasi* (leg no good).<br><br>Whereas *keta hoasi* refers to deafness, keta havite na'amo hoasia refers to misunderstanding where the "inner ear" (*keta havite*) is "no good." |
| *Kemevamo kavubo nokie* | His back hurts | Baksait bilong em i pen | |
| *Leta'amo kavubo nokie* | His knee aches | Skru bilong em i pen | |
| *Aaovamo opala asuna filie* | His body (skin) doesn't work (is "dead") | Bodi bilong em i dai | |
| *Amota filite* | Paralyzed hands | Han i dai | |
| *Aia filite* | His legs are paralyzed | Leg bilong em i dai | |
| *Amotamo kezakie* | Deformed hand | Han i krungut | |
| *Aia hoasi* | Non-functioning leg | Lek nogut | |
| *Lu a'aie* | Retarded growth | I no kamap bikpela (*lu*) hariap | |
| Noke | He sees | Em i lukim | *Mata kia*, most probably referring to a cataract is a commonly used expression which appears to be borrowed from coastal Austronesian languages. *Mata* means eye in most Austronesian languages. A local expression for the same condition may be *aulaga feli* where *feli* refers to a white colour. |
| Aulagamo filikao'ie | His eye is closed | Ai pas | |
| Foto no'ake | Short sighted | No inap lukim longwe. | |
| Aovalo no'ake | Long sighted | No nap lukim klostu. | |
| Mata kia | Cornea malfunction | Ai glob paia | |
| Aulaga ole ole | Double vision | Ai bilong em i luk tutu | |

Terms used provide insights into possible ways that people view impairments and disabilities. The use of the same term for people who are mentally unbalanced and

for those who have difficulty hearing and speaking is common [Even the formerly used English term "dumb" carried that double meaning.] Ears are "blocked." Eyes are "closed". A part of the body "dies." And all of these can be referred to in everyday speech as "nogut" or "bad."

**Table 2: Other Local terms used in the report**

| Kami-kuluka | English | Tok pisin | Comments |
|---|---|---|---|
| *Lukeva* | Dwelling place of masalai or evil spirits. | Ples bilong ol masalai. | People may not enter or engage in any activity in such a place. A place where the waste of the powerful traditional *lusa* healing ritual was thrown is also referred to as *lukeva*. "Tangets" (*Cordelyne terminalis*) and a special tree are planted to mark a *lukeva* place. |
| *Lusa* | Traditional treatment | Bus marasin | *Lusa de* refers to a male traditional doctor and *Lusa ana* refers to the female traditional doctor. There are different types of *lusa* for different ailments. Persons experienced in *lusa* have their own rituals and charms to perform for various maladies. |
| *Hapa* | Swamp | Graun malo malo | Some swampy areas are called *degi hapa* because the *degi* spirits that dwell there may cause problems leading to impairments like deafness. |
| *Ko hagayo* | Steaming food in a bamboo. | Subim mambu | The method of steaming food in a bamboo tube. It can be done as *lusa* medicine or for ordinary cooking. |
| *Aovamo lagahae* | Incising | Katim skin | If a person has a body part swollen and painful, a specialist in *Aovamo lagahae* cuts through the skin to remove "unhealthy blood." This is said to relieve the pain and the swelling. |
| *Utimo hau* | Literally means, shoot with the bow and arrow. | Sutim botel | A piece of sharp glass from a bottle is tied to a stick and shot as an arrow with a small bow. This is used to incise the aching part and is said to relieve pain. |
| *Kaia* | Stinging nettle *Dendrocnidae spp.* | Salat | A plant with leaves that itch or sting on contact with the skin. Used to hit or rub on the skin for pain relief. |
| *lifana* | Toktok i givim hevi | curse | See section 7.1.1 |
| *Nalisa* | posin | sorcery | See section 7.1 |

Later in this report we will look at perceived causes, which influence the way impairments are viewed and the form of treatment offered. In many cases people fight pain with pain – eg. "sutim botol" in which a sore back is treated by shooting it with arrows tipped with glass from broken beer bottles, or sore parts of the body are rubbed with stinging nettles.

## 7. Perceived Causes of Impairments

People have their own reasons to justify impairments and in most cases their reasons are influenced by their cultural beliefs and values. In order to discern causes, people look at the physical signs and symptoms of impairments and will then try to relate these to their past behaviour or to that of their parents.

We interviewed 32 people thought to have bodily, sensory or mental impairments or their carers, and conducted a focus group which included five people mainly with seeing and hearing difficulties. 13 interviewees mentioned more than one perceived cause for their impairment(s) while 14 interviewees gave one cause. Four interviewees do not know the cause of their impairment and one is unclear. The following discussion has two basic groups of causes: the Non-empirical including "cultural" and "religious" causes (7.1--7.4) and what might be termed Socio-Economic Causes (7.5 – 7.8), and .

### 7.1 Sorcery ("posin")[6]

Belief in sorcery (Melanesian pidgin – "posin"; Yagaria – *nalisa*) is strong in the Yagaria area and the whole Lufa district. Sorcery can kill or harm a person for the rest of his/her life. Eight interviewees mentioned sorcery (posin) as a cause. Four of these cases were associated with jealousy, three were a form of revenge and one was accidental.

The jealousy case of sorcery involved AV a former community leader whose right hand and leg are non-functioning. He was admitted to Goroka Base Hospital after a car accident. He feels that while in hospital he was subjected to sorcery by some of his visitors and their motivation was jealousy. He thinks that it was sorcery, not the car accident that caused his right leg and hand to be affected because he did not have serious injuries (yet in that same accident his wife died).

Another jealousy case of sorcery involved LB a mother who has problems with her genitals. She feels that others may have been jealous and worked sorcery on her while she was celebrating a close relative's new business venture. Her medical report states that she has a sexually transmitted disease but she does not believe it. Interestingly both AV and LB have their medical reports on the cause of their impairment and health condition but they do not believe the diagnosis in those reports.

Sorcery is involved in many cases of revenge. Three people with impairments mentioned that others took revenge for past grudges and worked sorcery on them.

[6] "Posin" is the Melanesian Pidgin word for Sorcery. There are two main types of sorcery: that using contagious magic or bespelled potents, and assault sorcery commonly known as Sanguma. We noticed that even when speaking English local people used the term "Poison" to refer to what we call sorcery.

KH has epilepsy. His father admits that he stole a pig from a clan member. The owners took revenge and worked sorcery on his son when he was small. Epilepsy is a mental illness traditionally believed to be caused by the thunder, but that in turn being due to rituals performed by a sorcerer (posin man). The sorcerer calls the thunder (*havosa*) to strike the victim and thus succumb to epilepsy (*havosa*).

NH has multiple limitations in moving, seeing, hearing and self-care. NH stated that because he was a well know traditional warrior in the Lufa district, enemies have targeted him with sorcery but have been unsuccessful in killing him.

> ....ol man i bin wokim posin long stik na ol gras nabaut na putim long rot mi save go kam long en ya, ol putim i stap na mi go long en ya mi tasim long lek bilong mi. Na em pen, ol man kisim mi go kam long en ya, sik bilong mi, dispela sik em i kam insait (Interview with MH (#28)15 March, 2006).
> (A spell was put on a stick or and left on the road where I normally walk. When I touched the stick or plant my legs were painful and started to have this difficulty.)

However, the sorcery has impaired him enough to restrict his movement and cause seeing difficulties so that he is dependent on others for help. This type of sorcery is called *Ki kea nalisa*) (See below).

AD unknowingly trespassed through a "poisoned" area targeted for another person over land disputes. Without realizing it he built a fence in that area and now attributes this to his right eye being totally blind.

**Table 3: Difficulties Caused by Sorcery and Type of Sorcery**[7]

| # | **Initials (M/F)** | **Difficulty** | **Why?** | **Type of sorcery**[8] (See section 7.1.1 for an explanation of these terms) |
|---|---|---|---|---|
| 1 | AV (M) | Movement | Jealousy | *Auwalo lida halaia* (literally: skin – hold – rub) |
| 3 | LB (F) | Movement | Jealousy | (Not known) |
| 7 | NH (M) | Movement | Revenge | *Ki kea* |
| 9 | TB (F) | Movement | Revenge | *Lifana* |
| 10 | KH (M) | Hearing<br>Seeing<br>Mental<br>Remembering<br>Speaking | Revenge | *Havosa* |

[7] Table 3 illustrates how various kinds of poison are believed to cause physical difficulties. The most common physical difficulty is body movement. In cases #3 and #9 our study found that the interviewees had problems of movement difficulty allegedly due to poison. According to the Lufa Survey they were listed as having severe mental problems, but we have entered here the difficulties that were presented to us.

[8] Most of our interviews were conducted in Tok Pisin. Perhaps because of this medium people generally did not name the type of sorcery unless specifically asked. Sometimes they would use the Yagaria term, eg "Ol tok, ating yu kaikai sampela *dami* o kain olsem (HS #15). Most often they would use an expression to describe it, such as "kainkain posin toktok" for *Lifana* (TB #9).

| | | | | |
|---|---|---|---|---|
| 15 | HS (M) | Movement | Jealousy | *Dami* |
| 16 | AD (M) | Seeing | Accidental | *Ki kea* |
| 20 | SL (F) | Cerebral Palsy | Jealousy | (Not known) |

From the summary chart above it may be seen how it is not sufficient to refer simply to "sorcery" in Lufa. One must go to a deeper level and enquire what sort of "sorcery" is involved and the possible motive for it.

We were told that sorcery is common in the "back pages" of the Lufa district and the whole of the Okapa district. The "back page people" are those living behind Lufa station near Mt. Michael and who have no access to government services. The "front page people" which includes mainly the Yagaria speakers, are those dwelling in the savannah valleys and who have access to government services. The "front page people" claim to have learned about sorcery only in recent times from the "back page people" and the tribes in Okapa. This is made possible especially through marriage links.

### 7.1.1 Types of sorcery

*Nalisa* is the general term for sorcery, but there are different sub-types. Some forms of sorcery are believed to result in impairments or even death. A sorcerer or "posin man" is called *nalisa de* and a woman *nalisa ana*.

*Ki kea* literally means "blocking (*kea*) the road (*ki*)". It involves a sorcerer putting a bespelled stick, stone or plant along the road where the victim is likely to walk. When the victim walks over or touches the stick, stone or plant he or she is believed to be "poisoned". The victim will then have swollen and painful legs and this will affect other body parts. NH was a well-known warrior in the past. Tribes in Lufa and neighboring tribes from Okapa and Unggai-Bena districts knew about his bravery in tribal fighting. So, he believes that since his enemies could not kill him in a fight, they have resorted to killing him by sorcery, but so far have been unsuccessful. He believes the sorcery *ki kea* was used to cause his legs a lot of pain making it difficult to sit, stand and walk.

*Dami* "posin" is a black dust-like lime or *kambang* put in food, or shared through cigarette smoke or beer. *Dami* "posin" bears a distinctive image. The victim "i save putim het i go daun long graun na as bilong em i go antap" (The head will touch the ground and the buttocks and lower parts will be in the air – referring to the severe pain from taking the *dami*). Eventually the victim will die if no quick treatment (*lusa*) is given.

*Lifana* is sorcery in the form of a curse. There are different types of curse: Cursing someone so that the victim will not get married, will not look after good healthy pigs, or will not have a good relationship with people (such as in sharing of food or in greeting others). In modern terms such a curse can cause a business person to go bankrupt reducing the victim to be just like others. X studied in university but did not complete his studies. This is attributed to village people having cursed him.

*Lunakave* is a type of assault sorcery in which the "posin man" (*nalisa de*) is believed to push a poisoned stick into the body. (This seems close to what is sometimes called "Sanguma".) A stick is pushed between the ribs toward the heart. When the heart is poisoned, the victim will die according to the time appointed by the posin man. It is said that other methods extract internal body organs through the anus. After damaging or poisoning the organs the posin man pushes the organs back through the anus again. This sorcery is done while the victim is unconscious. Without knowing that he or she was poisoned the victim walks away waiting for the time set for his or her death. This is the most dangerous form of *nalisa.*

*Yawakopa* sorcery works from a distance, but the victim has to be within sight. The posin man performs the damaging ritual while watching the victim.

*Yagasepaku* is a type of sorcery given through food or using left over food of the victim. *Yagasepaku* will cause the stomach to grow and swell "like a pregnant mother." Eventually the victim will die.

*Paimusagete* sorcery uses left over food and food wastes, human waste, urine, or genital fluids of the victim. These are then mixed with special bespelled substances, covered with leaves and tied tightly with vines. The parcel is then left on the roof of a house just above the fireplace. When the heat and smoke from the fire touch the parcel the victim will get sick.

*Havosa* is the local name for epilepsy. *Havosa* also means thunder. Epilepsy is believed to be caused by lightening striking someone after a sorcery ritual has been performed. Food wastes and personal belongings of the person along with charms are put in a human skull and the sorcerer calls for the thunder and lightening to strike the person.

Common items used in many types of sorcery are special types of tree bark. We noticed that people refer to such items using Melanesian pidgin terms, since the *Yagaria* speakers did not practice this type of sorcery traditionally, and do not have traditional names for the of tree bark. Human bones, stones and bamboo are also used. Rituals and spells play an important part and are particular to each type of sorcery. Traditionally in Okapa and the "back pages" knowledge was passed on from one generation to the next as young men learnt from other sorcerers at the time of initiation or followed rituals in the men's house. Today young men learn through experience and first hand witness of the execution of sorcery.

In modern Lufa society sorcery is in great demand. Each type of sorcery has a different rate. *Lunakave* the most dangerous one to perform would cost at least K1000. The *nalisa* people are on hire to perform sorcery within Lufa as well as outside of the district, which includes other provinces as well.

### 7.2 Relations with the living and spirits of the dead

Bad feeling between people can lead to cases of sorcery. However bad relationships themselves may also be seen as leading to misfortunes such as accidents which could cause permanent injury and impairment.

Mi stap long dispela hevi, mi yet ya. Kain olsem liklik sista bilong mi em kam na go ya taim em stap long Lufa hai skul na bikhet mi bin stikim em na papa bilong mi belhat na mitupela bin kros na pait. I kam nau long dispela taim mitupela i no wanbel o sekhan yet. Olsem na ol lain bilong mi tok olsem sapos mi painim wanpela bagarap o hevi bai ol blemim papa bilong mi (Interview with PI2 (#59) 27 September, 2006).
(I have this problem. My younger sister was going and coming in a way that I thought was head strong, so I beat her, and my father was angry at me and we had a fight. We still have not yet resolved our difference. So my people told me that if I encounter some misfortune, they will blame my father.)

There is a strong belief in Lufa that tension between husband and wife may affect their children causing them to get sick.

Sapos mi gat kros wantaim ol lain bilong meri bilong mi em stil bai afektim ol pikinini. Ol pikinini bai painim sik kisim bagarap nabaut. Ol bai pilai na brukim lek han, ka aksiden. Dispela hevi em mitupela pesim pinis. Lilyian liklik gel bilong mitupela em paia kukim em pinis long dispela tasol. (Interview with K&A (#74) 26 September, 2006)
(If I am angry with my wife's people it will affect the children. The children will get sick or suffer accidents. When they play they will break a leg, injure their hand or be involved in a car accident. We have faced such an occasion. Due to this reason our little girl Lilyian got burned by the fire.)

We found differences of opinion as to whether spirits of the dead can cause sickness or misfortune. Some, mostly committed Christians denied that it could happen. Others gave examples, such as the example in the case study below (Source, interview with S1 (#60) 27 September, 2006).

**Case Study: A dying mother's curse**

A woman had adopted a boy and cared for him. Then the time came when she became severely ill. She asked for the boy and told him, "I am not well. You have not cut firewood for me or brought me water. It has been difficult. If I die, then afterwards I will see to it that you do not have peace. You will go crazy." The woman died, and immediately the boy started exhibiting very strange behaviour. He did not attend his adopted mother's funeral. He went against local custom and killed small snakes and ate them. He appeared to be emotionally troubled and became a recluse. Fortunately after some time a woman who is a member of the Faith Mission took him into her home and cared for him along with her own son who was almost the same age. Gradually the boy responded to her care and now he acts like a normal person again.

In another interview (K&A #74, 26 September, 2006) we heard about an elderly person who felt he was not treated properly by his children and told them that after his death he would make life difficult for them.

"Mi kisim hat taim na mi holim bel bilong mi na mi dai ya na yupela bai stap na lukim" em tok. "Olgeta kago bilong yutupela, yutupela swet na kisim bai yutupela bai stap na lukim," em tok.
("I have had a hard time holding my belly (feeling angry?) and you will see. Everything you get you will have to sweat to get, you will see.")

### 7.3 Disobeying taboos

We have found that disobeying taboos and evil spirits/*masalai* are closely linked because in our interviews people spoke of breaking taboos when they entered a forbidden area – usually identified as an area inhabited by *masalai* spirits.

There are different types of taboos. Some apply to forbidden places. Eight impaired people spoke of disobeying taboos as the cause of their impairment. Seven of them stated that they disobeyed the cultural taboo on entering and working in a *degi hapa* (forbidden swampy area- see *degi hapa* in Appendix 5). A father stated that his son has a chronic sore on the leg because he collected firewood from a forbidden area (*lukeva*) where bad spirits dwell . This belief is still common today.

> ... sampela kain olsem ol pasin kastam ol wokim na ol tromoi sampela pipia long dispela hap long ol tambuim ol olsem i no ken kam long dispela hap. Dispela hap em i go na ol putim ples tambu long en em mangi em i no save na em i go tasol na em i brukim paiawut na kisim kam long en wanpela liklik stik em sutim em tasol long en em i kam na lek bilong em tasol solap nau na bihain em sikirapim olsem na nau dispela lek bilong en solap na sua i bruk (Interview with DJ and family (#31) 2 May 2006).
> (Places where cultural practices (ritual) were done and their wastes were thrown are forbidden for people to enter. In that place the boy was not aware and he entered and collected firewood. In there a small stick scratched his legs. But it swelled and eventually developed into this sore.)

NH noted that after he had made a garden in a forbidden swampy area he now has multiple difficulties with hearing, seeing and movement. OK blames his mental and hearing difficulties on his mother making a garden in a *degi* place while being pregnant. OK was born with skin peeling off and was seen as an abnormal child from birth.

The problem does not necessarily start after one or two days but can happen after 30 years. That was the case for NH. When he was young he made a garden in a *degi* place but now as he is getting older he relates his difficulties of poor eyesight and pains in his legs and back to working in that *degi* place. The difficulty comes because he once disturbed the dwelling place of a *masalai.*

We learned in the focus groups and discussion groups that there are a number of taboos related to pregnancy and childbirth. They may be classified as social and forbidden place taboos.
Social taboos include the following:

- A pregnant woman must not accept food from enemy clans or any clan other than her own.
- She should not cut food with a knife, but rather, break it with her hands.

- Normally a man should not sleep with his wife after it is clear that she is pregnant.
- A man cannot witness a woman's labour or the birth of a baby.
- The woman should not eat food from the "subim mambu" otherwise the child will be thin.

Taboos on entering forbidden places and disturbing the environment include the following:

- She must not go to taboo places to gather firewood or fetch water.
- The father of the child must not cut grass or trees in a taboo *degi* place

There are other taboos concerned with marriage rules and exogamy. K&A (#74) Interview 26 September, 2006) said that these marriage rules are being broken more often these days.

To disregard any of the taboos mentioned above is to risk bearing a defective child.

### 7.4 God's Anger

Christian churches may have helped bring about change in beliefs and values, but much remains. We heard in the discussion groups how when Christians bear disabled children their fellow worshippers may accuse them of holding back tithe money or of "playing up with God" so that God is punishing them.

O #18 is a boy born with an unperforated anus. As a baby he had to undergo emergency surgery to bring his bowel outlet out to his side so that he could dispose of bodily waste. Several operations failed in attempts to reconnect the bowel to his anus, so he lives with waste secreting uncontrollably from his side, with the resultant discomfort and smell. His parents had left the SDA church shortly before he was born and they attribute their son's impairment to God's "curse." We were told that two other children were born around the same time, with the same condition and that the parents of those two children had also left the church, thus reinforcing the perception that the cause was God's anger.

At least one pastor interviewed said that people must confess their sins to God first before expecting healing – indicating that "sin" acts as a block to God's power, and could be seen also as a causal factor.

> So mipela i save tokim em, yu mas tok sori long sin bilong yu na daunim yu yet na God em bai fogivim yu na God bai hilim yu tu. (Interview with JS (#51) 31 August, 2006).
> (We tell them that they must be sorry for their sin and humbly ask God to forgive you and then God will heal you also.)

**Case study of B as God's punishment**

B is now a 4 years old boy. He had clubfoot when he was a baby. His mother shared her experience of how she encountered the problem and faced it. The mother was not convinced with the suggestions from others that her son had clubfoot because his legs could not balance his upper weight. Rather, the mother presumed that it was God punishing the parents. This happened because the father took some money from a church youth group and used it not in the way intended but to drink alcohol. The mother said, since then they have left the church and have not repaid the

money. The child was from God as a present and God did not want to put a scar on creation so he only turned his leg so that the parents will come back to the church and repay the credit to the church youth group. The father rejected the mother's views and has not returned the money. Later the parents took the baby to the local Aid Post and the nursing officer referred them to the Goroka Base hospital. There the physiotherapists diagnosed and treated B. Back at home, the parents continued to visit the nursing officer and eventually the child was able to step and walk properly. (Source: Interview with AL (#33) 31 August, 2006)

Our interviews with Church personnel centred more on healing than on causes, though sometimes the "cure" gave some indication of the perceived cause. For example, an evangelist with the Faith Mission (JS #51) spoke about praying to cast out a "Sanguma" spirit from a woman, and a member of the Revival Centre (AJ2 # 38) referred to casting out an evil spirit to in a case of repeated fits which showed all the symptoms of epilepsy.

### 7.5 Disease/illness

Hospital medical reports indicated that at least 4 people from our sample had problems caused by disease or illness: through a STD, premature birth and cerebral malaria. IK's parents accepted the medical explanation of premature birth and dismissed other culturally motivated causes. IK was born premature after his mother was admitted to hospital with malaria and typhoid. However in many other cases people do not believe the medical reports and give priority to other causes.

LB a widow believes that she was "poisoned" and does not have syphilis as stated in the medical report. SH is a young girl who has difficulty remembering. Her parents attribute her condition to causes other than cerebral malaria as diagnosed at the Goroka base hospital. The parents think the cause is incomplete immunization treatment and mosquito larvae in food and water (which is closely related to the cause in the medical report). However, because SH had a different type of fits from the those typical of epileptic fits, they thought the child must have taken food from people the parents have grudges with.

Additional diseases/illnesses that we as researchers observed were Down Syndrome, Palsy and possible Prostate problems, each having their own perceived cause. A combination of perceived cultural causes and medical causes will be addresses further below (7.9).

### 7.6 Accident/injury

Five people in our Cultural Study gave accident or injury as a cause of their impairment. In most cases accident or injury lead to difficulty with movement. Two people gave hard physical work as the perceived cause and the other three mentioned a road accident, domestic violence and fighting respectively.

The environment, style of gardening and the type of physically demanding manual work done by men and women in the Lufa district can lead long-term biophysical problems.

TB lives with her two children. Living far from her husband for more than 10 years she has tried to raise the children by herself. She has to work hard by doing both

men and women's work in both house and garden. Given the type of environment where the soil is very hard during the dry season and muddy in the rainy season, much time and energy is required for such work – a difficult task for a woman alone. She tells how she suffered pain in her body starting from the back as she cleared brush-covered wasteland to make a new garden.

> Kain pitpit gaden, mi wok long en ya mi ting olsem dispela mekim na em pen ya nogat em tok mi kisim sik. Em ting olsem em brukim dispela pitpit garden, graun ya em brukim ya em ting olsem dispela garden mi brukim long en olsem em ben daun na wok na dispela kain long en em ting olsem em pen nating em sik tasol mi kisim em tok (Interview TB (#9) 23 March 2006).
>
> (I think that this pitpit garden that I cleared must have caused the pain and sickness. This is because I bent my back to dig this new garden. I thought the back pain was temporary but it was the beginning of a chronic illness.)

### 7.7 Ageing

Ageing was not perceived as an independent cause for difficulties even though some people mentioned ageing as a cause. Some of the pidgin terms relating to old age include the following: HS stated, "Mi pilim olsem. Mi no nap bai 'go antap' olsem yupela, mi 'kam daun'" (I feel that I will not go up like you but I am coming down). An old women stated "Gro go antap na go daun" (Growing up and going down).
HS felt ageing is one of two causes of his seeing difficulty. PI (#29) has movement and seeing problems and in the interview (26 April 2006) his son related both to the ageing process as the cause. Difficulties coming with age are a biological fact. However, six others in the middle to old-age bracket did not mention ageing as a cause.

### 7.8 Substance abuse: Marijuana and alcohol

A person who takes drugs is called a "drug body". The person is called *degi* if he or she acts abnormally due to taking marijuana. Two people from our interviews said that they took drugs at some stage in their lives. One is a former drug addict with a hearing difficulty, while the other has increased his rate of taking drugs in an attempt to deal with chronic backache. These two gave their perceived causes as a mother working in a *degi* place while she was pregnant, and injury in fighting respectively. It seems that marijuana has not helped and may well have contributed to their problems. CBR volunteers we spoke with said that problems related to taking marijuana are not common in Lufa.

Most men and some women in the Lufa District consume alcohol – normally beer. Drinking is at its peak during the coffee season and during that time it was hard at times to find a man sober. However, only one man from our interviews (HS #15) related his disability to consuming a lot of alcohol when he was young.

### 7.9 Combination of Cultural and Medical Causes

There were instances where people gave both cultural and medical causes to one impairment or even multiple difficulties. They had reasons to justify the perceived causes from a cultural perspective even though they had medical reports. Of the six people with medical reports, only four had parents or carers who gave priority to the medical explanation over the culturally perceived cause. The uncle of one disabled

child is the Eastern Highlands CBR coordinator and this might have had some influence also.

People judge the difficulty to be traditional (sik bilong ples) or from outside depending on the signs and symptoms. New and unfamiliar signs and symptoms are believed to be sicknesses caused by outside influence and will more likely be judged from a medical point of view. An elderly man used the phrase "em sik bilong gavman" (literally - illness of the government), meaning that health centres, clinics or a hospital will be able to treat the sickness. AIDS is sometimes referred to as "sik bilong ol waitman" (Illness of the white people).

### 7.10 Don't know

There were 4 interviewees who said that they did not know the cause of their difficulty. This was either because people have not tried any treatment or because both traditional and medical treatment seemed not to help.

**Case Study: Cultural and Medical Causes**

LB has 7 children. She has lived away from her husband nearly 18 years. Her husband lives in his own village some kilometres away. She is a faithful member of the Seventh Day Adventist Church. In between 2004 and 2005 she began to develop sores and pain around her genital area. The pain then moved to the umbilical cord area, then her head, back and other parts of the body. This difficulty has stopped her from working in the garden and house. Her children and relatives have not been concerned to help her in the gardens or house. Furthermore, no financial help was contributed to send her to the clinic. She says that she struggles to meet her needs and to get money to go to the clinic. At the clinic she was told that she has Syphilis – a sexually transmitted infection. She does not believe the clinic report because she has lived apart from her husband for nearly 18 years and she says she has not gone around with any other men. Furthermore, the medicine from the clinic did not heal her illness. This convinced her that someone had worked sorcery on her. She and others were celebrating the opening of a new business by one of her brothers. There perhaps some jealous people could have worked sorcery on her. She finds it difficult to accept either the cultural or medical cause. She is now resorting to God's healing and has decided to live as healthily as she can. On the one hand, the anxiety she has due to lack of family support and doubting the medical cause causes her to think a lot. On the other hand, it all started because of her illness. If her medically approved cause of illness is correct, then we may see how Syphilis is a health condition leading to impairment, activity limitation and restriction on leading a regular social life (social disability). (Source: Interview with LB #3, 23 February, 2006)

One possible cause – incestuous relationships -- was alluded to in interviews, but not spoken of openly as a possible cause of birth defects. K&A #74 referred to five cases in five years in his community, with the offenders paying over a thousand kina in asking forgiveness of the community. UB2 #68 from the same community referring to unions between clan "brothers and sisters," said that it is shameful but it does occur.

## 8. Varied Causes for Difficulties

The way different causes may be attributed to similar difficulties may be observed in the case of seeing difficulties. Local Community Based Rehabilitation volunteers said how seeing difficulties are very common in the Lufa area. LBi (#11) an interviewee with seeing difficulties confirmed this. Nine interviewees gave different responses for the cause of difficulty in seeing.

**Table 4: Type of Seeing Difficulty and Perceived Cause**

| # | Initials, (M/F) | Difficulty | Perceived causes |
|---|---|---|---|
| 2 | AJ (F) | Objects obscure at more than 50m | Clinical injection and sun's radiation. |
| 5 | JH (F) | Objects obscure at more than 50m. Watery, double vision, confused colours. | Sun's radiation, tree dust, smoke from open fire in the house. |
| 7 | NH (M) | Watery, double vision | Sorcery |
| 11 | Lbi (M) | Objects obscure at more than 50m | Sun's radiation, coffee dust, theatre operation. |
| 12 | RB (F) | Objects obscure at more than 50m, double vision, dark | Not sure |
| 15 | HS (M) | Objects obscure at more than 50m, can't read the Bible | Old age, smoke from open fire in the house. |
| 16 | AD (M) | Right side totally blind, can't read clearly | Sorcery. |
| 26 | UB (M) | Can't read, can't recognize things from a distance, | Reading by light of kerosene lamp. |
| 28 | MH (M) | One eye badly affected by scaring | Eye injured by kunai grass. |
| 29 | PI (M) | Cannot see clearly without glasses | Not sure, possibly age. |

Two of the above involve physical injury. The others involve activity limitation, possibly due to growths on the eye or to deterioration of eyesight due to age, however, the perceived causes are varied. Of the above, only PI (#29) had sought help, and it was only he that (with suggestion of his son) realised that the deterioration might be part of the ageing process, so that he took the initiative to be tested for eye glasses.

## 9. From the Biophysical to the Social

To what extent do physical, sensory and mental impairments translate into social disabilities? Just because one is blind, deaf or physically disabled does not mean that one is inevitably socially disabled. We found that cultural, social and personal factors intervene. Communal/cultural factors include: Isolation and not being able to participate in communal activities, dependence, shame, fear and stigma, labels, and the type of impairment. Social factors include status, sex, age and marital status. The main personal factor is the person's own attitude to his or her impairment.

### 9.1. Isolation and not being able to participate in communal activities

Children who cannot walk or talk tend to be isolated from other children and cannot play as other children do. DJ (#31), a young boy lamented the fact as he sat unable to walk, nursing chronic disabling sores on his leg. Disabled children may be confined to the house, relating only to their immediate family. IK (#6) is 6 years old

but looks like a child of 2 years. Lying unable to walk or talk, we found him left in the house in the care of his young sister. Not being able to go to school is not seen as a big problem in Lufa. Some able children do not go to school, and the community places greater value on capacity for work than formal education. For the older person, isolation will be experienced in not being able to attend the weekly market or other communal activities such as marriage feasts or church services. Isolation can be a serious problem for women, particularly widows. In a predominantly patrilineal society women depend to a large extent on their husbands to link them with the community. With her husband dead, she must depend on her children. RB (#12) left her husband's place and returned "home" because she felt isolated and mistreated. If she remarries the new husband will have to repay some of the bride price to the dead husband's people.

**9.2 Dependence**

Children naturally depend on their parents and other members of the extended family. However, children with impairments often remain highly dependent for an indefinite period. We interviewed the parents of two young men, one with Epilepsy and with what appears to be Palsy. KH (#10) is now an adult, but needs continual guidance from his family if he is to help in the garden or do other work. He needs assistance to wash. His primary help comes from his parents, but when community members see him wandering away, they help take care of him and bring him home. AVi (#23) is a young man who, though physically an adult, and able to move independently, has not learned to be independent for toilet, so his parents have to be available to clean him after urinating or defecating, which they find very embarrassing. Naturally such dependence leads to activity limitation and participation restriction amounting to social disability not only for the persons with impairments but affecting their close relatives also.

**9.3. Shame.**

In Lufa, shaming a person is a psychological punishment of an individual in the community for misbehaving and having no regard for the ethics and norms of the community. A typical way of shaming a person would be to take him or her to a public court case and accusing them of stealing, adultery or attending a feast uninvited.

In some cases, for example, with Cerebral Palsy, we were told that parents will feel ashamed because culturally such severe impairments in children are attributed to the father or mother having broken taboos associated with pregnancy and childbirth or taboos on entering places inhabited by masalai spirits. However, several parents of children with severe impairments said that they accepted the fact that their child was not disabled and they did not feel ashamed at all. The Maternal and Child Health Nurse confirmed this (Interview with WH #71, 27 September, 2006).

Impairments in children can also be interpreted as a situation where the parents have tried to work sorcery on someone and the sorcery has "turned back" to "hold" their child. People we spoke to in Lufa said that the churches have made a difference in lessening stigma and encouraging care for impaired people and their families. On the other hand some attribute impairments in children to "backsliding" on the part of the parents. ZP's parents were members of the SDA church, however while she was pregnant she and her husband became "backsliders", and there was finger-pointing when she bore a deformed baby. Thus not only must the child deal with activity

limitations of the impairment, but also the social impact of their parents' embarrassment or shame.

This traditional beliefs are now changing for some parents as they receive medical explanations from the hospital. This was the case for IK's (#6)parents. The child's parents are following medical advice and are adjusting to the situation with their daily activities so that there will always be someone available to look after the disabled family member. It is worth noting that they felt embarrassed about bringing IK out in public such as the market, not because others looked down on them, but because people so many well-meaning people wanted to give food to their disabled child.

Older people have to deal with the shame of having others help them with self-care activities such as washing and toileting. The experience of dependence on others is particularly shameful for a man like NH (#7) who in his earlier days had been a well-known fight leader. People who cannot hear or speak are labelled "degi", with its negative connotation of being mentally impaired or crazy. This can have a significant negative social effect as we saw in the case of OKK (#4). He reacts negatively to being labelled as "degi," isolating himself from the community.

### 9.4 Fear and Stigma

Fear and stigma can make an impairment more disabling than the direct effect of the impairment itself. The community fears aggressive mentally disabled people like KH (#10). In an interview his father described KH as a "wel long long man" (wild and mad person). At first people were afraid of him because he would bite people or mistreat babies. Now his father says that he seems to be improving but is still called "degi" (mad) and socially marginalised.

OKK (#4) is known to have used marijuana and many people attribute his erratic behaviour and his hearing problems to the side-effects of marijuana use. The topic of drinking alcohol and smoking marijuana came up in the discussion group meeting. From that discussion it appears that people in Lufa overlook a lot of antisocial behaviour due to alcohol consumption, but have little sympathy for those who smoke marijuana, saying that they have brought the problem on themselves. We observed how people who do not talk clearly due to the side effects of marijuana are sometimes mocked in public. This can turn into a vicious circle of rejection and more drug use as we found in the case HN (#8) who was also using marijuana and called "hap sens" (stupid) by people in the community.

> A-i-o mi bai wari long wanem samting ya, em meri wanpela samting ya na mi bai wari long wanem samting. Em meri wanpela tasol ya na mi no save bai mi marit long en mi no save. ..... Nau ol man save tok yu hap sense ya (Interview with HN (#8) 15 March, 2006)
> (Oh, what will I be worried about, a woman is the only thing, and what else will I be worried about? I don't know whom I will marry. Now people call me stupid -- "half sense")

Nowadays people often attribute the onset of mental illness later in life to marijuana use. In the local language the person would be called *degi*, but in pidgin the term "drag bodi" might be used.

Stigma associated with talking publicly about sexual behaviour or sexually transmitted diseases is common in PNG. Yet, in our interviews we found that some older people appeared not to be ashamed to talk to us about their problem, as, for instance, HS (#25) whose problem prevents him from having sex with his wife, or LB (#3) talking about the medical report saying that she had syphilis. In the latter case, her candour is possibly due to her rejecting the conclusion of the medical report.

### 9.5 Labels

To some extent disability is culturally constructed through the ways people talk about it. Often people are called "nicknames" connoting their impairment, for example, "hanbruk" (deformed arm) or "ai nogut" (blind). Frequently people with impairments accept these labels, though sometimes they resent it.

> Dispela olsem, ol save tok, ol man olsem ol longlong man ya maski. Kain toktok nabaut ya ol save wokim ya. Tasol olsem mi yet mi harim long en ya, mi yet mi save, narapela kain ... Mi man tasol, mi man tasol ol save bagarapim mi na toktok long en ya, olsem mi belhat man olsem mi pulim drug kain man olsem em wok pinis long skin bilong mi na olsem, taim mi laik, ol wokim liklik toktok mi save kirap na wokim eksen long ol ya. Em mi wokim kain kain olsem mi save pait o, pait wantaim ol o kain nabaut em mi save mekim... (Interview with OKK (#4) 28 Feb. 2006)
>
> (Calling a person mentally impaired is not good. But I am a different person. I am a person but they hurt me. But because I am a drug addict which causes me to be short tempered and when they hurt my feelings I react quickly by fighting with them.)

Some people have speech impediments but are able to live normal lives. T does not talk clearly and meaningfully. Sometimes people refer to him as *degi* because of his inability to express himself clearly. However, he would be angry if he hears that label because mentally he is quite normal. He can do gardening, pick coffee, look after his family and do everything expected of a man except express himself verbally in public.

Sometimes nicknames will be used in private, but not in public. If the person is easy going he or she can be given nicknames referring to their impairment, but if the person is very aggressive or easily hurt, people hesitate to call them by such names. Their attitude will influence their social relationship. An impaired person who is more open will most likely have a better social relationship in the community, but for others, being labelled will result in participation restriction leading to social disability.

**Case study of O as labelling and stigmatizing**

O is about 10 years old but looks 6 years old. O is from Nupuru. Since birth he has not been able to excrete through the anus. Therefore, he was operated on at the Goroka Base hospital to allow his waste to exit (uncontrollably) through the right side of his stomach. He covers the opening with pieces of cloth that he can find. But this problem does not impede O from assisting his parents in the garden and house. He can break firewood, fetch water and work in the garden.

His hopes of seeking another attempt for operation seemed less likely when his father declined financial assistance for the operation from a local nursing officer at the Nupuru Health Centre. We were not able to get the father's reason for declining the financial assistance, as he was not available during the interview.

This is in fact a very difficult and shameful situation for him. It was clearly visible during the interview that he did not talk much and felt embarrassed when we asked if we could see how he covers the outlet. As a child he is and will be a prey to being stigmatized and labelled negatively by his peer groups. According to his mother who was there during the interview, "ol save kolim em ful gro pikinini" (They call him a retarded growth person). This was because his younger brother has grown taller and looks older than O. Others would describe him as, "skin bilong em toilet smel" (He smells like a toilet).
He does play around with other children despite the negative attitude towards him. His future seems unclear. He cannot go to school because he feels it is unhygienic to be among other children with the smell and possibly more stigmatizing and labelling. Whether he will get married is uncertain.
However, according to past interviews (D & A #43, 27th July, 2006) whether educated or living as a bachelor is not a crucial issue. If the person can continue to work and support his family in the garden, coffee and able to contribute meaningfully to the community affairs then this will give him identity and status.
Neglected by the father to seek further medical operations and stigmatized and labelled by his peer group will certainly lead to more social disability. (Source: Interview with O #18, 26 September, 2006)

**9.6 Type of Impairment**

Physical and sensory impairments need not be an obstacle to living a "normal" social life. However, it is different with mental impairments. People with mental impairments are very often regarded as impaired persons. There are different types of mental impairments. Some are intellectually impaired. A is a young adult male who is considered "longlong olgeta" (*degi legepa* -- totally crazy). He cannot contribute to the community and exhibits childlike manic behaviour most of the day. He is totally dependent on others for his livelihood. People with long term mental impairments that prevent them relating to others may be considered socially disabled.

Another type of mentally impaired person is the one who suffers unbearable mental strain such as at the death of a loved one. People say, "Wari i save kilim em" (Worry kills him/her). Such people may have their good and bad days and if it continues on and off for a long time people comment "taim bilong em i kamap" (*degi kana tie* – his/her time has come). People are more understanding about this type of temporary impairment due to mental strain and generally will allow them time to be able to participate again in the regular life of the community.

**9.7. Social Factors**

Status, sex, age and marital status all have a bearing on the whether or to what degree a person may be socially disabled. A person with high economic standing may be able not only to contribute financially to the community and thus be considered a full member of the community, but he or she may also hire help to compensate for what they themselves cannot do. In our study RB's (#24) husband was wealthy enough to hire people to help his wife so that she was not forced to carry heavy loads with her painful back.

As noted earlier in 9.1 isolation can be a serious problem for women, particularly widows. Culturally, women have a lower status in Lufa society. Moreover, by leaving

their home and marrying into their husband's clan they are at a disadvantage when it comes to family support. Nevertheless, those we spoke to said that it is hard to generalise on the situation for women and that it depends on what sort of family they belong to. One area where it seems girls are at an advantage is as illegitimate children.[9] People said that they would be happy to adopt an illegitimate girl child knowing that one day she would receive bride price to be distributed to her family. Illegitimate boys, however, however are less welcome as they would be inheriting land and possessions in an area which is already feeling pressures of increased population density.

Whether age is a factor also depends primarily on the sort of family they come from.

> Em papa ya, na mipela save sori long en na olsem mipela save fidim em. Na ol, mitupela sista ya, bikpela sista em save slip long hia mi save slip long hap sait. Olsem ya na em mitupela save lukautim em na ol bubu bilong em, tu em ol planti i stap. Olsem ya na mipela i save lukautim em (Daughter speaking in interview with NH (#7) 15 March, 2006).
> (He is the father we feel sorry and feed him. My elder sister sleeps here and I sleep over there so we look after him. He also has many grandchildren. Therefore, we take care of him.)

On the whole the elderly are respected for their wisdom and experience in life. Their contribution to the well being and identity of the community is gratefully acknowledged.

An unmarried person is a rarity in Lufa. Two main reasons are given for why a person would not marry. Either they have some form of impairment which makes them undesirable for marriage, or they are the victim of a curse (*lifana*). In Lufa, when it comes to marriage, physical beauty or ugliness do not count nearly as much as family background and a person's attitude and behaviour.

### 9.8 Personal Factors

We found that in many cases, whether a person is social disabled depends more on the person's own attitude and behaviour than that of the their family or community. Some impaired people feel ashamed despite declarations of encouragement and good will of those around them. AV (#1) lives in fear and does not move freely because he feels he is still a target for sorcery. His fear of his enemies is causing considerable restriction in participation in the life of the community. Both HS (#15) and AD (#16) used to be able to read the Bible in church but now are limited to sitting and listening to others. They find it hard to accept this role change. In discussion groups people mentioned how social acceptance depends a great deal on attitude and behaviour. A person like UB (#26) feels ashamed at not being able to recognise others some distance away and consequently is limited in how he participates socially. He does not appreciate how most people understand his situation and bear no malice.

---

[9] Illegitimate children are called "rot pikinini" (children of the road -- *kito bade* [male] *kita abade* [female]

People who experience the onset of some impairment in later life may think back to what is was like before, and this may cause them to feel useless and dependent.

> Taim mama bilong mi karim mi nogat dispela kain sik. Mi kamap gutpela man. Mi raun na mi marit mi karim ol pikinini bilong mi. Ol pikinini bilong mi ol stap. Tasol long dispela kar eksiden ya meri bilong mi dai nau mi bagarap mi stap long ples (Interview with AV #1, 16 Feb, 2006).
> (When my mother gave birth I did not have this sickness. I became a handsome man, married and had children. My children are here. But in that car accident my wife died and I was injured and I stay at home. )

Others, through their personal qualities are able to minimise social disability despite physical or sensory impairments. An interviewee said that men find FW unattractive because of her badly burned hands. Yet she is raising a family with the help of her mother. She is disabled in terms of marrying, but has largely overcome that disability with the help of her natal family and her own resources. A man Te was supposed to marry, but when he refused the woman offered to him, her sisters are thought to have put a curse on him so that he would never marry. He remained unmarried reputedly because his brothers would not pay the bride price. However he contributes to the community and is not considered severely socially disabled.

ML is profoundly deaf from birth. He is married with two children. He is the sort of person who by watching others can do almost anything, such as building a house or harvesting coffee. He contributes to community activities and plays sport. People say, "even though he is deaf he works with us and we accept him in the community, and regard him as normal." So ML is not disabled in the sense that his impairment restricts participation.

In Lufa most people, even if with some form of impairment, try to work and participate in community affairs as much as they are able. BF is a boy with one withered arm and only 3 fingers on other hand. He is limited but helps to build houses and plays sport. Elderly people, often with sight, hearing and movement impairments, also find many ways to be useful, even though they have limited strength. They can care for children, bring in washed clothes when it rains, cover coffee beans from the rain, and feed the pigs.

How severe must impairment be before it is disabling? Even "minor" difficulties such as sore eyes caused by coffee dust could affect a person in terms of productivity and income. Thus the term "socially disabled" is a relative term. It would be obvious if the problem would keep a person in the house, or mean social disapproval, but there are many other cases where a person will be affected in terms of their not being able to live a normal social and working life to a lesser or greater degree.

> Kofi em mi ken pikim. Na ol bikpela bikpela wok ya ol haus sik em i pasim mi pinis. Ol tok yu stap faivpela moa yia pastaim. Dispela kain ya mi bai go stap i go go na dai tasol. (Interview with HS #15, 16 April 2006)
> (Coffee I can pick. But the hospital authorities have told me not to do heavy physical work. They said to rest for 5 years. That means I will be like this and die).

There are others in the community , however, who are socially disabled even though without apparent physical or mental impairments. These are people who have a reputation for being lazy and incompetent – who will not or cannot do things right. To this extent their activity participation is minimal They are classed as *Jaro veka* (man) or *Jaro ana* (woman) – *jaro* being the word for "wrong". This person is not *degi*, just clumsy and incompetent. When that person faces a problem or has a heavy task that requires the community's help he or she may well be neglected. The community knows that he or she will not be able to give a hand in return. There are others who because they steal and commit adultery very frequently will be disliked and shunned by the community. Formerly the community might spear (kill) such a person. Now they will give him a beating and if that doesn't help, send him away – the ultimate form of participant restriction.

In sum, social disability is culturally constructed, and activity limitation, impairment and problems of participation depend on how the community and the impaired person him or herself defines them. Being married and raising a family, and contributing (with pigs, money or labour) to the community appear to be important factors in defining a person as socially abled. Some people have impairments that make it difficult for them to perform tasks that are considered normal, yet by contributing to the community they come to be regarded as "normal.

**10. Social Disability and Perceived Causes**

How is social disability related to perceived causes of impairments? As noted above, perceived causes range from the non-empirical such as sorcery and breaking taboos to the biophysical such as accidents and illness. Often accidents or illness are not considered as causes in themselves, but symptoms of a disharmony in relationships with the living or the dead (see 7.1 and 7.2 above). Thus impairments may point to social and relational problems that must be faced on the social level.

From a religious-cosmic point of view causes of impairments could be related to the other forms of misfortune also, such as crop failures or fights. Thus faults in the body and mind may reflect problems in the social and spiritual order. Such defects are hard to cope with -- the community having to rely on (and pay) diviners, healers and ritual experts. For example, the accident in which AV (#1) was badly injured has been blamed on sorcery against one of the others involved in the accident (who died – "em pises olgeta" – [his body was mutilated in the accident]) (Interview with K&A #74, 26 September 2006). Sorcery might also bring a businessman to ruin (Interview with PI2 #59, 27 September, 2006; and Discussion with D&A #43, 27 July, 2006).

Tension can be as commonplace as, for example, dissatisfaction with the distribution of brideprice. If brideprice is not distributed satisfactorily, someone might curse the parents so that their child will die or be disabled.

> Bipo mi nogat klia tingting mi gat bikpela kros long meri bilong mi. Mi gat bikpela kros long meri bilong. Meri bilong mi, em bilong narapela hap. Ol lain mama bilong en kisim em go long narapela hap na ol lukautim em bikpela nau ol kisim moni na kaikai. Ol lain papamama bilong meri ya ol no kisim moni na kaikai. So mi ting olsem, ol papamama bilong en ol i no wanbel long en em i go kam go kam long en ya, mi ting olsem dispela hevi em kisim em. So bihain nau mi go long haus sik nau ol dokta explenim na ol tokim mi nau mi klia olsem em long

malaria na typhoid em bagarap. Olsem na em bagarap. Em bon erly tu na em bagarap. Mi go na mi kisim advais long ol dokta na ol tok, ol dokta tokim mi nau, long tingting bilong mi kam klia na mi nau mi save olsem malaria na typhoid em bagarapim em. I no long samting long ples (Interview with IK #6, 28 February, 2006)
(At first having no clear understanding I blamed my wife. I was really angry with her. My wife is from another place. Her mother's people brought her to their place and looked after her. When she grew older they took money and had it – bride price. So I thought that her biological parents were not happy and she took the burden. Then I went to the hospital and doctors clarified the situation for me. Through malaria and typhoid she had the problem. He was born 2 months early and had the problem. The doctor's advice cleared my thoughts. It is not from something in the village).

In this case the husband, thinking that the cause lay in strained social relations with his in-laws, blamed his wife. This would surely have affected the relationship with their severely disabled child. However, having realised that the cause was biophysical, he now understands his wife and from all accounts they have a stable marriage and their disabled child is fully accepted as part of their family.

Perceived causes can be a factor in social disability, depending on the degree to which those causes contribute to the cultural, social and personal factors discussed in section 9 above. Isolation, dependence, shame, stigma and labelling all have a negative impact on the community or on the social life of the individual. Yet, in terms of perceived causes, isolation may be linked causally to breaking a taboo (#23), dependence may be linked causally with sorcery (#10), and stigma may be linked causally to the side-effects of marijuana use (#4). Table 4 lists seeing difficulties and various perceived causes. It is one thing to say that $\alpha$ caused $\beta$ to be blind, however, for our purposes the more relevant issue is what $\beta$'s blindness means in terms of cultural, social and personal beliefs and values -- the "local moral world" (Whyte 1995: 279). Such beliefs and values help form the social disposition towards a person and the self-understanding of the person him or herself, affecting social participation and the way they may or may not lead a normal social or working life.

Having identified cultural, social and personal factors leading to social disability, we found little evidence that would allow us to prioritise these factors or to be able to predict how beliefs and values would function in any particular case. Personal factors seem to figure as much as communal ones -- for example, the number of cases we encountered in which social disability seems to depend more on the impaired person's own attitude and behaviour than that of the their family or community (section 9.8), or cases of mental problems where the affected person is seen as bringing the problem on himself through drug use. Social disability is culturally defined, but both the family or community and the individual are part of the defining process.

**11. Care and Coping**

The family -- of parents, and brother and sisters take the principal responsibility of caring for the impaired person. The wider community comes to help where needed, for example if a disturbed person has wandered away from home or if they need to contribute money for someone they want to send to hospital or to a village doctor (KH #10).

Attitudes to care vary greatly depending on the type of impairment and personal factors. Some feel ashamed and isolate themselves. Others, with more common problems like sight and hearing problems have little to be ashamed of. The pattern of seeking help is shown in Table 6 in the appendix.

We found that some people seemed not to have sought help. However, twenty two out of thirty two had sought medical help at a hospital or health centre, thirteen out of thirty two say they had sought help with one of the churches, and nine out of thirty two mention having tried traditional methods of cure. Seven out of thirty two used their own knowledge and skills to treat their difficulty. AV and NH with movement difficulty each use a walking stick made by their children. Two others use warm water with a cloth to relive their backaches and eye problem respectively.

Seven factors emerged as influential in the way persons with impairments or their family seek help: costs, church membership, the apparent failure of traditional methods, fear, not knowing where to get help, the presence of CBR workers, and self-initiative.

### 11.1 Costs

Eight people (mostly with eye problems) told us that they did not have money for consultation or treatment. It costs K6.00 by public transport to travel to Goroka and back and consultation at the Government eye clinic costs K2.00. The ear clinic is free for children or people over 60 years and costs K2.00 for others. A pair of classes through the Eye Care Centre in Goroka cost K25.00 for cataract classes and between K65.00 and K145.00 for reading glasses. Prices are negotiable according to the economic situation of the clients. A cataract operation at the eye clinic costs K20.00. These costs should not be an impossible sum in a community receives considerable income from coffee each year. The Eastern Highlands exports K117.5 million worth of coffee each year, which in a province of 239,169 persons amounts to approximately K50 per head.[10] Admittedly there are overhead and production costs, so the export figure is not all available to the grower in ready cash. Nevertheless, during the coffee season from April to July there seemed no shortage of money for beer supplies to the District.[11] So it comes down to a matter of values and priorities. We doubt that cost is the principal factor influencing whether or how a person seeks help.

### 11.2 Church Membership

Most people belong to one of the seven churches in the area: Lutheran, New Tribes, Four Square, Faith Fellowship, Seventh Day Adventist, Revival, and Baptist. This would have an effect on attitudes to traditional healing methods as the majority of the churches listed fall into the "conservative" category and thus theologically place little value in traditional culture. Several of our respondents said openly that they have "faith in God and so have not tried traditional treatments." Some of the pastors we spoke to said that they will not accept people trying traditional cures as it would be a

[10] Personal Communication 4 October, 2006, with Mr Sterla Frisa of the Coffee Industry Corporation, Goroka

[11] Another major element in the local economy is bride price. In the area we worked it was estimated that there are 5 or 6 pride price payments each year – a bride price payment involving usually around K3,000.00 to K4,000.00

sign of lack of faith in God (Interview with W #75, 31 August, 2006) "Satan wantaim papa God tupela i no stap long wanpela tebel" (Satan and God do not remain at the same table) Interview with JS #51, 31 August, 2006). Church help seems to be limited to prayer, though one person said that the Lutheran Church had helped with eye medicine.[12] Prayer can take different forms. A nursing officer (AL #33) encourages pastors to come and pray that God's healing power will be effective through the administration of medicine. We note also how several of those we interviewed have asked for help from the churches and also tried traditional healing methods such as *subim mambu* (AV #1 and NH #7) or *subim botol* (HN #8).

As for the order of help-seeing, it appears that those claiming to be faithful Christians seek church help through prayers first. Medical help is the next option. If the problem persists, it is said to be God's plan in their lives.

> ...mi stap na em tok, mi helpim mi yet long waswas na olsem helt bilong mi em tok mi lukautim gut..... mi save putim olgeta tingting go insait long Bikman. Na em tok, mi save stap. (Interview with LB #3, 22 February 2006)
> (I help myself by washing and keep healthy and look after myself well. I remain with my thoughts focused on God.)

Some Christians try medical help first and then traditional treatments. One reason for this is the relatively high cost of traditional treatments -- between K10 and K30 for the healer, and as much again for the ingredients for one session of "subim mambu" and only about K5 for "subim botol").

### 11.3 Apparent Failure of Traditional Curing Methods

A number of those interviewed had tried traditional healing methods such as "subim mambu", but most had lost faith in such methods after experiencing failure in the first attempt. RB (#12) describes it as "nogat kik bilong bus marasin" (traditional medicines do not have power). Nine people said they had tried traditional methods and it had not helped and one said that it had made matters worse. With the relatively high cost of traditional curing methods people want to see results. The carers of IK (#6) said that they had "wasted a lot of money on 'subim mambu' with various local healers." Some feel that there are no traditional healers with skills to deal with their particular problem (LBi #11). Today, education and modernisation are factors that influence people in seeking medical help rather than traditional treatments.

### 11.4 Fear

Goroka Base Hospital is a an impersonal and confusing place for someone used to living in a rural village

> Long hap nes i stap long skrining tebel ol i save salim ol i go i kam o tok, dokta i bisi na yu kam bek tumoro, na ol i save givap, na ol i save serim dispela eksperiens wantaim ol arapela na stori i go raun na ol i les long go (Interview with TT # 67, 27 September, 2006).
> (There [at Goroka Base Hospital] the nurse at the screening table will send them here and there, or tell them that the doctor is busy and they should come

[12] No one seemed aware of the commitment from the Catholic Church through Mt Sion to support the CBR network. The Christoffel Blindenmission (CBM) agency in Germany and Save the Children supply funds annually for the training of CBR volunteers.

back the next day. They return and share their experience with others and the story goes around and others feel less inclined to go there).

A more significant factor would be fear of what might happen there. AJ (#2) said she was afraid to have her eyes tested in case the doctor would want to "cut" them.

> Sapos mi go long haus sik ol bai katim ai bilong mi na dispela kain tingting (Interview AJ #2, 22 February, 2006).
> (If I go to the hospital they might operate [cut] and injure my eyes.).

Despite success stories of successful cataract surgery, people still fear going to the hospital. Others live in fear of further malicious attacks and so are cautious about appearing in public.

> Yu save, pasin bilong singraun, nogut mi go maket. Nau mi gat laip na mi stap. ... ol mangi mekim mekim na mi kam bek na stap. Tasol mi go long maket, nogut ol belhat na nogut ol pinism laip bilong mi. Olsem na tingting bilong mi nau tokim mi nogut mi go nau nogut mi no lukim ol pikinini bilong mi (Interview with AV #1, 16 February, 2006).
> (This is a custom of the sinful earth but through my children I have recovered from the first attempt of sorcery. If I go out to the market they will be angry and "poison" mi again and I might not see my children.)

**Case Study - HA – Three Ways of Seeking Help**

HA was a child of two and a half years when we first interviewed his father and grandmother. He was born on 30 Nov 2003, weighing 3kg. A year after the birth the parents' marriage broke up and HA was left with his father, with his father's mother helping to look after the child. HA appeared slow in development and his health book notes "malnutrition" as a cause, with instructions for the child to take multivitamins and to have an improved diet including eggs, fish and greens. Where money allowed they tried to give the child better food. At two and a half years the child appeared quite "chubby" but still could not walk, so they tried various remedies. HA's grandparents requested a local village doctor to perform a *lusa* ritual to counter the possible effects of the mother, while pregnant, having visited a *degi* place. They performed "supim mambu" and a ritual involving rubbing and pulling at his legs. At the same time, his father JA, who had been trained with CBR constructed parallel bars from saplings and encouraged little H to hold the bars and walk. This he did morning and night. Also the grandmother put in a prayer request to the SDA church leaders. By August 2006, when HA was 2 years and 10 months old he began to walk unaided, and now appears to move normally. He still says very little. JA is unsure whether it was the special food, the traditional ritual, the exercise on the parallel bars or the SDA prayer that helped his child.

### 11.5 Not knowing where to get help

A number of those interviewed said they did not know where to turn for help. Several said that they were not aware of traditional cures for eye problems or hearing problems. One man who thought that sorcery was the cause of his eye problems had used a traditional method that involved rubbing mushrooms on his eyes (AD

#16), but this had not brought about any change. The few who said they knew of Mount Sion Resource Centre for Disabled Persons (which they pass on the road to Goroka town) thought its services are limited only to those with eye problems. We noticed that those in the bus when passing Mt Sion referred to it as "Ai pas" (blind). A CBR volunteer also confirmed this saying:

> ...planti bilong mipela even olsem Eastern Highlanders mipela save na lukim olsem Mt. Sion em i stap but mipela i no save wanem wok ol Mt. Sion i save wokim. (Interview with TJ #30, 26 April 2006)
>
> (Most Eastern Highlanders know where Mt. Sion is but do not know what kind of work they do.)

### 11.6 Presence of CBR Workers

The Lufa area was chosen because it has a network of Community Based Rehabilitation Volunteers associated with Mount Sion Resource Centre for Disabled Persons. In Lufa they work with the *Kevo* Club under the supervision of the district coordinator. These volunteers have made a big impact on giving a higher priority to disabled people in the community.

Unfortunately, at the present time they seem to be disorganised and lacking morale. From our observation only a few of the original number of 48 volunteers are active and in our interviews and discussion groups (usually organised by the CBR co-ordinator) few people mentioned the help of CBR volunteers. A volunteer explained their situation in which they feel they do not have the support expected from the Mt Sion Centre.

> "Nogat fidbek bilong Mt. Sion nau ol stat drop olsem lus interest ol i no wok wantaim Mt. Sion. Planti stap nabaut tasol kam bilong yupela mekim nau olsem long maket ples em yumi kam bung olsem. Otherwise em bai ignorance long Mt. Sion bikos yumi stap tri yias na nogat wanpela luksave bilong Mt. Sion kam long ol voluntias (Focus Group 2 May, 2006).
>
> (After the 3 years CBR volunteers lost interest due to lack of feedback from Mt. Sion. Today since you came and we were at the market so we were willing to come. If it was Mt. Sion we would ignore them.)

Workers from Mt Sion say that the CBR volunteers are trained to be somebody who works with no form of payment. They are expected to be able to identify disabled people, give basic treatments, make referrals, and to do awareness work. They are trained to help their own people and are expected to dedicate one day each week to the disabled in their community. The CBR Unit coordinator at Mt Zion admits that "In the Lufa district recently our network with them has not been very good. Volunteers have given up and there is something wrong somewhere" (Interview with H #47, 14 September, 2006). Volunteers and ex-volunteers told us that the ill feeling is over the payment of allowances, specifically several thousand kina in allowances supposedly paid during the initial Lufa Survey. They feel that the funds were not distributed fairly. If a solution can be found to this ill feeling and CBR volunteers become active again in the community, they can be a very important resource for providing direct help and in referrals to other agencies.

### 11.7 Self-Initiative

Several people told us how they helped themselves. MK (#14) finds it helpful to rub her eyes with a cloth soaked in warm water, RBa (#24) soothes her painful back with

hot pads, and TB #9 rubs leaves of salat (stinging nettle) on parts of her body to counter her aches and pains. The father of HA (#21) made a set of parallel bars from tree branches to encourage his son to walk.

The question arises as to how much people are motivated for change. One man explained how if a person follows custom and cuts off a finger to show how sad they are at the death of a friend, then why try to repair it again? The whole point of this self-inflicted impairment is to demonstrate one's sorrow so there was no point in covering or hiding it.

If a condition is curable, then people would welcome that. But if not, then the impaired person and their family simply have to get used to the idea and learn to live with it. For many people in Lufa, rehabilitation in the sense of a continuous effort of improving and accommodating the living conditions of persons with disabilities seems a foreign concept.

**Case Study of IK as acceptance of a disabled child**

IK is a 6 years old boy. He was born 2 months early due to his mother having severe malaria and typhoid. Because of that he developed cerebral palsy and now relies on a wheel chair. This wheelchair was donated by the Mt. Sion center for the disabled through their Community Based Rehabilitation program.

At the first, traditionally motivated, IK's father thought it was due to unequal distribution of bride price by the mother's people. He was really angry with his wife. Since the mother was adopted when she was small, only the adopted parents shared the bride price and the biological parents were neglected. The biological parents were really angry with their daughter, which in turn must have affected the innocent child. Therefore, they spent more than K1000 on traditional healers but all has been unsuccessful.

However, this did not prevent them from seeking medical help and advice from the local Community Based Rehabilitation volunteers. After receiving continuous medical help and advice, the father was convinced that it was due to the premature birth that IK had cerebral palsy.

Despite the inexperience and the first time to have a disabled child the parents showed great care and love. They are not ashamed of having a disabled child because they know it is a biomedical mishap.

IK's problem does not stop him from socializing with others. His sister or parents will push him around to market places and other social activities to meet some of his friends. His father boasted that IK has plenty of friends and is well known in the Yagaria area. At times he would prepare big feasts to show his appreciation towards IK friends. For IK his bright eyes and happy expressions on his face will show his happiness. The parents confirmed that there has been no case where IK was stigmatized or labelled. He appears to be respected and cared for by everybody.

This case study is one of the few in our study where the parents have showed great care and commitment towards the well being of the disabled child. The community's reaction towards IK has been encouraging for his parents.

## 12. Unanswered Questions and Lessons Learned

At the end of our study we realised that there were factors that we should have given more attention than we did – factors such as the people's educational level and

whether they are literate or not. It might have been of interest also to consider the possible different impact of impairments on men and women. Are blind men or blind women more likely to experience social disability? In Papua New Guinea it could be that a blind woman who can bear children would be considered more socially abled than a woman who is unable to bear children. One must take care not to confuse disability and inability. Future studies might take such factors into account.

We also wonder why our enquiries located so few disabled children. One theory is that parents are ashamed and will hide such children. This is fine in theory, however, in the cases of impaired children that we did encounter, parents seemed not to be ashamed. Moreover, the parent of one disabled child questioned how one could hide a child from a community. Sooner or later people would know (K&A #74). It could be that parents don't realise that their child has impairments like hearing problems or mental problems until they are older. We noted the results of screening for ear and eye problems by Mt Sion staff in the three primary schools in the area under study (Kuluka Primary School, Kami SDA Primary School, and Oliguti Primary School). Of 520 children tested only two had eye problems (one blind in one eye and the other with a cataract), and 48 or almost 10% were found to have ear problems (27 with perforated eardrums, 11 with retracted eardrums, 8 with impacted wax, 1 with ottitis externa, 1 a foreign body and 1 a fungal infection). Some of these ear conditions could lead to serious hearing difficulties, but are not so apparent to people other than those trained to detect such problems. Screening for other conditions such as intellectual impairment might well reveal other potentially disabling situations.

Brother Martin Tnines in his MA Thesis entitled: "The Experience and Expression of Epilepsy in the Highlands of Papua New Guinea: exploratory study," interviewed 22 epileptics and/or their family members. Tnines' studied people of Yagaria of the Lufa District in much the same location as ourselves. In our enquiries, we encountered only one person suffering from Epilepsy (#10) and few people with serious burn injuries often associated with that condition. Tnines notes the high level of social stigma attached to Epilepsy. To what degree did stigma prevent us from locating more person's with that condition? This raises a wider question of the degree one can derive general conclusions from our sample of 32 people experiencing difficulties. We think that the findings of this study are valid, however, if future studies would be concerned with representativeness, it would be advantageous to have a larger sample.

## 13. Conclusion

To what extent do physical, sensory and mental impairments translate into social disabilities? We found that cultural, social and personal factors intervene. Cultural factors include: Isolation and not being able to participate in communal activities, dependence, shame, fear and stigma, labels, and the type of impairment. Social factors include status, sex, age and marital status. All these factors may play a part in preventing a person from living a normal social and working life. It is difficult to prioritise or to single out any one major factor. We encountered cases illustrating all the factors we have noted, but whether cultural or social factors will intervene in any particular case of physical, sensory or mental impairment is impossible to forecast. A major personal factor would be the impaired person's own personal qualities and the person's own attitude to his or her condition. We can only point out the cultural,

social and personal factors in the hope that this will lead to greater awareness and be of assistance to those supporting or caring for persons with impairments.

How is social disability related to perceived causes? The perceived causes as set out in section 7 of this report a linked to various associated impairments, some of which would be more likely to lead to social disability than others. For example Sorcery is seen as the cause of a wide range of ailments and problems, some of which could make a person so unwell that they would not be able to live a normal social or working life. However, aside from the physical, sensory and psychological ailments attributed to these perceived causes, there is often also a factor, which for simplicity we would call the "social disposition", which might also have a negative impact on a person's social life. The social disposition, which is part of what is sometimes termed the "local moral world" is a major factor in how an impaired person may or may not lead a normal social or working life. Sorcery is often attributed to jealousy or the desire for revenge, which indicates a situation where there is a conflictual relationship prior to the alleged act of sorcery. This might well also mean that the person affected by sorcery will be afraid to move freely in public lest the sorcerer strike again. Other perceived causes will also often impact negatively. Relations with the living or the spirits of the dead as a cause of impairment presumes that an uneasy relationship exists in the first place. Disobeying taboos as a perceived cause more often than not leads to a condition where a person is called "degi" or crazy, with the social disability associated with that. Disease and illness need not lead to social disability, however there are diseases such as STDs and AIDS, which, if made public would most surely lead to stigma and the marginalisation of the person concerned. We found that ageing is not a major cause of social disability because of the commonly-held respect for old people even though they might be restricted in their movement and the work they can do. Substance abuse as a perceived cause varies because while use of marijuana may lead to marginalisation, alcohol consumption is seen as promoting social life. Those perceiving God's anger as a cause have to deal, not so much with the feelings of the church congregation, but their own feelings of guilt or shame. Thus, while there is no clear causal relationship between perceived causes of impairments and social disability, there may well be underlying factors contributing to a social disposition affecting the impaired person and their families. The community, families and individuals are all part of the process of defining that social disposition.

What are the factors influencing the way a person with impairments or their family seek help? We found that costs, church membership, the apparent failure of traditional curing methods, fear, not knowing where to get help, the presence of CBR volunteers, and self initiative are all significant factors. Again, it is difficult to prioritise or to predict what factors would apply in any particular case. However, underlying help seeking there appeared to be an element of "fate". Many people say that they have no money to go to the clinic to be checked by a medical professional, yet pmv trucks run frequently and the amount of cash circulating, especially during the coffee season reduces the credibility of the claim to have no money. A more serious claim is that they are unaware of where to find help. Yet if they enquired they could surely discover some means of assistance beyond the family. This makes us wonder if there is an element of fate operating, perhaps in conjunction with the perceived causes of the difficulties. If a condition is curable, then people would welcome that. But if not, then the impaired person and their family appear to get used to the idea and learn to live with it. If the focus on cure is based on discovering the cause and

ways of dealing with the perceived cause have been exhausted, then rehabilitation which deals with adaptation to a condition that cannot be changed requires a different attitude. When one gives up on treatment, does this mean there is no hope of making a change in the situation? This raises serious questions for people interested in rehabilitation. The focus on causes and fatalistic attitudes seems to work against long term rehabilitation in the sense of a continuous effort of improving and accommodating the living conditions of persons with disabilities.

## 14. Suggestions and Recommendations

1. Service providers and helping organisations need to make greater efforts to counter fatalistic attitudes so that impaired people and their carers might consider possible ways to improve the living conditions of persons with disabilities. This will require a culturally sensitive educational process.

2. CBR volunteers have the potential to provide an important service in the communities. At the moment their morale is low and many have dropped out. It might be helpful to arrange a series of meetings with interested parties, including medical personnel, community and church leaders, to look for ways to overcome the present ill-feeling and inertia. An issue to be addressed would be payment and/or allowances for "volunteers."

3. Churches provide help through prayer and social ministry, but it would be beneficial for all parties if the churches could have better communication and cooperation networks with Mt Sion Resource Centre for Disabled Persons and the CBR leaders and volunteers. Together these agencies could mount awareness campaigns about physical and social conditions making people more vulnerable to developing impairments, and about ways that disabled people can be better integrated into the community. There is room for more education in the communities so as to lessen tendencies towards stigma or shaming disabled people or their families.

4. It might be helpful to have an in-service course with teachers and others such as church leaders to discuss ways to reduce stigma and social disability in schools and in the wider community.

5. Rehabilitation, which deals with adaptation to a condition that cannot be changed requires a different attitude from one that focuses only on treatment associated with perceived causes. People interested in the rehabilitation of the disabled might need to develop an educational process focusing on beliefs and values, whereby people see value in improving the living conditions of persons with disabilities even when there is little hope of changing their physical, sensory or mental impairment.

6. This study has mentioned traditional treatments, and describes at greater length forms of traditional treatments in Appendix 3 and 4. More research needs to be done from an interdisciplinary perspective, to understand, and perhaps learn from, traditional treatments. At the same time people need to be aware of the possible side effects of the traditional treatments such as potions made from tree bark and the cutting of the skin with sharp implements.

7. Prevention programs could be upgraded, including checking that all school classrooms have adequate light, early intervention for hearing difficulties for school aged children and ways people can be better protected from exposure to dust during coffee processing.

8. Screening in schools and follow-up with teachers and parents should be encouraged. Screening could cover conditions besides ear and eye conditions – such as movement and mental/emotional dimensions.

9. It would be beneficial for health centres and aid posts to keep thorough records, particularly records about people with impairments, and that health officials and CBR coordinators make use of these records.

10. People working with the disabled should be aware of the cultural perceptions of impairments and their causes and treatments. For example, this could form part of the training for physiotherapy students.

11. Secular education about the biomedical causes of some conditions (such as epilepsy for example) might help reduce the number of accusations of sorcery and allow people to be more open to seeking help at the public health facilities.

12. Some pastors and church leaders promote a theology whereby impairments in children may be seen as God's curse on the parents. This questionable theology should be addresses. Also some pastors and church leaders look for signs and wonders often in terms of casting out demons or the power of Satan. They might benefit from further education about the biomedical causes of some conditions and ways of ministering to people with impairments, based on the principles of integral human development.

**References**:


Berndt, R.M. 1962. *Excess and Restraint*, Chicago, University of Chicago Press.

_____. 1972. "The Kamano, Usurufa, Jate, and Fore of the Eastern Highlands." In *Gods, ghosts, and men in Melanesia*, ed. P. Lawrence and M.J. Meggitt. New York: Oxford University Press.

Byford, J. and Nina Veenstra. 2004. "The Importance of Cultural Factors in the Planning of Rehabilitation Services in a Remote Area of Papua New Guinea," *Disability and Rehabilitation* 26.3, pp. 166-175.

Gibbs, P. 2003. "Perceptions and Causes of Disabilities in Wosera, East Sepik Province," *Catalyst* 33.2, pp. 149-181.

Langness, L.L. 1965. "Hysterical Psychosis in the New Guinea Highlands: A Bena Bena example. *Psychiatry* (August 1965) 258-277.

_____. 1967. "Sexual antagonism in the New Guinea Highlands: a Bena Bena example. *Oceania* 37, pp. 161-177.

Lindenbaum, S. 1971. "Sorcery and Structure in Fore Society," *Oceania* 41, pp. 277-287.

Meigs, A. S. 1984. *Food, Sex and Pollution – A New Guinea Religion*. New Brunswick: Rutgers University Press.

Read, K. E. 1965. *The High Valley*. London: George Allen and Unwin.

Renck, G. L. 1977. *Yagaria Dictionary*. Pacific Linguistics C-37, Canberra: Research School of Pacific Studies, ANU.

_____. 1990. *Contextualization of Christianity and Christianization of Language*. Erlangen: Verlag der EV.-Luth. Mission.

Ritchie, J. and Jane Lewis. 2004) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage.

Robbins, Sterling. 1982. *Auyana: Those Who Held onto Home*. Seattle and London: University of Washington Press.

Salisbury, R.F. 1965. "The Siane of the Eastern Highlands." In *Gods, ghosts, and men in Melanesia*, ed. P. Lawrence and M.J. Meggitt. New York: Oxford University Press.

Smith, R.M. 1981. Conversion and Continuity: Response to Missionisation in the PNG Highlands. Unpublished Ph.D Thesis, Australian National University, Canberrra.

Tnines, M. 2006. "The Experience and Expression of Epilepsy in the Highlands of Papua New Guinea: exploratory study." MA Thesis. Manila: University of the Philippines.

Whyte, S.R and B. Ingstad. 1995. *Disability and Culture*. University of California Press.

## Appendix 1 Tables

### Table 5: Summary of Interviews of people experiencing difficulties or their carers

(MO – moving; M – mental[13]; L – learning; T – talking; SC – self-care; H – hearing; S – Seeing; R – remembering)

| # | Place | Initials, M/F, Age | Difficulties from Survey List | Impairments identified in Cultural Study | Perceived Causes (from Cultural Study) |
|---|---|---|---|---|---|
| 1 | Kami-Ketiaro | AV (M) Adult | MO, SC | Right leg and hand not functioning | Accident, Sorcery (*nalisa*) |
| 2 | Kami-Kerokotu | AJ (F) Adult | S | Poor eyesight | Anesthetic injection. Sun's radiation |
| 3 | Kami-Ketiaro | LB (F) | M | Debilitating effects of STD (syphilis) | Sorcery (*nalisa* ) |
| 4 | Kamamo | OKK (M) Adult | H, M | Poor hearing | Smoking drugs (marijuana), Spirit / taboo (*Degi Hapa*) |
| 5 | Kamamo | JH (F) Adult | S | Occasional minor problem with eyes | Tree Dust, Smoke from fire |
| 6 | Kamamo | IK (M) Child of 6 yrs | M, SC | Hands and legs weak. Problem with speaking. Slow growth | Mother sick when pregnant. Premature birth (*inare*) leading to form of Palsy |
| 7 | Atra Hapa | NH (M) Elderly man | H, M, MO, S | Poor eyesight. Chronic pains in legs and back | Sorcery (*Ki kea*), Spirit/Taboo (*Degi Hapa*) |
| 8 | Atra Hapa | HN (M) Adult | M | Backache affecting movement. Mental slowness | Hit by stones in a fight. Drugs (Marijuana), |
| 9 | Kami-Ketiaro | TB (F) Middle-aged | M | Backache. Moderate mental strain | Sorcery (*nalisa*), clearing new garden. |
| 10 | Fogo | KH (M) Adult | H, L, M, R, SC, T | Hearing loss. Reduced mental function. Problem with talking. Problem with self-care | Epilepsy (*Havosa*) (From sorcery) |
| 11 | Fogo | LBi (M) Middle-aged | S | Problem seeing long distance, or small objects | Effect of operating camera in a theatre. Coffee dust, bright sunshine |
| 12 | Kami-Bipamo | RB (F) Adult | H, MO, S | Backache. Problem seeing at | Domestic violence, sorcery (*nalisa*) (But |

[13] Questions on Mental Health in the Survey asked about the presence of feelings or behaviour within the last month (whether worried overmuch, sad overmuch or talking in a mixed way overmuch). Another question used the local term *degi* to inquire whether a person was talking in a mixed-up or mad way.

| | | | | | |
|---|---|---|---|---|---|
| | | | | a distance or small objects | she has some doubts about this) |
| 13 | Fogo | SH (F) Child of 3 years | R | Problem with remembering | Cerebral Malaria (from Health book) |
| 14 | Hogogusa | MK (F) Middle-aged | R | Problem seeing clearly at a distance | Not sure |
| 15 | Oliguti | HS (M) Middle-aged | MO, S | Problem with seeing. Chronic stomach ache and back pain | Work of clearing a new garden. |
| 16 | Fole | AD (M) Middle-aged | S | Right eye totally blind | Sorcery (*nalisa*) |
| 17 | Nupuru | K (M) 2 yr old child | (*Not on the list*) | Both legs paralized | Difficulty walking after sickness shown in one month of diarrhoea |
| 18 | Nupuru | O (M) Boy 15 yrs | (Not on the list) | Imperforated anus with no control over waste discharge from colostomy | God's curse on his parents. (Some thought too about his mother breaking a taboo) |
| 19 | Kami | B (M) 4 yrs | (Not on the list) | Club foot | God's punishment |
| 20 | Oliguti | SL | (Not on list) | Cerebral Palsy | Fever when 4 months |
| 21 | Atra Hapai | HA (M) 2 yrs | (*Not on list*) | Problem with walking | Spirit/ broke Taboo (*Degi Hapa*) |
| 22 | Fogo | JF (F) Teenage girl | (*Not on list*) | Retarded growth. Problem with mental function, and speaking. (Down Syndrome?) | Spirit/ Broke taboo (*Degi Hapa*) |
| 23 | Fogo | AV (M) Teenage boy | H, R, SC T | Problem with hearing and talking. Problem co-ordinating movement. Problem with self-care. | Spirit/ Mother broke taboo (*Degi Hapa*) |
| 24 | Kami-Bipamo | RBa (F) Adult | M | Chronic back pain. Worry. | Don't Know |
| 25 | Hogogusa | HS (M) Middle-aged man | MO | Problem urinating and with sexual activity | Don't Know |
| 26 | Fole | UB (M) Middle-aged man | (*Not on list*) | Problem with sight in one eye | Reading by light of kerosene lamp |
| 27 | Oliguti | JJL (M) Middle-aged man | S, MO | Problem seeing small objects like ants | Don't know (advanced age?) |

| | | | | | |
|---|---|---|---|---|---|
| 28 | Oliguti | MH (M) Adult | *(Not on list)* | Left eye completely dysfunctional | Eye injured by kunai grass |
| 29 | Kamamo | PI (M) Middle-aged man | S, MO | Problem seeing (without glasses) | Don't know (advanced age?) |
| 30 | Kamamo | TJ (M) Young man | *(Not on list)* | Cannot hear or speak | Fell in fire as a child. Doesn't know why that happened. |
| 31 | Kami-Korokotu | DJ (M) Young Boy | *(Not on list)* | Chronic sore on one leg. | Spirit/ Broke Taboo |
| 32 | Oliguti | J (F) | (Not on list) | Cannot hear and difficulty speaking | Spirit/Broke Taboo |

**Table 6: Abled interviewees who gave invaluable information**

| | **Initials** | **Date of Interview** | **Place** | **Comments** |
|---|---|---|---|---|
| 33 | AL | 31st Aug. 06 | Fore Kamamo | Nursing Officer – Fore Kamamo Aid Post |
| 34 | AK | 2nd May 06 | Fore Kamamo | Discussion group member |
| 35 | AN | 2nd May 06 | Fore Kamamo | Discussion group member |
| 36 | A | 27th Sept. 06 | Fore Kamamo | A CBR volunteer interviewed at Nupuru about a client |
| 37 | A2 | 27th Sept. 06 | Fore Kamamo | A CBR volunteer interviewed at Nupuru about CBR |
| 38 | AJ2 | 4th Sept. 06 | Korokotu | Member of the Revival Centre |
| 39 | AAv | 22nd Feb. 06 | Kami-Ketiaro | Son of a disabled person |
| 40 | AA | 2nd May 06 | Kami-Ketiaro | Lufa district CBR Coordinator |
| 41 | BK | 2nd May 06 | Fore Kamamo | Discussion group member |
| 42 | CK | 2nd May 06 | Hibuhenagaru | CBR volunteer |
| 43 | D&A | 27th July 06 | Kami-Ketiaro | Leader and a community member |
| 44 | DK | 2nd May 06 | Fore Kamamo | Discussion group member |
| 45 | FE | 2nd May 06 | Fore Kamamo | Discussion group member |
| 46 | GP | 2nd May 06 | Korokotu | CBR volunteer |
| 47 | H | 14th Aug. 06 | Mt. Sion | CBR coordinator |
| 48 | IA | 2nd May 06 | Fore Kamamo | Discussion group member |
| 49 | IB | 2nd May 06 | Fore Kamamo | Discussion group member |
| 50 | JA | 2nd May 06 | Atrahapa | CBR volunteer |
| 51 | JS | 31st Aug. 06 | Fore Kamamo | Evangelist of the Faith mission |
| 52 | JHe | 2nd May 06 | Fore Kamamo | Discussion group member |
| 53 | JPK | 26th Mar. 06 | Kema Kamate | Interviewed him as a poison doctor |
| 54 | JZ | 2nd May 06 | Fore Kamamo | Discussion group member |
| 55 | JN | 2nd May 06 | Fore Kamamo | Discussion group member |
| 56 | JK | 2nd May 06 | Hibuhenagaru | CBR volunteer |
| 57 | KT | 2nd May 06 | Fore Kamamo | Discussion group member |

| | | | | |
|---|---|---|---|---|
| 58 | PK | 2nd May 06 | Fore Kamamo | Discussion group member |
| 59 | PI2 | 27th Sept. 06 | Fore Kamamo | About relationship of the living and the dead causing misfortune. |
| 60 | S1 | 27th Sept. 06 | Fore Kamamo | In car on the spirits of the dead |
| 61 | X & A3 | 27th Sept. 06 | Fore Kamamo | CBR Assistant coordinator and volunteer |
| 62 | X | 2nd May 06 | Fore Kamamo | EHP Assistant CBR coordinator |
| 63 | SA | 2nd May 06 | Fore Kamamo | Discussion group member |
| 64 | SK | 2nd May 06 | Kami-Ketiaro | Discussion group member |
| 65 | TR | 30th Mar. 06 | Kami-Ketiaro | Interviewed for information on poison |
| 66 | TB2 | 17th May 06 | Kami-Ketiaro | Interviewed her as a traditional healer. |
| 67 | TT | 27th Sept. 06 | Nupuru | Nupuru Health Centre |
| 68 | UB2 | 26th Sept. 06 | Fore Kamamo | Evangelist of the Lutheran church |
| 69 | VN | 2nd May 06 | Fore Kamamo | Discussion group member |
| 70 | WR | 2nd May 06 | Fore Kamamo | Discussion group member |
| 71 | WH | 27th Sept. 06 | Nupuru | Nupuru Health Centre |
| 72 | WB | 2nd May 06 | Fore Kamamo | Discussion group member |
| 73 | JA2 | 27th Sept. 06 | Atrahapa | A follow up interview |
| 74 | K&A | 26th Sept. 06 | Fore Kamamo | A follow up on IK |
| 75 | W | 31st Aug. 06 | Kami-Ketiaro | Member of the SDA church |

**Table 7: Help Seeking**

| # | Person: Initials, M/F, Age | Impairments identified in Cultural Study | Help Seeking | | | |
|---|---|---|---|---|---|---|
| | | | Medical | Family | Church | Traditional |
| 1 | AV (M) Adult | Right leg and hand not functioning | Yes (admitted to Goroka Base Hospital after the care accident). But did not go for further help later. | His children helped him to seek help. Take care of him with his daily needs | Yes[14] His children are "good Christians" | Yes was involved in the traditional treatment by *Subim mambu.* (See appendix 2). His children made a walking stick for him. |
| 2 | AJ (F) Adult | Poor eyesight. Cannot see objects at a distance or fast moving objects | She did not seek medical help due to no money and fear of cutting her eyes. | Family members help her to identify people he cannot see. | None, she did not mention any church help. | None, she has not heard of any traditional eye problem healers. |

[14] Personal Communication 22 Feb, 2006

| | | | | | | |
|---|---|---|---|---|---|---|
| 3 | LB (F) | Debilitating effects of STD (syphilis) | Yes (diagnosed as syphilis). But she was not convinced. | Her children have not been very concerned. They do not help her in gardening. | Yes others pray for her in the church as well as praying herself. | She has faith in God and has not tried any traditional treatments. |
| 4 | OKK (M) Adult | Poor hearing | Does not know who and where to seek help. | The family neglect him and does not have a good relationship with the community. | Yes, he is now a converted Christian. | None, since he has not heard of any traditional healers for hearing. |
| 5 | JH (F) Adult | Occasional minor problem with eyes | She has no money. She is seeking help through this project. | She does not need the family's help. | None, she did not mention any church help. | None, she did not mention any traditional treatments. |
| 6 | IK (M) Child of 6 yrs | Hands and legs weak. Problem with speaking. Slow growth | Yes, admitted to GBH due to premature birth. | He is being cared for and is respected by the family and the wider community | None, parents did not approach any church. | Yes, a lot of money was spent on *subim mambu* with various local healers. |
| 7 | NH (M) Elderly man | Poor eyesight, chronic pains in legs and back | Yes, he was admitted at GBH | His children and grandchildren look after him very well daily. The community respect him. | Yes, pastor and his family pray for him. | Yes, once did the *subim mambu* for his knees but did not heal and became worse. His children made him a walking stick. |
| 8 | HN (M) Adult | Backache affecting movement. Mental slowness | Yes, he gets clinic supplies and then treats himself. | His family does not care about him, he looks after himself in what he can afford | Yes church pastor prays for him. | Yes, once did the *sutim botol* (see table 2) on his back but this was not effective. |
| 9 | TB (F) Middle-aged | Backache. Moderate mental strain | Yes, GBH and Port Moresby General Hospital. Treatments given have not cured her illness. . | Her children help in doing gardening and in the house. There is little support if any from the community. | None, she has not sought any church help. | Yes, she has tried different traditional healers. The *subim mambu* and herbs were given but this has not helped. |
| 10 | KH (M) Adult in | Hearing loss. Reduced | They have not gone to the | The family and | Yes, the church | None, since they do not |

| | | | | | | |
|---|---|---|---|---|---|---|
| | mid-30s | mental function. Problem with talking. Problem with self-care | hospital. Father knows about Mt. Sion but thought it was only for the blind, since people call the centre *ai pas* – "blind". They only came to recognise the work of CBR volunteers through the training and survey father attended. | community take care and support him because he relies on them for his daily needs. | members have been praying for him and has improved slowly. Starting the CBR volunteers is seen as an answer to their prayers. | believe in the traditional treatments. |
| 11 | LBi (M) Middle-aged | Problem seeing long distance or small objects | None, he has thought of seeking medical help but has not gone yet. | The family does not care much because it is not severe. Only that they help in identifying people in the distance. | He did not mention any approach to the Christian community . | He is willing to try traditional eye healers but have not heard of any. |
| 12 | RB (F) Adult | Backache. Problem seeing at a distance or small objects | In the past her back pain was treated at a Health centre but has not gone to the hospital for x-ray as advised since she has no money. A local CHW advised her not to incise her knees with *sutim botol.* | | None, she is not a church member but complains of no visitation. Instead church members visit their own church members if they have problems. | Yes. Traditional leaves warmed on fire were rubbed on her knees but did not work. "Nogat kik bilong em." Complained that she wasted K10. Later she cut her skin (tattooing) on the knees and felt a bit better. |
| 13 | SH (F) Child of 3 years | Problem remembering | Yes, admitted to GBH for cerebral palsy. Made attempts to visit Mt. Sion for help but did not | The parents sought medical help with the financial contribution from the | None, father did not mention it but she used to be an active | None, father did not mention any traditional help. |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | persist. | community. | participant in the church. | |
| 14 | MK (F) Middle-aged | Problem seeing clearly at a distance | She visited clinic when it started but now due to money problem she has not gone again. | Her family or the community does not support her. She says she requires no help from the family or community. | None, she did not mention any help from her church members. | None, no money to seek traditional healers. Self treats by rubbing with a cloth and warm water. |
| 15 | HS (M) Middle-aged | Problem seeing well. Chronic stomach ache and back pain | Yes, visited eye clinic but not enough money to buy the prescribed glasses. Visited aid post and admitted to GBH for chronic stomach ache. | The family assisted him financially to seek medical help but in the house, his children are neglecting him. His wife supports him only. | Yes praying by church members. He believes that things on earth won't help but only God can. | A traditional healer to heal his stomach ache visited him but the herbs did not help. He does not try remedies for other problems. |
| 16 | AD (M) Middle-aged | Right eye totally blind | He claims to have no money to seek medical help. But uses the money he has for dealing with other community and family problems | The family only advised him to seek medical help. | None, he did not mention any church help but he is a church leader. | A mushroom was rubbed on his eyes by a traditional healer but it did not help. |
| 17 | KJ (M) 2 yr old child | Both legs paralysed | Yes, visited Aid Post for treatment. | The parents look after him and sought medical help. | The father did not mention any church help. | Did not try any traditional treatments. |
| 18 | O (M) 12 yr old boy | Unperforated anus | Yes, visited Goroka Base hospital for operation. | The parents brought him to seek medical help but three operations have not helped. | The parents are alienated from the SDA church. | A *subim mambu* was done but it did not help. |
| 19 | B (M) 4 yr old | Born with a clubfoot | Visited the local Aid Post and GBH. | The community provided only advice. | Did not mention any church help. | There was no traditional help sought. |
| 20 | SL (F) | Cerebral Palsy | GBH, Nupuru health center | The husband's | The Christian | Herbs and *subim* |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | and a CBR volunteer were consulted. | people offered less help as they blamed her for the child's disability. | people prayed for the child. | *mambu* were done several times. |
| 21 | HA (M) 2 yrs | Problem with walking | Local Health Centre said it was malnutrition and developmental delay. As a CBR volunteer the father made parallel bars and it seemed to help. | The family and especially the father were worried and helped in whatever they could. | Christians did pray over him. | None, but the father knows there are traditional treatments available. |
| 22 | JF (F) Teenage girl | Retarded growth. Problem with mental function, and speaking. (Down Syndrome?) | The nurses saw her when she was fully developed. According to the father, the nurses mentioned she had slow growth. Asked us if we could help. We only advised that Down Syndrome has no medicine. | The family care and support him to live a normal live. | No help mentioned from the Christian community . | He did not mention trying any traditional treatments. |
| 23 | AVi (M) Teenage boy | Problem with hearing and talking. Problem co-ordinating movement. Problem with self-care. | It started as a sickness when he was a baby and he was brought to the GBH. Since then he has not sought any medical help. | Within the family they communicate with their own sign language. He socializes well with other children. | Yes, the SDA church members were asked for prayers and it seemed to help. | The parents tried various *Lusa* rituals (*kevo ko* literally meaning 'bamboo of non-functioning limbs'). |
| 24 | RBa (F) Adult | Chronic back pain. Worry. | She visited the GBH and received medication. Also buys pain relief such as Panadol. | People are hired to help with her work. The family and friends support her with her heavy physical | Yes, the SDA church members and pastors pray and support her. | None, she did not mention seeking any traditional help. Treats her back pains with a cloth moisten with hot water. |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | work. | | |
| 25 | HS (M) Middle-aged man | Problem urinating and with sexual activity | Visited the Aid Post and a private doctor and was given medication. He sought help through us and we only gave advice to seek medical help. | The children help in gardening and in the house. | He did not mention any church help. | He has not tried any traditional treatments. |
| 26 | UB (M) Middle-aged man | Problem with sight in one eye | He uses eyeglasses to read. When he has enough money he is thinking of going to the eye clinic. | His children and family members help with his garden and house work. | Yes, the Lutheran church provided eye medicine. The church members help him in his gardens. | He did not mention any traditional treatments. |
| 27 | JL (M) Middle-aged man | Problem seeing small objects like ants | He has not sought any medical consultation for his eyes. We advised him to seek medical help. | He did not mention any support or care from the family. | He did not mention any church help. | He did not mention trying any traditional treatments. |
| 28 | MH (M) Adult | Left eye completely dysfunctional | He was admitted at the GBH but he has not gone back for further treatment. He sought help through us but we only provided advice to see an eye specialist. If he has enough money he is thinking of going to the hospital. | He did not mention any help from the community or family. | He did not mention any church help. | He did not mention trying any traditional treatments. |
| 29 | PI (M) Middle-aged man | Problem seeing (without glasses) | Eyes tested at the eye clinic and got glasses | The young people do help with fetching water and | He did not mention any church help. | He did not mention having tried any traditional treatments. |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | breaking firewood. | | |
| 30 | TJ (M) Young man | Cannot hear or speak | The relatives do not seem to know about the availability of Mt. Sion to seek help. | He is accepted and included in all the social activities. | He did not mention any church help. | He did not mention having tried any traditional treatments. |
| 31 | DJ (M) Young boy | Chronic sore on one leg. | He received treatment from GBH but parents have no money to seek further medical help. They are thinking of visiting a private doctor for better treatment. | The parents care for him and look after him. | Parents are members of the Revival church and the members have prayed for him. | They have no faith in traditional treatments. They believe help will come from believing in God and treatment at the hospital. |
| 32 | J (F) 12 years old | Cannot hear and talk. | The father refused to send her to Mt. Sion because she is still young. But now they are thinking of visiting them. | The parents seeking help to have her get help such as at Mt Sion | The Four Square church prayed for her but it did not help. | *Subim mambu* was done but it did not help. |

## Appendix 2: Observations on Daily Life (Paul Petrus)

Observations made during field trips to Lufa. These observations and comments are apply only to the *Yagaria* constituency.

Housing

Most houses are traditional (bee hive and rectangular shape, with kunai roofing and woven *pitpit* walls). A few people have modern houses (roofing iron with timber walls) with electricity yet to be connected. Others already use generators to provide electricity. Such houses are owned by families with business connections, and the elite. There are not longer separate *haus man* and *haus meri*. The family lives together in one house. The pig, goat and sheep houses are also built close beside the family houses.

Weekday Schedule

Tuesdays is the market day at *Kamamo* and Wednesdays and Fridays at *Oliguti*. This is the day when people have the chance to sell their garden produce or store goods. It is an opportunity for those living in the mountains to come and buy store goods. It is also the day when most court cases are heard by village magistrates and peace officers. Besides this, people in their respective places have morning and afternoon markets daily.

Most people with minor impairments can go to the market. Others who have severe movement impairments stay at home. People who have been targeted for sorcery also stay away from such public places.

During weekends most people do not go to the gardens, coffee or markets. They spend their weekends attending church services, others just stay at home or spend time playing cards. Some go into town (Goroka).

Health Services

There are 4 health clinics in the Lufa district (Nupuru, Gouna, Lufa station and Uva Guvi). There are more than 10 Aid Posts in Yagaria area. Gouna is the only health center run by the Faith mission church. The other three are run by the government. Most of those who have sicknesses or health problems get treatment from these Aid Posts or health centers. If it is a chronic illness or disability, referrals are made by the Nursing officers to Goroka Base Hospital.

Coffee season

Coffee season is one of the busiest, enjoyable and troublesome seasons. It starts around April and finishes around end of August. People are busy picking their own coffee cherries to be pulped and to sell as coffee parchment or green beans. It is hard work picking coffee planted mainly along the banks of rivers and hills and bringing the bags of cherries up for pulping. Relatives and neighbors help those who have many plots of coffee. Giving money or dining with rice and tinned fish is enough to show appreciation to the helpers.

It is easy to sell the dried coffee because there are local buyers available 24 hours and two coffee factories. One is located in Kami and another in Oliguti. People are happy to clean their sweat with brand new kinas and toeas from the bank.

The surplus money available during the coffee season brings both good and bad. The daily life style of the people is changed. New clothes for the family and cooking utensils are bought. Young boys buy small walkmans or stereos. Nearly every household will have *Yumi FM* or NBC Goroka echoing in the ears of listeners. Issues pending that need money to solve like school fees, bride price, repaying old debts and so on are done during this season.

However, the season also brings unhappiness in the community and family units. Gambling is rife in the public places and houses day and night. Alcohol consumption is high among the men. Adultery seems to be common behind the scenes. This brings disunity, domestic violence and family break up. Violence among men under the influence of alcohol has also been noticed during the fieldwork. I also witnessed arguments and conflicts between women over alleged adultery. Some of these issues are brought to the attention of village courts. Those who have severe impairments remain in the village. Their families give them some money and buy clothes when they sell their coffee.

Income and Expenses

Money has been mentioned often as the major obstacle to seek medical help. Listed below are some of the principal ways mentioned and observed for expenditure and income.

*Income*

Coffee
Garden produce
Selling store goods in the market
Chicken and pigs sales.
Betel nut and cigarette sales

*Expenses*

School fees
Food and clothing
Solving conflicts
Bride price
Socializing

Division of labor

The division of labor follows traditional beliefs and customs. Some work is restricted to men only while other work is restricted to the women only. Jobs that require more strength are normally done by men.

*Responsibilities and job requirements in each setting for men*

*Garden*

- Fencing
- Cut bush for a new garden
- Drainage
- Plant only banana, sugar cane, taro and yam. It is forbidden for women to plant these foods.

*House*

- Represent the family
- Collect firewood (carry one substantial log, not collected pieces of firewood)
- Build a house

*Public feasts*

- Heat the stones
- Cook food in the ground oven
- Serve the food.

*Responsibilities and job requirements in each setting for women*
*Garden*

- Dig the soil.
- Planting (apart from those mentioned above)
- Collect kunai for roofing house

*House*

- Household duties and chores

*Public feasts*

- Prepare the food
- Collect water and banana leaves

Types of work and Disability

Some people have mentioned in interviews that their problem started when they did certain work in the garden or coffee plots. It seems that this type of work can cause physical damage. One woman spoke of the heavy work involved in digging a new garden and planting it. The soil is muddy during wet season and hard during the dry season. This soil type is found from Forapi 1 to Oliguti between the grassland valleys. Carrying a netbag filled with food from the garden with an extra bundle of firewood on the head is another heavy work for the women. It is harder when the gardens are a long way from the house.

For men the heaviest work is in building a house, cutting down trees and splitting them and digging drainage. After doing these types of work, both men and women experience back aches and sometimes feel sick. It is even more difficult for people who have knee and back problems.

## Appendix 3: Treatments for Sorcery in Lufa

Traditional doctors have treatments for traditionally perceived sicknesses. It is believed that traditional doctors cannot treat "sik bilong gavman" while medical doctors cannot treat "sik bilong ples". "Sik bilong gavman" literally means - sick for the government). The health centers, clinics and hospital will hopefully be able to cure that form of illness. "Sik bilong ples" literally means-sick from the village, and this is the field for traditional doctors. In Yagaria a traditional treatment is called *lusa* and the traditional doctor is called *lusa de* (traditional male doctor) and *lusa ana* (traditional female doctor).

Traditional illness caused by a type of *nalisa*, *degi hapa* (bad spirits dwell in swampy areas as well as other forbidden places) have possible medicine available in the natural forest pharmacies. Only traditional chemists can identify these medicines in the thick wild forests. Each traditional illness has its own special medicine. The medications comes in the form of tree bark, leaves and fruit. While the preparation by specialists of each illness and the traditional medicines are different, the method used to prepare it is similar. This method of preparation is called *'subim mambu'*

Subim mambu

*Subim mambu* literally means "push into the bamboo". This is the practical ritual of mixing food with traditional medicine and charms, stuffing the mixture into a bamboo tube and steaming it on the fire. The *subim mambu* was also a traditional way of cooking ordinary daily food, which is still practiced today.

What follows is a description of how a *lusa de* performed a *lusa* for a woman. She felt that her chronic backache was due to sorcery. We were invited to witness the whole ritual. She was one of the interviewees.

Soft greens, pig meat, ginger, salt and a special tree leaf were the ingredients used. The pig meat was cut into small pieces and mixed with the soft greens. Some gingers were also chewed and spat onto the soft greens and pig meat. Salt was added to give more flavor. Lastly the *lusa de* cut the plant leaves into small pieces and sprinkled it onto the whole mixture. The *lusa de* then put the mixture into a bamboo marked for the sick woman to be steamed on the fire. Other bamboos were prepared for the family to share, but these are without the special tree leaves. After the bamboo is properly steamed the *lusa de* says silent spells on the food served on the plate. When the bamboo for other family members is served the *lusa de* said a Christian prayer. Thus a modern idea is included. The sick person had to finish the whole bamboo with food by herself. When the payment of money is made the *lusa* treatment process comes to an end. No payment means that the ritual is not complete.

The saying of prayer, flavoring of food with salt and payment of money are modern items included in the ritual. They use these items because they go well with the other traditional items. The *lusa de's* explanation of why he prayed was, after all God is the creator and we are using his creation to heal people. In nearly all *lusa* ritual a form of meat is used. This is in order for the protein to drive the tree bark or leaves to all

parts of the body and especially to the affected part. Some *lusa* doctors prefer chicken and pork meat because they feel that the protein in chicken and pork works more effectively than lamb meat. In some *lusa* special gingers are used to cure sorcery but special gingers are also used to perform sorcery. In other *lusas* ordinary ginger is used to flavour food so that the sour taste of the tree bark or leaves will not predominate.

Each *lusa ana* or *de* has his or her own tree bark and leaves to treat a traditional sickness. If a first *lusa* does not heal the difficulty another *lusa* person is hired to try. If all *lusa* tried are unsuccessful some explain that it is one of the new "sik bilong gavman". Others resort to God for healing while some just accept the result without seeking any further help.

This is a general explanation of traditional treatment done in Lufa. Depending on the difficulty and sickness of the person treatments range from the simple to the very complex. There are also traditional pain relieving methods discussed in the next section.

## Appendix 4: Traditional Pain Relieving Methods in Lufa

1. Sutim Bottle *(Whotimo au botel)*
The traditional name for this method in *Yagaria* is *Whotimo au.* It involves using a sharp piece of bottle to spear the part of the body that is aching. This seems to be a common practice in Lufa and maybe other parts of the province. A small bow (made from a stick and a rope) and arrow is used. The arrow is made from a small stick with a tiny sharp piece of bottle tied to the end with string. This procedure of shooting the arrow at the paining part of the body can be done by anybody. It is believed that the blood in that part of the body is *'blut nogut'* (unhealthy blood). The body does not need it and wants to discharge it, hence the ache.

Parts of the body that swell accompanied by aching are also shot with this small bow and arrow to remove the blood and to deflate the swelling.

2. Salat (*phai/kaia*)
Salat is a common traditional leaf from the *Dendronidae spp* (a stinging nettle plant) used through out Papua New Guinea to temporarily relieve pain. The leaves are dark green or pink with a hairy surface that will sting the skin. People hit the leaf on the skin where it is aching. Sometimes it can be rubbed on the skin. People disabled with chronic pain associated with movement problems and swelling use this leaf for temporary relief. It is planted in gardens and beside houses. Anybody can use it. It can be used in self-treatment or by another.

3. Tattooing (*Maki*)
Tattooing is common in PNG. It is used commonly for body decorations among women especially on their faces. In the past sharp edged bamboo instruments were used. A woman would cut the selected designed on the fore head, cheek and even hands and legs. Currently in some places women still have this traditional practice particularly in rural areas. However, they use razor and surgical blades to cut the designs.

In Lufa people do *maki* to relieve pain and to decrease swelling. Cuts are made on the skin of affected parts of the body to allow the blood to exit. This is the *blut nogut* (unhealthy blood) that was there to cause the pain and swelling.

4. Ginger (*Patu)*
*Keti Patu (*a special ginger) yellow in colour can be used to heal aches in the body. Traditional doctors cook the ginger in a bamboo tube with greens and a protein for the person in pain to eat and thus relieve the pain.

5. Tree bark
There are some special kinds of tree bark used by traditional doctors to cure pain. One of them is, *spak (traditional term is not known).* The scraped tree barks with greens and some protein is steamed in a bamboo tube by the *lusa de* for the sick person. When the person eats this food his or her pain will be relieved

Lufa people have their own means of relieving pain. Those disabled with movement problems on the knee, back etc. use these temporary pain relievers frequently as mentioned in some of the interviews.

## Appendix 4: Traditional Pain Relieving Methods in Lufa

1. Sutim Bottle *(Whotimo au botel)*
The traditional name for this method in *Yagaria* is *Whotimo au.* It involves using a sharp piece of bottle to spear the part of the body that is aching. This seems to be a common practice in Lufa and maybe other parts of the province. A small bow (made from a stick and a rope) and arrow is used. The arrow is made from a small stick with a tiny sharp piece of bottle tied to the end with string. This procedure of shooting the arrow at the paining part of the body can be done by anybody. It is believed that the blood in that part of the body is *'blut nogut'* (unhealthy blood). The body does not need it and wants to discharge it, hence the ache.

Parts of the body that swell accompanied by aching are also shot with this small bow and arrow to remove the blood and to deflate the swelling.

2. Salat *(phai/kaia)*
Salat is a common traditional leaf from the *Dendronidae spp* (a stinging nettle plant) used through out Papua New Guinea to temporarily relieve pain. The leaves are dark green or pink with a hairy surface that will sting the skin. People hit the leaf on the skin where it is aching. Sometimes it can be rubbed on the skin. People disabled with chronic pain associated with movement problems and swelling use this leaf for temporary relief. It is planted in gardens and beside houses. Anybody can use it. It can be used in self-treatment or by another.

3. Tattooing *(Maki)*
Tattooing is common in PNG. It is used commonly for body decorations among women especially on their faces. In the past sharp edged bamboo instruments were used. A woman would cut the selected designed on the fore head, cheek and even hands and legs. Currently in some places women still have this traditional practice particularly in rural areas. However, they use razor and surgical blades to cut the designs.

In Lufa people do *maki* to relieve pain and to decrease swelling. Cuts are made on the skin of affected parts of the body to allow the blood to exit. This is the *blut nogut* (unhealthy blood) that was there to cause the pain and swelling.

4. Ginger *(Patu)*
*Keti Patu (*a special ginger) yellow in colour can be used to heal aches in the body. Traditional doctors cook the ginger in a bamboo tube with greens and a protein for the person in pain to eat and thus relieve the pain.

5. Tree bark
There are some special kinds of tree bark used by traditional doctors to cure pain. One of them is, *spak (traditional term is not known).* The scraped tree barks with greens and some protein is steamed in a bamboo tube by the *lusa de* for the sick person. When the person eats this food his or her pain will be relieved

Lufa people have their own means of relieving pain. Those disabled with movement problems on the knee, back etc. use these temporary pain relievers frequently as mentioned in some of the interviews.

## Appendix 5: Degi Hapa - A perceived cause

During the cultural research some interviewees mentioned *degi hapa* as a perceived cause of impairments.

*Degi* is a local term with negative connotations. It literally means "crazy." Combined with the term *hapa* it means a "bad place" *or* a forbidden place. A swampy or muddy place is called *hapa.* Therefore, the term *degi hapa* means a bad swampy area. It is bad because people who enter this place get sick. People and especially children are warned by parents not to go into certain swampy areas.

The history and myths of the Degi Hapa
People were not forthcoming with a history of *degi hapa* or a possible belief in a myth about the swampy areas

The belief of '*degi hapa*'
People in the Yagaria constituency believe that those who enter a *degi hapa* risk becoming ill. Rusty (yellowish orange colored) algae, is found along the small streams in the swampy areas. These are the common physical signs of a *degi* place. Pitpit brush that grows in and along the swamps is another physical sign of such a place. If a person gets sick after entering a swamp which is not known as *degi* place, people begin to warn others that about it.

People are forbidden to go in to these places to clear the area for gardening, get wood, vines, or to wash themselves, clothes, babies and soiled nappies in the small streams in the swamps. Human activities of any kind are not allowed there. Normally when a human activity is involved, something is left behind, such as sugar cane and kaukau skins, or torn clothes and material from soiled nappies. According to an interview with a *lusa ana* (a female traditional doctor (Interview with AD #16, 26 April, 2006), it is believed that the dragonfly takes this rubbish and drops it into the mud. The mud in turn creates an effigy of a human person out of leaves and vines in the swamp. The waste material of the person remains in the belly of the effigy. Others have mentioned that it is the ants and dragonfly that put the wastes in to the mud and an insect called *degi kawai* creates this effigy. "... dispela ples, mi wokim gaden long en, em tok olsem em graun mud na ol man save tok olsem i gat wanpela long long (*Degi*), samting em i stap insait kain olsem binatang. And it is also referred to as the 'bad spirit'. Ol dispela kain ol binatang o spirit nogut bilong dispela hap ol kisim i go na planim insait" (The area that I cleared for gardening is a swampy area and people say a crazy thing is there. It is like an insect or a bad spirit. This thing brings it [waste material] there and dips it inside [the swamp]) (Interview with NH #7, on 15 March).

A baby can also be born physically disabled, unable to walk, move and grow if the mother being pregnant went to a *degi hapa.* Also a pregnant mother taking food from a garden made in a swampy area can affect the child. "Em mipela ol famili i stap em kain bilip na dispela kain em ol tok olsem....bubu bilong mangi ya em go na katim bus, kliaim dispela hap na wokim gaden na long dispela hap em kamautim taro, katim banana na kamdaun na givim em taim meri gat bel na givim em na em kaikai so that is why the child has movement problems" (Among the family this belief is there ... that the grandfather cleared the overgrowth in that area for gardening. In

that garden he harvested taro and banana and gave it to the mother to have when she was pregnant.) (Interview with father of HA #21, on 15 March, 2006).

Signs and symptoms of sickness

Some of the signs of illness from the *'degi hapa'* according to (Interview TB #9, 17 May, 2006) are; discharge of pus in the ear and deafness, becoming thin and skinny, a potbelly with small head and legs, and body aches. Babies will not walk when they reach the expected age. Other signs and symptoms mentioned are sore eyes, discharging pus and water, body aches, swollen skin, and slow growth in a child. The slow growth is because the spirit binds tightly the wastes or something belonging to the affected person (See Interview father of JF #22, 29 March 2006).

**Treatments**

When the people are sure that the person is sick because of going into a *degi hapa* they engage a *lusa* person to perform the treatment called *degi lusa.* Some *lusa* people will go with relatives to the swampy area and heat stones to make a *mumu* on the side of the swampy area. From there they will dig around the mud to find the effigy of the person. In an interview with father of JF #22, 29 March, 2006) it is said that the *lusa de or ana* creates the effigy and hides it in the mud and the sick person's relatives have to dig around and find it. Different traditional doctors have different ways of doing the *lusa.* An interview with TB #9, 17 May, 2006) with a female traditional doctor gives the description of how she does her *lusa.*

TB tells the person who has the illness to go and get young shoots of any kind of plant growing in the swampy area that the patient has entered. These young shoots are steamed in the bamboo (*subim mambu or degi ko*) with a protein (chicken, pig meat or lamb meat) and crushed ginger. There should be a protein in there, in order to make the food tasty and to transport the digested food to parts of the body quickly. The cooked food is then served on a banana leaf. She wraps the food in the banana leaf and goes out to the back of the house. Behind the house she will charm in *kami-kuluka* by whistling to the spirits of that place. And at the same time she waves the wrapped food in the direction that is being called and then in the other direction. This is what she says in the spell.

"Yupela of man bilong (Kosarobikave) kam na tok sori long mangi ya" (You men of [Kosarobikave] come and apologize to this man).

Then it is believed that the spirits will respond:

"Mipela ol man bilong (Kosarobikave) mipela nogat wanpela wrong mipela stap nating, so yu askim ol man long (Kubaipa)" (We men of [Kosarobikave] we do not have any ill feelings, ask the men from [Kubaipa].

Then the lusa person faces another direction and chants a spell.

"Yupela ol man bilong (Kubaipa) kam hariap tasol long nait na yupela tok sori na dispela samting em bai pinis" (You men of [Kubaipa] come immediately in the night and apologize so that this thing will be over.).

The names of the two places can always be changed depending on where she is performing the *lusa.* Then she brings the food in and the sick person consumes it. When the sick person, eats the food he or she should become well again. The main task of the *lusa* is to call the spirits so that they can come and be sorry and heal the

person. In this case she does not go into the mud to look for the effigy of the sick person.

These are brief descriptions of *degi hapa*, the type of sickness associated with it and the treatment involved. Collecting peoples' wastes and belongings and putting in the mud to cause illness are also done in sorcery. Lindenbaum gives the *kuru* illness in South Fore as associated with sorcery where the sorcerer collects human belongings and food remnants of the target which is wrapped with certain leaves and a sorcerer's stone and tied with vines. Beating the bundle with a stick while calling the target and charm, he then places the bundle in a muddy ground to rot and likewise the target's health will deteriorate. (Lindenbaum 19971:280-281). The south Fore people also have a similar belief of pregnant women going into a *degi* place or eating food from a *degi* and giving birth to a physically disabled child. This also happens to pregnant women in south Fore. If they touch a certain tree, vine or other spirit-inhabited object in the reserved parts of the forest of her husband's place the child will be born with physical disabilities (Lindenbaum 1971:282-283).

Sutim Botol

Supim Mambu