

**Identifying Children with Disabilities in
Kilifi, Kenya:**

**The use of Participatory Rural Appraisal
(PRA)**

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Abstract:

Surveys have been widely used as methods for identifying children with disabilities.

However these methods are expensive and take a long time to carry out. A cheaper and fast method is therefore desirable for the majority world countries.

This study used Participatory Rural Appraisal to identify children with disabilities in a rural setting in Kilifi, Kenya. Methods of data collection used were focus group discussions and social mapping. Teachers, village leaders and women groups participated in the PRA. Their perceptions of disability are first established before the identification of the children.

The results indicate that the perceptions of disability are diversified. Disability is perceived as existence of impairments, activity limitations and participation restrictions and traditional beliefs that include witchcraft, evil spirits or punishment from God. These perceptions are in some cases held separately and in other cases they are treated together. Orphans were also perceived as disabled children. In the identification of children with disabilities, the results revealed a 6.9% prevalence rate. The process shows that PRA is a fast and cheap method of identifying children with disabilities.

In comparison of the groups of key informant used, the results showed that village leaders were better than the other two groups in the identification of children with disabilities.

Key message box:

What is already known:

- Many services for disabled people are still set from an impairment perspective.
- Surveys are widely used methods of identifying children with disabilities and are expensive and time consuming.
- Different perspectives of disability affect the prevalence rates of these surveys.
- Many disabled people object to the amount of money spent on surveys, they think that there should be ‘no survey without service.’

What is new:

- Traditional beliefs and orphans are perceived as disability.
- Village leaders in two sub-locations of Kilifi District identified greater numbers of children with disabilities than the other stakeholder groups.
- PRA approach for the identification of children with disabilities is a fast and cheap way of identification of disabled children.
- People in the community accept and enjoy PRA approach.

Dedication:

This thesis is dedicated to my late beloved mother, Maria Mbucho Gona, for her inspiring love and encouragement to me.

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Abbreviations:

DB: Database

DPOs: Disabled People's Organisations

ICF: International Classification of Functions

ICH: Institute of Child Health

ICIDH: International Classification of Impairment, Disability and Handicap

ILO: International Labour Organisation

NHIS-D: National Health Interview on Disabilities

NI: Neurological Impairment

KEMRI: Kenya Medical Research Institute

PRA: Participatory Rural Appraisal

UN: United Nations

WHO: World Health Organisation

CHAPTER 1

1.0. Introduction:

Identification of children with disabilities is problematic throughout the world. Survey methods used in most of the world are costly and time consuming. The cost is particularly a problem in in the majority world countries.

Perceptions of what constitutes a disability vary from culture to culture, making interpretation of the data and comparison between studies problematic. The social perspective of disability (Helander, 1999) puts more emphasis on a wide variety of socio-cultural perceptions and expectations than the medical model of disability.

So far surveys have been largely based on an impairment perspective. The major focus is on the impairment and what can be done to the impairment. This is at odds with the present thinking that disability has many interactive dimensions.

Surveys are usually imposed from outside the community and do not encourage participation, and ownership, even their results are not often communicated back to the community. This means that communities often reject the information that they produce.

Limited funds for disability are sometimes spent all on surveys. As a result, there is nothing (particularly in majority world countries) left to develop the service they require.

The above points indicate that there is a need to identify an alternative way of identifying disabled children that is cheaper and more community based. This study sets out to examine if the use of PRA is a viable solution to this problem.

Research Question:

Can Participatory Rural Appraisal approach be used in the identification of children with disabilities?

General Objective:

To evaluate the application of Participatory Rural Appraisal in identifying children with disabilities in a rural area of Kilifi, Kenya.

Specific Objectives:

- a) To examine local perceptions on disabilities.
- b) To utilise teachers, village leaders, and women groups to identify children with disabilities.
- c) To give feedback to participants.

1. Literature Review

1.2. Data search.

Search for data was done using different databases to explore different issues on the identification of disabilities. These databases included the DB text works (United Nations Enable), Popline and the Pub Med version. Journals of Neuro-epidemiology, Disability and rehabilitation were also searched through databases and manually. The SOURCE collections in the Institute of Child Health (ICH) library and grey literature were also searched. Key words used were **participatory rural appraisal; disability; survey; prevalence; identification.**

The resulting data is presented in three sections. The first section looks at different definitions of disability in relation to both the medical and social models of disability. The second section focuses on the prevalence of disability and social perceptions influencing identification of disabilities. The final section examines the survey and participatory methods of identifying children with disabilities highlighting the strengths and weaknesses of both methods.

1.3. Definition of disability.

Definition of disability with a global perspective is very problematic due to the fact that it is not an easily understood concept, and has multiple interpretations (Stone, 1999). "The cultural notions of disability are concerned with the origin and consequences of

disability, and connect disability to many doctrines, religious beliefs, perceptions of sickness disorder or abnormality" (Helander, 1999). This has led to different forms of definitions of disability both in western and majority world countries (Helander, 1995). As a result of this, coming up with a definition that will have a global outlook, though very desirable, is in reality almost impossible, (Altman, 2001).

The definition of disability has been changing for the last century. The International Labour Organisation (ILO) defined disability as 'an occurrence which prohibits the prospects of a person from securing, retaining and advancing in suitable employment as a result of a recognised physical or mental impairment' (ILO, 1978). But this definition was not holistic as it only focused on the physical and mental aspects of disability and not the other aspect of social life.

In pursuit of a better definition, WHO defined disability using the International Classification of Impairments, Disability and Handicaps (ICIDH) (WHO, 1980)

Impairment was any 'temporary or permanent loss of a body structure or function, whether physiological or psychological, or a disturbance affecting functions that are essentially mental or sensory, internal organs, the head, the trunks and the limbs.'

Disability was 'a restriction or inability to perform an activity in a manner within the range considered normal for a human being, mostly resulting from impairment.'

Handicap was defined 'to be a result of an impairment or disability that limits or prevents the fulfilment of one or several roles regarded as normal on age, sex and social and cultural factors.' The focus of this model was on the correction of the person's

impairments, assuming any difficulties lie in the individual's deviation from normal rather than lack of acceptance within the environment (Finkelstein, 1991). The guiding factor in this model was the principal of normalisation. It was believed that normalisation would transform the disabled person to become normal and be valued in the society (Chapell, 1997). In this medical model, which is also referred to as the individualistic model of disability, impairment and disability are not seen to be different; hence dealing with the impairment is regarded as dealing with the disability (Oliver, 1996, Crow, 1996). This has led to misconceptions and uncertainties in dealing with disability issues. Borsay, (1986) argues that this medical approach to disability has brought about real divisions within the disabled population.

In trying to come up with a multi-dimensional definition of disability from a holistic perspective, several definitions have come up from different people and organisations. Hahn, cited by Altman (2001) says disability can be defined as an occurrence that has been described from a number of different domains including medical, economic and socio-political. Other scholars have come up with different definitions. Helander, (1999) defined a disabled person as one whom; in his/her society is regarded as disabled because of a difference in appearance or behaviour. This was revealed from studies he carried out in Mali, Somalia and Kenya. However Finkelstein looks disability from another perspective and defines it as the outcome of an oppressive relationship between people with impairments and the rest of the society (Finkelstein, 1980). The environment is the major focus in making people disabled. But the Americans with Disabilities Act (1990)

adopted the ILO (1978) definition of disability that looks disability in terms of the ability to secure, retain and advance in employment.

The Standard rules on the Equalisation of opportunities for persons with disabilities (PWDs), (UN, 1994), summarises a great number of limitations occurring in any population in any country to be disabled. People maybe physical, intellectual or sensory impaired. They may also have poor medical conditions or mental illness. This definition reflects a combination of all the issues contributing to disability. This definition is used by the Planning Commission of India (Baquer, 1997) in the government's programmes.

People with disabilities advocated for the social model of disability that changed the way people viewed disability. This led to WHO coming up with another definition of disability, the International classification of disability and health (ICF) (WHO, 2001). It recognises two health dimensions in defining disability that are described from the perspective of the body, the individual and the society. In this classification, **functioning** is a term for body functions, activity or participation restrictions. **Disability** involves impairments, activity limitations or participation. Environmental factors include physical, social and attitudinal environment in which people can conduct their lives (WHO, 2001). This ICF definition was geared towards the holistic integration of PWDs in the society. The social model of disability sees the problems PWDs encounter not entirely as a result from the nature of their disabilities (Quinn, 1995.), but in part from the unfounded stereotypes and prejudices towards PWDs (Funk, 1987). Such attitudes can reinforce an expectation of bad manners, incompetence and poor health that may limit social, vocational and recreational participation on the side of PWDS, (Gartner, 1987). In an

effort to fight these negative notions on disability, the Disabled People's Organisations (DPOs), through their definition of disability, which is based on the Human Rights Model, advocates for equal access to what limited services available, especially in health and education, (Coleridge, 1999). The social model emphasises the idea that the society must come to terms with their disabilities and accept PWDs as they are, (Helander, 1999). This argument further broadened by French (1993) who says that in social model focus should be on the removal of social and environmental barriers to allow maximum social, physical, career and religious participation. It requires the society to address barriers to inclusion rather than spending money on segregation of PWDs (Finkelstein, 1991). In the majority world countries, the social model of disability makes sense across cultures and countries as all people are regarded to belong to one society. (Newsletter of Disability Awareness in Action,). It is the social and economic structures of a particular society that create disability through processes of prejudice, exclusion and discrimination (Chapel, 1997). There are no limitations imposed by impairment that cannot be removed by social and environmental manipulation (French, 1993).

1.4. Prevalence of disability.

Due to difficulties in the definition of disability as seen in the previous section it is not easy when one compares evidence of prevalence studies between western cultures and other cultures in relation to the difference between impairment and disability (Helander, 1995). These differences in prevalence could be due to different reasons behind the definitions of disabilities (Altman et al, 2003). This is when organisations come up with definitions to suit and meet their objectives. In most cases these objectives are meant to

meet the needs of these organisations. However the United Nations estimates that between 0.2% - 20% of each country's population are PWDs, (UN, 2003). This ranges from mild to severe disabilities. Using this same range of mild to severe disabilities, the National Health Interview Survey on Disabilities (NHIS-D) carried in the United States revealed a disability prevalence rate of 19.4% (Fedeyko & Lollar, 2003). A survey looking at the prevalence of disabilities in different countries carried by the Health Systems Trust (2001) revealed that 5% of Kenya's population were persons with disabilities. In this survey, disability was defined as a physical or mental handicap that has lasted for six months or more and which prevents the person from carrying out daily activities independently, or from participating fully in educational, economic or social activities. It can be argued that the focus in this survey was on impairments rather than disabilities. In a recent survey study on the identification of impairments carried out in rural Kenya, (Mung'ala et al, 2004) found out that between 5-7% of the children screened had moderate to severe impairments. Helander, (1993) estimates a prevalence rate of between 6-7%. But he further argues that this estimate depends on what counts as a disability in different cultures.

1.5. Impact of social perceptions of disabilities on prevalence.

Social perceptions on disabilities arise as a result of cultural beliefs and practices existing in communities (Helander, 1995). Some societies perceive disability as incurable illness (Ingstad, 1991). The Somali people on the other hand regard disabled as ill and impairment as disease, and in Mali disabling condition for a woman is to be ugly (Helander, 1995). Helander further argues that all aspects of disabilities are located in a

network of social relations and dependent on social resources of various kinds. These perceptions which focus on stigma and severe maltreatment of PWDs may be a product of lack of understanding of other fundamental social processes that shape the lives of the disabled persons (Ingstad, 1995).

According to Groce (1989), cultural beliefs about disabilities are strongly influenced by religion, socio-economic status and educational background. In turn, these beliefs about disabilities affect how PWDs are treated in each culture. In a study looking at the existing practices underlying attitudes towards children with epilepsy in Kilifi, Kenya, (El Sharkawy, 2002) found that cultural beliefs and perceptions the community had towards persons with epilepsy determined treatment and positions in terms of social acceptance. The belief that epilepsy could be contagious made people fear coming into contact with epileptic people when fitting. In this respect, such attitudes could possible influence their identification by people in the community.

Admasu and Derso, (1991) argue that parents' attitudes towards their disabled children are very significant because they are the first group of people with whom the child comes into contact. Epstein, (1997) further says that PWDs' feelings about their disability were found to reflect their parents' attitudes towards them. Parents' attitudes towards their disabled children could influence the attitudes of other people in the community, and this could consequently influence identification of disabilities by these people in the community (Baquer, 1997). Attitudes are built upon beliefs, but can be shaped by experience and encounters with PWDs (Helander, 1999). Negative social attitudes to impairments can act against effective community participation (Coleridge, 1993).

Groce, (1999) suggests that cultures view disability in three dimensions; by its cause, by its effect on the valued attributes and by the social position of the disabled person in adulthood. With regard to the cause, PWDs are treated well or badly depending on cultural beliefs and how and why they became disabled. This could be through witchcraft, reincarnation, gods' wrath or genetics. On the side to attributes, if society values physical strength, then the physical disabled is at a disadvantage, if on the other hand society values intellectual accomplishments, then the fact that a person is on a wheelchair is not as limiting. As for social position, this depends on whether the PWD will have an adult role in the community in order for the society to set aside resources for him or her. In such circumstances, knowing the social perceptions on disabilities is vital when it comes to reflecting on what influences disability identification in participatory approaches (Groce, 1999).

However traditional beliefs about disability are not always negative. Studies from Northern Mexico and Botswana have revealed that the birth of a disabled child is viewed as evidence of God's trust in specific parents' ability to care well for a delicate child, (Ingstad, 1988). But Groce, cited by Higgins (2002) still argues that people with disabilities are far more limited by the society's view of disability than their actual disability. Therefore determining how people in the community perceive disability could be a possible indicator in reflecting how the participatory method of identifying disability would be influenced (Zanetell et al, 2004).

1.6. Survey methods for the identification of disabilities.

National surveys have been used in different countries of the world as a means of data collection for government planning (Hendershot, 2003). The National Health Interview Survey (NHIS) has been a standard measure for assessing health in the United States, but the disability supplement was added to NHIS in the 1994-1995 survey (Fedeyko & Lollar, 2003). This is when policy makers, and programme operators could get strategies to improve the health of persons with disabilities. The National Health Interview Survey for Disabilities (NHIS-D) is used to determine the prevalence of disabilities for policy planning (Altman, 2003). This survey is to determine the number of PWDs entitled for Social Security Disability income (SSDI), or Supplementary Security Income (SSI), (Brandt & Pope, 1997). But the problem is, that measurement of disabilities in national surveys is not standardised (Altman et al, 2003). This could be due to differences in the perception of disabilities by different cultures. For example some cultures in Kenya consider not being able to look after cattle as a big disability, (Helander, 1999). Other surveys including the Survey of Income and Programme Participation, National Health Interview Survey and Medical Expenditure Panel Survey are also limited by whether the respondent answers questions for himself/herself or answer given by a proxy (Altman, 2003). In such situations, information given could have aspects of unreliability. This is why in countries with well-developed services for children with disabilities, administrative data and registries are useful source of population-based information (Durkin, 1994).

In low-income or developing countries, census surveys have been used to identify children with disabilities (Durkin, 1994). House-to-house surveys have also been widely used in the identification of children with impairments, (Mung'ala, 2004). However these surveys methods tend to take a long time to carry out and they are also expensive, (Shyma, 1999). The cost of identifying one child with a disability in a survey method would possible cost US\$ 7, (Calculation from a survey method done in Kilifi, Kenya). This could be quite expensive to most of the majority world countries.

1.7. Participatory methods for the identification of disabilities.

There are studies which have used participatory approaches to identify children with disabilities. Shyma, (1999) used Rapid Rural Appraisal to identify children disabilities in rural India. The method appeared to be good at picking social dynamics during the process. The social dynamics in this context included positive arguments, cohesiveness and coming to agreements. Identification was influenced by the local perceptions and definition of disability, and associated social implications and stigma of that disability (Shyma, 1999). The Key Informant Survey is also a participatory approach used in the community. It is an important tool for planning and evaluating community health programmes (Eyler et al, 1999). Information from key informants is useful in identifying support in service delivery and gaining access to potential influences for community change (Eyler, 1999). This approach has been used in Bangladesh to identify childhood blindness, (Muhit, 2002).

Studies have shown that participation by local people is one of the critical components of success in different projects in the community, (USAID, 1987, World Bank, 1994, Pretty, 1995). Without this participation, projects geared to benefit the community could be rendered useless. Participatory Rural Appraisal (PRA) is used to make people be responsible of their own undertakings. PRA is therefore a methodology being used not just for local people to inform outsiders, but also for the people's own analysis of their own conditions, (Chambers, 1993). This might have the capacity to reflect more closely a socially constructed view of disability. PRA evolved as a research approach to give the poor and the powerless a voice (Pretty, 1995). The poor become active analysts of their own situation and then set their own priorities on how to change their situations (Chambers, 1998). This results in the empowerment of the people and therefore and therefore giving them the sense of ownership.

The interactive involvement of many people in this system has promoted innovation and ownership (Chambers, 1993). According to Pretty, (1994), PRA is a defined methodology and systematic learning process. Its focus is on the involvement of all the participants through learning and interaction. It stresses changes in the behaviour and attitudes of outsiders to become not teachers but facilitators, not lecturers but listeners and learners, (Chambers, 1998). As a result the outsiders respect the ideas and suggestions of the local people leading to mutual trust. Pretty, (1994) portrays PRA as a group learning process. It involves the recognition that the complexity of the world will only be revealed through group inquiry interaction. This implies possible blending of professionals and local people (Chambers, 1998).

The methodology is concerned with the transformation of existing activities to try to bring changes which people in the situation regard as improvement, (Pretty, 1994). The role of the expert is helping people to achieve something regardless of their social or financial situations. It leads to debate about change and the debate changes the perceptions of the actors and their readiness to contemplate action. Action is agreed upon and the changes to be implemented will therefore represent an agreement among different conflicting views, (Pretty, 1994). The coming to an agreement on particular issues in the identification of disabilities portrays the accommodation of different conflicting opinions. Chambers (1998) says, “PRA calls for a good rapport with the local people, hence leading to substantial community involvement and commitment.” In the identification of disabilities, PRA brings greater community participation (Shyma, 1999). This participation provides a greater understanding of disability issues that might influence the identification of children with disabilities.

1.8. Conclusion.

The use of the survey method in the identification of disabilities, though widely used as the conventional approach is narrow and it is focused in the identification of impairments (Coleridge, 1993, Baquer, 1997, Brandt, 1997, Oliver, 1996). Disability is perceived from a more diversified spectrum which incorporates the social well-being of a person (Morris, 1991, Chapel, 1997, Crow, 1996).

The social perspective of disability emphasis a lot on a wide variety of socio-cultural perceptions and expectations that influence the definition of disability, (Groce, 1990,

Helander 1999, El Sharkawy 2002). These same perceptions and expectations could possible influence the identification of children with disabilities in the community. In relation to this context, participation of the people in the community in the identification of disabilities may come closer to identifying disability as a social construct, as opposed to survey method which is related to impairment groups.

As regards cost and time, the survey method needs a lot of preparations in terms of the production of materials to be used, training of fieldworkers and administration of the questionnaire (Brandt, 1997, Hendershot, 2003). For poor rural communities, this approach tends to be burdening and beyond their limits.

The ultimate goal for the identification of disabilities is service delivery for PWDs. (Miles, 1996). The implementation of services in relation to disabilities in resource poor communities is never realized to a meaningful level if the community is not involved right from the initial stages. In a survey approach, the community is not consulted or involved in the identification process. The shortcomings of this exclusion could be reflected in the lack of community involvement and participation in regards to the implementation of disability services (Uzuchuku, 2004, Zanetell, 2004). On the other hand, participatory approaches give the people in the community a sense of responsibility, value and ownership (Pretty, 1995, Chambers, 1997).

In Kilifi, Kenya, studies have been carried out which collected information on disabilities.

- 1) A Neurological Impairment (NI) survey about the prevalence of disabilities using the Ten Question Questionnaire (Mung'ala et al, 2004).
- 2) Another study looked at the Burdens of Rearing a Disabled Child in a poor rural setting (Meehaan, 2003).
- 3) The Communication Study which used women groups as agents of change (Hartley, 2003).
- 4) Existing Practices and Attitudes towards children with epilepsy (El Sharkawy, 2002).

These studies which were carried out by the staff at the Kenya Medical Research Institute (KEMRI) revealed the following issues.

- 1) The NI study found out that the house-to-house survey was reliable and useful for detecting moderate/severe impairments in children aged between 6-9 years in rural Africa. However it revealed that the method was insufficient for use in detecting mild impairments. The passive involvement of the people in the community in the identification process was evident, and this could possible lead to negative response of the community to disability issues. The identification took a long time and it was expensive.
- 2) The Burdens of rearing a disabled child study on the other hand came up with the results that rearing a disabled child was a social responsibility to be met by all parents. However the problem arose when the disabled child

got sick. Through focus-group discussions, the cohesiveness of the people, and their sense of responsibility despite their financial limitations were observed. The sharing of information and coming to agreed conclusions which were evident in the study could be indicators to support the idea that identifying disability using the participatory method could enhance community participation and involvement in disability issues.

3) The communication study came up with results which had the view of women groups being well placed in terms of bringing changes in helping children with communication problems through community involvement and participation.

4) Existing practices and attitudes revealed how these elements could influence the perceptions of the community on how they treated persons with epilepsy.

Establishing what the community regards as a disability could be a necessary pre-determinant factor in the participatory method of disability identification. This was not done in the above –mentioned studies. As such, this study will start by establishing what constitute a disability from the community’s point of view. Then in view of the limitations of the survey methods used in the identification of children with disabilities, a participatory approach will be used. The results will highlight the rigour of PRA in the identification of children with disabilities.

CHAPTER 2

2.0 Design and Methodology

2.1 Study Site.

The study was carried out in two of the fourteen sub-locations which a study of Neurological Impairment (NI) in children aged 6-9 years was conducted in 2004. This was in the northern study area that is under surveillance by the Kenya Medical Research Institute (KEMRI) in Kilifi District.

Kilifi is at the coastal part of Kenya, about 60km north of Mombasa. The KEMRI northern study area stretches for about 30km inland with an area of 3000sq km. It borders the Arabuko-Sokoke forest in the north, the Mida creek in the east, the Indian Ocean in the south and the Kilifi creek in the west. Annually mean rainfall is approximately 1077mm and daily mean temperature of between 24 and 32 degrees centigrade.

The two sub-locations for this study were those close to the KEMRI unit. These were Kibarani and Konjora sub-locations. These sub-locations are rural, where approximately 85% of the population is involved in agriculture. The Mijikenda tribe, of which the Giriama sub-group predominates, make the majority of the population. The two sub-locations have a of 3,427 children aged between 9-15 years.

2.2 Study Design.

This was a pre-dominantly qualitative design with a small quantitative component. The processes used were participatory. These were aimed to involve the local people in the whole process of disability identification.

2.3 Subjects.

Three groups of key informants (KI) which were thought to be good representation of the population in the two sub-locations chosen were:

A- Village Leaders. They were chosen due to the fact that they are conversant and well informed in community issues, hence being in a better position of identifying children with disabilities.

B- Women Groups. They were included due to the fact that being mothers, shared the same sentiments and feelings. Their groups included women from all parts of the sub-location.

C- Teachers. Teachers in this community are regarded as the knowledgeable group of people. People easily confide in them. As a result of this, they could be potential capable of knowing children with disabilities in the community.

2.4 Sampling Procedure.

All village leaders were selected using comprehensive sampling. This was because there were about 8-10 in total in every sub-location. Since comprehensive sampling was used, there were no inclusion or exclusion criteria for this group.

Women groups were selected through purposive sampling. The most active groups were involved. This was determined by the number of meetings they had in a month and the number of projects they had initiated. Social workers from the Kilifi County Council helped the researchers in identifying the appropriate women groups. Inclusion criteria for this group included being active and meeting regularly, at least twice in a month. The group should also have started at least one project that is performing well.

The schools the teachers were drawn from were selected using comprehensive sampling. This was because there were only three primary schools in each sub-location and all of them were involved in the study. The teachers were selected using purposive and convenience sampling according to the following criteria.

- Having taught for more than a year.
- Having free time to participate.
- Having some knowledge in disability issues.

2.5 Sample Size.

Focus group discussions had between 10-12 participants. This is the accepted number for an effective discussion. But most of the groups had between 8-10 participants. The total number of participants in focus groups discussions was 125. The same number of participants was also involved in the social mapping activities. This was for the purpose of equal contribution by every participant. Therefore the sample size for this study was 250 participants.

2.6. Methods.

Participatory Rural Appraisal was the method of data collection. Data collection tools in the method included:

- i. Focus Group Discussions.** These were conducted to explore how disability was perceived in the community. They were done with village leaders, women groups and teachers to look at the local perceptions of what constitute a disability. Open-ended questions were used to guide the discussions.

- ii. Social mapping.** Social mapping was performed according to the established procedure (Shyma, 1999). In this procedure the participants mapped the area. Then identify children with disabilities and then placed them in their respective homes on the map. Identification of households was done to make sure children are not identified by more than one group in every sub-location.

Table 1: Research Activities with Different participants.

	Kibarani Sub-location			Konjora Sub-location 2			
	Village Leaders	Women Groups	Teachers	Village Leaders	Women Groups	Teachers	Total
Social Mapping	1	2	3	1	2	3	12
Focus Group Discussions	1	2	3	1	2	3	12
Total	2	4	6	2	4	6	24

A- Focus Group Discussions.

Focus group discussions with village leaders and women groups were conducted by the researcher in Kigiriyama, which is the language of the Giriama tribe. Discussions with teachers were conducted in Kiswahili language because they were a mixture of different tribes. Kiswahili is the national language of Kenya. Checklists with open-ended questions were used find out what the community perceives as a disability (see Appendix 1 for focus group checklist).

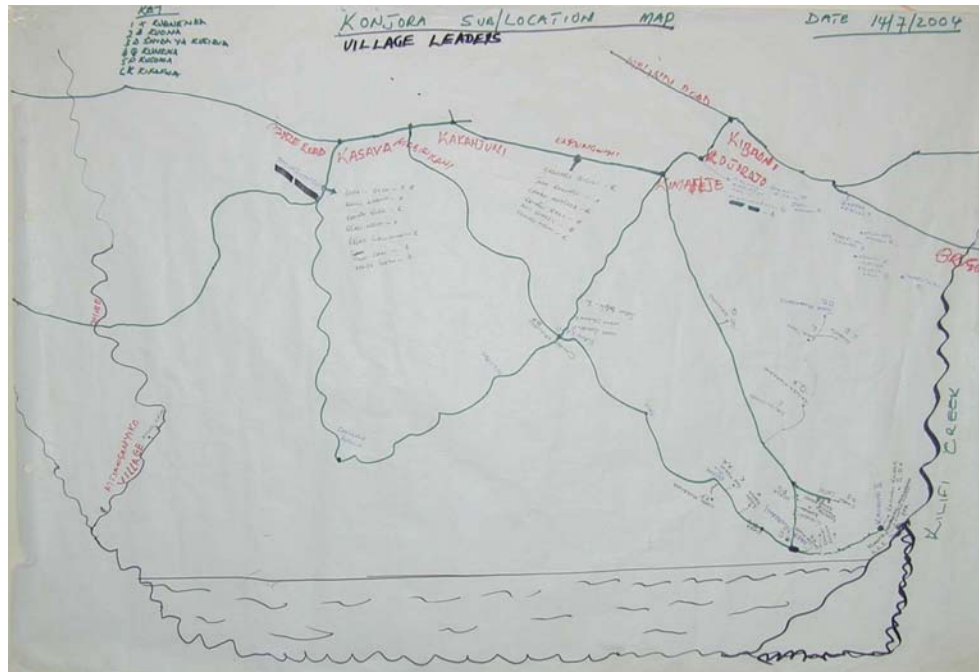
Picture 1: Focus Group Discussions with teachers in Kilifi, Kenya.



Social Mapping.

Social mapping was facilitated by the researcher in Kigiriyama language when with village leaders and women groups. Kiswahili language was used with teachers. The social mapping was used to identify children with disabilities together with their households.

Picture 2: Social mapping done by village leaders in Kilifi, Kenya.



2.7. Ethics.

In trying to avoid raising the participants' expectations, the researcher made the aim of the research clear before beginning the activities. Information about the study was read to them and were allowed to ask any questions they had (see appendix 2). This gave them the opportunity to decide whether to participate or not.

Before the beginning of the activities, the participants were reminded by the researcher that taking part was voluntary and that anybody was free to leave any time he/she wished without any consequences.

2.8. Analysis.

The qualitative data collected was analysed using the computer software Nudist Vivo.

The first step of this analysis was to over-view the whole set of transcripts to identify the

main themes. Then nodes were created for each of the themes. Then the data was coded.

General ideas were then inferred from the participants' specific responses. Other

researchers from KEMRI unit read the transcripts and came up with themes for the

purposes of triangulation which was well followed.

The quantitative data was analysed using comparison. The rigour of PRA was compared

with that of the Kilifi survey. Comparison was also made between the key informant

groups.

2.9. Implementation

2.9 (a) Tools.

The researcher prepared checklists of questions in English for the focus group discussions

and the social mapping activities, (See Appendice 1 & 2). These checklists were

translated into Kigiriana by a fieldworker fluent in the language and then translated back

to English by a different fieldworker to counter check that the original message is not

distorted. The purpose of the checklists was to provide guidelines so that the moderator

or the participants are within what is supposed to be done. Focus group discussions and

social mapping activities with teachers were carried out in Kiswahili, as some teachers

did not understand the local language.

2.9 (b) Training.

Training of research assistants was not done due to the fact that the researcher did everything alone. Being a native of the study area and fluent in the local language and Kiswahili, it was found that there was no need for research assistants.

2.9 (c) Piloting.

Two pilot focus group discussions and two social mapping activities were carried out with teachers and village leaders. These teachers and village leaders were not from the sub-locations used in the main study. This pilot was done in order to assess the validity of the checklists. Both checklists were found to be appropriate for the study.

2.9 (d) Data Collection.**A- Focus Group Discussions. (FGD)**

Discussions with village leaders were done at the offices of the sub-chiefs. Those with teachers took place at their schools. Women groups had their discussions at their meeting centres. Before each FGD, an opening prayer was said by one member of the group. The researcher introduced himself to the group, and then gave an introduction about the study. There was no written consent form for the participants to sign. However the participants were asked for their approval to participate in the study verbally. Nobody refused to take part.

Focus group discussions with village leaders were productive. All these leaders were aware of the existence of children with disabilities in the sub-location. Their good

contributions were manifested through the involvement, argument, and cooperation they had throughout the discussions.

For the women groups, their discussions were involving and exciting. Some members could remind the shy ones in the group that they had duty to contribute. This acted as a stimulus to the shy ones, and therefore contributed.

On the side of teachers, their discussions were impressive. They had to look for more information on the topic under discussion. Dictionaries were used to get the meaning of disability (Ulemavu) so that they could all be talking about the same issue.

B- Social Mapping.

Social mapping with village leaders was done at the office of the sub-chief. Women groups had their activities at their meeting places. The teachers were met for the same activities at their schools. In the social mapping, participants were supposed to identify homes/households, and children with disabilities. They were also to identify the type of disability. All the information was to be put on a map which they would have drawn.

Social mapping activities with village leaders were successful in terms of the effort used to get all of them to attend. This group could not come on time. The researcher had to wait for more than three hours before starting to arrive, one at a time.

Women groups did social mapping activities with a lot of concern. A lot of arguments were evident when naming homes of the children. Nonetheless, a few women showed

shyness when mentioned to contribute. A few looked down as they contributed. Others repeated responses already said.

Teachers did social mapping activities in a professional manner. They made sketch maps to work on, and then transfer that to a fair copy. In the social mapping, female teachers were more involved than the male ones.

From the social mapping activities, there also were interesting data from all the groups in terms of identifying the child's name. It was observed that a good number of members in the women groups were illiterate. This was observed when one group had to use a school girl during the activities.

Chapter 3

3.0 Results.

This chapter presents the results of the study by first looking at what people in the community think qualifies a child to be termed as one with disabilities and then considering the identification of these children using PRA. The results are the reflections of the key informants' perceptions of disability and the rigour of PRA in the identification process.

The chapter is divided into two sections. The first section presents the results from the analysis of the focus group discussions. This data was analysed to generate the local perceptions of what constitutes a disability. The results revealed a number of categories that reflected the perceptions on disability. These categories were in the form of functional difficulties and local perceptions. These included difficulties in seeing, hearing, walking, learning, and speaking. Other perceptions identified were epilepsy, poor health, orphans and lack of social needs. The second section presents data from the social mapping. Analysis of the data was done to determine the number of children and households identified by each group. Comparison of the groups was done by looking at the number of children and households identified by each group in both sub-locations. The rigour of PRA was compared with that of the Kilifi survey.

3.1 Perceptions of disability.

The perceptions of disability are presented from the viewpoints of the different groups that participated in the study. Analysis of the data revealed that all the three groups of key informants used in the study had almost similar views as to what constitutes a disability. All the groups perceived children who were orphans to be considered as belonging to the category of children with disabilities. The following is a summary of the different perceptions of disability as given by the groups.

Difficulties in seeing.

“First seeing. If he has a disability of not seeing properly.” (*Teachers*).

“There are those who cannot see. I think they are in this group.” (*Women groups*)

“There are those who can talk and hear but cannot see.” (*Village leaders*).

Difficulties in walking.

“What makes one be regarded as disabled is like, for example one who cannot help himself in walking.” (*Teachers*).

“He has very big elephantiasis and he cannot walk.” (*Women Groups*).

“He is all right but cannot walk.” (*Village Leaders*).

Difficulties in hearing.

“Maybe hearing, but he can’t hear properly.” (*Teachers*).

“There are those whose ears cannot hear.” (*Women Groups*).

“You can become sick, affects ears, then you cannot hear.” (*Village leaders*).

Difficulties in learning.

“You are teaching the child but he is not getting anything.” (*Teachers*).

“Some children have mental limitations. His actions are not to his age”. (*Women Groups*).

“You can see a person is physically fit but his mental capacity is not all right.” (*Village leaders*).

Difficulties in speaking.

“Could have speech problems.” (*Teachers*).

“They cannot speak.” (*Women Groups*).

“The voice can disappear due to sickness. This is disability.” (*Village leaders*).

Epilepsy

“Epileptic children are disabled because most of the time they fit and can’t continue with their normal life.” (*Teachers*).

“The consciousness is taken away, becomes a child who does not even understand himself. He drools.” (*Women Groups*).

“When he gains consciousness he goes to bed for three days without eating.” (*Village leaders*).

Orphans without help.

“Those who cannot get help from their relatives, then these can be in the disabled group.” (*Teachers*).

“If they get somebody to care for them because they are orphans they are not disabled.” (*Women Groups*).

“There are some orphans who have relatives to help them. So village leaders look for those who really need help.” (*Village leaders*).

Poor health

“They are disabled because he is there and cannot help himself.” (*Teachers*)

“If the child has sickness like sickness of the kidney, the lungs, like that. This can also lead to disability.” (*Women Groups*).

“This is because the sickness will have rendered him useless.” (*Village leaders*).

Punishment from God

“Maybe mother committed adultery with a brother-in-law. This can lead to disability.”

(**Village leaders**).

Evil

“Or calamities from evil spirits. (**Village leaders**).

Witchcraft

“Problems brought by our cultures, like something bad or evil is put on the road, and this mother gets it when pregnant.” (**Village leaders**).

Behavioural

“In class there are some children who are too naughty than others. This is disability.

(**Teachers**).

3.2. Identification of children with disabilities.

3.2. (a). In Kibarani sub-location.

In Kibarani sub-location teachers identified a total of 40 children. 7 children (17.8%) had difficulties in seeing, 1 child (2.5%) had hearing difficulties, 6 children (15%) had walking difficulties, 8 children (20%) had difficulties in learning, 8 children (20%) had difficulties in speaking and 10 children (25%) had epilepsy.

Village leaders identified 25 children in total. 8% of these had seeing problems (2 children), another 8% had hearing problems (2 children), 48% were children with walking difficulties (12 children), 8% had learning difficulties (2 children), another 8% for speaking difficulties, (2 children), and 20% (5 children) had epilepsy.

Women groups identified a total of 34 children. A part from difficulties in seeing which they did not identify any, all the other difficulties had children identified. 8 had problems in hearing (23.5%), 11 had difficulties in walking (32.3%), 4 in learning (11.8%), 1 in speaking (2.9%), and 10 had epilepsy (29.4%), (See table 2).

Table2: Identified children in Kibarani sub-location.

Group	Seeing	Hearing	Walking	Learning	Speaking	Epilepsy	Total
Teachers	7 (17.5%)	1 (2.5%)	6 (15%)	8 (20%)	8 (20%)	10 (25%)	40
Vleaders	2 (8%)	2 (8%)	12 (48%)	2 (8%)	2 (8%)	5 (20%)	25
Wgroups	0 (0%)	8 (23.5%)	11 (32.4%)	4 (11.8%)	1 (2.9%)	10 (29.4%)	34
Total	9 (9.1%)	11 (11.1%)	29 (29.3%)	14 (14.1%)	11(11.1%)	25 (25.3%)	99

3.2. (b). In Konjora sub-location.

In Konjora sub-location teachers identified 35 children in total. Only one child was identified with difficulties in seeing (2.9%). Difficulties in walking had 9 children (25.7%), learning difficulties had 7 children (20%), difficulties in speaking were 7 children (20%), 2 had hearing problems (5.7), and 9 (25.7%) had epilepsy.

Village leaders identified the highest number of children. They identified 66 children. There were 18 children identified with epilepsy (27.3%). Difficulties in seeing had 2 children identified (3%), hearing difficulties 9 children (13.6%), walking had 14 children (21.2%), learning 10 children (15.2%) and difficulties in speaking were 13 children (19.7%).

Women groups identified a total of 37 children. 8.1% (3 children) had seeing difficulties, 2.7% had hearing difficulties (1 child), 18.9% had walking problems (7 children), 35.1%

had problems in learning (13 children), 13.5% had speaking problems (5 children), and 21.6% had epilepsy (8 children). (See table 3).

Table 3. Identified children in Konjora sub-location.

Group	Seeing	Hearing	Walking	Learning	Speaking	Epilepsy	Total
Teachers	1 (2.9%)	2 (5.7%)	9 (25.7%)	7 (20%)	7 (20%)	9 (25.7%)	35
Vleaders	2 (3%)	9 (13.6%)	14 (21.2%)	10 (15.2%)	13 (19.7%)	18 (27.3%)	66
Wgroups	3 (8.1%)	1 (2.7%)	7 (18.9%)	13 (35.1%)	5 (13.5%)	8 (21.6%)	37
Total	6 (4.3%)	12 (8.7%)	30 (21.7%)	30 (21.7%)	25 (18.1%)	35 (25.4%)	138

3.2. (c). In Kibarani and Konjora sub-locations.

A total of 237 children with disabilities were identified in both Kibarani and Konjora sub-locations. These children were expected to be between 9-15 years. The two sub-locations had a total of 3,427 children aged between 9-15 years. From these figures, a disability prevalence rate of 6.92% was established.

Out of the 237 children identified, 6.3% (15 children) had difficulties in seeing, 10.1% (24 children), had difficulties in hearing, 24.9% (59 children) had difficulties in walking, 18.6% (44 children) had difficulties in learning, 15.2% (36 children) had difficulties in speaking, 25.3% (60 children) had epilepsy. Village leaders identified the highest number of children. Then teachers followed. Women groups identified the least. (See table 4).

Table 4: Identified children in Kibarani and Konjora sub-locations

Group	Seeing	Hearing	Walking	Learning	Speaking	Epilepsy	Total
Teachers	8 (10.7%)	4 (5.3%)	15 (20%)	15 (20%)	15 (20%)	19 (25.3%)	75
Vleaders	4 (4.4%)	11 (12.1%)	26 (28.6%)	12 (13.2%)	15 (16.5%)	23 (25.3%)	91
Wgroups	3 (4.2%)	9 (12.7%)	18 (25.4%)	17 (23.9%)	6 (8.5%)	18 (25.4%)	71
Total	15 (6.3%)	24 (10.1%)	59 (24.9%)	44 (18.6%)	36 (15.2%)	60 (25.3%)	237

3.3. Identification of households.

3.3. (a). In Kibarani sub-location.

In Kibarani sub-location teachers identified a total of 29 households. 6 households (20.7%) had children with seeing difficulties, 1 (3.4%) had children with hearing problems, 6 households (20.7%) had children with learning problems, 2 households (6.9%) had children with walking difficulties, 7 households (24.1%) had children with speaking difficulties, and 7 households (24.1%) had children with epilepsy.

Village leaders identified 6 households. They did not identify any household for seeing, hearing and speaking. However 2 households (33.3%) had children with walking difficulties, 1 household (16.7%) had children with speaking problems, and 3 households (50%) had children with epilepsy.

Women groups identified 14. 3 households (21.4%) had children with difficulties in walking, 2 households (14.3%) had children with learning difficulties, and 9 households (64.3%) had children with epilepsy. No households were identified for seeing, hearing and speaking difficulties.(See table 5).

Table 5. Identified households in Kibarani sub-location.

Group	Seeing	Hearing	Walking	Learning	Speaking	Epilepsy	Total
Teachers	6 (20.7%)	1 (3.4%)	2 (6.9%)	6 (20.7%)	7 (24.1%)	7 (24.1%)	29
Vleaders	0 (0%)	0 (0%)	2 (33.3%)	0 (0%)	1 (16.7%)	3 (50%)	6
Wgroups	0 (0%)	0 (0%)	3 (21.4%)	2 (14.3%)	0 (0%)	9 (64.3%)	14
Total	6 (12.4%)	1 (2.0%)	7 (14.3%)	8 (16.3%)	8 (16.3%)	19 (38.8%)	49

3.3. (b). In Konjora sub-location.

In Konjora sub-location teachers identified 35 households. 2.9% (1 household) was for children with seeing problems, 5.7% (2 households) had children with hearing problems, 25.7% (9 households) had children with walking difficulties, 20% (7 households) had children with learning difficulties, 17.1% (6 households) had children with speaking problems, and 28.6% (10 households) had children with epilepsy.

Village leaders identified a total of 52 households. 2 households (3.8%) had children with seeing difficulties, 6 households (11.5%) had children with hearing difficulties, 17 households (32.7%) had children with walking difficulties, 6 households (11.5%) had children with learning difficulties, 11 households (21.2%) had children with speaking difficulties, and 10 households (19.2%) had children with epilepsy.

Women groups identified 31 households. 2 households (6.5%) had children with seeing difficulties, 6 households (19.4%) had children with walking difficulties, 9 households (29%) had children with learning difficulties, 6 households (19.4%) had children with speaking difficulties, and 8 households (25.8%) had children with epilepsy. (see table 6).

Table 6: Identified households in Konjora sub-location.

Group	Seeing	Hearing	Walking	Learning	Speaking	Epilepsy	<i>Total</i>
Teachers	1 (2.9%)	2 (5.7%)	9 (25.7%)	7 (20%)	6 (17.1%)	10 (28.6%)	35
Vleaders	2 (3.8%)	6 (11.5%)	17 (32.7%)	6 (11.5%)	11 (21.2%)	10 (19.2%)	52
Wgroups	2 (6.5%)	0 (0%)	6 (19.4%)	9 (29%)	6 (19.4%)	8 (25.8%)	31
Total	5 (4.2%)	8 (6.8%)	32 (27.1%)	22 (18.6%)	23 (19.5%)	28 (23.7%)	118

3.3. (c). In Kibarani and Konjora sub-locations.

Identified households in the two sub-locations were 167. 6.6% (11) had children with seeing difficulties, 5.4% (9) had children with hearing difficulties, 23.4% (39) had children with walking difficulties, 18% (30) had children with learning difficulties, 18.5% (31) had children with speaking difficulties, and 28.1% (47) had children with epilepsy. (See table 7).

Table 7: Identified households in Kibarani and Konjora sub-locations.

Group	Seeing	Hearing	Walking	Learning	Speaking	Epilepsy	Total
Teachers	7 (10.9%)	3 (4.7%)	11 (17.2%)	13 (20.3%)	13 (20.3%)	17 (26.6%)	64
Vleaders	2 (3.4%)	6 (10.3%)	19 (32.8%)	6 (10.3%)	12 (20.7%)	13 (22.4%)	58
Wgroups	2 (4.4%)	0 (0%)	9 (20%)	11 (24.4%)	6 (13.3%)	17 (37.8%)	45
Total	11 (6.6%)	9 (5.4%)	39 (23.4%)	30 (18%)	31 (18.5%)	47 (28.1%)	167

3.4. Identification of orphans in Kibarani and Konjora sub-locations.

. The number of all the orphans identified in the two sub-locations was 51. This was 1.5% of the total number of children in the two sub-locations aged between 9-15 years. 19.6% of these orphans were identified by teachers and 80.4% were identified by women groups. Village leaders did not identify any. (See table17)

Table 8: Identified orphans in the two sub-locations.

Sub-locations	Teachers	V.leaders	W.groups	Total
Kibarani	10 (30.3%)	0 (0%)	23 (69.7%)	33
Konjora	0 (0%)	0 (0%)	18 (100%)	18
Total	10 (19.6%)	0 (0%)	41 (80.4%)	51

Chapter 4.

4.0. Discussion.

4.1. Perceptions of disability.

The study revealed that the community perceives disability in a diversified phenomenon with a number of different dimensions. It is not only the existence of impairments that constitutes a disability, but also the traditional and social aspects like witchcraft, evil spirits, and punishment from God that affect the normal life of a person. This is resonance with the International classifications of disability and functioning (ICF). Functional difficulties featured in all the three groups of key informants used in the study. Disability was perceived as the existence of impairments, activity limitations and participation restrictions. “But he has very big elephantiasis that he cannot walk.” (FGD, Women Group, Kilifi). “The consciousness is taken away, becomes a child who does not even understand himself. He drools.” (FGD, Village leaders, Kilifi). What was not clear from the discussions was whether the groups were aware if the environment influenced all these aspects.

Teachers felt that behavioural problems should be categorised as a form of disability. “*In class there are some children who are too naughty than others. This is disability.*” (FGD, Teachers, Kilifi). Village leaders regarded that as lack of good manners that could be dealt with by the police. . “*This is not disability. It is bad manners. Lack of good manners deserves the child to be sent to the police.*” (FGD, Village leaders, Kilifi). This is suggestive that teachers make keen observations on the behaviours of children as they

teach them. It can be argued from that information that children with behavioural disabilities could be mistaken from undisciplined ones.

Epilepsy was regarded as a disability in all the discussions. This could have been as a result of the conflicting perceptions people have towards epileptic persons in the community. These included regarding epilepsy as contagious, caused by evil spirits or witchcraft. However the results of the study suggests that it is the effects of the epilepsy that determines whether a person is disabled or not. Active epilepsy could lead to speech deficits to a child, (Carter et al, in press). This further suggests that if the fitting could be controlled, then effects of epilepsy would be minimised greatly, hence reducing the chances of the child becoming disabled.

Orphans without help were a new category of disabled children. It was clear why women groups and teachers thought this group of children was disabled. However this could possible signify a disaster in the community that is killing both parents. As a result the social welfare of these children is at stake and therefore their normal lives are affected. This could have possible led to the people in the community to revisit their way of thinking regarding the orphans. *“Those who are not well fed, they go to school without breakfast, no lunch. You will find that their growth is not normal.”* (FGD, Teachers, Kilifi).

Village leaders and women groups thought disability was incurable. “*He is deaf and he will ever be deaf.*” (FGD, Village leaders Kilifi). “*You will take the child to a witch doctor or a medical doctor, but the child is the same.*” (FGD, Women groups, Kilifi.) The teachers did not come up with this ideology. This suggests that the less educated people in the community perceive disability as incurable, as punishment from God, evil spirits or witchcraft. According to government of Kenya census (1999), 65% of Kilifi population is illiterate. This could suggest that majority of the people in the community are tied down by cultural beliefs, traditions, and superstitions.

4.2. Identification of children with disabilities.

4.2. (a) The rigour of PRA.

The results revealed an overall prevalence disability of 6.92%. This suggests that PRA could be achievable in the identification of disabilities in the community. This study had a higher prevalence than the study of Shyma (1999) done in India that had 6.7%. The house-to-house carried out in Kilifi (Mung’alla, 2004) had a prevalence of between 5-7%. The PRA study was comparable to the Kilifi survey. But an important factor that enhanced the quality of information obtained in the PRA was group dynamics, particularly cohesiveness and the ability of coming to a consensus. This ingredient was not reflected in the Kilifi survey. Similar dynamics were reflected in Shyma’s study (1999).

Considering the time span of the PRA study that was two months, it could be argued that this approach could be a fast method of screening disabilities in rural areas in the

majority world countries. The Kilifi survey was carried out for one year before any results were realised. This could be a long time for people who are already overburdened. The fastness of the PRA was highlighted in the study of Shyma (1999).

One person did the PRA study in two months. The Kilifi survey was carried out by a total of 10 fieldworkers in twelve months, (Kilifi database). Basing on calculations, one child in the Kilifi survey cost about \$7 (calculations from Kilifi survey). This evidence could possible suggest that PRA is cheap to carry out in the community. Shyma (1999) also sighted the cost-effectiveness of participatory approach in his comparative study between RRA and a house-to-house survey method.

4.2 (b). Feedback

After every PRA activity participants could be heard commenting, *“This is our own work. So we can identify them and then put them on a map.”* (Social mapping with village leaders, Kilifi). Such comments could possible suggest that PRA gave participants a sense of ownership and empowerment. These are vital elements when it comes to community participation in disabilities issues. Uzoichuku (2004) highlighted similar arguments. This emphasises the fact that giving feedback of the study to the participants gives them a sense of achievement and success.

4.2. (c). Comparision of key informants.

The results revealed that certain disabilities are easily detected at school while others could be noticed at homes. In both Kibarani and Konjora sub-locations, village leaders identified more children with difficulties in walking than the other groups. (Tables2 & 3).

The total number identified was 59 children. Out of this number village leaders identified 26. (Table 4). This could possibly suggest that many children with difficulties in walking are not going to school.

Teachers identified more children with difficulties in seeing than village leaders and women groups. (Table 4). This could imply that seeing is a very important element in the learning process. This could also suggest that difficulties in seeing are hardly noticed at homes.

Village leaders and women groups identified more children with hearing problems than the teachers. This suggests that many children with hearing difficulties are not sent to school. Hearing difficulties being a hidden disability, those who are in close contact with the children will be in a better position to identify them. (Table 4)

All the groups identified children with learning difficulties in almost equal proportion. This suggests that this type of disability is very common in the community. It can easily be noticed by almost everybody.

Teachers and village leaders identified equal number of children. Women groups identified the least. Possible explanations for this could be that many children with speech problems are in school. It can also be argued that village leaders take great concern in aspects that affect the child.

Children with epilepsy were identified by all the groups in almost the percentages. (Table 4). This could possibly suggest that epilepsy is a common problem with children in the community.

Village leaders identified more children than the other two groups. From this evidence it can be argued that village leaders could be a better group to use in the community in terms of identifying children with disabilities. (Table 4).

In the identification of households, teachers identified more households than the other groups. This could possibly suggest that teachers take the responsibility of knowing the homes of the children they teach. It could also suggest good relationships between the parents and the teachers do exist. This could further suggest that teachers could be a good key informant group to use in locating the children and in follow-ups with service initiatives. (Table 7)

4.2. (c). Proportion of children identified.

25.3% of the children identified in Kbarani and Konjora sub-locations had problems of epilepsy. This evidence suggests that fitting could be very common amongst children. It could possibly be attributed to the fact that the area is prone to malaria, (Mwangi, 1997).

24.9% had difficulties in walking. It can be argued that many children encounter incidences that leave them with difficulties to walk.

The area has few children with difficulties in seeing (**6.3%**). This suggests that diseases that cause problems in seeing are quite rare in the community. Children with learning difficulties are quite many (**18.6%**), speaking **15.2%** and hearing **10.1%**. This evidence suggests that a number of disabilities exist in the community. (Table 4)

4.2. (d). Orphans.

A total of 51 orphans were identified in the two sub-locations. This was equivalent to 1.5% of children aged between 9-15 years. Women groups identified **80.4%** of these children. (Table 8). This evidence suggests that the issue of orphans is now becoming a matter of concern in the community. It can further be suggested from the evidence that women are more bothered by the orphans than the men.

4.3. Limitations of the study.

The following were some of the study limitations:

- a) Verification of the children identified was not carried out, though identification of households was carried out to make sure same children were not identified by different groups. Verification was necessary for confirming their ages.
- b) The researcher did all the focus group discussions and social mapping alone. There is a possibility that some important non-verbal information could have passed unnoticed by the researcher. Non-verbals in PRA help the researcher to distinguish from genuine and honest points from the false ones.
- c) Geographic bias: the two sub-locations used were in close proximity to the Kenya Medical Research Institute (KEMRI) unit. Given that it is a major service provider with a lot of impact on the community, maybe participants from far away would have different perceptions of disability.
- d) Need to be done in more sub-locations

Chapter 5.

5.0. Conclusion.

This study addressed the question: “Can PRA be used in the identification of children with disabilities?” Asking this question meant finding out whether people in the community could be used in the identification of children with disabilities.

The results of the study reveal that people in the community are aware of the existence of children with disabilities. The perceptions of disability have diversified interpretations. This would range from functional difficulties, epilepsy, orphans without help, poor health, and punishment from God, evil spirits or witchcraft. It was all perceived as activity limitations and participation restrictions.

The results also suggested that some perceptions of disability were influenced by the social beliefs in the community, (Helander, 1999), or the nature of the people’s job. Teachers felt that excessive unbecoming behaviour in children was a form of disability. On the other hand village leaders thought unbecoming behaviours in children could be dealt well by the police.

Epilepsy was perceived by all the groups as a form of disability. However it was the effects of epilepsy that brought disability. If fitting could be controlled, then the effects of epilepsy could be minimised.

Orphans without help formed another group of disability. This was a new group of disabled children. This indicates that the community is now coming up with new perceptions of these children.

Disability was also perceived by village leaders and women groups as incurable. This highlights the issue of disability being permanent.

In the use of PRA in the identification of disabilities, the results revealed that the approach could be used in the identification of disabilities. It is a cheap and fast method of screening disabilities in a rural setting with limited facilities.

Village leaders in Kilifi were found to be in a better position in the identification of children with disabilities than either teachers or women groups. These results suggest that the village leaders could possibly be the best group as regards issues pertaining to disabilities. But all the groups are needed to get the coverage of the different perceptions of disability.

In conclusion, it is clear in relation to the findings of Shyma (1999) that it is true that PRA is achievable in the identification of disabilities in poor resource countries. It achieves a similar prevalence rate, and it is cheaper and faster. It is also acceptable in the community as all the groups took part without any shortcomings. In recognition to this are the following recommendations:

- I. That, PRA could be used in the identification of disabilities in poor resource countries.

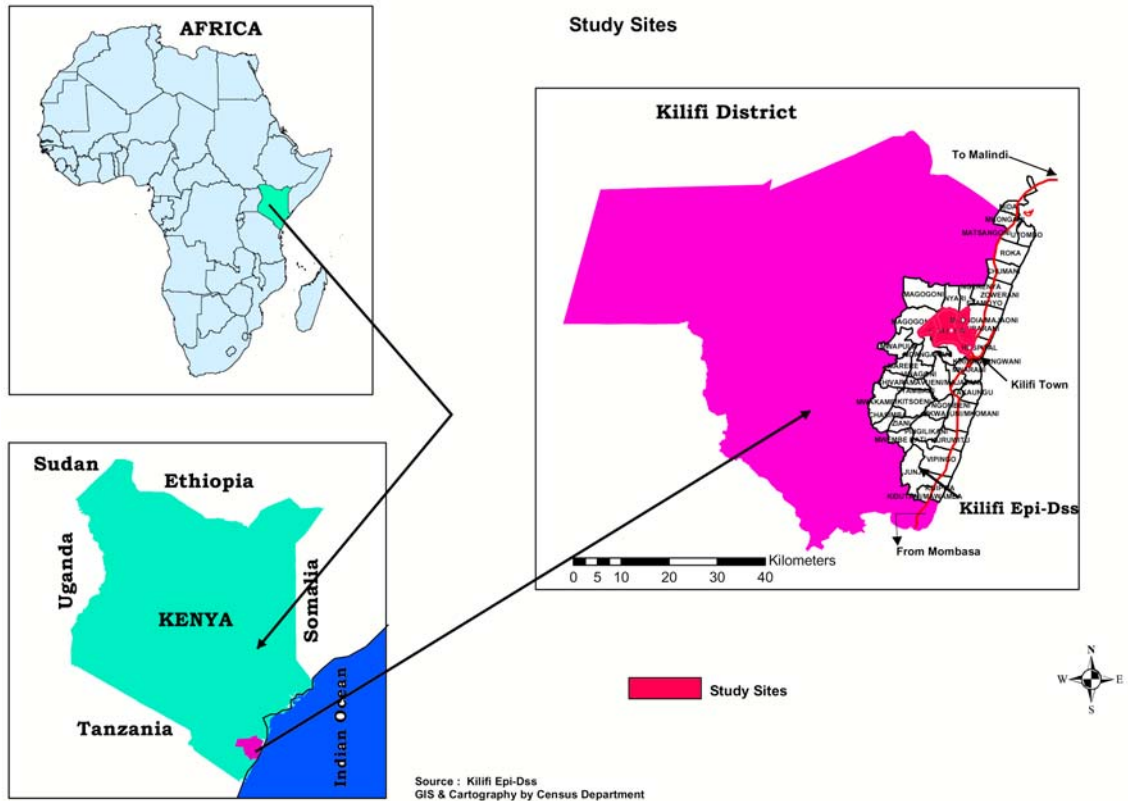
- II. Perceptions of local people on disability should be regarded as a base for disability encounter because disregarding them could mean cutting off the community from disability programmes.

The following are suggestions for further research:

- A study using children and youth groups as identifiers using PRA. This is because in some schools teachers had to ask pupils where disabled children lived.
- Making a comparison between the children identified in this study and those identified in the Kilifi NI study. This is to establish the rigour or to make a distinction between an impairment approach and a social approach.

Word count: 11,540

The Study Site



Appendices:

Appendix 1: Checklist for focus group discussions with village leaders/teachers/women groups:

Introduction:

- Greet the participants.
- Introduce myself.
- Show interest in the participants.
- Give participants background information about the study.
- Give information about the focus group discussion.
- Assure the participants that they do not have to participate if they don't wish to
- Ask for their approval to participate.
- Assure participants of confidentiality.
- Ask for the participants' approval to record the interview on the tape.
- See if the participants have any question to ask before the discussion.

- Check that the equipment is working well.
- Start the focus group discussion

Check list of questions:

- What do you think are the perceptions of people in the community as to what constitute a disability?
- What are your own opinions on what makes one disabled?
- Do you have anything else to add?

Appendix 2: Checklist for Social Mapping with teachers/village leaders/women groups.

Introduction

- Greet the subjects.
- Introduce myself.
- Show interest in the group by establishing good rapport with the group.
- Give background information about the study.
- Give the subjects information about the social-mapping.
- Assure the subjects that they are free to participate and free to leave anytime they feel like.
- Ask for the subjects' approval to participate in the social-mapping.
- Assure them of confidentiality.
- See if any has a question to ask.
- Start the social-mapping.

The social-mapping.

- You will map your sub-location using sticks/white wash/stones/etc.
- Then you will name all types of disabilities you know.

- Then you will identify children with these disabilities and place them in their respective homes on the map.
- You can discuss amongst yourselves till you come to a consensus, and then you place the child in his/her correct home.

Summing up:

- Now we are going to put this information on a chart.
- Ask if subjects have anything to add.
- Make a quick check to make sure all points are covered.
- Reassure of confidentiality.
- Thank the group.
- Greet them and leave.

Appendix 3: Information sheet for community leaders, teachers and women groups:

I am working at KEMRI and Joseph Gona is a student in London but comes from this area. We are very much interested in finding an easy way of identifying children with disabilities which will involve people from the community.

Therefore, we intend to use you people in identifying these children with disabilities in this sub-location. It is going to be through discussions and activities. The information you will give us will be given to KEMRI and other organisations that carry out services for children with disabilities.

As such, we would appreciate your participation very much. If you agree to participate with us, we will have a discussions and activities for about one hour, trying to identify these children with disabilities in this locality. Anything you tell us will not be shared with anyone except the research assistant and the researcher.

You can choose not to participate if you do not wish to. Even if you participate, you can drop out anytime you feel like.

Is this clear to you? Do you have any questions? Do you agree to participate in the project?

Appendix 4: Identified households:

Ali Kahuzo
Bahati Baya
Bandiko
Baraka Kaingu
Baya Mweri
Baya
Yaa
Bemhac
he
Biganga
Bobo
Chadi
Chai Mangi
Charo Kakuro
Charo Jefwa
Charo Magaba
Charo Mwaboma
Charo Mwangaba
Charo Mwzani
Charo Paka
Charo Polisi
Charo Shuhuli
Charo Thubu
Chengo Mangi
Chifu
Choloto
Daniel
Daniel Chengo
katana
Daniel Kongo
Dena
Dengere
Dogo Masha
Geji
Balози
James
Jane Kazungu
Joh
Kanuni
John Mwanongo
Jumwa Kalama
Kabulo
Kabwere

Kadenge Andrea
Kadenge Mangi
Kahindi Katoshi
Kahindi Kindi
Kahindi Konde
Kahindi Ngala
Kahindi Ngasi
Kahindi Simu
Kahindi Thoya
Kaingu Baya Mulu
Kaingu Kalu
Kaingu Katana
Kalama Nguma
Kalume Karisa
Sheti
Kamang
a
Kani
Kani Mwarandu
Kanjabi
Kanyenz
e
Kanze Gunga
Karisa
Karisa Bindundi
Karisa Charo
Karisa Jambo
Karisa Kalama
Karisa Kalu
Karisa Kalume
Karisa Mwakiru
Karisa
Mwambogo
Karisa Mwanzani
Karisa Nzai
Karisa Thethe
Kasiwa Mwakiru
Katana Budza
Katana Kitsao
Kimutu
Katana Mautu
Katana Mangi
Katana Mingonyo
Kazugu Karisa
Kazung Bigili
Kazungu Gombe

Kazungu Karisa
Kazungu Mrimi
Kazungu Omar
Kenga Makitu
Kenga Mwanzala
Kenneth Kalu
Kenyatta
Kimanje
Kimburu
Kimtu
Kipu Karisa
Kiru
Kithethe
Kithi Kombe
Kitsao Kahingo
Kitsao Kajilo
Kitsao Kenga
Leso
Luwali Mweni
Mangi
Mapenzi Gambo
Mbogo Konde
Mbosho
Mbura
Mbura
Moses Kambi
Mote
Msuko
Mtengo
Mwalimu Fungo
Mwalimu Fungo
Mwana Kafadzi
Mwend Hariri
Mwenya
Nafuu
Ndala
Ngasi Mrimi
Ngonyo Ndungo
Ngowa
Ngumbao Fondo
Ngumbao Kahathi
Nzai
Nzovu Maitha
Omar Kagozi
Rajabu Selemani
Rashid Katana

Mbeo
Safari Bangili
Safari Bigiri
Samuel Ngala
Simba
Tabu Unda
Chogo
Thimothy Mbura
Thoya
Thubu
Toi
Shilingi
Tsori
Tsuwi
Chai

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