Perceptions of Causes of Disabilities in Wosera, East Sepik Province, PNG

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Abstract:

Together with Callan Services, and the Institute of Medical Research, the Melanesian Institute formed a team to study attitudes and practices towards persons with disabilities in the Wosera area of the East Sepik Province. The team collected basic data concerning the local categories of disabilities, the numbers of persons with disabilities and estimates of the severity of those disabilities. Using the filters of severity and old age, they concluded that the prevalence of severe to medium levels of disability in persons not suffering from the effects of old age, occurs at a rate of 3.2% in the area studied (34 villages). The rate varies considerably between the different villages. In the North Wosera there is a greater tendency to attribute illness to the work of spirits and sorcery. In the South, people are more likely to attribute their illnesses to malaria and other medical conditions. This difference could be due to the greater isolation of the North Wosera area.

The team collected data on the nature of traditional beliefs and attitudes towards persons with disabilities. They found that physical disabilities do not necessarily translate into social disabilities unless the person is feared as a sorcerer or someone capable of harming others. In responding to the questions about causes of disability people indicated both natural and supernatural causes. Many (39%) answered that they did not know the cause. In order to go beyond the facts and figures of the quantitative data the paper draws on the insights in qualitative information from recorded interviews. Recommendations are offered for health workers and church personnel in the area.

1. Introduction

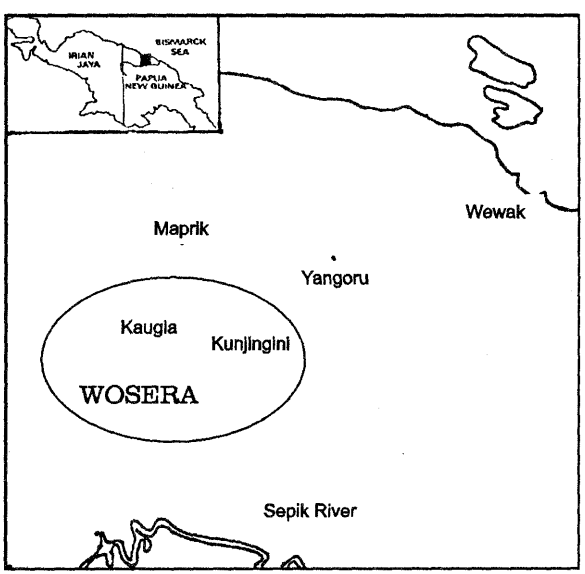
One of the goals of the National Health plan is to improve the health of all Papua New Guineans through the rehabilitation programs that enable people with disabilities to be less dependent and more

able to participate in community life. In the East Sepik Province, Callan Services, a non-Government organisation, has been at the forefront in working to improve the lives of persons with disabilities. Moreover, the Institute of Medical Research (IMR) has been active, monitoring sickness and health care in selected areas of the Province.

Following a request for assistance by Callan Services, in 2002 the Melanesian Institute (MI) formed a team to study attitudes and practices towards persons with disabilities in the Wosera area of the East Sepik Province.[1] The team, composed of four members of the MI and two persons from Callan Services spent ten days visiting villages in the area.

Do people in different cultures perceive persons with impairments and disabilities differently? Do people who perceive persons with disabilities differently also treat persons with disabilities in a different way? If so, is it possible to improve the quality of life of a person with disabilities by raising awareness among caregivers of the abilities and needs of persons with disabilities? These are the questions that motivate this study.

2. Papua New Guinea and the Wosera



The Wosera Area

One of the greatest challenges for Papua New Guinea (PNG) is how to maximise the welfare of its more than five million people now facing an economic crisis with the rapid fall in value of the local currency (the kina), and some of the lowest social indicators in the Pacific Region. The 2002 Human Development Index by the United Nations' Development Program (UNDP) measuring achievements along three dimensions of longevity, knowledge and decent standard of living, shows PNG's global rating at 133. (The "low" human category begins at 140). Social indicators in the 2002 Human Development Index show a life expectancy of 57.7 years for females and 55.8 years for males, an infant mortality rate of 79 per 1000 live births (as compared to Fiji with 18 and New Zealand with 6). Health expenditure per capita in 1998 was US$25 per person (as compared to US$1,714 per person in Australia).

Our study was limited to a group of 34 villages, with a total population of 12,545 people, in the Wosera area of the East Sepik Province, lying between the coastal mountains and the middle Sepik River.[2] All but one of the villages visited are inhabited by Abelam speaking people. One village - Tatemba - is Arapesh speaking. We chose these villages because they have been monitored by the IMR over a number of years. Our intention was to make use of the structures and background health census data collected by the IMR.

The Wosera have a subsistence system of agriculture, though in recent times they have tried growing coffee for export and more recently have been experimenting with growing vanilla as a cash crop. Their staple foods are yams and taro, supplemented by bananas, breadfruit and sweet potato. Sago supplies food during the lean garden months, and also its leaves and branches are used as building materials (Schroeder 1992:68). Besides gardening the people also raise pigs and a few chickens, though we were told that chickens are not popular because they are easily stolen. Wosera is considered a poor area with problems of land shortage, overpopulation, malnutrition, and high child and maternal mortality.

3 Religious Beliefs in the Wosera

Today the majority of people in the area studied are Christians (mostly Catholic). However, beliefs in spirits and sorcery and the consequences of breaking taboos persist.

One type of spirit are the *wale* (Tok Pisin: *masalai*) which are localised spirits living in a particular spot like a pool in a river. The *wale* are clan related. In a particular village there are a number of

clans each with associated *wale*, and often a village will be identified by the *wale* of the predominant clan (Schroeder 1992: 98).

There are also *niangwaldu* (literally father's father's men) which are spirits associated with individual clans and their ancestors. These spirits figure in male initiations and are also linked with a yam cult. Likewise, the ancestors provide group identity with both the living and the dead (Schroeder 1992:98) Ancestors are believed to intervene with power in daily life bringing either harm or blessing to the living.

In the Wosera district there is also strong belief in sorcery (*daap*). Schroeder says that all deaths, except in the cases of infants and the very elderly are attributed to sorcery (Schroeder 1992:107). According to Schroeder, Wosera people consider sorcery as evil, but admit its importance for dealing with those who cause trouble and disputes. Because of this, disputes over land, adultery, broken relationships and other social problems often eventually become associated with sorcery. Finding the sorcerer and discerning the reason for sorcery is usually a community affair. Sometimes a diviner is employed.

Besides sorcery, there is also witchcraft (Tok Pisin: *sanguma*), known throughout Wosera as *kutakwa*. In North and East Abelam, *kutakwa* are women responsible for the deaths of babies or other calamities related to women's sphere of household activities. However, in the Wosera area *kutakwa* are men hired to harm those with whom one has a dispute. They are said to be responsible for accidents, like for example, falling out of a tree, or today, even for influencing judges or magistrates to make a decision in one's favour.

There are many restrictions on behaviour or taboos in Wosera, some pertaining to former rituals and others still applying today. For example, young women are not permitted to cook food while menstruating. This is a traditional taboo which is still significant today. During the initiation rites, which have largely been abandoned, there were certain taboos, particularly taboos restricting food intake during that period of transition. Breaking taboos is thought to result in illness and even death.

4 What is Impairment and Disability?

The United Nations World Health Organisation (WHO) has changed its definition of "persons with disabilities". Over 20 years ago WHO defined disability as "a restriction or lack of ability to perform an activity within the range considered normal for a human being" (WHO 1980). This leaves open the question, Who is doing the con-

sidering? What one culture considers "normal" varies widely with what another culture considers normal. The International Classification of Impairments, Disabilities and Handicaps has undergone much criticism and revision in its 30 years of history (Ustun et al 2001). Persons classified as having a disability in one culture may not be placed in a special category in another culture. In some cultures the disability, assuming we could agree that it is a disability, is not an important aspect for constructing a person. In other cultures, the disability may be the defining feature of the person.

The WHO, in 1999 suggested three basic definitions (ICICDH-1) Thus, an "impairment" is any loss or abnormality of psychological, physiological or anatomical structure or function. "Disability" is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered to be normal for a human being, e.g. inability to walk. A "handicap" is a disadvantage for an individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Recently the WHO has revised the classification of impairments, disabilities and handicaps (ICICDH-2). ICICDH-2 in fact avoids the term "disability" because it is felt that the term gives a negative impression, and has replaced it by "activity." According to ICICDH-2 "Limitation in activity" reflects the difficulty an individual has in performing a task or an activity. This is what was formerly called "disability. The ICICDH-2 terminology is new and unfamiliar to all except specialised health professionals. While acknowledging the limitations and undesirable connotations in some of the older terminology, this paper continues to refer to "impairments" and "disabilities" because they are the most commonly used terms.

In Melanesian Pidgin the terms generally used to describe types of impairment or disability are the following:

Ai pas	is often used to describe a person with vision disability
Yau pas	is often used to describe a person with a hearing problem.
Maus pas	is often used to describe a person with a speech problem.
Lek or *han nogut*	is used to describe a person with physical problems.

Sik muruk is used to describe a person with epilepsy or fits.

Longlong/het i paul is used to describe a person with mental disturbance or retardation.[3]

5. Studies of Disability

Some studies have shown that in societies where people are related in many ways, disabilities are often not emphasized and do not define the person (Howard and Rensel 1997). By contrast, societies made up of many single-strand relationships often highlight disabilities because of narrow concerns about competence rather than broad concerns about relationships. So, perceptions of persons with disabilities do differ, and perceptions make a difference.

Other studies imply that cultural beliefs are a hindrance to developing better care for persons with disabilities. Yet, because the person with a disability is integrally linked within the community, village care often exceeds that of nursing homes and day care facilities in Western societies in some respects (van Amstel, Dyke and Crocker 1993:319). In other cases, traditional beliefs and attitudes sometimes seem to limit care and potential for persons with disabilities.

A helpful recent study has been done in the Middle Ramu area of the Madang Province (Veenstra et al. 2002). The overall prevalence of disability in the area studied was calculated at 3.2%. A high proportion of disabilities were found to be due to trauma and accidents, while disabilities affecting hearing were frequently associated with illness and infection. The onset of disability was mostly attributed to social or supernatural causes. The writers of the Middle Ramu study found that most disabled individuals were physically well rehabilitated, and there was little or no stigma associated with disability. However, disabled individuals and their families identified a range of outstanding needs. Analysis of these needs suggests that Community Based Rehabilitation Programs (CBR) should focus on disability prevention, the construction of mobility aids out of local resources, the provision of accurate information concerning disability, social support for caregivers, and income generation for families with a disabled individual.

What kinds of disabilities are said to exist in East Sepik Province? For part of the Wosera area, Gorlin reported a rate of "physical deformities" of 2.6% of the population. He suggested causes of major

deformities as "saber tibia (tertiary yaws), osseous malocclusion from infantile injuries, and quite commonly extensive contractures of muscle groups due to tropical ulcers" (Gorlin 1973:102). In addition, he saw a "high percentage of individuals with physical deformity resulting from accidents" (Gorlin 1973:102). Gorlin also devotes a section of his dissertation to the question of the relationship between disease and work, and disease and marriage. More detailed information about persons with disabilities in the Province is lacking.

What is the people's perception of persons with disabilities? In his study of the understanding of illness in a Sepik society, Dr. Lewis devotes four pages to deformities" (1975:77-79,131). His main focus is on the local diagnosis of illness, and the general answer here is that there is no such thing as accidentally or randomly acquiring an illness or impairment according to Melanesian thinking. Ultimately, there is a spiritual cause for illness, and the care of the ill always takes place within a social context (Lewis 1975:332).

6. Method

The Wosera study was planned in four stages, some of these overlapping.

i. Dr Michael Rynkiewich conducted a literature search to find books and articles that have been published about cultural attitudes towards persons with disabilities in Papua New Guinea. The Melanesian Institute also conducted a pre-study of the focus area in the East Sepik Province. This study was carried out from 1-15 May, 2002 by Br Martin Tnines. Br. Martin established contact with Callan Services personnel in Wewak, with mission personnel in Kaugia and Kunjingini, and with IMR personnel in Maprik and around the Wosera area. He also conducted a number of interviews, particularly on people's beliefs about the causes of disease and disabilities, and how that related to treatment and care.

ii. The Melanesian Institute had discussions and exchanges of information with Ms Nina Veenstra, who was carrying out a similar project in the middle Ramu area of the Madang Province. The Institute also had discussions with Mr John Taime of the IMR and secured their commitment to cooperate with the research by provision of background health census data for the area, the use of facilities on the ground in the Wosera area, and the cooperation of their workers in Maprik and the Wosera area. Thus the MI, through the IMR sent out

an initial questionnaire to be filled in by field reporters in the villages of the focus area. The purpose of this questionnaire was to assess the number and type of disabilities in the different villages in the focus area so that the team could plan visits to those villages.

iii. A team of six researchers, four from the MI and two from Callan Services conducted intensive research in the villages of the focus area between 21-31st August 2002. There were various dimension to the field research:

a. Administration of a questionnaire designed to identify persons with disabilities, the severity of the disability, beliefs about the causes of the disability, attitudes towards persons with disability and their access to help. The category of "perceived cause" was also found through questions or through in-depth interviews with the disabled persons and their families or care-givers. Researchers administered the questionnaire to 773 persons.

b. Interviews with families, caregivers and disabled persons themselves in order to elicit case histories and to gauge the effects of the disability on the person's life in the village and their concerns about the future. Most of these interviews were recorded on tape. Interviews were normally conducted in Tok Pisin, though at times village assistants helped by translating questions and answers in the local language.

c. Interviews with health workers to find out their beliefs about the causes of disabilities and to learn their views about the present level of care for persons with disabilities and how the level of care could be improved.

iv. The different types of data collected needed to be coded, sorted and correlated. Responses to the questionnaire administered to 773 persons was entered onto computer using Statpac software. The software allows statistical analysis and exporting to Microsoft Excel for the construction of tables and charts. Comments by interviewers were included in the Statpac analysis, and these could be accessed to provide further information. Life histories and case studies based on recorded interviews were transcribed and written up to allow for qualitative analysis. In weekly meetings over several months, the MI team correlated the results and located examples that would illustrate themes emerging in the stories that people told.[4]

7. Prevalence of Disability

The team administered the principal questionnaire to 773 people in 34 villages. These were people who came or who were referred to the team members as experiencing problems with mental functions, sight, hearing, or movement. Some appeared to be seriously impaired, others less so. For this reason two filters were built into the questionnaire (See Appendix).

In Question 8 the interviewer was to note whether the condition was severe, medium or minor. Obviously there was some subjectivity in making such a judgement. However, in most cases a local village reporter was at hand to assist. If a person was totally blind or deaf, or could not move at all unaided, or was disabled to the degree that he or she could not be married, then the impairment would be classed as "severe." 88 persons interviewed (0.7%) were classed as severely disabled.

If a person appeared to be able to live a regular social life in the community, but was impaired to some degree by being short-sighted or hard-of-hearing, or a bodily ailment that made walking painful, then their impairment would be classed as "minor". Others in between these two extremes were classed as "medium." The team decided to use this severity filter so as to focus on those people with disabilities that were classed as severe or medium (S/M). Of the 773 people interviewed, 491 fell into this category, which gives a 3.9% prevalence of disability.

The second filter was that of "old age". Some people experience difficulty thinking, seeing, hearing or moving, not because of any congenital deficiency or as a result of an accident or severe illness, but simply because they are of advanced age. When calculating the prevalence of disability we filtered out people who appeared to be suffering impairment because of old age. These would be people who had been fit and well for most of their life, but who were experiencing loss of function as they approached the end of their life. If one filters out those affected solely by advanced age, the prevalence rate then remains at 0.7 for the severely disabled, drops to 5.2% for all those presenting themselves, and to 3.2% for those classed as having severe or medium disability. It is notable that 3.2% is exactly the same percentage arrived at by Veenstra et al (2002: 14) in their study of disability in the Middle Ramu. Disability rates for individual villages ranged between 0.4% and 11.5%. This large variance warrants further study.

8. Biomedical Causes of Disability

People were able to identify the biomedical causes of only 54% of their ailments leading to severe or medium disability (See Table 1 below). They noted that 8% were congenital, 15.9% were caused by severe illness (such as malaria or epilepsy), 9.1 % were caused by accidents (such as falling from a tree), 3.2 % were caused by fights, and 17.9% by advanced age. 28% said they did not know the cause, and in 17.5% of cases it seemed that there were "other" causes.

Comments made while answering this question helped shed some light on the "don't know" and "other" responses. Many complained of chronic pains and restriction in movement, probably caused by arthritis. A number complained of shortness of breath (Tok Pisin: *sotwin*) (asthma?), and many showed sores on their feet (warts?) which did not heal, and which caused them much pain so that they limped or had to walk with a stick. There were a number of cases of people who appeared relatively healthy, but who complained of fits and losing consciousness (epilepsy?). In Tok Pidgin this condition is known as "sik muruk" because it is said that the muruk (cassowary) suffers from the same condition and that one can be infected by eating cassowary meat. One man admitted that he had been drinking mentholated spirits and that this had affected his eyes, and several people claimed that their withered leg was caused by a needle having damaged their sciatic nerve when receiving an injection as a child (possibly also polio?).

However some comments indicate that the "don't know" and "other" responses could be a way of saying that there was a cause that is difficult to explain in medical terms. A number explained their eye or ear condition by saying that "smoke" went into their eyes, or "water" went into their ears. Such smoke or water would not be just any smoke or water, but most probably smoke from an object that had been bespelled, or water from a pool inhabited by a *masalai* spirit. Others revealed that the cause was "poison" or having broken a taboo.

Table 1: Causes of S/M Disability by Type of Impairment [Biomedical Cause] (includes multiple causes)

Biomedical Cause	Type of Impairment					
	Mind	Sight	Hearing/ Speech	Leg, hand & body	Multiple	Total [%]
Congenital	7	20	18	10	5	60 [8.0]
Severe Illness	11	28	36	42	2	119 [15.9]
Accident	1	21	16	29	1	68 [9.1]
Fight	1	7	9	6	1	24 [3.2]
Old Age	3	70	16	43	2	134 [17.9]
Don't Know	9	71	40	83	11	213 [28.4]
Other	7	43	28	42	11	131 [17.5]
Total [%]	39 [5.2]	260 [34.7]	163 [21.8]	255 [34.0]	33 [4.4]	749 [100]

As can be seen in Chart 1, from a biomedical point of view, impairment of the mind is most likely to be caused by severe illness (particularly malaria), impairment of the eyes is most likely to be attributed to advanced age, impairment of hearing falls more often into the "don't know" category, though illness is seen as a significant factor. Impairment of the body and movement related functions very often evoked a "Don't know" response.

9. Perceived Causes of Disability

Seeking perceived causes is like asking the question about what lies "behind" the biomedical cause: - Why did X fall from the tree? Why was Y bitten by a snake? Why did malaria cause the child to become deaf, when other children get malaria but they don't go deaf?

There were three ways the study team tried to find perceived causes. Firstly we asked people directly. After having asked them the simple question of "why" the person was disabled, then, in question 11, we asked "Yu ting wanem as tru bilong dispela..." (What do you think is the real reason behind this disability?) We classed the responses into nine categories. These are shown in Table 2. One can see that almost 60% of the respondents answered either "don't know"

or "other cause". "Poison" (forms of sorcery) was significant for mental disability, and accidents and poison are the next most important factors for the other forms of disability.

The second way of finding perceived causes is to see what comments people made while responding to question 11. For example, people are well aware of hereditary defects and a number of people said that their disability came from a parent because it "follows the blood." Others mentioned "poison", stepping over bespelled leaves, eating food cooked by a menstruating woman, poison from a *sanguma* woman, being harmed by a *masalai* spirit, and breaking taboos, especially dietary taboos. The carers of one child said that her growth was stunted because she had drunk milk from her mother, after her mother had died!

Table 2: Perceived Cause of S/M Disability by Type of Impairment

Perceived Cause	Type of Impairment					
	Mind	Sight	Hearing/ Speech	Leg, hand & body	Multiple	Total %
Accident	3	23	17	30	2	75 [11]
Broke Taboo	2	20	8	16	3	49 [7.2]
Sanguma/Poison	7	32	13	29	4	85[12.5]
Evil Spirit	1	7	3	5	0	16 [2.4]
Ancestral Spirit	1	11	5	11	2	30 [4.4]
Parents' Fault	3	5	4	5	1	18 [2.7]
Drug/Marijuana	2	1	0	1	0	4 [0.6]
Don't Know	10	87	50	104	13	264 [38.9]
Other	6	52	38	39	3	138 [20.3]
Total [%]	35 [5.2]	238 [35]	138 [20.3]	240 [35.3]	28 [4.1]	679 [100]

The third way of finding perceived causes is through in depth interviews and case studies. Insights from these interviews and case studies will be introduced in the later discussion based on these quantitative data.

Table 3 compares perceived causes of impairment and biomedical causes.

Table 3: Perceived Cause of Disability[S/M] by Biomedical Cause of Impairment

Perceived Cause	Biomedical Cause of Impairment						
	Con genital	Severe Illness	Accident	Fight	Old Age	Don't Know	Other
Accident	3	3	42	7	6	4	5
Broke Taboo	2	4	2	0	14	5	13
Poison/Sanguma	0	18	5	2	11	10	21
Evil Spirit	3	2	0	0	2	3	7
Ancestral Spirit	4	5	0	0	6	4	6
Parents' Fault	6	4	1	0	0	7	3
Marijuana/Drug	0	0	0	2	0	0	1
Don't Know	34	33	3	1	39	133	20
Other	8	25	5	9	21	15	35
Total	60	94	58	21	99	181	111

With those where the cause was biomedically a congenital problem, 57% said they "didn't know" the cause. 15% identified supernatural causes, either sanguma, poison, or malicious spirits.

With those where the cause was biomedically a severe illness, 35% said they didn't know the cause, while 19% identified supernatural causes.

Where the cause was biomedically attributed to an accident, people were consistent in their responses, 72% agreeing that it was caused by an accident.

Where the cause was biomedically attributed to a fight, 33% said it was an accident and 48% preferred to say they didn't know or that it was some other reason. Two said they thought it was caused by a drug or marijuana (perhaps also alcohol).

Where the cause was biomedically attributed to old age, 14% felt that it was caused by breaking a taboo, 11% felt it was caused by poison or *sanguma*, and 61% preferred to say they didn't know or that there were other causes.

Where the cause received a "don't know" response in the biomedically question, 73% were consistent and said they didn't know in the perceived causes question.

Where the cause received an "other" response in the biomedical question, 50% responded that they didn't know or that there were "other" causes, 12% felt that they had broken a taboo, and 19% said that the problem was the result of poison/sanguma.

Apart from the accident and don't know categories which are relatively consistent in both biomedical and perceived cause responses, we see a high number claiming not to have clear knowledge of the cause of the disability. On this point, one of our national researchers has this to say: "The number of people with a disability who did not know the cause of their disability is large. From the statistical data, it is not so easy to ascertain the reason for this, but perhaps the comments on the raw data may provide us with a clearer understanding as to why such a huge number? One possible explanation could be, that the 'I don't know,' answer given by a respondent, was a way of protecting oneself from answering the question. A response like that is sometimes used as a pausing interval, while deciding whether to answer the question truthfully or not. From personal experience, if they do not really know you, they take their time to answer you. Most times, they hedge around first and size up the situation. Most often, their spontaneous response is 'I don't know', then once they've worked you out, they then answer you truthfully."

"'I don't know', may also be saying; 'I know the answer but I'm not going to tell you!' This means the person is not too sure of you and how you would react to his/her answer. In our case, our religious identity and our status in the church could have been a factor. People might hesitate to tell us if they believed they had been poisoned or attacked by the sanguma. This then is another reason why the number of people who responded with 'I don't know', is so large in proportion to the others."

10. Help Seeking

Do people with disabilities seek help, and if so where do they seek help? We found that in 58% of cases of severe-medium disability people did seek help. Those with sight problems are less likely than the others to seek help (48%). Those with movement related or multiple difficulties are more likely to seek help (64%).

Where do they go for help? Considering that the two nearest

sub-health centres are both church run, it is not surprising that half those responding sought help at a church run health facility. The figure of 2% for "family" is surprisingly low. As for the "other" category, 21 people mentioned Callan services. It is not clear whether they consider Callan services under the banner of a church run facility or (most likely) as an independent entity. Others mentioned treating themselves with traditional herbs like "salat" (nettles) and several mentioned that they had tried a "singsing" (=song, presumably a magic spell) to help deal with their condition.

Table 4: Type of Impairment by Place of Seeking Help [S/M]

Place of Seeking Help	Type of Impairment					
	Mind	Sight	Hearing/ Speech	Leg, Hand & Body	Multiple	Total [%]
Family	1	3	1	5	1	11 [1.7]
Govt. Hospital	10	60	32	76	10	188 [29.4]
Church Hospital	14	91	67	134	14	320 [50]
Village Doctor	4	14	8	23	2	51 [51]
Church Healing	0	2	2	5	1	10 [8]
Other	3	26	15	14	2	60 [9.4]
Total	32	196	125	257	30	640

Looking at help-seeking from the perspective of perceived causes (See Table 5) one may notice how people seen as having had accidents are more likely to go to a government medical facility, those perceived as being harmed by evil spirits tend to go to a church run facility, but only one person in this category sought healing through the church's spiritual resources. People suffering from poison or sanguma tend to go to a "village" doctor, but notably only one person out of 31 claiming to be afflicted from breaking a taboo went for help to a village doctor, and no one claiming to be affected by ancestral spirits said they sought help from within their family.

Table 5: Help Seeking by Perceived Cause of Impairment [S/M]

Perceived Cause	Place of Seeking Help						
	Family	Govt. Hospital	Church Hospital	Village Doctor	Church Healing	Other	Total [%]
Accident	2	24	26	3	0	7	62 [11.7]
Broke Taboo	2	4	21	1	0	3	31 [5.9]
Sanguma/ Poison	2	21	29	14	1	6	73 [13.8]
Evil Spirit	1	3	8	3	1	0	16 [3.0]
Ancestral Spirit	0	3	9	5	0	4	21 [4.0]
Parent's Fault	0	5	6	2	0	3	16 [3.0]
Marijuana/ Drug	0	2	0	0	0	1	3 [0.6]
Don't Know	2	58	109	7	4	15	195 [36.9]
Other	1	37	53	9	2	10	112 [21.2]
Total [%]	10 [1.9]	157 [29.7]	261 [49.3]	44 [8.3]	8 [1.5]	49 [9.3]	529 [100]

Looking at help-seeking from the perspective of biomedical causes (Table 6) one may see the heavy reliance on church-run medical facilities. It is notable too that church spiritual healing is sought more in the cases where the cause is unknown. It is surprising to see that in cases where the biomedical cause is congenital, or because of a fight or old age, no one said that they sought help within their family.

Table 6: Help Seeking by Biomedical Cause of [S/M] Impairment

Biomedical Cause	Place of Help						
	Family	Govt. I Hospita	Church Hospital	Village Doctor	Church Healing	Other	Total [%]
Congenital	0	13	22	2	1	6	44 [7.8]
Severe Illness	5	31	51	10	1	6	104 [18.3]
Accident	2	21	24	4	0	7	58 [10.2]
Fight	0	9	9	0	0	1	19 [3.4]
Old Age	0	27	44	5	1	8	85 [15.0]
Don't Know	2	37	76	11	4	11	141 [24.9]
Other	2	33	55	12	2	12	116 [20.5]
Total [%]	11 [1.9]	171 [30.2]	281 [49.6]	44 [7.8]	9 [1.6]	51 [9.0]	567 [100]

11. Perceived Natural and Supernatural Causes

In the presentation of our results above, we have focused on the quantitative data from the questionnaire. However, the opportunity given for comments and our in-depth interviews uncovered a great deal more information about people's perceptions of causes of disability. Some causes are "natural" but most have what could be termed "supernatural" causes involving sorcery or spirits. Some summary examples are given below.

Accident

i. J's jaw is locked and three teeth of his right upper jaw are missing. He cannot open his mouth when he eats or speaks. When he eats, he breaks cooked food and inserts it through his right upper jaw where three of the teeth are missing. J's condition is due to an accident suffered two years previously. He climbed a betel nut tree and fell down. There is no explanation given as to why he fell. No sinister or supernatural reasons were offered. People seem to regard it as an "accident.

ii. S lost the use of an eye when he was holding a bird and the bird pecked at his eye with its beak.

iii. L lost half his left hand when hit by a bulldozer while he was working in an oil palm plantation in the West New Britain Province.

iv. N broke his leg playing soccer and the leg healed in a way that prevents him from walking normally.

v. Y. dislocated her hip when a Tulip tree she was climbing broke and she fell to the ground. In this she mentions a lizard that she encountered in climbing the tree and wonders if someone turned a "curse" into a lizard which made the tree break.

"Natural" causes were given mostly in responses associated with "accidents". The researchers suspected that people might have other reasons for these accidents, but no other reason was given, except in the last case above, which illustrates how even in cases of an accident caused by a coconut falling or a tree branch breaking, people will ask "why" the branch broke, and seek a sinister or supernatural cause.

Marijuana or other drug

i. F is a young man who spends much of his time drinking "*stim*" (distilled liquor), and smoking marijuana. When asked why he smokes, he replied that when he smokes "the music styles are better." When asked about the future he replied, "My future is just music and marijuana." F's father admitted that his son is very confused and laments that his son will probably not marry and that he and his wife will have to care for him for the rest of their days.

ii. F was smoking marijuana when he noticed his baby son fall off the veranda of the house onto the ground. He rushed over and found the child was not breathing. He tried mouth to mouth resuscitation. The baby survived but is deaf. People accuse him of causing the child to be deaf because he gave mouth to mouth resuscitation after smoking marijuana.

The team noticed that drinking "stim" was a common pastime with the young men in the Wosera villages, and while walking around the area we encountered many men obviously under the effect of alcohol. It is not clear to what degree this "natural" cause will result in disabilities in the long term.[6] Some young men consume distilled liquor and smoke marijuana together, claiming that it has a more powerful effect.

Breaking a Taboo

i. R is a 42 year old man with his legs swollen from the thighs down

to his feet. He cannot walk or stand. In planting yams he did not follow the taboos associated with such planting. During this time, until the young shoots of the yams have appeared, men are restricted from drinking cold water, having sex, and eating greens that are watery. R says, "I broke the taboo and I ate Aibika and other soft greens and both my legs swelled up." Though R believes that his sickness is linked to breaking a taboo it seems no elders in the village can help him, because, he says, they have forgotten the rituals used to help people in his situation. He would like to go to the Kaugia sub-health centre, but R claims that his relatives told his wife that R and his wife should arrange some form of payment first before they will help carry him to the health centre.

ii. M has a cleft pallet. People say this is because his father broke the taboo against working with a spade while his wife was in labour. Working with a sharp instrument like a spade is thought to affect the unborn child.

"Poisen" and *Sanguma*

i. Here is an example of a man who believes that his present disabled condition is caused by his participation in an act of sorcery many years ago. C is a 67 year old man who cannot see things clearly and can hardly hear if spoken to in a normal voice. He said that his disability is due to his involvement in a sorcery killing. He participated in killing an enemy from a neighbouring community. He insists that he was only a passive participant in that killing and played no role in performing the sorcery. His group mates were the ones actively involved in the ritual killing. However they have all died without holding a "pasim pik" ceremony as a form of reconciliation. That ceremony is intended to stop a conflict including stopping further attacks by sorcery. The ceremony is usually initiated and hosted by the party that feels responsible and benefits from it. The host prepares pigs and shell money. The shell money is given to the victim's extended family members, while the pigs are slaughtered for a feast that ends the ceremony.

ii. *Sanguma* is another type of sorcery practiced by a *sanguma* man or *sanguma* meri who uses destructive powers to harm or kill other people. The main motivations for this are grudges over land disputes, fights and consequent retaliation, refusal to marry a chosen partner, jealousy, and the non-payment or insufficient payment of bride price.

D and his wife J have two daughters, both of whom are practically blind with what seems to be a congenital eye condition. D's mother believes that J's family are unhappy because he has not completed paying the bride price. So they are using sorcery to harm the children and thus get back at D the father.

iii. M is afflicted with chronic scabies and feels that she has been "poisoned" by stepping over a bespelled object. She believes that the cause is her refusal to marry again after her husband died. The angry suitor does not want her dead but is making her suffer for refusing to marry him.

iv. S became sick and went unconscious. People say the sickness came about because he went to a place in the river that is taboo for children because the men go there to practice rain magic. After his sickness he ate chicken and his arm became small and deformed "like a chicken wing."

We encountered many stories of "poisen" and sorcery, but the examples given above illustrate how fear of "poisen" and sorcery are still very prevalent in the Wosera community. Usually "poisen" or sorcery is employed when there is a grudge against a person or the community. However the sorcery may affect others, as, for example, when children are believed to be made blind or impaired in some way in order to get back at the parents.

Evil Spirits

N is a 15 year born with "club feet.' His mother says, "While I was pregnant I used to get coconuts and tulip and I was alright, but about the time he was born I got water from a place where there is a *masalai* spirit. I sat down on a stone there. The next day he was born and I saw that his legs were deformed." The child tried to stand but couldn't, so she got a sharp thorn from a sago palm and put it into his foot so he had to turn his foot in order not to feel the pain. The mother's intervention appears cruel, but in fact it did help cure one of his club feet. However she did not "treat" the other foot and so it remains badly deformed.

ii. L has very poor eye sight. He says that his father unintentionally burned the eyes of a frog at a time when his wife was expecting L. A month later L was born and it was soon obvious that he had eye problems. His parents associate this condition with the burning of the frog's eyes. The spirit living in the place where L's father had ill-

treated the frog had now retaliated and spoiled the eyes of their child.

Ancestral Spirits

i. P is a 27 year old woman who seems to be suffering from epilepsy. She has a big burn scar on her arm where she fell into the fire. She describes her condition as follows: "I am walking along and then this thing makes me fall down. I fall and lie there and then I get up. It must be a sickness caused by something around here. They want to affect my thoughts and I go unconscious and fall down." She continues: "There is also something inside my abdomen that makes my arms and legs go numb and it goes to my head. It is not epilepsy. Someone must be angry with my father." She goes on to explain how some people say that the spirit of a dead person is affecting her. They are angry with her father and want to kill him but instead it is affecting her.

ii. Y got sick as a child while they were living in the coastal town of Lae. Her parents had an argument after her father went to a dance. He cursed Y and her mother, using the "bun" (name) of his ancestors. The next day her mother noticed the child had a big sore on her arm. Later she developed a hydrocephalic condition (enlarged head). Her mother believes that it was caused by the curse of her father, calling on the ancestral spirits.

iii. A is paralysed on one side. A's grandfather died and they buried him. Afterwards A's uncle had an argument with his father and in the process damaged the grandfather's grave. It is believed that A was born disabled because of the damage to his grandfather's grave.

Fault of Parents

Already several examples have been given where it is believed that parents have broken taboos and their children have suffered as a consequence. Other examples include the following:

i. M is a young man with a cleft lip. While his mother was pregnant his father dug a drain to let water out from a creek to catch fish. Later his father told him, "I was digging the drain and cut your lip with my spade."

ii. H is a 38 year old woman who is blind. People believe this is because her parents fought over her when their marriage broke down. Her mother took her away so her father's people "poisoned" her and now she cannot see.

12. "Don't know" Responses

In 264 cases people said that they did not know the cause of the disability. It may be true that a person just does not know the cause of their disability. However, as noted above, this could mean that he or she needed time to decide whether to answer the question truthfully or not, or it could mean "I know the answer but I'm not going to tell you."

Consider the case of a 42 year old woman from a village near Kunjingini.

> B has ugly growths that look like burn scars over much of her body. In fact they are some form of growth. How did this start? She replied: "Em kamap nating nating" (It just came for no reason). She continued: "ol soa i gro na i kamap sanap wanwan na em wok long join. Em kamap bikpela na em join join. Soa i drai em kamap olsem. Em gro nau." (The sores appear individually and then they join up and grow. The sore that appears healed came like that. It is still growing) She went to Boram hospital where they operated on her to reduce the growths. However, the growths have started again. She has told the doctor that she doesn't want another operation. It is too painful
>
> Upon enquiring about what others are saying about the origins of her illness she replied: "I no wanpela i wokim *sanguma*. Papa bilong mi i gat dispela kain sik, na bikpela sista bilong mi mitupela wantaim na em wok long bagarapim mipela. Ol brata bilong mi ol i orait" (It is not sorcery. My father had it and my big sister is afflicted by it. My brother is alright.) She went on to explain how she experiences a lot of pain. She lives with her mother. Her friends are all married and she feels alone. She has chosen not to marry. She comes regularly to Kunjingini mission station and is a regular church-goer.

There were many others like B who say that their illness just happened for no reason. Consider the case of a young man, also from a village near Kunjingini.

> J is a young man with badly deformed legs so that he has to walk with his hands. When he was young he was able to walk normally, but then he got sick and ended up in the Kunjingini sub-health center. According to J the trouble started when he developed two big sores at the back of his legs. The sores never healed properly and he has not been able to walk since. Now he is very limited in what he can do as he has to walk in a

crouched position with his hands pulling his legs after him. He finds it very frustrating not being able to move around like before. He is grateful that the children do not make fun of him, but it does not stop him from being sensitive about his situation. He does not think he will ever get married since he feels he would not be able to support a family of his own. His brother looks after him in the village.

What is the cause of his condition? J says he was not poisoned and it was not sorcery. The sores appeared for no reason. One time he went to a Revival Mission to seek healing. However, that did not help. So he is learning to live with his disability.

We have no reason to disagree with the sentiments expressed above. It appears that they do not know the cause of their disability, admit it, and are trying their best to live as best they can.

13. Perceived "Other" Responses

In 138 cases people gave "other" reasons for the causes of disability. There were many different reasons given. However, several reasons recurred. For example:

- A number of older men blamed their poor eye sight on having had ashes and nettles affect their eyes during their initiation rites.
- Several cases of withered legs are thought to have been caused by a misplaced injection (Could some have been caused by polio?).
- In a number of cases people put their disability down to a congenital condition - "bihainim blut," (following the blood).
- In many cases of deafness people said that it was because dirty water had got into their ears.
- In many cases of blindness people said that smoke or ashes had blown into their eyes.
- Some realize that their condition has resulted from fighting. One man cannot see properly after being involved in a drunken fight. He says, "em asua bilong mi," (Its my fault).

Some reasons given seem unique:

- T is mentally disordered, and his father feels that he is

being punished by God. We encountered very few people who attributed their disability to God's punishment.

- Y has a speech defect. People say that at the time her mother died when she was a child she must have drunk milk from her dead mother's breast.
- R has a stutter (known as *kwakumakmak* in Abelam language). This is attributed to her mother giving her too much milk as a child!

14. Social Disability

One of our aims was to make estimates about the standard of living of persons with disabilities, that is, how a mental or physical disability translates into a social disability.

We were particularly interested in the following issues:

- Immediate needs: food and water, toilet, water for washing, housing, clothing
- Intermediate needs: garden, market, school, village meetings, church, clinic
- Long term needs: marriage, land rights, vocation

In general we found that disabled people were well accepted in their communities. We did not find anyone whose immediate needs for food and water, toilet, water for washing, housing or clothing were not available or being denied them. Several mentally disabled persons themselves refused to wear clothes. We found one young child with severe mental disabilities whose mother locks him alone inside the family home when she goes to the garden.

Whether intermediate needs were met, depended to a large extent on the type of disability. Those with mental problems who might easily disrupt social events like village meetings or church services were discouraged from attending such gatherings. Those who could not walk were obviously limited in attending market, school or other meetings. In a few cases disabled persons complained that relatives wanted some form of payment if they were to carry them to the health centre.

Consider the two cases, one of a young man who is well accepted and another an older man feared and rejected by the community.

Case A. D is a young man of about 25 years of age. He is active in parish life. He walks with a pronounced limp. When he was about 4 years old he had severe malaria and was taken by his mother to hospital. He was given an injection and says that the needle hit a nerve. This caused paralysis of one leg. D. has learned to walk again and had to undergo a lot of exercises in order to do so.

D is involved in youth work and feels he is the same as everybody and can do anything his friends are involved in except climb trees. He does not think that his limping will stop him from getting married if a chance presents itself. He hopes to find a nice girl to marry. He prides himself in the fact that he built his own house.

D says that he has already received help from Callan services and has learned skills from them. He also use the skills he received from Callan to help other disabled individuals. He is very positive about life in general. He explained that if his leg would be operated on, it would be worse for him, so he is accepting of his disability, believes in himself and can manage well on his own.

Case B. N cannot see well because of cataracts on his eyes. He is married with eight children: one boy and seven girls. The last two girls are disabled, one being deaf and possibly mentally retarded, the other being mentally affected. Though she is about 20 years old she refuses to wear any clothes and talks incoherently.

M one of their older daughters believes that the main cause of the younger children's disabilities is the fault of their father. She blames both parents because they don't talk to each other. One of the disabled girls was born after the mother had been bitten by a snake. When another of the girls was small N fed her with a piece of pork. The father knew that he should throw some of the pork into the river, but he did not do so, and M believes that is why the girl is now deaf and makes "ah, ah" noises like the sound a pig makes.

The mother continued, "Nau em i gat dai muruk - dispela sik muruk i kamap bihain. Abus bilong muruk ol i kaikai o kaikai kiau bilong en - wanpela lain i kaikai na samting i kalap na kam long pikinini. Ol i tok em kalap olsem VD or Gonorrhea" (Now she has epilepsy - it appeared later. They [men including her hus-

band] ate cassowary meat or an egg and the sickness spread to the child - spread like VD or Gonorrhea).

N is from another village, but after an argument came to settle in his present village. He and his brother settled and made gardens but later they fought over the land. The brothers parted on bad terms and shortly afterwards N got cerebral malaria. He suspected his brother of poisoning him. After a while N himself became known as a sorcerer or *sanguma* man. Following these accusations he separated from his wife and family.

One of the principal differences between the first and second cases above is the perceived cause of their impairment. D has a problem walking, but is well accepted. N. in the case above has a problem with his eyes, but he is also reputedly a sorcerer and for this reason is not accepted by the community. His short sightedness can be rectified by visiting the eye doctor or Callan services, but it will be much more difficult to erase the "social stigma" and the fear associated with his reputation as a sorcerer. Most probably the social stigma will remain with him for the rest of his life.

15. Obstacles to Seeking Help

As noted in section 11, 58% of cases of severe-medium disability people did seek help. Why then did 48% of the cases not seek help? We did not ask this specific question, however, information coming from our interviews indicates the following:

- Distance was the most frequent explanation for reluctance to visit the health sub-centres in the study area. The unavailability and cost of transport corroborated this claim, especially for those needing medical attention from Maprik, Boram Hospital in Wewak and Callan Services in Wewak. Wewak is a three-hour drive from Kunjingini, and costs at least K10 by public transport. Several people said that they had obtained spectacles from Callan Services in Wewak, but when the frames broke, they had not gone back to have them repaired.
- The research team experienced transport problems while there, as the bridge between Kunjingini and Kaugia was unusable (damaged for political motives) and we had to wade (swim) across a large river to travel between the mission stations.
- Some think that disability is curable and they expect the

nurses or Callan services to give them medicine that will "cure" their problem. If they don't get a cure they may not return. For example, a short sighted person told one of the researchers that he did not want to come to see the nurses or Callan services for his eye problem because the nurses had told him that there was no medicine for such an ailment. In another case the father of a son with a deformed leg refused to return to Callan services because they could not make his leg good again.

- Some delay seeking aid from modern health services when a sickness is perceived to be "sik bilong ples" (caused by sorcery, evil spirits, etc.).
- Some have financial problems, either in having to pay people to carry them to the health centers or in the case of patients having to go to town, to support guardians accompanying them.
- Some appear to just not care. For example, at Bethlehem, some five minutes walk from the Kunjingini several people came to us complaining of eye problems. When asked if they had been to see the nurse with special training in eye problems at the Kunjingini sub-health center, they said that they intended to go, but had not done so.

16. Health Workers' Beliefs and Attitudes

There is a credibility gap between the health worker's beliefs of the cause of illness and what the health workers find with the village people. All the health workers said that they did not believe in "poisen" or sorcery as causes of illness. One health worker said, "Mi no bilip long ol spirit nogut o poisen. Epilepsy em i epilepsy tasol, tasol planti manmeri ol i pilim ol i gat wanpela spirit nogut insait," (I don't believe in evil spirits or "poisen". Epilepsy is epilepsy, but many people feel there is some sort of evil spirit inside). A nurse noted, "Mi no bilip tumas long *sanguma* tasol sampela taim ol man i save stori na mi pret," (I don't really believe in sorcery, but sometimes when people talk about it I feel fearful.) Another nurse commented that accusing others of sorcery is shifting the blame to someone else rather than facing the problem in "me."

The majority of people coming for treatment, are seeking treatment for malaria, and one nurse noted that malaria is the main cause of disabilities around Wosera. However, according to the health work-

ers most people coming to the sub-health centres feel that their illness is caused by "poisen" from sorcery (*sanguma*). The health workers say that they try to discourage people from such beliefs but it is very difficult to convince people that illnesses or disabilities are not caused by sorcery or "poisen". One health worker mentioned that they seldom if ever see severely deformed children because the community is ashamed of them and because such children usually die quickly.

How do the health workers' deal with people's strong beliefs in "poisen" and sorcery? Some said that they tried to convince the people otherwise, but added that this was seldom effective.

Some said that they pray with the patients and this helps.

Asked if many disabled people were coming to the clinic, one of the health workers at Kunjingini replied that there were many coming, some with eye problems caused by play-fighting with the sharp shoots of Kunai grass, some having pierced their ear drums in trying clean out their ears with *nok* (like straw), some with eye and ear infections, some with congenital sight and hearing problems, others suffering from the effects of severe malaria attacks.[7]

The nurses noted that people often refer to disabled people as "nogut" (bad/ruined) or "longlong" (crazy). They feel that such terms do not help the disabled because everyone has a "nem and namba" (individual identity and dignity) and should be addressed by their own name and be treated as any human person, not as someone crazy because they cannot talk normally. A nurse at Kunjingini said that there was only one really crazy person around there - a mature man who walks around all day stark naked.

17. Conclusion and Recommendations

Generally people refer to people with noticeable disabilities as *kaprae* or (bad/ruined/not good), and in the local language use modifiers meaning "blocked" or "dead". These are terminological issues that could be investigated further by researchers with a deeper knowledge of the local language.

We collected data on the nature of traditional beliefs and attitudes towards persons with disabilities. In the North Wosera there is a greater tendency to attribute illness to the work of spirits and sorcery. In the South, people seem more likely to attribute their illnesses to malaria and other medical condition. This difference could be due

to the greater isolation of the North Wosera area.

There were three ways we tried to find perceived causes. Firstly we asked people directly. After having asked them the simple question of "why" the person was disabled, then, in question 11, we asked "Yu ting wanem as tru bilong dispela..." (What do you think is the real reason behind this disability?) We classed the responses into nine categories.

The second way of finding perceived causes is to see what comments people made while responding to question 11. For example, people are well aware of hereditary defects and a number of respondents said that their disability came from a parent because it "follows the blood."

The third way of finding perceived causes is through in depth interviews and case studies. Where people were able to identify causes, the majority could be classed as "supernatural" involving broken taboos, sorcery, or the work of various types of malevolent spirits. We found that physical disabilities do not necessarily translate into social disabilities unless the person is feared as a sorcerer or someone capable of harming others.

The two sub-health centres in the area are well patronised, with over 13,000 people seeking treatment over the six month period prior to our visit (in an area with a total population of 12,500). People seen as having had accidents are more likely to go to a government medical facility. Those perceived as being harmed by evil spirits tend to go to a church run facility. People suffering from "poison" or *sanguma* tend to go to a "village" doctor. We noted that 48% of the cases of disability claimed that they had not sought help. In section 16 we have suggested some reasons for this surprisingly high figure.

We have the following recommendations for health workers and church personnel in the area.

- There is a need for greater awareness of what we mean when we talk about people with disabilities. There needs to be more discussion on the classification and terminology of impairment, disability and handicap, and the social and medical aspects of disability.
- Interested persons should continue to find ways to bridge the communications gap between biomedical understandings of illness and commonly held supernatural perceptions of the causes of illness. This matter could be raised at in-

service training, with knowledgeable people invited to attend.

- Encourage regular village visitation so that medical workers come not just for Maternal and Child Health clinics, but also to visit and check with the disabled persons in the village.
- Train more medical workers to specialise in work with and caring for people with disabilities.
- Provide greater awareness on how to deal with people with disabilities. Churches could do more in making people aware that everyone, disabled or not has a "nem na namba" (unique identity and dignity).
- Since many of the disabled people are receiving basic care within their communities, attention should be given to training and education which might help lower the incidence of disabilities in the future.
- Try to help people deal with unreal expectations. Many forms of disability cannot be "cured", but this should not prevent people coming for assistance with rehabilitation.
- People generally trust the church personnel and local health workers, so their support and encouragement will go a long way in getting people to go to Wewak hospital or Callan Services when there is a need.
- Look for ways to work closely with the younger generation who appear to have little meaning in life, spending much of their time and resources on home brewed alcohol and marijuana.
- The local communities could work with the Health Department in order to have better ground-well or water tanks in each village.
- The local communities could be assisted to work even more closely with IMR and DPI to find ways of gardening that will improve nutrition in this heavily populated area.
- Parishes should continue the practice of integrating pastoral counselling into pastoral work so as to help people deal with the psychological, social and spiritual effects of long-term disabilities.

- Find effective ways, acceptable to the community and the Church that will help married couples have more control and interest in spacing children in their families.

ENDNOTES

1 Our team on this project was made up of Dr Michael Rynkiewich (who led the study in its initial stages before departing for the USA), Dr. Philip Gibbs, Sr Jeline Giris, Brother Martin Tnines, Fr Arnold Afaneng, and Mr Robert Nugue. All contributed their own particular expertise. Mr Henny Heyer (Callan Services) joined the team in the latter stages of field research, and Fr Nick de Groot (MI) helped with the questionnaire construction and data analysis. Ms Elizabeth Kimirambah (MI) joined the team during the data entry and analysis stage of the project.

2 The name "Wosera" traditionally applied only to a group of seven villages, but the term now is generally accepted by most people for the whole area. The government, for administrative reasons has divided the Wosera area into two census divisions - North and South Wosera (Schroeder 1992:58).

3 During the study we classified disability according to the international classification of functioning Disability and Health code (ICF): Global mental functions; Seeing and related functions; Hearing and vestibular functions; Neuromusculoskeletal and movement-related functions.

4 Ethical issues arise involving the freedom of people to participate or refuse, the confidentiality of the information gathered, and the effect of the research on the people's expectations for the future. The researchers were aware of these issues and were expected to get informed consent or to abandon the interview. Informed consent usually consisted of a question and a verbal response from the disabled person or their care-giver indicating agreement.

5 We classed 491 persons as medium or severely disabled. However, we allowed for multiple impairments and multiple causes of disability, hence the number of "causes" (749) is higher than the number of persons.

6 We obtained a bottle of "stim" (distilled liquor) made from fermented banana. Laboratory tests showed that it contained ethyl alcohol and no traces of the more dangerous methanol. This test was merely a trial and wider testing would be required to produce conclusive results.

7 Two of the health workers, one at each health centre have received special training in the care of the disabled. Because of shortage of staff and the volume of work, the trained nurse at Kaugia finds little time for dealing with disabled patients or for work in Community Based Rehabilitation (CBR). The nurse at Kunjingini has arranged to meet people with eye and ear problems on Fridays, and she is trying her best to coordinate some CBR, but finds it difficult with the pressure of other work.

Appendix: Wosera Questionnaire

1. Rekod _____ 2. Viles/ ples _____

3. Yu gat hamas krismas? _____ 4. Man/ Meri M=Man F=Meri

5. Yu pinisim hamas yia long skul?

i. No bin go long skul
ii. Praimeri skul tasol
iii. Hai skul
iv. Tertiary
v. Arapela (eksplein) _____

6. Dispela man/meri o wasman bilong em i kisim intaviu o nogat? Y=Yes N=Nogat

7. Dispela man o meri i gat wanem kain hevi o sik?

i. Long tingting/long het
ii. Aipas
iii. Yaupas
iv. Lek-han o bodi i nogut
v. Planti samtin nogut

8. Emi i aipas/yaupas/tingting nogut olgeta (longlong) o olsem wanem?

i. Olgeta ii. Liklik iii. Namel

9. Wanem taim dispela hevi i bin kamap - long taim mama i karim em? Y=Yes N=Nogat

10. Sapos i kamap bihain long mama i karim em, wanem as bilong dispela hevi?

i. Bikpela sik i kamap
ii. Aksiden i kisim em
iii. Pait
iv. Lapun pinis
v. Mipela i no save
vi. Narapela samting (eksplein) _____

11. Yu ting wanem as tru bilong dispela yaupas, aipas, lek nogut, longlong?

i. Aksiden i painim em
ii. Em i brukim sampela tambu
iii. Posin o sanguma
iv. Sampela spirit nogut
v. Spirit bilong tumbuna
vi. Rong bilong papamama
vii. Spak brus o arapela drag
viii. Mi no save
ix. Narapela samting (eksplein) _____

12. Yu ting dispela man/meri yet i as bilong dispela sik o narapela i as bilong dispela?

i. Long em yet ii. Long narapela iii. Mi no save

13. I gat sampela i laik painim helpim long dispela hevi? Y=Yes N=Nogat

14. Husat i laik painim helpim?

i. Yu yet ii. Famili iii. Narapela (eksplein)_____

15. Ol i laik painim helpim we?

i. Famili
ii. Gavman haus sik
iii. Sios haus sik
iv. Dokta bilong ples
v. Hiling long sampela sios
vi. Narapela samting (eksplein) _____

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