Disability in the Middle Ramu, Madang Province, Papua New Guinea: perceptions, prevalence and the role of community based rehabilitation

Prepared by: Nina Veenstra
Physiotherapist
Modilon Hospital

Supervisors: Dr Julia Byford
Senior Research Fellow
Centre for Family Health and Midwifery
University of Technology
Sydney

Prof Rodney Ehrlich
Department of Public Health
University of Cape Town

Submitted for the partial fulfilment of MPH degree, University of Cape Town.

ACKNOWLEDGEMENTS

I would like to thank the following people and organisations that made this study possible:

Friends of the Disabled Association Inc. (FODA), Port Moresby who provided the funding for this research.

BP Papua New Guinea Ltd, for sponsoring a drum of boat fuel.

MAF Papua New Guinea Ltd, for discounted airfares.

The fieldworkers, especially Suckling Gi, who worked tirelessly to collect data and help to analyse it.

The Aiome District Administration, for their support.

The staff at the Aiome Health Centre, for their assistance with accommodation, their company, and their encouragement.

Councilors and health workers in the Aiome area, who supported us in our work.

The disabled individuals and their families, without whose inspiration and willingness to share their experiences, this study would never have evolved.

Finally, thanks to go to everyone who is not mentioned above but has contributed to this study in one way or another.

ABSTRACT

Worldwide, disability is a major public health problem and the socio-economic impact of disability puts disabled individuals at risk of being amongst the poorest in society. Many disabilities in developing countries are preventable. Community Based Rehabilitation (CBR) is a rehabilitation model promoted by the World Health Organisation for addressing the problems of disability in developing countries. However, for this model to be effective accurate information is required about the socio-economic and cultural context prior to implementation.

The purpose of this research was to gain a better understanding of disability in the remote Middle Ramu district, Madang Province, Papua New Guinea. Baseline data concerning the prevalence and types of disability, biomedical and culturally perceived causes of disability, and help-seeking behaviour was collected.

A two-phase village screening was done, first to identify and register disabled individuals for the study. Following this in-depth interviews were conducted with selected key informants. The purpose of these interviews was to determine the participation of disabled individuals in community life, as well as the impact of cultural attitudes and perceptions on their lives.

The overall prevalence of disability in the area studied was calculated at 3.2%, using the two-phase screening method. A high proportion of disabilities were found to be due to trauma and accidents, while disabilities affecting hearing were frequently associated with illness or infection. The onset of disability was most commonly attributed to social or supernatural causes. Western medicine was widely accepted and utilised. 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 any future CBR program in the area 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.

CONTENTS

such measures. For example, a disabled person living in a developed country may be given a wheelchair and be able to transport him or herself to work in a specially adapted motorcar. The workplace is likely to be fitted with ramps and wider doors to facilitate access. Many of these technologies and opportunities are not available to disabled individuals in the developing world and this often accentuates the participation restrictions they experience. A disabled person in a developing country may not have a wheelchair, and even if this is provided it might prove impossible to use over difficult terrain, even to get around the village in which he or she lives.

As well as a lack of biomedical knowledge about disability and rehabilitation, cultural or religious beliefs in many societies contribute to widespread social segregation of disabled individuals (United Nations 1983:4). These beliefs may impose severe restrictions on the roles given to disabled individuals outside the home (Groce and Zola 1993:1051). These limits on the participation of many disabled individuals in daily life activities can contribute to diminish opportunities for them to lead socially fulfilling lives.

The main task for rehabilitation workers is to minimise disability by enabling people to become more functionally independent. Rehabilitation workers also need to address factors hindering participation, especially those created by societal perceptions and beliefs. Clearly this is impossible to achieve without an adequate understanding of what these perceptions and beliefs are and how they affect behaviour in the society concerned.

Community Based Rehabilitation

Rehabilitation services, in particular Community Based Rehabilitation (CBR) services, are concerned with 'disability' as described in the ICF, and with efforts to improve the functioning of an individual in their home environment. In the past rehabilitation involved long-term institutional care in hospitals and special centres, however this simply served to compound the isolation of disabled persons from mainstream community life and did not meet the needs of the majority of disabled persons (Mitchell 1999:459). An estimated 20% of people with disabilities are likely to require referral to a specialist facility, while rehabilitation at the community level will satisfy the needs of 80% of people with disabilities (Miles 1999:30). As a result, the WHO developed an innovative approach to the delivery of rehabilitation services in the form of Community Based Rehabilitation. CBR is defined as:

> A strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities.

> CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services. (WHO 1995:iii)

CBR is now widely accepted as a model for disability prevention and rehabilitation in primary health care and is recognised as such in PNG by all organisations working in the field of disability. CBR combines both the 'medical model' and the 'social model' in its holistic approach to disability, along with a commitment to understand the social dynamics of the community. Medical care is provided in the form of physical rehabilitation, while the participation and empowerment of disabled individuals and their community assists in addressing social issues. Local indigenous knowledge and practices are valued through the utilisation of existing expertise in the community (DFID 2000:9). Local knowledge is one of the main building blocks of successful CBR programmes.

Unfortunately there has been little research about CBR. This lack of research can be explained in part by the scarcity of resources typical of the contexts in which CBR was developed and implemented (Mitchell 1999:460). Where resources are scarce, research and evaluation are not seen to be a priority. Whilst it is important to evaluate CBR programmes for their effectiveness, it is even more important that disability-related data obtained through research informs the planning of these programs. More recently the need for research has been recognised by people working in the field (Mitchell 1999, WHO 1988).

Papua New Guinea and Madang province

Mainland New Guinea and its archipelagos are situated in the south-eastern pacific region, between the equator and 14° south. Papua New Guinea (PNG), occupying the eastern half of mainland New Guinea, gained independence from Australia in 1975. Although PNG is ranked as a middle-income country, many social indicators (e.g. income distribution, life expectancy, infant mortality, and literacy rates) are comparable with some of the poorest countries in the world (Lipscomb et al 1998:27). With its added vulnerability to numerous natural disasters (earthquakes, volcanoes, tsunamis etc), PNG scores very low on all of the various development indices.

Madang, one of twenty provinces, lies on the north coast of PNG between 4° and 6° South of the equator. Covering an area of 29 000 square kilometres with a population of approximately 300 000 (35 000 in Madang town) Madang is one of the most geographically diverse provinces in the country. There are 45 islands off the coast, and the province displays the tectonic activity

typical of much of PNG. Culturally Madang is very interesting, being the most linguistically diverse province of a nation with more than 800 distinct linguistic and cultural groups. Tok Pisin (or Melanesian pidgin) is the most widely used national language although English is used extensively by those involved in government and is the language of education.

The Middle Ramu area of Madang is geographically very isolated, 120 kilometres west of the township of Madang, close to Western Highlands province. There are no roads into this area of the province, which gets its name from the Ramu River running from the Sepik down through Madang Province. Only the mission flying service visits Simbai and Aiome, the two major centres, which are connected by a road. As flying is unaffordable for the vast majority of the population, people from the Middle Ramu have to walk for many days to access road networks into the township of Madang.

Melanesian society

The social organisation of Melanesian societies is centred on kinship groups identified primarily by clan membership. Kinship systems are characterised by a number of aspects, the most fundamental is the communal nature of society and the importance of social relationships. Ancestors continue to influence the ways of the clan and are, along with local spirits, important in religion (Whiteman 1984:98). The subsistence economy accentuates the importance of land that is inherited through clan membership.

Even though social organisation in Melanesian societies is based on kinship, a variety of social systems, incorporating different residential and genealogical patterns, are evident in PNG. This variety reflects the diversity of other cultural domains seen within the country (Whiteman 1983:57). Most notably, a marked distinction exists between those dwelling near the coast and those living in the mountainous interior. Nucleated villages are much more common on the coast, while dispersed hamlets are more typical of the highlands (de Lepervanche 1973:2). Societies can also be patrilineal or matrilineal, or sometimes even utilise a combination of both unilineal criteria for different purposes (de Lepervanche 1973:10).

Therefore, the characteristic Melanesian social unit or 'ethnic cultural entity' consists of many autonomous, economically self-governing villages or local clusters of hamlets, the formation of which are based on kinship or descent. These entities are all equal in political status and similar in organisation (Sahlins 1970:204). Leaders do not achieve their position by birth alone, although this can be an advantage. More commonly, '*bigman*' status is achieved by exhibiting initiative, being industrious and having some access to resources (de Lepervanche 1973:21).

In the rural areas of PNG the structure of traditional Melanesian society is still largely preserved. Whereas in the more urban settings values associated with industrial societies are more evident.

Connecting culture and rehabilitation

Mention has already been made of the cultural diversity of the people of PNG. The impact of cultural diversity on health and disability is evidenced by a substantial amount of research[1]. Rehabilitation has been noted as being similarly culturally diverse by a number of authors[2], although less has been written about this. As noted by Banja:

> If culture distinguishes how we engage the world, rehabilitation universally addresses the form of that engagement in its physical, behavioural, and/or cognitive manifestations. (Banja 1996:283)

Many key elements of rehabilitation, including a person's attitude, motivation and co-operation, are greatly affected by cultural beliefs (Banja 1996:279). As all these elements are fundamental in facilitating the rehabilitation process, cultural beliefs play a significant role in determining the participation restrictions associated with certain impairments. Criswell (1968:6) suggests that participation restrictions could also be due to the values that disabled individuals place on different rehabilitation goals and processes. These individual values are influenced by the broader social context in which a disabled individual is situated, and thus the outcome of the rehabilitation process is greatly affected by the cultural context.

In planning CBR, there is a need to recognise the cultural context in which services will be delivered and to ensure the services are culturally appropriate. Furthermore, as most of the rehabilitation models currently used in developing nations have come from the developed world, there is a need to critically evaluate the appropriateness of these models in entirely different cultural settings. In relation to disability planning in South Asia, Miles concludes that:

> Western information concepts risk overwhelming indigenous knowledge and diminishing the cultural confidence needed for South Asians to find their own appropriate solutions. (Miles 1996:485)

This sentiment is often expressed in different cultural contexts and yet little effort is focused on developing models of disability planning that are culturally appropriate.

---

[1] Groce and Zola, , Hershenson, 2000, Kleinman et al, 1978, Reynolds Whyte & Ingstad, 1998, Scheer and Groce, 1988, Stone, 1992, Byford, 1999

In PNG, despite a number of studies investigating perceived causes of illness, there has been little research investigating the ways that culture impacts on disability and rehabilitation. The work of Van Amstel et al (1993) is one exception. This study investigates the possible benefit of a community based rehabilitation program in the highlands and considers people's explanations for their disability. However, methodological constraints prevented any significant data collection on this.

Purpose of the study

When trying to define the current situation concerning disability within a district, guidelines issued by WHO (1995) suggest that the first step is to review the extent of disability and different types of disabilities occurring. At the same time it should be possible to describe the conditions of disabled people and their families by examining the physical and social environment of their homes and communities. Establishing a demographic profile of disability in the targeted population is necessary before a closer examination of the day-to-day experience of disabled individuals. This closer examination provides a deeper understanding, vital to the development of successful rehabilitation programmes.

The purpose of this research in the Middle Ramu area, Madang Province is to gain a better understanding of disability - including prevalence of different types of disability, possible causes, people's attitudes and perceptions towards disability and needs of the disabled. This area of the province is very isolated and currently has no CBR. Consequently, the community has responded to disability with little external assistance. By conducting the research in this area, it was anticipated that valuable insights would be gained into traditional perceptions and mechanisms for responding to and coping with disability. A particular emphasis was placed on the need to gain a better understanding of how people experience and explain disability, and what they feel their greatest needs are. This understanding is vital to facilitate planning of CBR in a culturally appropriate way and to ensure it responds to the needs of disabled people and their families.

This research integrates and acknowledges the relevance of biomedical and social perspectives in its attempts to acquire a more comprehensive understanding of disability. The biomedical perspective offers initiatives focussed on the prevention of disability, while the social perspective informs rehabilitation. Both the prevention of disability and the process of rehabilitation are integral to CBR.

---

[2] Criswell, 1968, Hershenson, 2000, Reynolds Whyte and Ingstad, 1998, Stone, 1992

Primary objectives

The primary objectives of this research are:

1. To collect baseline data concerning the prevalence and types of disability.
2. To develop a method of acquiring this information that is appropriate in the context of rural PNG and appropriate for use by CBR workers.
3. To explore and document cultural attitudes and perceptions of disability, and to assess how these may influence help-seeking behaviour and rehabilitation.
4. To determine the needs of disabled people.

Subsidiary objectives

This research offers the potential to fulfil other objectives as listed:

1. To create a greater awareness of disability prevention through both formal and informal interactions.
2. To counter discrimination against people with disabilities by raising awareness of their potential contribution to the community.
3. To train more people in basic aspects of rehabilitation – primarily recognition of different types of disabilities, assessment of traditional coping mechanisms and determining the needs of disabled people.
4. To train CBR workers in quantitative and qualitative research methods, using a participatory approach to enhance understanding and facilitate the use of these methods.

In the PNG National Health Plan 2001-2010: program policies and strategies (PNG Ministry of Health, 2000:83), very little is written on rehabilitation or other services for disabled people. However, the lack of relevant data and information and subsequent lack of policy and legislation is noted as a challenge to development in this area. In line with the recommendations from this National Health Plan, this study noted and was informed by a concern for more information at provincial and local levels, including the need to: 'co-ordinate data collection and reporting', 'plan, co-ordinate and support community-based programs', and 'undertake public awareness activities and secure community support' (PNG Ministry of Health, 2000:83). Unfortunately it was not possible to sight a provincial health plan for Madang Province.

Currently, the only services available to disabled people in the Madang Province are CBR conducted in a limited geographical area (not the Middle Ramu) by a local Non Government Organisation (NGO) and hospital-based physiotherapy at the provincial hospital. In recognition of the need for more information of the type proposed in this study, the Madang Provincial Hospital is fully supportive of this research and any efforts to obtain information on disability and do outreach work, especially since these responsibilities are documented in the National Health Plan 2001-2010. The Medical Research Advisory Committee of PNG also supported the planned research and gave it ethical clearance.

Methodology

Study site and study population

The population chosen for this study comprised people living in a total of 31 villages in the sub-district of Arabaka, Middle Ramu, Madang province. Based on the PNG National census 2000 data, the size of this population was estimated to be 4946. Gathering information about people with disabilities who live in remote and isolated situations was one of the intentions of this study. The Middle Ramu area fulfils the 'remote and isolated' criteria. Villages visited belonged to the *Tok Ples* groups of the Rao, Aren, Mand and Kalam. The obvious difference between these *Tok Ples* groups is language, however there are also other economic and cultural differences (Kasprus 1973:15). Within the sub-district of Arabaka, some villages are located along the Ramu River, while others are up in the mountains. As well as cultural differences between particular *Tok Ples* groups, there are also distinct differences between river people and mountain people, although there is no clear divide. This study focused mostly on the river people, although the Kalam people do live in a broad area that stretches up into the more mountainous regions of the province.

Data was collected from villages belonging to a number of different *Tok Ples* groups in order to see if there were traditional beliefs relevant to remote populations in general, and beliefs perhaps specific to a particular *Tok Ples* group or context. The Rao in particular, living right on the Ramu River, have a very close relationship with the river, which permeates their belief system. They survive mostly on a diet of sago and fish, while the Aren and Kalam people living further away from the river grow a variety of garden foods including *kaukau* (sweet potato), taro and yams. Apart from linguistic related work, little has been written about these specific *Tok Ples* groups in recent times. For people along the river, first contact with Europeans could have been as early as 1896 when Lauterbach went on a scientific expedition to Annaberg (Kasprus 1973:7). The Catholic Mission then founded mission stations at both Atemble and Annaberg (both on the river) in 1933. Since then outside influences have continued to affect the lives of these people. Today the district administration is located at Aiome, within walking distance of many of the villages studied.

Since the introduction of boats with motorised engines, travel up and down the Ramu River is easier and many local people can visit Madang, the nearest big town. However, despite outside influences, elements of traditional Melanesian society are still largely preserved. The residence pattern of these people had particular implications for this research. People in the Middle Ramu tend to live in a number of smaller hamlets rather than big nucleated villages. However,

hamlets are not as small and dispersed as is typically seen in the highlands. Kasprus (1973:18), in his ethnography of the people of the Middle Ramu, described each hamlet as an autonomous unit, with various hamlets assuming more importance due to their population size, which could make them the centre for ritual performances, barter or marketing. For the purposes of this research, the bigger hamlets were referred to as villages and were identified as suitable meeting places by the local people. In total, 27 meetings were conducted to include people from 31 villages documented in the 2000 census.

Study design, survey instruments and methods

This research used both qualitative and quantitative methods and involved a questionnaire and semi-structured interviews with selected key informants. The questionnaire was used for the disability survey, to determine the prevalence of various types of disability in the targeted villages. Questionnaires/data entry sheets were only completed for individuals identified as 'disabled' following a two-phase screening process. For the qualitative component of the research, the 'disabled' population was sampled purposively, and key informants (disabled individuals and their families) were identified and co-opted into the study according to their willingness to participate. They were interviewed to gain information as to how disabled people explain and experience their disability, and to ascertain their needs. A day was spent in each village to collect the data required.

A team of two fieldworkers (diploma/degree graduates) were involved in collecting the data over a two month period from late February to April 2002, following three weeks of training in disability issues and research methods by the primary researcher. The primary researcher also accompanied the team initially in the field for a three-week period, until such time as the fieldworkers were confident to continue with data collection on their own. The fieldworkers (both men) worked together to collect the data wherever possible, and one of the fieldworkers was familiar with the area as he came from another sub-district of the Middle Ramu area. The second fieldworker was from a coastal area of Madang Province.

At an initial meeting in each village, the purpose of the survey was introduced in Melanesian Pidgin by the fieldworkers. This initial meeting was set up a day or two in advance to ensure maximum attendance. Prior to this the fieldworkers visited the councillors (who had been informed of the study earlier by letter) and the headman to gain their support. Once the villagers were familiar with the purpose of the study, they were then informed about the type of person targeted for second phase screening if they agreed to participate in the research. This formed the basis of the first phase screening which is described in greater detail below.

Durkin (2001) reviewed some of the work on the development of an instrument to acquire accurate information concerning the frequency of childhood disability in populations. She describes four methods that are frequently utilised: the use of administrative data and registries, the use of census data, the 'key informant' approach, and household surveys (Durkin 2001:2). In PNG the lack of information, registries, and census data make it impossible to use the first two approaches. The 'key informant' approach relies heavily on having suitable 'key informers' (teachers, health care workers etc), and has been shown to miss disabilities that are not publicly evident. Therefore, the 'household survey' approach was deemed most appropriate to establish the prevalence of disability in PNG.

As community is the predominant feature of a kinship society, the 'household' is not usually a discrete unit, and thus can not be viewed in the same way as a household in an industrial society. In the PNG context it is more appropriate and efficient to conduct a two-phase village survey, using a series of questions/statements initially to identify disabled individuals in the village and then to screen people to identify a range of disabilities.

The 'Ten Question screen for childhood disability' is one instrument that has been investigated extensively for its use in establishing the frequency of childhood disability (Durkin et al. 1994). This instrument has been used for the 2-9 year old age range and has shown to be more than 80% sensitive for most serious cognitive, motor and seizure disabilities, but less sensitive for vision and hearing disabilities. A low positive predictive value of less than 30% has indicated the need for second phase assessment (Durkin 2001:10). Therefore, this instrument had potential application for use in a two-phase survey such as this one conducted in the Middle Ramu. However, a number of factors made it impossible to apply accurately in the PNG context, not least the difficulty in trying to gauge the age of children who have no birth records.

If the Ten Question screen had been used in its pure form, the focus would have been on individual households rather than villages or hamlets. This focus is not appropriate in a kinship society and would have meant changing the village-orientated approach currently used by CBR workers in PNG. Although some elements of this instrument were applicable in the PNG context, it was not appropriate to apply it in its original form, not least because it only covers a narrow age range. One of the objectives of this research, as noted above, was to develop an appropriate method for CBR workers to use when undertaking village disability surveys. For a variety of reasons, including the inappropriateness of applying an instrument that has been developed and tested in other socio-cultural and economic contexts, the instrument was adapted to suit the context of this study. For this research the series of questions was

converted into a series of statements that described to the villagers the type of person we wanted to participate in the second-phase screening. The instrument was also adjusted to apply to the general population, rather than children of a specific age group (See Appendix 1).

The second-phase screening involved a series of basic screening tests currently taught to CBR workers in PNG, and documented by Werner (1984) in his manual for rehabilitation workers. All individuals who considered themselves to have a disability following the first phase screening were included in second phase screening, and once identified as 'disabled', a questionnaire was administered in order to complete the data entry sheet (See Appendix 2). Classification of impairments was according to selected domains from the level two classification of the ICF 'body functions and structures'. Due to the simplicity of the screening tests used, it was not possible to make a detailed diagnosis or grade the impairments. As such the only qualifiers used for these domains were 'NO impairment' or 'impairment'. More detailed qualification was not deemed appropriate for the purpose of CBR in PNG and did not fulfil any of the objectives of the research. In addition, it was unlikely that CBR workers would have the skills required to qualify domains more accurately or use level three classifications. Mild disabilities affecting mental functions sight and hearing were noted but not included in the study. For instance many people presented to the researchers with sight impairments requiring correction with spectacles, but the impairment did not limit their daily activities.

In addition to the disability survey data, other information obtained through the questionnaire was also recorded on the data entry sheet completed for each of the identified disabled individuals. This information included where the individual and/or their family had been to seek help for the disability and the perceived cause of the disability. As it is not possible to accurately determine that an impaired state of health is the result of a specific cause, the ICF takes a neutral stand with regard to aetiology. However, where it is possible to determine cause, this information can assist with the prevention of disabilities. In this research there were some instances where the biomedical cause seemed clear, for example when a disability was evident from birth or due to an accident. In such cases the cause of the disability was recorded. The fieldworkers through a series of questions determined biomedical causes, while the category of 'perceived cause' was used to record causes proposed by disabled individuals and their families.

Proxy reporting by family members was not accepted, as disabled individuals were unlikely to move far out of their villages and so were, in most cases, easy to access. Information from family members may not have been reliable. As the survey was only a pilot study and had limited scope, the method used was not comprehensively tested for reliability and validity.

Qualitative methods were used to look at 'activities and participation' and 'contextual factors', as described in Part II of the ICF, with a particular focus on cultural influences. Qualitative techniques were chosen in preference to the more quantitative approach demanded by the ICF, in order to gain a deeper understanding of the cultural influences involved. Semi-structured interviews were conducted with disabled individuals and their families to understand how they explained and experienced disability. In addition, interviewees were asked to describe their needs (See Appendix 3). Interviews with disabled individuals and their families were conducted in Melanesian Pidgin (*Tok Pisin*) in a quiet area away from the other villagers. To facilitate consistency in the way interviews were conducted, the interviewing method was practiced extensively prior to commencement of the study. The data itself was recorded on tape. The most relevant information for the purposes of this study was then isolated, transcribed and coded, both manually by the fieldworkers and by the primary researcher using NVivo. This allowed for coding categories to be compared, thus improving the reliability of data analysis. The quantitative data was analysed using EpiInfo 2000.

Results

1. Disability Prevalence

Twenty-seven villages belonging to the *Tok Ples* groups of Kalam, Aren, Mand and Rao were surveyed to determine the prevalence of disability. A total of 158 disabled individuals were registered (see Appendix 4), giving a prevalence rate of 3.2% across the population studied (based on data from the PNG National census 2000). Disability prevalence rates for individual villages ranged between 0.9-11.1%. (see Table 1.1)

TABLE 1.1 Prevalence of disability in the villages studied

Village number	Village name	*Tok Ples* group	Population size (2000 census)	Number of disabled individuals	Disability prevalence rate (%)
1	Animunk	Kalam	211	6	2.8
2	Anuemtz	Aren	124	2	1.6
3	Sisiat	Aren	62	1	1.6
4	Iporaitz	Aren	129	4	3.1
5	Kurakem	Aren	107	7	6.5
6	Iragarat	Aren	125	6	4.8
7	Ukurari	Aren	291	6	2.1
8	Dobrait	Aren	195	8	4.1
9	Atiapi	Aren	117	8	6.8
10	Apanam	Kalam	116	1	0.9
11	Atemble	Mand	315	9	2.9
12	Jitibu	Rao	226	11	4.9
13	Djam	Rao	344	3	0.9
14	Gragebu	Rao	113	2	1.8
15	Wukibu	Rao	176	3	1.7
16	Bangrobu	Rao	65	1	1.5
17	Sabu	Rao	108	4	3.7
18	Nodabu	Rao	622	25	4.0
19	Goribu	Rao	63	7	11.1
20	Paibu	Rao	106	9	8.5
21	Wrebu	Rao	271	6	2.2
22	Badobu	Rao	151	2	1.3
23	Moibu	Rao	203	2	1.0
24	Annaberg	Rao	33	2	6.1
25	Vimptobu	Rao	147	8	5.4
26	Watabu	Rao	345	9	2.6
27	Dibu	Rao	181	6	3.3
			4946	**158**	**3.2%**

3. Perceived cause of disability

Perceptions of the causes of disability were examined in two ways in this study. A few brief questions were asked of disabled individuals and their families by the fieldworkers to determine whether they had any definite ideas as to what had caused the disability in question. These responses were categorised and then registered on the data entry form (see Appendix 2). In addition, more detailed interviewing was conducted with selected informants who volunteered to participate (see Appendix 4 for details of selected informants).

From data collected for all cases of disability, 30% (N=48) of the disabled individuals and their families did not know what had caused the disability. In most of these cases the response was '*mi no save*' (I do not know). Sorcery and other supernatural causes accounted for a greater proportion than any other cause, with 32% (N=50) of disabled individuals and their families attributing disability to a cause in the social or supernatural world. 15% (N=23) believed they had been the victims of sorcery, while other supernatural causes including evil spirits and the spirits of deceased relatives accounted for 9% (N=14) and 3% (N=5) respectively. The violation of dietary or sexual taboos, usually punishable through sorcery or spirits, was thought to be responsible in 5% (N=8) of cases. Of the remainder, 15% (N=24) believed the disability was due to a natural cause, while 13% (N=20) reported suffering some type of trauma or accident. The remaining 10% (N=16) of perceived causes did not fit into the categories listed above. (see Figure 3.1) Of the 'other' perceived causes of disability (N=16), 19% (N=3) thought that the disability resulted from smoking marijuana. In all these cases the disability affected global mental functions. Other perceived causes occurring less frequently included: disobedience of a child to a relative, unsettled arguments between family members, anxiety/depression due to a marriage problem, problems in the exchange of clan rights, and the mishandling of ritual practices.

Discussion

Disability prevalence rates

Disability prevalence studies use a wide range of indicators and as these are often specific to a certain age category, international comparisons are difficult. Barbotte et al. (2001:1047) conducted bibliographic research to determine the prevalence rates of morbidity in the general population. Using the WHO (1980) classification of 'impairment, disability and handicap', 20 articles where reviewed and prevalence rates of 0.1-92%, 3.6-66% and 0.6-56% respectively were obtained. Barbotte et al. (ibid) identified various factors to account for the wide range of prevalence rates. For example, as impairment indicators become more general and the age of the study population becomes older, prevalence rates increase. However, where a survey covers a larger geographical area, rates are generally lower. This research also noted that rates vary according to the socio-economic status of the study population and the cultural perceptions of disability.

Considering the factors identified in the review that influence disability prevalence rates, the prevalence of disability in the Middle Ramu identified in this study may be underestimated. Even though the relatively small geographic area facilitated data collection, assessment of the indicators was crude as the study was designed to use assessment methods appropriate for CBR workers rather than more highly skilled professionals. Fieldworkers did not have the means to evaluate the degree of impairment in cases of mild disabilities. In addition, the low socio-economic status of the study area meant that people had limited resources to access assistance for their disabilities and thus accepted disability as part of life. This may have affected the number of individuals presenting for second phase screening.

Other factors also affected the identification of disabled individuals in the area. For example, many people live out of the main villages in smaller bush hamlets that are difficult to access, which meant that some people did not hear about our meetings and fieldworkers were unable to visit all the smaller hamlets. The population is mobile and people frequently travel considerable distances out of the hamlets to go to their gardens or to other villages and thus may have been absent when the research was being undertaken. In some instances people were reluctant to come for screening due to their past negative experiences with programmes in the area.

The Ten Questions Screen in the PNG context

The Ten Questions screen, used in an adapted form for this research, has been extensively evaluated as an instrument for two-phase screening of childhood disability[3]. Surveys using this instrument in Bangladesh, Jamaica and Pakistan have generated prevalence estimates of up to 20% for mild disabilities and 1-4.4% for severe disabilities (Durkin 2001:4). As skilled professionals (doctor and psychologist) were involved in the second phase screenings, they were able to identify children with mild disabilities.

Although there has been minimal research in PNG to determine the number of disabled people and the nature of their disabilities it is useful to examine the findings of this research. One study in the Southern Highlands calculated a prevalence level of physical disability (encompassing walking disability, deafness and blindness) of 0.46% (Van Amstel et al. 1993:317). The researchers attributed the low prevalence rate to the use of a crude definition of disability. Another study, in East New Britain, found an overall disability prevalence of 0.65%, with figures ranging between 0.06% to 1.59% in different areas (Hamilton and van Zwarenberg 1988:166). The researchers in this study identified a number of factors, including under referral and poor access to services, which contributed to the wide range of prevalence rates. A third study was done in the Western Highlands (Sullivan et al. 1992) to determine the numbers of disabled individuals residing within 15km of Mt Hagen. However, this study used only reporting and no population figures were given to calculate prevalence rates. Lastly, Colody and Griew (1982) also piloted a questionnaire to identify major disability in PNG using non-medical interviewers, but details of this study could not be obtained for discussion in this research.

As noted previously, comparing disability prevalence studies is difficult because of the variety of methods used and the diversity of contexts. However, the method used in this study to identify disabled individuals appears to be more sensitive than other methods used previously in PNG. The disability prevalence figure of 3.2% obtained for more severe disabilities is not out of the range expected. The variation in prevalence rates for individual villages could be attributed to many factors including the mobility of the population, people's willingness to participate in this study, naturally occurring disease patterns, and inconsistencies with the census data.

[3] See Zaman et al. (1990), Thomburn et al. (1992), Durkin et al. (1995), Durkin et al. (1994)

Causes of disability and opportunities for prevention

Wherever possible in this study, an attempt was made to identify a biomedical cause for each disability through a series of questions asked by the fieldworkers to disabled individuals and their families. This information is important for planning strategies to prevent disability. Without an understanding of both biomedical and other perceived causes and how these interact with each other, disability prevention strategies are unlikely to succeed. A large proportion of disabilities resulted from trauma or accidents, and this finding could be targeted in village prevention strategies. In this study, it might appear surprising that disabilities affecting only global mental functions were not attributed to trauma or accidents. However as most head injuries tend to be quite severe they are likely to be associated with movement problems as well.

The high proportion of hearing disabilities caused by illness or infection also warrants attention when considering initiatives for prevention. Van Amstel et al. (1993:319) noted from their study in the Southern Highlands of PNG, that untreated or poorly treated otitis media was causing most of the deafness in young people. Hamilton and Van Zwanenberg (1988:167) also commented on the high prevalence of severe hearing impairment, possibly occurring for the same reason. A culturally sensitive strategy to educate CBR workers, health workers, teachers and the population at large on how to avoid and treat otitis media could lower the prevalence of hearing disabilities.

Cultural considerations

In any culture, how someone explains disease and ill health is informed by their own experiences of the world, as well as how the society in which they live understands and describes disease and ill health. Kleinman et al. (1978:256) use an 'explanatory model' to describe the meaning that people give to their illnesses. This model takes account of personality and cultural factors, and is deeply embedded in a specific context. The explanatory model can be likened to a story that people create to provide explanations for the cause of illness, onset of symptoms, pathophysiological processes, the course of the illness, and treatment. This story helps to 'explain, organise and manage particular episodes of impaired well-being' (Helman 1995:95). Disabled individuals and their families also construct a story to give meaning to their disability, and this story influences the rehabilitation process and guides the interaction between the patient, their family, the rehabilitation worker and broader society.

Certain culturally dependent aspects of a disability explanatory model have an especially strong influence on decision-making and behaviour. Groce and Zola (1993:1049) identified three aspects that appeared consistently in cross-cultural studies. The culturally perceived cause of a disability may determine family and community attitudes towards disabled individuals. These attitudes in turn operate to define participation restrictions placed on these individuals. For example a young child whose disability is attributed to past deeds of the family may experience limited options in life, both socially and/or economically, because of the actual disability as well as the perceived cause. Moreover the parents are also likely to suffer as they are blamed for the disability.

Other aspects identified by Groce and Zola (1993:1049) that influence the lives of disabled individuals include expectations for their survival that affects long-term planning and has implications for the allocation of scarce resources. For example where parents cannot afford to send all their children to school they are unlikely to send a disabled child which further exacerbates the impact of the disability for that child. Groce and Zola (1993) concluded that society dictates the social role(s) deemed appropriate for a disabled person, and in some instances this may be limited.

Reynolds Whyte and Ingstad (1998:43) also acknowledge the impact of cultural perceptions of disability. They suggest that, in any context, identification of the cause of an impaired state of well being will determine the appropriate course of action. For example when people attribute ill health or disability to social or moral problems the affected individual might seek symptomatic relief from external health services but will probably be more committed to follow treatment and advice from people within the community. The perceived causes of disability influences help seeking behaviour and rehabilitation.

To date there have not been any studies that have successfully examined culturally perceived causes of disability in PNG or the affect that these perceptions have on the lives of disabled individuals. However, aetiological categories of disease in general have been examined in a number of societies in PNG[4]. Stanhope (1968), in particular, describes categories used by the Rao-Breri people, who live in an area overlapping the site for this research.

[4] See Feinberg (1990) on Nukumanu, Lepowsky (1990) on Vanatinai, Stanhope (1968) in the Middle Ramu, Allen (1989) in the Torricelli foothills, Barker (1989) in Collingwood Bay, Hamnett & Connell (1981) in the North Solomons, Herdt (1989) among the Sambia in Eastern Highlands Province, Strathern (1989) in Mt Hagen, Carrier (1989) on Ponam Island, Jenkins (1989) among the Amele in Madang Province, Roscoe (1989) among the Boiken in the East Sepik Province, Chowning (1989) in Kove, Counts & Counts (1989) among the Lusi in West New Britain, Lipuma (1989) among the Maring in the Western Highlands Province, Lewis (1975) among the Gnau in the Sepik

illegitimate disabled child felt ashamed and this limited her social relationships and her participation in community life.

Even though the social roles deemed appropriate for disabled individuals in the Middle Ramu were generally not found to be limited, there were recorded instances of limited participation. In these instances, limited participation was due to a lack of information and understanding about the disability in question. As stated previously, in one example one of the reasons that a young man with epilepsy felt that he should not get married was in case he would die and leave his wife on her own. This was despite the fact that he did not actually experience any epileptic attacks while on medication. Through education it is possible that this young man could develop a better understanding of his condition, which would give him the confidence to live a normal life in the village. The provision of information is an area that needs to be addressed through CBR. New information, if presented in a culturally sensitive way has the potential to work alongside traditional beliefs to enhance the quality of life of disabled individuals. Many of the disabled individuals and some of the caregivers experienced anxiety associated with their particular disability, especially concerning the prognosis and uncertainties of how to deal with the problem. Here too, a lack of knowledge could have been a contributing factor. Thus the provision of information may work to alleviate anxiety.

The potential role of CBR in the Middle Ramu

Previously, the observation that disabled people in PNG are otherwise physically well rehabilitated led Van Amstel et al (1993) to the assumption that CBR is unnecessary. This suggests that these researchers had a very narrow definition of rehabilitation, and a poor understanding of the fundamental concepts of CBR. Mitchell describes the main goal of a CBR program as the optimisation of the functional and social abilities of disabled individuals (1999:465). This goal can be accomplished through a variety of approaches, depending on the context. For example, some CBR projects in PNG are now targeting the link between poverty and disability in their efforts to improve the economic situation of families supporting disabled individuals. The issue of poverty has the potential to intensify as the cash economy penetrates into the more rural areas and people can no longer rely purely on subsistence activities. Many of the disabled individuals interviewed in this study expressed financial concerns. The only other work investigating the potential role of CBR in PNG was done by Sullivan (1992), but unfortunately could not be sighted for discussion in this research.

Menon (1984:64) identified a number of aspects in his review of the 'essence' of CBR, all of which have potential application in the Middle Ramu: an emphasis on prevention, early access

to the disabled in their own communities, utilisation of non-specialised personnel within the community, and the use of low-cost aids. In this study in the Middle Ramu, significant scope has been acknowledged for the prevention of disabilities. In addition, there are clear opportunities for developing people's skills in constructing low technology, low-cost, appropriate aids. In many instances disabled individuals and their families expressed a need for a mobility aid, yet little evidence was found to suggest that communities had made an atternpt to construct these themselves. It appears that currently disabled individuals are reliant on obtaining mobility aids from the Health Centre or Provincial Hospital. It would be more sustainable and empowering if the community could be assisted through CBR to use locally available materials to design and make their own aids. Aids produced in this way will be also be more appropriate. Another target area identified for CBR in the Middle Ramu is the social support systems available to caregivers of disabled children. Communities could be facilitated to support caregivers in their efforts to look after their disabled children and accomplish daily tasks.

The provision of accurate information concerning disability also allows and empowers disabled individuals and their families to make informed decisions about their situation. This may reduce anxiety and increase participation. The most effective and appropriate way of disseminating this information to local communities would be via people within the community who have received some training. If CBR programs are truly community driven, then traditional coping mechanisms can be used as building blocks, and additional knowledge has a better chance of being incorporated into traditional belief systems. In this way there is a two-way knowledge transfer, where the rehabilitation worker and the community can learn from each other and work together to achieve their goals.

References

Ahai, N. 1993. *An evaluation of the Western Highlands Association for the Disabled Programme.* National Research Institute.

Allen, B. J. 1989. "Infection, innovation and residence: illness and misfortune in the Torricelli foothills from 1800," in *A continuing trial of treatment.* Edited by S. Frankel and G. Lewis, pp. 35-68. Dordrecht: Kluwer Acedemic Publishers.

Banja, J. D. 1996. Ethics, values and world culture: the impact on rehabilitation. *Disability and Rehabilitation* 18:279-284.

Barbotte, E., F. Guillemin, N. Chau, and Lorhandicap Group. 2001. Prevalence of impairments, disabilities, handicaps and quality of life in the general population: a review of recent literature. *Bulletin of the World Health Organisation* 79:1047-1055.

Barker, J. 1989. "Western medicine and the continuity of belief: the Maisin of Collingwood Bay, Oro Province," in *A continuing trial of treatment.* Edited by S. Frankel and G. Lewis, pp. 69-94. Dordrecht: Kluwer Acedemic Publishers.

Bowe, F. G. 1990. Disabled and elderly people in the First, Second and Third Worlds. *International Journal of Rehabilitation Research* 13:1-14.

Byford, J. 1999. Dealing with death, beginning with birth: women's health and childbirth on Misima Island, Papua New Guinea. PhD thesis, Australian National University.

Carrier, A. H. 1989. "The place of Western medicine in Ponam theories of health and illness," in *A continuing trial of treatment.* Edited by S. Frankel and G. Lewis, pp. 155-180. Dordrecht: Kluwer Academic Publishers.

Chermak, G. D. 1990. A global perspective on disability: a review of efforts to increase access and advance social integration for disabled persons. *International Disability Studies* 12:124-127.

Chowning, A. 1989. "The doctor and the curer: medical theory and practice in Kove," in *A continuing trial of treatment.* Edited by S. Frankel and G. Lewis, pp. 217-248. Dordrecht: Kluwer Academic Publishers.

Colody, D., and A. Griew. 1982. Surveying for disability in the developing world: suggestions for a methodology. *International Journal of Rehabilitation Research* 5:317-324.

Counts, D. R., and D. A. Counts. 1989. "Complementarity in medical treatment in a West New Britain society," in *A continuing trial of treatment.* Edited by S. Frankel and G. Lewis, pp. 277-294. Dordrecht: Kluwer Academic Publishers.

Criswell, J. H. 1968. Anthropology and rehabilitation. *Rehabilitation Record* 9:6-8.

D'Arcy, R. 1973. "Marriage," in *Anthropology in Papua New Guinea.* Edited by I. Hogbin. Melbourne: Melbourne University Press.

de Lepervanche, M. 1973. "Social structure," in *Anthropology in Papua New Guinea*. Edited by I. Hogbin. Melbourne: Melbourne University Press.

DFID. 2000. *Disability, poverty and development*. DFID.

Durkin, M. 2001. "Measurement of childhood disabilities in population studies." *International Seminar on the Measurement of Disability, New York, 2001.*

Durkin, M. S., L. L. Davidson, P. Desai, Z. M. Hasan, N. Khan, M. J. Thornburn, P. E. Shrout, and W. Wang. 1994. Validity of the ten questions screen for childhood disability: results from population-based studies in Bangladesh, Jamaica and Pakistan. *Epidemiology* 5:283-289.

Durkin, M. S., W. Wang, P. E. Shrout, S. S. Zaman, Z. M. Hasan, P. Desai, and L. L. Davidson. 1995. Evaluating a Ten Questions screen for childhood disabilities: reliability and internal structure in different cultures. *Journal of Clinical Epidemiology* 48:657-666.

Feinberg, R. 1990. Spiritual and natural etiologies on a Polynesian Outlier in Papua New Guinea. *Social Science and Medicine* 30:311-323.

Glick, L. B. 1973. "Sorcery and witchcraft," in *Anthropology in Papua New Guinea*. Edited by I. Hogbin. Melbourne: Melbourne University Press.

Groce, N. E., and I. K. Zola. 1993. Multiculturalism, chronic illness, and disability. *Pediatrics* 91:1048-1055.

Hamilton, J., and T. D. van Zwarenberg. 1988. Three year's experience of the East New Britain Project for the Disabled. *PNG Medical Journal* 31:163-167.

Harnnett, M., and J. Connell. 1981. Diagnosis and cure: The resort to traditional and modern practitioners in the North Solomons, Papua New Guinea. *Social Science and Medicine* 15B:489-498.

Helman, C. G. 1995. *Culture, health and illness*, 3rd edition. Oxford: Oxford University Press.

Herdt, G. H. 1989. "Doktas and shamans among the Sambia of Papua New Guinea," in *A continuing trial of treatment*. Edited by S. Frankel and G. Lewis, pp. 95-114. Dordrecht: Kluwer Academic Publishers.

Hershenson, D. B. 2000. Toward a cultural anthropology of disability and rehabilitation. *Rehabilitation Counselling Bulletin* 43:150-157.

Jenkins, C. 1989. "The Amele and Dr Braun: a history of early experience with Western medicine in Papua New Guinea," in *A continuing trial of treatment*. Edited by S. Frankel and G. Lewis, pp. 181-198. Dordrecht: Kluwer Academic Publishers.

Kasprus, A. 1973. *The tribes of the middle Ramu and upper Keram rivers*. Bonn: Studia Instituti.

Kleinman, A., L. Eisenberg, and B. Good. 1978. Culture, illness and care: clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine* 88:251-258.

Lepowsky, M. 1990. Sorcery and penicillin: treating illness on a Papua New Guinea island. *Social Science and Medicine* 30:1049-1063.

Lewis, G. 1975. *Knowledge of illness in a Sepik society: a study of the Gnau, New Guinea*. Vol. 52. *Monographs on Social Anthropology*. London: The Athlone Press.

Lipscomb, A., R. McKinnon, and J. Murray. 1998. *Papua New Guinea*. Hawthorn: Lonely Planet.

Lipuma, E. 1989. "Modernity and medicine among the Maring," in *A continuing trial of treatment*. Edited by S. Frankel and G. Lewis, pp. 295-310. Dordrecht: Kluwer Academic Publishers.

Mayer, J. R. 1982. Body, psyche and society: conceptions of illness in Ommura, Eastern Highlands, Papua New Guinea. *Oceania* 52:240-260.

McDowell, N. 1988. "Reproductive decision making and the value of children in Papua New Guinea," in *Reproductive decision making and the value of children in Papua New Guinea.* Edited by N. McDowell. Port Moresby: Institute of Applied Social and Economic Research.

Menon, P. B. 1984. Developing community-based rehabilitation services for the disabled by the primary health care approach. *International Rehabilitation Medicine* 6:64-66.

Miles, M. 1996. Community, individual or information development? Dilemmas of concept and culture in South Asian disability planning. *Disability and Society* 11: 485-500.

Miles, S. 1999. *Strengthening disability and development work*. BOND Discussion paper.

Mitchell, R. 1999. The research base of community-based rehabilitation. *Disability and Rehabilitation* 21:459-468.

PNG Ministry of Health. 2000. *National Health Plan 2001-2010: program policies and strategies* Vol II.

Pulsford, R. L., and J. Cawte. 1972. *Health in a developing country: principles of medical anthropology in Melanesia*. Port Moresby: The Jacaranda Press.

Reynolds Whyte, S., and B. Ingstad. 1998. Help for people with disabilities: do cultural differences matter? *World Health Forum* 19:42-46.

Ring, A., and R. Scragg. 1973. A demographic and social study of fertility in rural New Guinea. *Journal of Biosocial Science* 5:89-121.

Roscoe, P. 1989. "Medical pluralism among the Yangoru Boiken," in *A continuing trial of treatment*. Edited by S. Frankel and G. Lewis, pp. 199-216. Dordrecht: Kluwer Academic Publishers.

Sahlins, M. D. 1970. "Poor man, rich man, big man, chief: political types in Melanesia and Polynesia," in *Cultures of the Pacific*. Edited by T. G. Harding and B. J. Wallace. New York: The Free Press.

Scheer, J., and N. Groce. 1988. Impairment as a human constant: cross-cultural and historical perspectives on variation. *Journal of Social Issues* 44:23-37.

Stanhope, J. M. 1968. Competing systems of medicine among the Rao-Breri, lower Ramu River, New Guinea. *Oceania* 39:137-145.

Stone, L. 1992. Cultural influences in community participation in health. *Social Science and Medicine* 35:409-417.

Strathern, A. 1989. "Health care and medical pluralism: cases from Mt Hagen," in *A continuing trial of treatment.* Edited by S. Frankel and G. Lewis, pp. 141-154. Dordrecht: Kluwer Academic Publishers.

Sullivan, W.C. 1992. Community-based rehabilitation in Papua New Guinea. *Journal of Visual Impairment and Blindness* 86:375-376.

Sullivan, W.C., J. Wanis and M. Carey. 1992. Disability in Western Highlands Province. *PNG Medical Journal* 35:121-123.

Thornburn, M. J., P. Desai, T. Paul, L. Malcolm, M. S. Durkin, and L. L. Davidson. 1992. Identification of childhood disability in Jamaica: evaluation of the Ten Question screen. *International Journal of Rehabilitation Research* 15:262-270.

United Nations. 1983. *World Programme of Action Concerning Disabled Persons.* United Nations.

Van Amstel, H., T. Dyke, and J. Crocker. 1993. Would people in the highlands benefit from a community-based rehabilitation program? *PNG Medical Journal* 36:316-319.

Werner, D. 1984. *Disabled Village Children: A guide for community health workers, rehabilitation workers, and families*: The Hesperian Foundation.

Whiteman, D. 1983. *Melanesians and missionaries: an ethnohistorical study of social and religious change in the southwest Pacific.* Pasodena: William Carey Library.

Whiteman, D. 1984. "Melanesia: its people and cultures," in *An introduction to Melanesian cultures: a handbook for church workers.* Edited by D. Whiteman. Goroka: The Melanesian Institute.

World Health Organisation. 1988. *Report: regional working group on applied research on community based rehabilitation.* Regional office for the Western Pacific of the World Health Organisation.

World Health Organisation. 1980. *World Health Organisation International Classification of Impairments, Disabilities and Handicaps: a manual of classification relating to the consequences of disease.* Geneva: World Health Organisation.

World Health Organisation. 1995. *Disability prevention and rehabilitation in primary health care: a guide for district health and rehabilitation managers.* Geneva: World Health Organisation.

World Health Organisation. 2001. *ICF - International classification of functioning, disability and health*. Geneva: World Health Organisation.

Zaman, S., N. Khan, S. Islam, S. Banu, S. Dixit, P. Shrout, and M. Durkin. 1990. Validity of the Ten Questions for screening serious childhood disability: results from urban Bangladesh. *International Journal of Epidemiology* 19:613-620.

Appedndix 1: First phase screening information for villagers

We are coming around to see the following children and adults:
Dispela grup mipela kam raun long luksave long ol pikinini na bikmanmeri:

1. Anyone who has a problem with his/her ears or a problem with hearing
1. *husait igat problem/baggarap long eau long harim samting*

2. Anyone who has a problem with his/her eyes or a problem seeing
2. *husait igat problem/baggarap long eye long lukim ol samting*

3. Anyone who has a problem walking or moving his/her arms or legs, or has tightness or stiffness
3. *husait igat problem/baggarap long wokabaut or movim lekhan na tu pasin bilong lekhan isave tait na indai nating*

4. Anyone who does not seem to understand what you say to them
4. *husait ino klia long wanem toktok yu tokim ol long mekim*

5. Anyone who does not speak well or is hard to understand
5. *husait ino save toktok gut o traim hard long mekim ol yet klia long narapela*

6. Anyone who does not seem to think the same as other people their age or seems mentally slow
6. *husait we pasin bilong ol ino wankain olsem ol lain krismas bilong ol i wankain*

7. All children who have not yet learnt to sit, stand or walk at the same time as other children
7. *ol pikinini we ol ino lainim ol yet long sindaun, sanap na wokabaut hariap olsem ol narapela pikinini*

8. All children who have difficulty learning to do things compared to other children their age
8. *O ol pikinini husait ino lainim samting wankain long krismas ol kamap long en*

Appendix 2 MIDDLE RAMU DISABILITY SURVEY - DATA ENTRY FORM

Record number: ☐☐☐☐ Village: ☐☐ (Code number)

Age of individual: ☐☐ (Years) Sex of individual: ☐ (M=male) F=female)

(may have to be estimated)

Was this individual/their caregiver interviewed? ☐ (Y/N)

Body functions:

Code: 0 = NO impairment 1 = impairment

b139 ☐ **Global mental functions, other specified and unspecified**

b229 ☐ **Seeing and related functions, other specified and unspecified**

b249 ☐ **Hearing and vestibular functions, other specified and unspecified**

b799 ☐ **Neuromusculoskeletal and movement-related functions, unspecified**
(any problems with movement)

Does this person have multiple disabilities? ☐ (Y/N)

Noted cause (if known or documented in clinic book): (Mark only one box "Y")

Qu: Dispela ibin kamap taim em bon or ikamap bihain? Na ikamap olsem wanem stret?

Congenital	☐ (Y/N)	Trauma/accident	☐ (Y/N)
Illness/infection	☐ (Y/N)	Not evident	☐ (Y/N)

Perceived cause of disability: (mark only one box "Y")

Qu: As bilong dispela sik em wanem?

Natural cause	☐ (Y/N)	Sorcery/witchcraft	☐ (Y/N)
Trauma/accident	☐ (Y/N)	Evil spirits/masalai	☐ (Y/N)
Disobeying dietary/sexual taboos	☐ (Y/N)	Not evident	☐ (Y/N)
Other	☐ (Y/N)	Please note:	

Help seeking:

Qu: Yupela bin go long sampela hap long painim halivim tu? Yupela famili yet ibin bung na traim stretim? Yupela lukluk long sait long ples? Yupela go long hausik tu? Yupela bin go lukim sampela pater/pastor?

Has help ever been sought for this disability? ☐ (Y/N)

Source :	Family meeting	☐ (Y/N)	Traditional healing	☐ (Y/N)
Government/church medical services		☐ (Y/N)	Spiritual healing	☐ (Y/N)

Appendix 3: Interview questions for interviews with disabled individuals (no family members present)

1. All disability has a cause. You must have some idea of what caused this disability. Please could you tell us what you feel has caused this disability.

1. Olgeta (sik) igat as. Yu yet mas igat sampela tingting long as bilong dispela _____(hevi/problem/sik). Inap long yu stori liklik long as bilong _____(sik) or ol tingting bilong yu long dispela _____(sik).

- Why do you think you acquired this disability?
- *Bilong wanem na yu ting yu kisim dispela _____ (nem bilong sik)?*
- How did this disability start?
- *Dispela _____(sik) bin kamap long yu olsem wanem?*

2. How do you experience life in your village?

2. Nau sindaun bilong yu i olsem wanem insait long ples?

- How do other people in the village treat your disability?
- *Manmeri long ples luksave long _____(sik) bilong yu olsem wanem?*
- How do the children in the village treat your disability?
- *Ol pikinini luksave long _____(sik) bilong yu olsem wanem?*
- How do you feel about living with this disability?
- *Long istap wantaim dispela _____(sik), yu pilim olsem wanem?*
- Do you feel as much a part of this village as your brothers and sisters?
- *Yu pilim olsem yu bilong dispela ples olsem narapela brata susa long hia?*

3. Do you take part in all village activities? Or do you miss out on some?

3. Yu save wok bung or stap namel long ol samting or pasin ikamap long ples? Or ol no save kisim yu?

- What sort of work do you do around the village, and what don't you do?
- *Wanem kain ol wok yu ken wokim, na wanem kain ol wok yu pilim yu no nap wokim long ples?*
- If you do feel able to do something, why is that?
- *Sapos yu pilim olsem yu no nap wokim wanpela wok long ples, blong wanem yu no nap mekim? Wanem samting i pasim yu? (olsem ol pasin bilong ples)*
- Do you feel that you can marry and have a family?
- *Yu pilim olsem yu inap marit na kamapim famili?*
- Do you feel that you had/have a chance to go to school like the other children?
- *Yu pilim olsem yu gat sampela sans long go long skul?*
- Do you join in with all church activities, or not?
- *Yu save wok bung wantain sait bilong lotu tu, o nogat?*
- Do you join in with all other activities in the village eg. community work, celebrations etc?
- *Yu save wok bung wantaim ol lain long ples tu? (community work, singsing, etc)*

4. How do you see your future in the village? What do you think will affect this?

4. Yu ting sindaun bilong yu bai kamap gut? Sapos orait o nogat, em bai olsem wanem?

- What do think will help you to have more chances in life?
- *Yu pilim wanem samting stret bai senisim yu long kisim o usim ol dispela sans?*

Interview questions for interview with family/caregiver of disabled individual (if adult, disabled individual should not be present)

1. All disability has a cause. You must have some idea of what caused this disability. Please could you tell us what you feel has caused this disability.
1. Olgeta (sik) igat as. Yu yet mas igat sampela tingting long as bilong dispela _____(hevi/problem/sik). Inap long yu stori liklik long as bilong _____(sik) or ol tingting bilong yu long dispela _____(sik).

- What do you think is the real cause of this disability?
- *Yu ting (why) wanem as na _____(sikman) ikisim dispela _____(sik) (tok stret)?*
- How do you think that your relative acquired this disability?
- *Hau na _____(sikman) ikisim dispela _____(sik)?*

2. How do you feel about having a disabled family member?
2. Yu (yupela) save pilim olsem wanem stret long dispela disabol famili memba?

- How do the other villagers behave towards you?
- *Ol lain long ples save wokim wanem kain pasin long yu(pela)?*
- How do you feel and what is it like, when your disabled relative stays with you?
- *Wanem kain filing or sindaun yupela igat, taim dispela kain sikman istap wantaim yupela (nem stret bilong sikman)?*

3. Do you think your disabled relative is able to participate in everything in the village?
3. Yu ting _____(nem bilong sikman) inap long stap insait long olgeta samting ikamap long ples?

- What activities does your relative participate in, and what doesn't he/she do?
- *Wanem ol samting _____(sikman) inap wokim or stap insait, na wanem ol samting em ino inap?*
- What do you think prevents your disabled relative from participating in everything?
- *Yu ting wanem samting istopim em long wokim or stap insait long ol samting ikamap long ples?*

4. Do you think there is some way that your task as caregiver can be made more easy for you?
4. Yu olsem wasman bilong _____(disabel sikman), yu ting igat sampela wei, we iken mekim sindaun or laip bilong yu i isi?

- Do you think there is anything that can help you to care for your disabled relative?
- *Yu ting wanem samting iken halpim or mekim isi long yu long lukautim disabel famili memba bilong yu?*

Appendix 4: Complete data set

Note: Highlighted records indicate those disabled individuals/their families who were interviewed.

ID	Village	Age	Sex	Interview	Type of disability	Noted cause	Perceived cause	Help seeking	Source of help
1	1	38	Male	No	b249	Trauma/ accident	Trauma/ accident	No	
2	1	28	Male	No	b229	Other/ not evident	Evil spirits/ masalai	Yes	Medical services/ Spiritual healing
3	1	22	Female	No	b249	Illness/ infection	Spirits deceased relatives	No	
4	1	1	Male	Yes	b799	Congenital	Spirits deceased relatives	Yes	Medical services
5	1	23	Female	No	b229	Congenital	Natural cause	No	
6	1	6	Female	No	b139	Illness/ infection	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Traditional healing
7	2	11	Female	No	b139	Other/ not evident	Other	Yes	Family meeting
8	2	9	Female	No	b139	Illness/ infection	Natural cause	No	
9	3	45	Female	No	b139	Other/ not evident	Not evident	Yes	Spiritual healing
10	4	9	Female	No	b139	Illness/ infection	Evil spirits/ masalai	Yes	Medical services/ Traditional healing/ Spiritual healing
11	4	29	Male	No	b799	Congenital	Not evident	Yes	Medical services/ Traditional healing
12	4	27	Male	No	b139/ b249	Congenital	Not evident	No	
13	4	25	Male	No	b139	Other/ not evident	Other	No	
14	5	16	Male	No	b249	Illness/infection	Natural cause	Yes	Family meeting/ Traditional healing
15	5	9	Female	No	b139	Congenital	Not evident	No	
16	5	4	Female	No	b139	Congenital	Not evident	No	
17	5	25	Male	No	b139	Other/ not evident	Other	Yes	Medical services
18	5	28	Male	No	b139	Other/ not evident	Sorcery/ witchcraft	No	
19	5	15	Female	No	b249	Congenital	Not evident	No	
20	5	61	Male	Yes	b799	Other/ not evident	Sorcery/ witchcraft	Yes	Medical services
21	6	12	Female	No	b799	Illness/ infection	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Traditional healing/ Spiritual healing
22	6	26	Male	No	b249	Trauma/ accident	Trauma/ accident	Yes	Medical services
23	6	65	Male	No	b799	Other/ not evident	Not evident	Yes	Medical services Spiritual healing
24	6	26	Female	No	b139	Congenital	Evil spirits/ masalai	No	

25	6	34	Female	No	b249	Other/ not evident	Other	No	
26	6	1	Female	No	b139/ b249/ b799	Illness/ infection	Natural cause	Yes	Family meeting/ Medical services
27	7	65	Male	No	b229	Other/ not evident	Sorcery/ witchcraft	Yes	Family meeting/ Traditional healing/ Spiritual healing
28	7	16	Male	Yes	b139	Illness/ infection	Not evident	Yes	Medical services
29	7	20	Female	No	b139	Congenital	Evil spirits/ masalai	Yes	Medical services/ Spiritual healing
30	7	65	Female	No	b799	Illness/ infection	Trauma/ accident	Yes	Medical services
31	7	39	Female	No	b249	Illness/ infection	Natural cause	No	
32	7	62	Male	No	b249	Other/ not evident	Spirits deceased relatives	No	
33	8	7	Male	No	b249	Congenital	Not evident	No	
34	8	63	Male	No	b229/ b799	Other/ not evident	Not evident	No	
35	8	28	Male	No	b799	Other/ not evident	Not evident	No	
36	8	47	Male	Yes	b799	Illness/ infection	Natural cause	Yes	Medical serices/ Spiritual healing
37	8	17	Male	No	b249	Illness/ infection	Natural cause	Yes	Medical services
38	8	79	Male	No	b229	Other/ not evident	Natural cause	No	
39	8	39	Male	Yes	b799	Other/ not evident	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Spiritual healing
40	8	2	Male	No	b249	Congenital	Not evident	No	
41	9	9	Male	No	b139/ b249	Other/ not evident	Not evident	Yes	Medical services
42	9	20	Male	No	b249	Illness/ infection	Not evident	No	
43	9	38	Female	No	b249	Illness/ infection	Not evident	Yes	Medical services/ Traditional healing/ Spiritual healing
44	9	6	Female	No	b249	Illness/ infection	Natural cause	No	
45	9	50	Male	No	b799	Other/ not evident	Sorcery/ witchcraft	Yes	Medical services/ Traditional healing/ Spiritual healing
46	9	65	Male	No	b229/ b799	Other/ not evident	Sorcery/ witchcraft	Yes	Medical services
47	9	35	Male	No	b799	Trauma/ accident	Trauma/ accident	Yes	Medical services/ Spiritual healing
48	9	35	Female	Yes	b139/ b249	Other/ not evident	Other	Yes	Medical services/ Traditional healing/ Spiritual healing
49	10	5	Male	No	b229/ b249	Congenital	Evil spirits/ masalai	Yes	Medical services/ Traditional healing/ Spiritual healing
50	11	28	Female	No	b799	Other/ not evident	Sorcery/ witchcraft	Yes	Family meeting/ Medical services
51	11	7	Male	No	b249	Trauma/ accident	Trauma/ accident	No	

52	11	3	Female	No	b139	Congenital	Natural cause	No	
53	11	32	Male	No	b249	Illness/ infection	Trauma/ accident	Yes	Spiritual healing
54	11	57	Male	No	b249	Trauma/ accident	Evil spirits/ masalai	Yes	Medical services/ Traditional healing/ Spiritual healing
55	11	80	Male	Yes	b799	Illness/ infection	Sorcery/ witchcraft	Yes	Medical services/ Spiritual healing
56	11	37	Female	No	b139	Other/ not evident	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Traditional healing
57	11	35	Male	No	b799	Illness/ infection	Natural cause	Yes	Family meeting/ Medical services/ Spiritual healing
58	11	28	Female	No	b799	Illness/ infection	Natural cause	Yes	Medical services
59	12	47	Female	No	b229	Trauma/ accident	Trauma/ accident	No	
60	12	68	Female	No	b799	Illness/ infection	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Traditional healing
61	12	25	Male	No	b799	Illness/ infection	Spirits deceased relatives	Yes	Family meeting/ Medical services/ Spiritual healing
62	12	23	Female	No	b799	Congenital	Spirits deceased relatives	Yes	Medical services
63	12	65	Male	No	b229	Trauma/ accident	Sorcery/witch craft	Yes	Family meeting/ Traditional healing
64	12	65	Female	No	b249	Illness/ infection	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Traditional healing
65	12	22	Male	No	b139/ b249	Congenital	Not evident	Yes	Medical services
66	12	20	Female	No	b799	Illness/ nfection	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Traditional healing
67	12	16	Male	No	b249	Congenital	Not evident	No	
68	12	55	Male	No	b249	Other/ not evident	Evil spirits/ masalai	Yes	Medical services
69	12	48	Female	No	b249	Illness/ infection	Natural cause	Yes	Medical services
70	13	3	Male	No	b139/ b799	Illness/ infection	Natural cause	Yes	Medical services/ Traditional healing
71	13	62	Female	No	b799	Illness/ infection	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Traditional healing/ Spiritual healing
72	13	50	Male	No	b799	Trauma/ accident	Dietary/ sexual taboos	Yes	Medical services
73	14	38	Male	Yes	b799	Illness/ infection	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Traditional healing/ Spiritual healing
74	14	71	Male	No	b799	Other/ not evident	Not evident	Yes	Family meeting/ Medical services
75	15	32	Male	No	b799	Trauma/ ccident	Other	Yes	Family meeting/ Medical services/ Spiritual healing
76	15	36	Female	No	b799	Other/	Evil spirits/	No	

						not evident	masalai		
77	15	25	Male	Yes	b799	Illness/ infection	Natural cause	Yes	Family meeting/ Medical services/ Traditional healing/ Spiritual healing
78	16	23	Male	Yes	b799	Trauma/ accident	Evil spirits/ masalai	Yes	Medical services
79	17	2	Male	Yes	b139	Congenital	Natural cause	Yes	Family meeting/ Medical services
80	17	20	Male	No	b139	Congenital	Other	No	
81	17	38	Male	No	b229	Trauma/ accident	Not evident	Yes	Family meeting/ Medical services/ Traditional healing/ Spiritual healing
82	17	2	Male	No	b229	Illness/ infection	Natural cause	No	
83	18	30	Male	Yes	b799	Trauma/ accident	Other	Yes	Medical services/ Spiritual healing
84	18	37	Female	No	b799	Other/ not evident	Dietary/ sexual taboos	Yes	Medical services
85	18	28	Male	No	b799	Other/ not evident	Dietary/ sexual taboos	Yes	Family meeting/ Medical services/ Traditional healing/ Spiritual healing
86	18	37	Female	Yes	b799	Other/ not evident	Other	Yes	Medical services
87	18	26	Male	No	b799	Other/ not evident	Sorcery/ witchcraft	Yes	Family meeting/ Medical services/ Traditional healing
88	18	4	Female	No	b139/ b799	Illness/ infection	Evil spirits/ masalai	Yes	Medical services/ Spiritual healing
89	18	25	Male	No	b799	Trauma/ accident	Trauma/ accident	Yes	Medical services
90	18	26	Male	No	b799	Other/ not evident	Evil spirits/ masalai	Yes	Medical services
91	18	36	Female	No	b799	Trauma/ accident	Other	Yes	Medical services
92	18	27	Male	No	b139	Other/ not evident	Dietary/ sexual taboos	Yes	Medical services
93	18	53	Male	No	b229	Trauma/ accident	Other	Yes	Family meeting/ Medical services
94	18	17	Male	No	b229	Trauma/ accident	Trauma/ accident	No	
95	18	65	Male	No	b229	Other/ not evident	Natural cause	Yes	Medical services
96	18	60	Female	No	b229	Other/ not evident	Not evident	No	
97	18	90	Female	No	b229/ b249	Other/ not evident	Not evident	No	
98	18	27	Female	No	b799	Other/ not evident	Not evident	Yes	Medical services
99	18	67	Female	No	b799	Other/ not evident	Not evident	Yes	Medical services
100	18	37	Female	No	b249	Trauma/ accident	Trauma/ accident	Yes	Medical services
101	18	2	Female	No	b799	Congenital	Not evident	Yes	Medical services
102	18	32	Male	No	b799	Trauma/ accident	Trauma/ accident	Yes	Medical services
103	18	35	Male	No	b799	Illness/	Not evident	Yes	Medical services

						infection			
104	18	11	Male	No	b799	Congenital	Not evident	Yes	Medical services
105	18	33	Male	No	b799	Other/ not evident	Not evident	Yes	Medical services/ Traditional healing
106	18	55	Male	No	b229	Other/ not evident	Not evident	Yes	Medical services
107	18	25	Male	No	b799	Other/ not evident	Other	Yes	Family meeting/ Medical services/ Traditional healing
108	19	4	Male	No	b799	Congenital	Not evident	Yes	Medical services
109	19	13	Female	No	b249	Illness/ infection	Natural cause	Yes	Medical services
110	19	10	Female	No	b799	Other/ not evident	Not evident	Yes	Medical services
111	19	25	Male	Yes	b799	Congenital	Evil spirits/ masalai	Yes	Medical services
112	19	29	Female	No	b799	Congenital	Not evident	Yes	Medical services
113	19	30	Male	No	b139	Congenital	Dietary/ sexual taboos	No	
114	19	18	Female	No	b139	Other/ not evident	Not evident	No	
115	20	55	Male	Yes	b799	Other/ ot evident	Sorcery/ witchcraft	Yes	Medical services/ Traditional healing
116	20	50	Female	No	b799	Trauma/ accident	Trauma/ accident	Yes	Medical services
117	20	45	Male	No	b229/ b799	Other/ not evident	Not evident	Yes	Medical services
118	20	55	Female	No	b799	Other/ not evident	Not evident	Yes	Medical services
119	20	55	Female	No	b799	Other/ not evident	Not evident	Yes	Medical services
120	20	60	Female	No	b799	Other/ not evident	Natural cause	Yes	Medical services
121	20	55	Female	No	b249 b799	Other/ not evident	Not evident	Yes	Medical services
122	20	40	Female	No	b799	Trauma/ accident	Trauma/ accident	No	
123	20	65	Male	No	b799	Other/ not evident	Not evident	Yes	Medical services
124	21	55	Female	No	b799	Other/ not evident	Dietary/ sexual taboos	No	
125	21	57	Male	No	b799	Other/ not evident	Dietary/ sexual taboos	No	
126	21	45	Male	No	b799	Other/ not evident	Other	Yes	Medical services
127	21	7	Male	No	b799	Trauma/ accident	Trauma/ accident	No	
128	21	65	Male	No	b229	Other/ not evident	Not evident	No	
129	21	15	Male	Yes	b139/ b799	Other/ not evident	Dietary/ sexual taboos	Yes	Family meeting/ Medical services/ Traditional healing/ Spiritual healing
130	22	25	Female	No	b799	Trauma/ accident	Trauma/ accident	Yes	Family meeting/ Medical services/ Spiritual healing
131	22	50	Male	No	b229	Other/ not evident	Not evident	Yes	Medical services
132	23	7	Male	Yes	b139/	Congenital	Evil spirits/	Yes	Family meeting/

					b229/ b799		masalai		Medical services/ Spiritual healing
133	23	24	Female	Yes	b799	Other/not evident	Sorcery/ witchcraft	Yes	Medical services/ Spiritual healing
134	24	30	Female	No	b799	Illness/ infection	Sorcery/ witchcraft	Yes	Medical services
135	24	65	Male	No	b799	Other/ not evident	Not evident	Yes	Medical services
136	25	26	Male	No	b139	Other/ not evident	Other	No	
137	25	75	Female	No	b799	Other/ not evident	Other	Yes	Medical services
138	25	60	Male	No	b249	Other/ not evident	Not evident	No	
139	25	47	Male	No	b249	Other/ not evident	Natural cause	No	
140	25	16	Male	No	b799	Illness/ infection	Natural cause	Yes	Medical services
141	25	60	Female	No	b249	Other/ not evident	Not evident	No	
142	25	28	Male	No	b139/ b249/ b799	Congenital	Other	No	
143	25	30	Male	No	b139	Other/ not evident	Evil spirits/ masalai	No	
144	26	68	Male	No	b799	Trauma/ accident	Trauma/ accident	Yes	Medical services
145	26	60	Female	No	b799	Illness/ infection	Not evident	Yes	Family meeting/ Medical services/ Traditional healing/ Spiritual healing
146	26	67	Male	No	b799	Trauma/ accident	Trauma/ accident	Yes	Medical services
147	26	65	Male	No	b229/ b249/ b799	Trauma/ accident	Trauma/ accident	Yes	Medical services/ Traditional healing
148	26	30	Male	Yes	b139	Other/ not evident	Sorcery/ witchcraft	Yes	Medical services/ Traditional healing
149	26	55	Female	No	b799	Other/ not evident	Not evident	Yes	Medical services
150	26	10	Female	No	b139	Illness/ infection	Natural cause	Yes	Medical services
151	26	55	Male	No	b799	Trauma/ accident	Trauma/ accident	Yes	Traditional healing
152	26	2	Female	No	b139/ b799	Congenital	Natural cause	No	
153	27	33	Male	Yes	b799	Other/ not evident	Sorcery/ witchcraft	Yes	Family meeting/ Medical services
154	27	33	Male	No	b229	Congenital	Not evident	No	
155	27	30	Male	No	b229	Congenital	Not evident	No	
156	27	4	Male	No	b799	Congenital	Not evident	No	
157	27	55	Female	No	b229/ b799	Trauma/ accident	Trauma/ accident	Yes	Medical services
158	27	70	Female	No	b229/ b799	Other/ not evident	Not evident	No	