

# **WOMEN IN ACTION**

**Improving the quality of disabled children's lives**

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## **DEDICATION**

This book is dedicated to Mrs. Maria Kangere of COMBRA, Kampala, Uganda. Maria devoted her working life to improving the lives of disabled people and their families in East Africa. She set up services and training for people from all over the continent and was engaged in research in disability until just before her death in 2005. She was forthright, determined and persevering in her approach. This inspired many people, particularly other women.



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## FOREWORD

The power of women to change situations within their communities and throughout the world is being seen in all walks of life, from the political achievements of women in Afghanistan to the impact on agricultural output of educating women in food production. The potential power of women in the field of disability is still in its infancy but this publication gives many practical ideas about how this might be achieved and as such is a great addition to the disability literature.

The book may be small but it represents a great deal of work on behalf of women's groups, disabled people's groups, parents of disabled children and health professionals in Kenya. This powerful alliance is reflected in the balance of the output, which addresses communication disability in a holistic way, catering for a wide range of issues related to disablement. It is interesting to see that the result is not a prescriptive work but one that allows the reader to engage in the process. It provides the structure for this to be repeated within other settings. The result is a book to guide community workers on how they can facilitate a similar process in their own communities.

This book represents the ideas of the local community on how to support disabled children and their families and provides a very useful starting point for other women's groups who want to improve the quality of life of disabled children in their own communities. The process described can assist in establishing community led action for disabled people in resource poor areas of the world.

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The Centre of Geographic Medicine and Research in Kilifi, particularly the Director, Dr. Norbet Peshu for hosting this programme, and Dr. Charles Newton for providing research guidance and support with data collection.

All the women's group members and members of the other community groups involved in the research programme. Their participation with the researchers generated the ideas in this book and ensured the activities suggested are based on the perceptions and needs of this community.

The Berkley Trust, UK for the funding that has enabled us to publish this book at low cost and distribute it to disabled people and community workers throughout Africa.



## INTRODUCTION

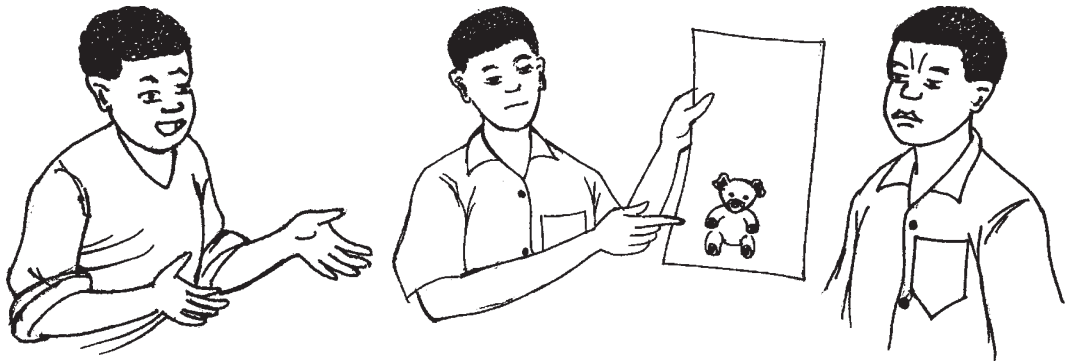
In every community, between 5% and 10% of children have some kind of impairment. They may have impaired hearing, sight, physical or mental abilities. Specialist services to support them and their families are usually based in large towns, that are inaccessible to the majority of children who live in rural areas. In such areas there are often community programmes and these programmes can do a lot to help such children. This book aims to provide ideas on ways in which communities can help support such children and their families.

This book is a collection of ideas for improving the lives of children with disabilities who have problems with communication. The book contains information, suggestions and examples to help and encourage families to include their disabled child in family activities and to improve his/her communication and quality of life.

Communication involves sending and receiving messages between people. We communicate in many different ways, mainly through using languages, which may be spoken, written or signed.



Other non-linguistic ways of communicating include gestures, pictures, body language and facial expression. Communication is much more than just speech.



We communicate for many reasons. To learn. To give and receive information. To let other people know our needs and feelings. When we communicate with other people, we build relationships with them.

All people communicate. Communication starts at birth when a baby cries and the mother responds, long before the child starts to talk.

A child learns language and communication skills by:

- having someone to communicate with.
- getting a response when he/she communicates (eg. by crying, pointing at something, saying something).
- experiencing language in everyday situations.
- hearing words spoken, or seeing signs/gestures/pictures.
- having the chance to use words, signs, gestures or pictures himself/herself in different situations.



Children with disabilities all attempt to and need to communicate, just like other children. Some children use speaking and others have different ways of communicating such as using signs or pictures.

Problems with hearing, learning or moving, sometimes mean that children have difficulty communicating. They may find it difficult to understand other people. Sometimes, other people have difficulty understanding them. Some families work

out different ways of communicating with their child, such as signs and gestures. Other families don't know what to do. They may face many problems. Here are some examples in the box below.

### From experience

#### Messages from women in a Kenyan community

##### Bearing the burden alone

*"With a normal child, you cannot always get someone to help share the responsibility but with a disabled child, it is even worse. Sometimes, even your own mother will not accept a disabled grandchild."*

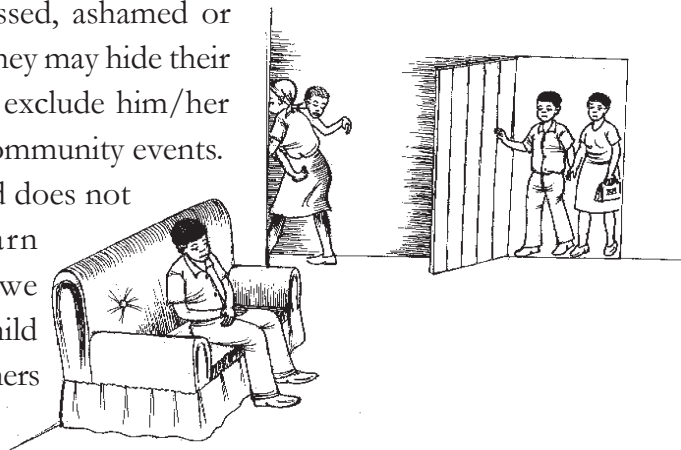
##### Facing gossip and social isolation

*"We used to have a child in our village who couldn't walk or talk. Nobody would associate with the mother; no-one would even share her utensils. The other women in the household would talk about her and others would later tell her what had been said. She was so depressed and eventually decided to move away."*

##### Facing family expectations or divorce

*"There is one man whose wife gave birth to a crippled child. He asked her 'Where does this disability come from? Do you have disability in your family? Because from mine, there is no-one with a disability'. Second time, the woman gave birth to a child who could not talk. This man sent his wife back to her parents together with her disabled children and got married to another wife."*

Some parents feel embarrassed, ashamed or worried about their child. They may hide their child away from visitors or exclude him/her from family activities and community events. This can mean that the child does not get the chances to learn communication skills as we described earlier. Also, a child who has little contact with others will be unhappy or lonely.



We have written this book for people who work in the community and come into contact with women's groups and children with disabilities. It aims to give ideas about how community groups, women's groups in particular, can help disabled children achieve better communication and so improve their quality of life. You may be wondering why we chose women's groups.

Women's community groups are common in towns and villages throughout Africa. Also, women have the responsibility of caring for children, including those who have disabilities. Women have the ability and opportunity to understand and communicate ideas effectively to other women. However, this is not meant to exclude other groups or individuals. Other community groups, community leaders or parents may find parts of this book helpful.



We have developed the ideas in this book in rural Kenya. We worked with women's community groups, to try to improve the communication ability and quality of life of local children with disabilities. We developed the programme using information from interviews, focus group discussions and workshops with women's groups and disabled and able members of the community. We also used information collected in previous projects in Uganda and Zimbabwe.

The book has four sections. First, there is a section explaining the theoretical background to the sessions. This is written for people who have a particular interest in the theory. It is not essential for understanding the rest of the book, but provides the theoretical information that supports and underpins the approach we describe. It is written primarily for people who have a background in communication and its breakdown. The second section explains how this manual can be used. The third section and main part of the book gives a detailed description of the group meetings.

The aim, objectives and desired outcome for each meeting are described. We have aimed to allow flexibility in the content of each session, so that facilitators can respond to the needs of particular communities. The fourth section of the book has examples and ideas, which can be used if the facilitator so chooses. In addition, we have included short stories (vignettes) and different scenarios, based on real life examples of how the groups in Kenya used the meetings.

The authors hope that the book will provide inspiration and practical help to women's groups and to other community groups throughout Africa and enable them to make their own contribution towards improving the quality of disabled people's lives.

*Note: All the names used in this publication are fictitious, but they represent the ideas and experiences of real people.*



## SECTION 1

# THEORETICAL BACKGROUND

Communication is recognised as an essential component of social, cognitive and emotional growth (Clarke and Clarke 1997, Kaiser 1993, Johnson et al, 1996, Aitchison 1996) and is classed as a 'basic human need', following closely behind food, shelter and safety (Mendis, 1993; MaxNeef, 1995; Helander, 1993).

Surveys in Pakistan (Miles, 1985), Uganda (Hartley, 1997) and Zimbabwe (Ministry of Health, Zimbabwe, 1997) indicate that up to half of all children with disabilities living in majority world countries, have communication problems. Often, these children live in rural areas, come from very poor homes and have little access to health and education services or community development programmes. Hartley and Wirz (2002) comment that specialist health services are often located in urban centres and that despite the introduction of community based rehabilitation, less than 2% of disabled people receive any services or support, other than from family and the local community.

The basis of participatory and community based rehabilitation methodologies is the recognition of a gap between the concepts and models used by professionals to interpret reality and those of different groups in the community. There are numerous cultural, historical, socio-economic and political factors that have a crucial influence on efforts to improve people's health. De Koning and Martin (1996) comment that these factors are often not apparent to outside professionals. In contrast, members of the community - the very people affected by social conditions - can use their intimate familiarity with their environment, their knowledge of one another as members of a community and their critical consciousness that their lives can change for the better, to arrive at satisfactory solutions to problems (Park, 2001). Myers (1995) comments on the importance of the knowledge base of the



local community: "...an unsystematic cultural accumulation of experience through trial and error over generations if not centuries...time-tested, rather than experimental knowledge" (p323). The rationale behind these methodologies is particularly applicable to the case of communication disability, which results from a breakdown between an individual and their social or physical environment (Hartley and Wirz, 2002). If these factors are to be effectively addressed, families and communities need to have a directive role in rehabilitation.

### **Communication Disability**

Is a response to an impairment (such as impaired hearing or seeing) together with a response to social and contextual factors (such as whether the person is spoken to or included in society). These factors interrelate with each other and the person themselves and can result in limited communication skills, ability and opportunity.

In this programme, we worked with women's community groups, which are active in Kenya and many other majority world countries. Such groups usually focus on income-generation. In many cultures community leadership is male-dominated while women work in the house, on the land and act as nurturers to the family. In situations where a member of the family has a disability, women are known to be the primary caregivers who dedicate their lives to providing care. Peat (1997) emphasises the value to CBR programmes of acceptance at the grassroots level by women caregivers and community groups, as a basic level support base.

In addition to the strategic role of women, there are few services for children with disabilities in many countries, emphasising the need to use existing strategies if results are to be practicable and sustainable. In the area on which this book is based, there are 900 women's groups, many of which have been active for several years and have already acted as positive forces for change, in the financial and social lives of the community.

## **From experience**

### **Examples of the positive force of women's groups**

#### **Through income generating activities**

The 29 women in the one Women's Group were given 12 cows and decided to start a heifer project. The individuals given the original 12 cows cared for them and when they calved, distributed the animals to other group members until each member owned a cow. The group has arranged training sessions on how to care for the cows and on how to both use and sell the milk to support their families.

#### **By registering with community development organisations where they learn skills and techniques to improve their living standards**

The 25 women in the Zowerani Farmers Field School Women's Group started in 1999, with the aim of researching which types of maize grow well on the coast. They approached the Kilifi District Development Programme (KDDP) for training in research and growing techniques. From experiments with four varieties of maize, the women were able to establish which one has the greatest yield and highest quality.

#### **By empowering other community members**

The women from the Zowerani Group set up demonstration plots where they have grown seedlings from different types of crops for community members to buy. The women give each potential buyer training on how to grow the crops, thereby spreading the knowledge they have acquired.

Park (2001), states that participatory action involves people engaging in three different kinds of activity. Firstly, inquiring into the nature of the problem by understanding its causes and meanings, secondly, getting together by organising themselves as community units and thirdly mobilising themselves for action, by raising their awareness of what should be done. For this reason, gathering and analysing necessary information, strengthening community ties and sharpening the ability to think and act critically, emerge as three important aims.

Heron and Reason (2001) describe 'four ways of knowing', differentiating them from the traditional view of 'objective' knowledge. These are *experiential, presentational, propositional and practical*. Experiential knowing, describes knowing through the immediacy of perceiving, as the result of a direct encounter with a person, place or thing. Presentational knowing is the product of experiential knowing and provides the first form of expressing meaning and significance through forms of imagery such as stories, music, drama or painting. Propositional knowing is knowing through ideas and theories, expressed in informative statements. Finally, practical knowing is knowing *how to* do something, usually expressed as a skill or competence. The importance of using all four ways of knowing is that if knowing is grounded in our experience, expressed through our stories and images, understood through theories that make sense to us and expressed in worthwhile action in our lives, then any action taken is more valid.

How the work is presented is as important as what is actually done and we aimed in these meetings, to reflect the different types of knowledge and methods of learning described earlier. Although learning is generally thought of as occurring when one person passes knowledge - verbally or via written communication - to another, many approaches may be required to ensure that the learning experience is both productive and empowering, for those involved.

Tolley and Bentley (1996) describe how the use of non-canonical approaches, such as visual or diagrammatic methods can shift the ownership of data from proprietary (owned by the facilitators) to shared, allowing equal participation between literate and non-literate group members. De Koning and Martin (1996), add that by making things easily understandable, critical reflection is enhanced in the group and can facilitate the communication of sensitive or emotional issues that cannot easily be shared verbally. This is not to say that verbal sharing of information and knowledge is inappropriate. On the contrary, dialogue is an important methodological link between activities, because of its existential significance for human life (Park, 2001). Dialogue makes it possible for participants to create a social space in which they can share experiences and information, create common meanings and forge concerted actions together.

In this way, the constituent parts of the group form a much larger common entity of thinking and feeling beings. The learning approaches used in the sessions are based on the theoretical concepts described here and are presented in the next section.

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# Notes

## SECTION 2

### HOW TO USE THIS BOOK

This book is designed to be a resource of ideas. The ideas can be adapted in different ways according to the needs of different children and different communities. The meetings described were conducted weekly with existing women's community groups, however they could be adapted to a timetable convenient and appropriate to the group's situation. The meetings described in this manual can be used in the sequence and manner they are presented from beginning to end. Equally, facilitators can choose to use individual sections of the manual or just some of the ideas for their own programmes.

*How* you do the activities described in this book matters as much as *what* activities you do. Different kinds of knowledge are needed for action. Different group



members may learn and contribute best, in different ways. For example, some people learn best by watching someone do something. Other people learn best by trying something themselves. Members of a group will learn and develop effectively if they are allowed to participate in different ways to different learning activities. The activities in this book represent examples of opportunities for four different ways of learning:

- experiential learning: watching and doing, a first-hand encounter.
- presentational learning: represented through drama.
- propositional learning: ideas and theories.
- practical learning: how to do something, a skill.

*Note: Read section 1 for more information on this.*

In Section 3 of this book, there are three parts. Part 1 relates to background information, part 2 finding the children and part 3, strategies for helping children with disability. The activities are presented in the order that was used in our study, but can be used in another order if the facilitator thinks it's appropriate (eg. if the women think there are no disabled children in the area, they could do part two first, about finding the children).

Each meeting is described in Section 3. This information is linked to the same meeting in Section 4 where ideas for the activities which were used in Kenya are described. These ideas can be used alone or together with other ideas from the resources suggested on page 62. They can also be adapted to the local situation.





# Notes

## SECTION 3

# MEETINGS WITH THE WOMEN'S GROUPS

## PART ONE: BACKGROUND INFORMATION

We communicate for many reasons. To learn about things. To give and receive information. To let other people know our needs and feelings. When we communicate with other people we build relationships with them. This process affects our quality of life. Some people cannot communicate well, due to, for example, impaired hearing, impaired brain function or impaired motor movements. This often makes them feel rejected and lonely.



### Meeting 1

**Aim:** To introduce the idea of taking action to improve the quality of life of disabled children to the group. To establish whether the group is interested in participating to this end. To raise awareness about communication disability.

**Objectives:**

1. Tell the group about the idea of taking action to improve the quality of life of children with disabilities.
2. Introduce and discuss the idea of communication disability.
3. Establish whether the women want to work together to take action.

**Desired outcome:** To stimulate interest and enthusiasm in the group for community action.

**Methods:** Focus group discussion; consensus agreement.

**Materials:** One or two balls of different sizes (if using the demonstration described in Section 4, page 63).



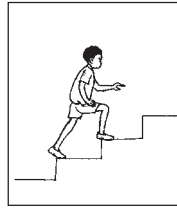
## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Ask each woman in the group (including the facilitator/s) to introduce herself to the other group members. Then, introduce the idea of taking action to improve the quality of life of children with disabilities. In your introduction, include the following points:

- The proposed action is for children with disabilities, particularly children who cannot speak or communicate well.
- We are looking for groups in the community who would like to work towards making these children's lives better. We would like to work with you to improve the communication skills and quality of life of children who have communication problems.
- If you agree to work with us, we will first, have a series of meetings so we can share ideas and experiences and work out a plan of action. There will be 16 meetings altogether. Each meeting will take about 1 hour 30 minutes. During each meeting, we will share with you some ideas and skills that might help children with disabilities. We will have discussions and demonstrations, so we can come up with suggestions about how we can help these children and their families.
- What do you think about this? Are you interested in working with us?

*Note: If the group agrees to participate in the community action, proceed to 'Steps'. If the group does not agree, discuss why they feel unable to participate. Then, thank the group members for their time and close the meeting.*



## Steps

1. Ask the group members if they know about any children who have disabilities. Which of these children have communication difficulties? Spend time discussing these children and the types of communication problems they have.
2. Give demonstrations of what is communication and different barriers to communication. Demonstration ideas can be found in Section 4 on page 63.
3. Continue the group discussion. Focus on the problems and barriers faced by children with communication disabilities.
4. Continue the group discussion. Focus on the problems faced by the parents of children with communication disabilities.
5. Split into small groups (about 4 women per group). Ask them to discuss problems that might be addressed by the women's groups and examine the feasibility and possible effects of the different ideas suggested by group members. Each group elects a spokeswoman to report their ideas back to the whole group.

### From experience

Most people like to participate, but if some would prefer not to, it is OK to let them go. Occasionally, we heard the following views:

*"Visiting these people is time consuming because it will take the whole day for no payment. I could use this time to do my business: get some coconuts and sell them to get food for my children. I am sorry to tell you that I am pulling out of this commitment."*

*"If we could be given a small packet of maize flour after visiting the homes, that would be better."*

6. Return to the whole group. Each group in turn, reports back their ideas.
7. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



## Meeting 2

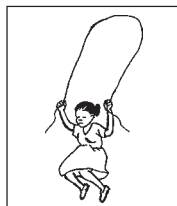
**Aim:** To develop the group's understanding of communication disability.

- Objectives:**
1. Explore the group's understanding of communication.
  2. Generate common words meaning **communication** in the group's mother tongue.
  3. Explore the group's understanding of factors that promote good communication.
  4. Explore the group's understanding of the factors that hinder good communication.
  5. Explore the group's understanding of communication disability and its causes.

**Desired outcome:** The group understands what is meant by **communication disability**.

**Methods:** Focus group discussion; role plays; role models.

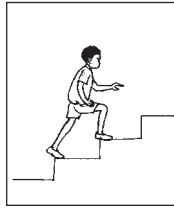
**Materials:** None.



## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current session, saying that today the group will look at what **communication** and **communication disability** mean. Say that this will be done by group discussion and role plays.



## Steps

1. Split into small groups (about 4 women per group). Discuss what each group member thinks is communication. Each group elects a spokeswoman to report their ideas back to the whole group.
2. Return to the whole group. Each group in turn reports back their ideas.
3. Group discussion about common words that mean **communication** in the mother tongue of the group members. The group produces a list of agreed terms.
4. Split into small groups again. Ask half of the groups to discuss the skills necessary for good communication. Ask the other half to discuss factors that hinder communication. Each group elects a spokeswoman to report their ideas back to the whole group.
5. Return to the whole group. Each group in turn reports back their ideas. Concentrate on skills necessary for communication first, then factors that hinder communication.
6. Group discussion about what is **communication disability**.
7. The facilitators give demonstrations of what can cause communication disability. Demonstration ideas can be found in Section 4 on page 67. After each demonstration, invite the group to discuss what they think the demonstration was showing.
8. Invite group members to give their own demonstrations about what can cause communication disability. The group discusses each demonstration. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



## Meeting 3

**Aim:** To sensitise the group to people who have a communication disability. To introduce the value of other modes of communication, such as sign language.

*Note: We invited a deaf people's group to participate in our session. You can invite any local group for people who have communication problems, for example, people with physical impairments or visual impairments.*

- Objectives:**
1. To give participants the opportunity to meet and interact with people who have communication disabilities.
  2. To raise awareness of the problems faced by people with communication disabilities. To give participants the opportunity to hear first-hand, how people with communication disabilities feel about the issues they face.
  3. To raise awareness of the ways in which people with communication disabilities overcome their problems.
  4. To raise awareness of the positive contribution people with communication disabilities can make in the community.
  5. To give participants the opportunity to experience using another mode of communication.

**Desired outcome:** The group appreciates that children who have communication problems are equal human beings. The group appreciates that these children can grow up to make a positive contribution in the world.

**Methods:** Joint meeting with local group for people with communication disabilities (eg. for people with hearing/visual/physical impairments).

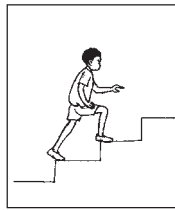
**Materials:** None.



## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current session by welcoming and introducing the group for people with communication disabilities. Say that the group has joined the meeting to explain the kinds of problems they face. Say that they will also contribute ideas about what women's groups can do to help children with communication problems.



### Steps

1. Invite each member of the guest group to introduce him/herself to the other group members. Provide an interpreter for group members who use sign language.

2. Invite the whole group to play an ***introduction game***. The aim of the game is for members of the women's group to communicate something about themselves to the guest group using a method of communication appropriate to the visitors. Instructions for the game can be found in Section 4, page 69.





3. Have an open question time. Members of the women's group have the opportunity to question the visitors.
4. Invite several members of the guest group to describe their experiences of communication disability. Ask each volunteer to include details about the problems they have faced, how they have overcome these problems and what they think women's groups can do to help children who have communication problems.

### From experience

#### Comments from deaf women on the problems they face

*"My sister used to mistreat me, overworking me with all of the household duties... I completed standard 8 and asked for money to go to college but she said there was no money."*

*"Some fathers even want to kill these [deaf] children and don't like having to buy food or clothes for them."*

*"Deaf people can go to school and acquire all of the same certificates as those who can talk but when it comes to getting jobs, only people who can talk get the opportunities."*

#### Comments from deaf women on how they have overcome their disability

*"You can marry, have children and end up with a good life... I am about to get married in December of this year, so I welcome all of you!"*

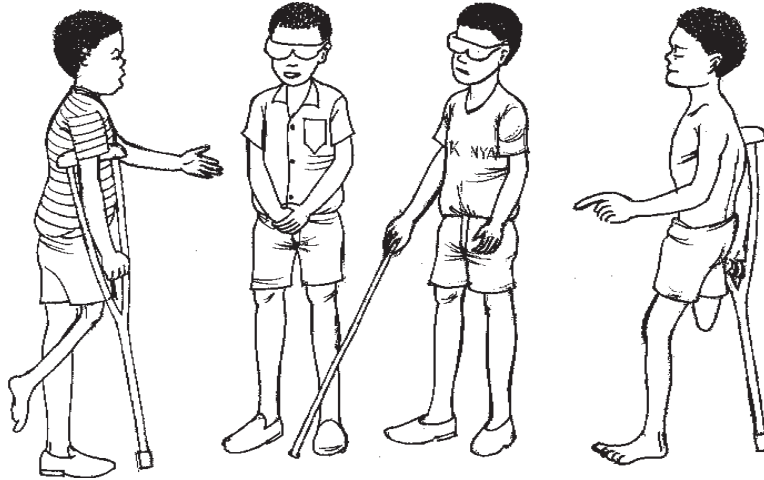
*"Maybe you are happy but you should know that we also have a degree of happiness. We got an education and now we are working."*

*"We may do well and if we think to help our parents... our fathers may cry and apologise because they realise the child is beneficial."*

5. Opportunity for further questions. Thank the members of the guest group for attending the meeting. Agree a time and place for the next meeting. Close the meeting.

### Comments from the women's group on what they learned from the session

*"We did not know that these children could be taken to school and have a good future. Now we will educate others about how to handle these children and where to take them."*



## Meeting 4

**Aim:** To explore different attitudes towards children with disabilities. To explore how negative attitudes can be changed.

- Objectives:**
1. To discuss women's perceptions about children with communication difficulties.
  2. To understand how children with communication difficulties are treated by the community.
  3. To understand how parents of children with communication difficulties are treated by the community.

**Desired outcome:** The group understands that people have both positive and negative attitudes towards children with disabilities. The group appreciates that these attitudes cannot be changed by *telling* people to think differently but by *repeated* positive experiences.

**Methods:** Focus group discussion, songs.

**Materials:** Songs performed by local group of traditional dancers.



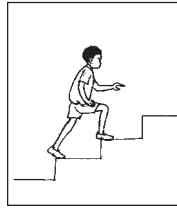
## Activity

### One month before meeting

Make contact with a local group of traditional singers/ dancers and ask if they are willing to participate in meeting 4. If they are willing, ask the group to produce two songs for the meeting: one about negative attitudes towards children with disabilities and one about positive attitudes. Discuss with the dancers different attitudes that could be conveyed through song and dance and the types of examples to include. Agree upon the content of each song.

### Introduction to meeting 4

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current meeting, saying that the group will explore people's attitudes towards children with communication disabilities and their families. Then introduce the traditional singers/dancers and explain that they will perform for the women.



## Steps

1. The traditional singers/dancers perform two songs and dances. The first is about negative attitudes towards children with disabilities. The second is about positive attitudes towards children with disabilities. An example of a song from Kilifi can be found on page 71.
2. Split into small groups (about 4 women per group), each with one or more performers. The performers lead a discussion about how they came up with the ideas in the songs and dances. Women contribute their ideas and experiences of different attitudes towards children with disabilities. Each group elects a spokeswoman to report their ideas back to the whole group.
3. Return to the whole group. Each group in turn reports back their ideas.
4. Continue discussion in the whole group, concentrating on the participants' experiences of how the community treats children with disabilities and their families.
5. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.

### From experience

#### **Comments from Kilifi women's group members on community attitudes towards children with disabilities**

*"A woman gave birth to a crippled child. Her husband asked 'Where does this disability come from? Do you have disability in your family? In ours there is none'. For the second time the woman gave birth to a child who could not talk. This man sent his wife away to her maternal home together with her disabled children and he got married to another wife".*

*"A parent who gives birth to a child with disabilities can be mocked by other people in the community".*

*"I have heard of parents mistreating these children by denying them food".*

*"Sometimes, the aids meant for disabled children are given to other children instead".*



## Meeting 5

**Aim:** To explore the group's perception of the problems faced by children with communication difficulties and their families.

- Objectives:**
1. To brainstorm problems faced by children who have communication difficulties.
  2. To understand the problems faced by children with communication difficulties and their families.
  3. To prioritise the identified problems.

**Desired outcome:** A list of agreed problems faced by children with communication difficulties. A list of agreed problems faced by the families (particularly mothers) of children with communication difficulties.

**Methods:** Focus group discussion, making lists, prioritising problems.

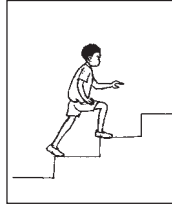
**Materials:** Paper, marker pens.



## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current meeting, saying that today the group will discuss the problems faced by children who cannot communicate and their families.



## Steps

1. The group brainstorms the problems faced by children who cannot communicate and their families. Ask one volunteer from the group to write a list of answers on paper.

### Comments from the Kilifi meeting

*"I was born with a twin sister, we could not hear. We were sent to look after the goats by my Dad, when we got home we were not given food. If we complained we were sent out to the goats again. We would get some wild fruits and cassava. We were not given good clothes so we were often cold. We used to come home late and told to sleep in a separate house with no bedding. We used not to go to school, but one day someone came looking for deaf children and we went to a special school. When we came home from our studies we helped in the house. One day I decided to run away. I spent the night in the bush and ran away the next day."*

*"Some girls are made pregnant by irresponsible people - men who do not want to marry them. These people should be taken to the chief."*

*"Some disabled people are given duties away from home, when they come back no food has been reserved for them."*

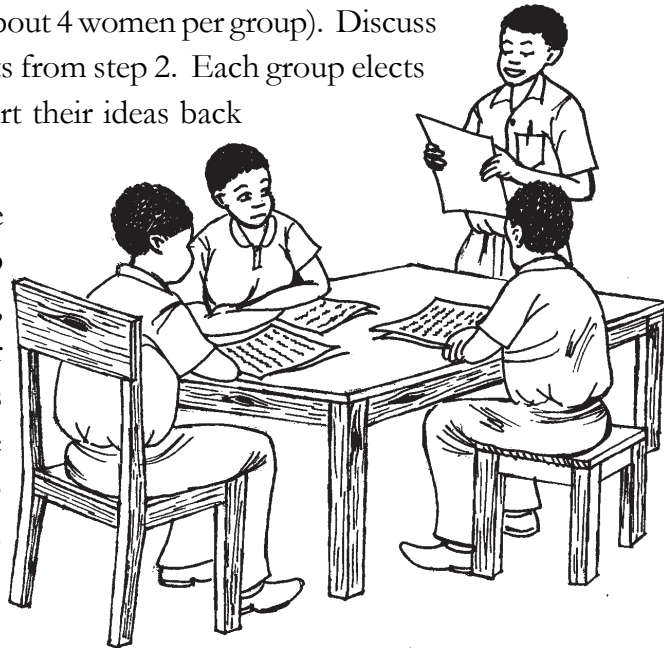
2. The facilitators present a list of problems they have previously drawn up. The women are invited to generate two lists of no more than 20 items each. The first list containing the children's problems and the second list containing the families' problems.

### Comments from the Kilifi meeting

*"A child was born and grew to 8 years old. He could not talk and he could not walk. His parents were tired of carrying him on their back for that long, but gave up hope that he would ever walk. They poisoned the child so he died."*

3. Split into small groups (about 4 women per group). Discuss and prioritise the two lists from step 2. Each group elects a spokeswoman to report their ideas back to the whole group.

4. Return to the whole group. One group reports back their lists, item by item. Other groups contribute ideas from their lists until the group has generated two agreed, prioritised lists, one containing problems faced by children with communication difficulties and



the other containing problems faced by their families. Each list should contain no more than 10 items. Some ideas from Kenya can be found on pages 72 and 73.

5. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



## Meeting 6

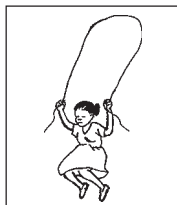
**Aim:** To develop a list of activities and strategies that are within the capabilities of the women's group.

- Objectives:**
1. To explore women's ideas about action *they* can take to make positive changes to the situation faced by children with communication difficulties and their families.
  2. To generate a list of possible activities and strategies that the group thinks can make positive changes to the situation.

**Desired outcome:** A list of activities and strategies relevant to the group.

**Methods:** Focus group discussion, documentation.

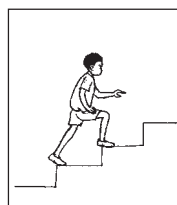
**Materials:** None.



## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of the lists that were discussed and decided in the last session. Introduce the current session by saying that the group will explore the action they can take to positively change the situation faced by children with communication difficulties and their families.



## Steps

1. Split into small groups (about 4 women per group). Divide items from the list of problems faced by children with communication difficulties drawn up in meeting 5 between the groups. Each group discusses their items and examines possible solutions. The discussion should include the following points:
  - the possible solutions.
  - how the solution will be carried out.
  - who will carry it out.
  - when it will be done.
  - what effect it will have.



- Each group elects a spokeswoman to report their ideas back to the whole group.
2. Return to the whole group. Each group in turn reports back their ideas.
  3. Split into small groups again (different groups to activity 1). Repeat activity 1 for the list of problems faced by families of children with communication difficulties. Each group elects a spokeswoman to report their ideas back to the whole group. Some ideas from Kenya can be found on pages 74 and 75.
  4. Return to the whole group. Each group in turn reports back their ideas.

### **Comments from the Kilifi meeting**

*"The child is doing well, he eats with the others, does household chores with the rest of the family members. The Mum and child are happy."*

*"Mum reports that his memory has improved, even in school performance. He is paired with other children in case he is sent to buy something, he has improved. Even nowadays he can go on his own."*

*"The child used not to stay at home, he would leave early in the morning and come back late at night, he would even go without food. Since we started visiting him, he stays at home, he can even go to the shops. In the evening he goes to play football with the other children at school."*

5. The group agrees on a final plan.
6. Opportunity for further questions or comments. Agree a time and place for the next meeting. Close the meeting.



## Meeting 7

**Aim:** To examine the key messages that group members can give to the families of children with communication difficulties.

**Objectives:** 1. To explore what women consider to be the key messages they can give to the families of children with communication difficulties.  
2. To generate a list of agreed key messages.

**Desired outcome:** A list of agreed key messages that the group can give to the families of children with communication disabilities.

**Methods:** Focus group discussion.

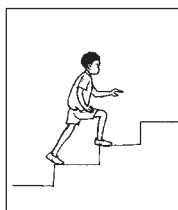
**Materials:** Flip chart paper / newsprint and stand, marker pens.



## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current meeting, saying that the group will discuss the advice members can give to families of children with communication difficulties.



## Steps

1. Invite a volunteer to read out the list of activities and strategies decided in Meeting 6.



2. Split into pairs. Each pair takes one activity from the list. Discuss the advice and key messages that women can give to the families of children with communication difficulties.
3. Return to the whole group. Each pair in turn reports back their ideas. Other group members can add further suggestions to generate a list of agreed key messages.
4. The facilitators present a list of key messages they have previously drawn up.
5. Using the two lists, the group agree upon a final list of key messages that women can give to families of children with communication difficulties. Some more ideas can be found on page 75.
6. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



## Meeting 8

### Evaluation and Reflection

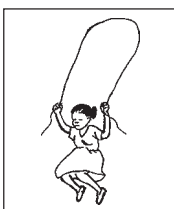
**Aim:** For group members to reflect on meetings in part one and to give feedback on their perceptions and experiences.

- Objectives:**
1. To receive feedback from group members.
  2. To discuss group members' reflections and experiences.
  3. To address problems raised.

**Desired outcome:** A report on progress so far.

**Methods:** Focus group discussion and evaluation.

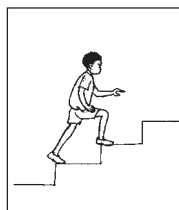
**Materials:** None.



## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite volunteers to briefly remind the participants of what has been covered in previous meetings. Introduce the current meeting, saying that the group will have the opportunity to provide feedback on their experiences of the intervention so far.



## Steps

1. Invite group members to give feedback about their experiences of the meetings up to now.
2. Group discussion about elements of the programme that have worked well or not as well.
3. Address each of the issues raised in Step 2. Facilitators provide reminders of strategies and points discussed in previous meetings, where appropriate.
4. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.

### **From parents:**

*“ Before the visits, I expected a treatment that would cure my child. The child used not to be involved in anything. He seemed dull and down always, but since I have heard the advice of the women, I am involving the child and can see that there is a great improvement.”*

*“The child can’t get healed, you do not bring drugs. You visit us and we take the child to hospital, but all in vain. In fact, I am now taking my child to the church, so you mind your own business.”*

### **From the women:**

*“ We are very thankful for this programme, we didn’t know that we could learn these good lessons. The parents welcome us, We have become famous and are even called doctors: Madaktari was Kemri. At first we were very afraid of going to the households, we even thought of getting someone from the chief’s office to guide us, but we found it was not necessary because the parents received us so nicely. Some parents even wish to be invited to our meetings.”*

## PART TWO : FINDING THE CHILDREN



### Meeting 9

**Aim:** To plan how to approach community leaders. To plan strategies for identifying children who need help in the women's home areas.

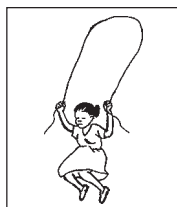
**Objectives:**

1. To plan how to meet with the community leaders.
2. To discuss what to tell chiefs about the project.
3. To plan strategies for identifying children in the community who need help.

**Desired outcome:** Agreed strategy for approaching and meeting the community leaders.

**Methods:** Planning meeting, role plays.

**Materials:** None.

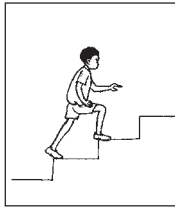


### Activity

#### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current meeting, saying that the group will plan how to approach and meet the community leaders. The aim of these meetings will be to inform them about the project and request their help and/or partnership. The group will also plan strategies for identifying children in the community who need help.





## Steps

1. Group discussion about strategies for approaching and meeting village chiefs. Focus on appropriate days and times to meet community leaders, the best place for a meeting (an office or the group's meeting place) and who should approach them (a representative of the group or the whole group). The group agrees on a feasible plan.
2. Continue group discussion on what to tell the community leaders about the project. Facilitators can refer the group back to the introduction given in Meeting 1.
3. Invite a volunteer to summarise the group's ideas about what to tell the community leaders.
4. Invite 3 or 4 different volunteers to role play a visit to a community leader. One woman plays the leader and the other 2/3 act as group members telling him/her about the project and requesting his/her help and partnership. Other group members observe and provide feedback on positive aspects of what the women told the leader and aspects that need improvement.
5. Group discussion about strategies for identifying children in the community who need help. Focus on different people and community events that could be used as a means of identifying children with disabilities.

### Task before next meeting:

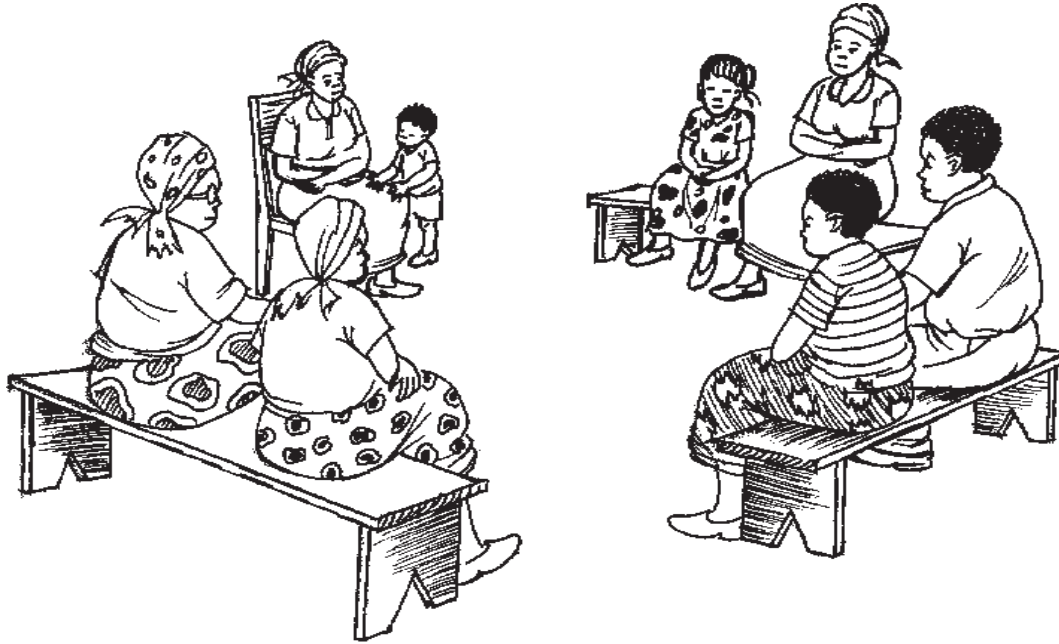
#### From experience

Women decided to visit the community leaders as a group. They elected a spokeswoman who briefed him about their plans.

- They told him about the problems that families who have disabled children face.
- They told him about the problems that children with disabilities face.
- They discussed what they felt they could do to help. What the community could do to help and what they thought the community leader could do to help.

*"Everyday the child was put in a drum (pipa) as everyone left the homestead, he was left there all day and only brought into the house at night. Other people were not allowed to move close to the drum. Village elders went to investigate to try to educate the family."*

6. Opportunity for further questions. Agree a time and place for the next meeting.  
Close the meeting.



## Meeting 10

**Aim:** To report back on the meeting with the community leader. To plan a joint session with parents of children with communication difficulties.

- Objectives:**
1. To discuss the outcome of the women's meeting with the community leaders.
  2. To devise a plan for a meeting between the group and parents of children with communication difficulties.

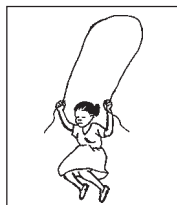
**Desired outcome:** A plan for the meeting between the group and parents.



**Methods:** Focus group discussion, role sharing.

**Materials:** None.

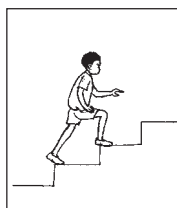
## Activity



## Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current meeting, saying that the group will decide how to contact the parents of disabled children who have communication difficulties.

## Steps



1. Ask a volunteer from the group to report the outcome of the meeting with the community leaders.
2. Group discussion about the community leaders' comments and suggestions. Focus on the feasibility of their suggestions and how they can be incorporated into the identification plan. If no suggestions were made, discuss why this occurred and if anything could be done about it.
3. The facilitators introduce the idea of a meeting with parents. Highlight the ways in which the meeting may be useful.

4. Group discussion about the meeting with parents, focussing on the following points:

- the agenda of the meeting.
- the venue of the meeting.
- the date and time of the meeting.
- who will participate.
- how the parents will be invited.

Group members volunteer for different roles in the meeting and agree on the programme. To help members to decide on the content of the meeting, discuss how they would feel if they were a parent of a disabled child attending such a meeting. Encourage group members to imagine what they would want from such a meeting as a parent. Encourage members to plan a participatory meeting (similar to the approach demonstrated in this programme), rather than a meeting in which they tell the parents what to do. Encourage members to ask parents what their problems are and how they can help.

#### **From experience**

##### **What happened with the chiefs**

*"At one meeting with a women's group, an assistant chief walked in and joined the discussion. He expressed his feelings that he is very thankful and impressed by the start of the project. He promised to support the women at all times. He encouraged the women to take this as a calling and be ready to uplift the community development. This will give prestige to the women too".*

*"He went ahead saying that in his location they have come up with an organisation for the disabled people themselves. The aim is to identify the disabled children and adults in the community and to educate them."*

5. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



**Task before next meeting:**

Conduct a meeting with parents and be ready to report back in the next meeting.



**Meeting 11**

**Aim:** To plan future activities.

- Objectives:**
1. To discuss the outcome of the meeting with parents.
  2. To make final plans for the women's future activities.

**Desired outcome:** An intervention plan involving group meetings, individual home visits and allocation of specific group members to specific families.

**Methods:** Focus group discussion, planning.

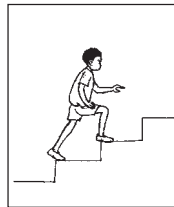
**Materials:** None.



## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current meeting, saying that the group will look at how to produce a final plan for future activities.



### Steps

1. Ask a volunteer from the group to report the outcome of the meeting with parents. Discuss aspects of the meeting that worked well and aspects that didn't work, responses from parents.

*Note: If group members have not met with parents, spend time discussing why not. The group attempts to address any problems identified. Agree to carry out the task before the next meeting.*

2. Invite a volunteer to summarise the activity ideas the group has produced in previous meetings. Refer to the key messages from Meeting 7 on page 32.
3. Group discussion about the parents' comments and which should be incorporated into the activity plan.
4. Continue the group discussion. Focus on the practical details of the activity plan, including the following points:
  - how to approach each family (individually, as a group, with the community leader).
  - when and where to meet with the families.

- how often and for how long to meet the families.
- the number of women required to support each family.

### From experience

One women's group decided to invite all the mothers of disabled children in the area to join their group. At first the women were very shy but now they are regular and active members of the group.

*"Some people have been inviting us to their homes to look at their children who have disabilities, which shows they like our teachings."*

*"At first we wondered what we would do, but after the training we have been doing the work happily."*

5. Group members volunteer to support specific families and to perform specific activities. Discuss this until every group member is happy with the final plan.
6. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



## Meeting 12

### Evaluation and Reflection

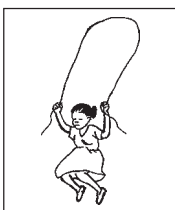
**Aim:** For group members to reflect on meetings in Part 2 and to give feedback on their perceptions and experiences.

- Objectives:**
1. To receive feedback from group members.
  2. To discuss group members' reflections and experiences.
  3. To address problems raised.

**Desired outcome:** A report on progress so far.

**Methods:** Focus group discussion and evaluation.

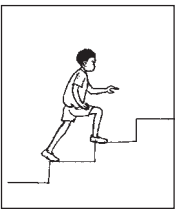
**Materials:** None.



## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite volunteers to briefly remind the participants of what has been covered in meetings since the previous evaluation meeting. Introduce the current meeting, saying that the group will have the opportunity to provide feedback on their experiences of the intervention so far.



### Steps

1. Invite group members to give feedback about their experiences of the intervention since the previous evaluation meeting.
2. Group discussion about elements of the programme that have worked well or not as well.
3. Address each of the issues raised in step 2. Facilitators provide reminders of strategies and points discussed in previous meetings, where appropriate.
4. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



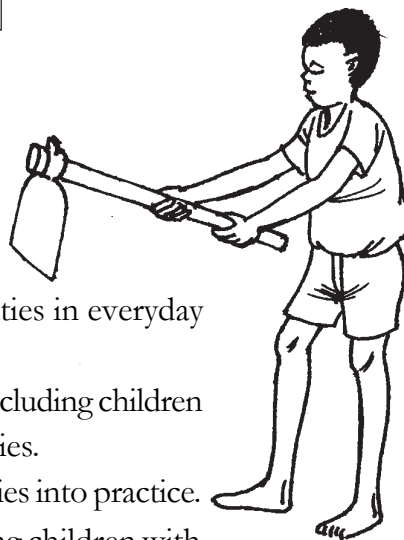
## PART THREE : STRATEGIES FOR HELPING CHILDREN WITH DISABILITIES



### Meeting 13

**Aim:** To generate strategies for including children with disabilities in everyday activities.

- Objectives:**
1. To explore the group's understanding of the importance of including children with disabilities in everyday activities.
  2. To generate a list of strategies for including children with disabilities in everyday activities.
  3. To discuss how to put these strategies into practice.



**Desired outcome:** A list of strategies for including children with disabilities in everyday activities.

**Methods:** Focus group discussion, role plays.

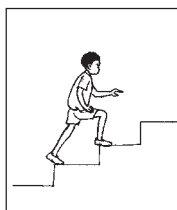
**Materials:** None.



### Activity

#### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current session, saying that the group will look at strategies for including children with disabilities in everyday activities.



## Steps

1. If meetings with parents have taken place since the previous meeting, ask a volunteer from the group to report the outcome of the meeting with parents (following the guidelines in Step 1 of Meeting 11).
2. Identify four volunteers from the group who do not speak English (or other language of the facilitators' choice). Facilitators explain that they will use two strategies to teach the volunteers some English words.

**Strategy 1:** The facilitator turns his/her back on the volunteers and doesn't say anything to them.

**Strategy 2:** The facilitator teaches the volunteers the names of three objects in English (or the chosen language) using demonstration, pointing and repetition. Ask the volunteers to decide which strategy they think works best and explain why. Invite the whole group to discuss the implications of this activity for the current discussion.

3. Invite group members to give *real-life* examples of disabled children they know, who are not included in family activities. Ask group members what the consequences would be for these children. Facilitators can also contribute their own examples.
4. Use the examples given in Step 3 to start a group discussion about the importance of including children in everyday activities.

### Question and Answer: 'Everyday activities'

What are everyday activities?

They are activities that happen as part of a family's daily routine, such as:

- Mealtimes





- Washing and bathing



- Dressing



- Household chores, such as cooking, cleaning, washing clothes, sweeping



- Outings, such as to the shops and attending a family wedding



5. Continue the group discussion, generating strategies for promoting the inclusion of children in everyday activities. Facilitators can introduce their own ideas. Strategy ideas can be found in Section 4 on page 76.
6. The group generates a list of strategies for including children with disabilities in everyday activities.
7. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



## Meeting 14

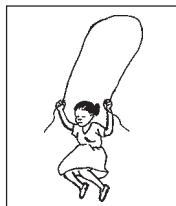
**Aim:** To generate play ideas that will stimulate the child.

- Objectives:**
1. To demonstrate that stimulation is important for children with communication difficulties (i.e. if people do not talk to children they will not learn to talk!).
  2. To draw up a list of activities and happenings which promote children's communication skills.
  3. To discuss strategies for making activities and experiences more stimulating for children.

**Desired outcome:** The group appreciates that play and talking to children about the activities and happenings around them, promotes their communication skills.

**Methods:** Focus group discussion, demonstrations.

**Materials:** Broom, soap, basin, toothbrush, water, cooking pots etc. (depending on the activities to be acted out).

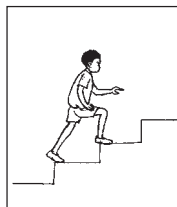


## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce

the current session, saying that the group will look at the activities and happenings that take place around the child, which stimulate communication.



## Steps

1. Group discussion focussing on what stimulation is and how it can be useful for children with communication disabilities. The facilitators can introduce the ideas of *reason*, *opportunity* and *means*.

### Reason, Opportunity and Means

Children need experience to have something to talk about (the *reason*).

Children need the *opportunity* to communicate.

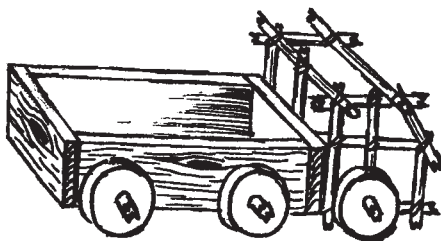
Children need the *means* to communicate (either through talking, signing or writing).

2. Split into small groups (about 4 women per group). Each group generates a list of activities and experiences that could be used to stimulate communication. Each group elects a spokeswoman to report their ideas back to the whole group.
3. Return to the whole group. Each group in turn reports back their ideas.
4. Facilitators contribute their ideas of activities and experiences that could be used to stimulate communication. Ideas can be found in Section 4 on page 78.
5. Split into small groups again. Each group chooses an activity from those suggested in steps 2 and 4 (facilitators ensure that each group has a different activity). Group members practise carrying out the activity and discuss how well they think it would work. More ideas can be found in Section 4.
6. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



## Meeting 15

**Aim:** To practise making and playing toys and games.

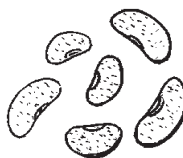
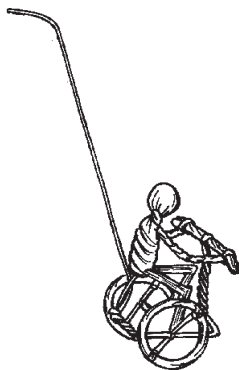


- Objectives:**
1. To explore women's knowledge of toys and games.
  2. To expose the group to other toys and games.
  3. To generate a list of toys and games that stimulates communication.
  4. To demonstrate how to make toys using locally available materials and how to play simple games.

**Desired outcome:** Improve group members' capacity to make toys and play games.  
A list of toys and games.

**Methods:** Focus group discussion, demonstrations.

**Materials:** Locally available materials for making toys such as beans, small stones, tins, empty boxes and bottles, gourds, material, banana leaves (add other materials from your own area).

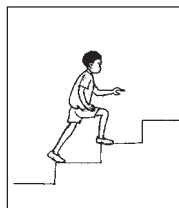




## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current session, saying that the group will look at toys and games that can help children to improve their communication.



### Steps

1. Split into small groups (about 4 women per group). Discuss simple toys and games the women know about, that can be made with locally available materials.
2. Return to the whole group. Ask for volunteers to demonstrate toys and games to other group members. Ensure that each group member understands how to play each game and use each toy, by allowing everyone to join in the demonstrations.
3. Facilitators demonstrate toys and games they know, involving group members in each demonstration. Ideas for toys and games can be found in Section 4, pages 78 - 81.
4. Group discussion to sort the toys and games presented in steps 2 and 3, highlighting the ones that stimulate communication.
5. Free session for women to practise making some of the toys and games, using locally available materials. Concentrate on toys and games that stimulate communication.
6. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



## Meeting 16

**Aim:** To appreciate that signs and gestures can be developed relevant to individuals.

**Objectives:**

1. To discuss the importance of having a simple, local sign language.
2. To give group members the opportunity to learn local signs from a person with hearing impairment, from the local community.
3. To generate a list of simple signs for key words that children and parents may find useful.

**Desired outcome:** To generate simple, locally relevant signs of key words useful to children with communication difficulties and their families.

**Methods:** Focus group discussion, demonstration from guest signer.

**Materials:** None.



## Activity

### Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current session, saying that the group will explore the usefulness of simple, local signs. Welcome and introduce the visitor with hearing impairment. Say that the visitor has joined the meeting to share some simple, local signs for key words that may be useful to children with communication disabilities.

Hungry



Sad



Good Evening



Drink



Sister



Truck



Brother



Happy



Father



Mother



Where



Tired



Hello



What



Good afternoon



Come



No



Yes



Go

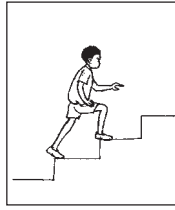


Good morning





## Steps



1. Invite the guest to introduce him/herself using signs. Provide an interpreter if necessary.
2. Invite a volunteer from the women's group to introduce each member of the group, using signs. Provide an interpreter for the guest if necessary.
3. Group discussion about the usefulness of a simple, local sign language. Invite the guest to contribute his/her ideas.
4. Ask the guest to teach the group some simple signs for key words useful to children with communication difficulties and their families.
5. Split into small groups (about 4 women per group). Practise the signs taught in Step 4 and try to make up other simple, useful signs. Invite the guest to visit each small group and give his/her comments on their progress.
6. Return to the whole group. Group discussion to generate a list of local signs for key words that children with communication difficulties and their families may find useful. Facilitators can contribute their ideas. Ideas for useful signs can be found in Section 4 on pages 85 - 86.
7. Opportunity for further questions. Thank the guest for attending the meeting. Agree a time and place for the next meeting. Close the meeting.



## Meeting 17

**Aim:** To learn how to make communication aids, including items that stimulate children, special seating and communication boards.



### Objectives:

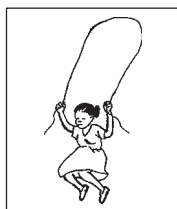
1. To discuss the purpose and uses of communication aids.
2. To explore what women know about making communication aids.
3. To expose women to other communication aids.
4. To generate a list of useful communication aids.

**Desired outcome:** For group members to feel confident about making and using different communication aids.

**Methods:** Focus group discussion, demonstrations, role play.

**Materials:** Locally available materials such as cane, tins, bottles, cups, cartons, paper, pens, pencils, paint, wood (add other materials from your own area).

### Before the meeting

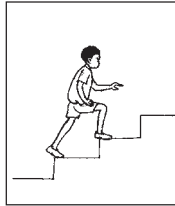


### Activity

Make some examples of communication aids using locally available materials to demonstrate to group members. Ideas for these aids can be found in Section 4, page 87.

## Introduction

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current session, saying that the group will explore how to make communication aids.



## Steps

1. Invite three volunteers for a role play. Ask:
  - one volunteer to lie down and pretend to be a child who cannot stand, walk or talk, but who can hear and see.
  - one volunteer to pretend to be a child who cannot hear. Ask the volunteer to block her ears with cotton wool.
  - one volunteer to pretend to be a child who cannot see. Ask the volunteer to wear a blindfold.

Invite the volunteers to join in the next activity like this.

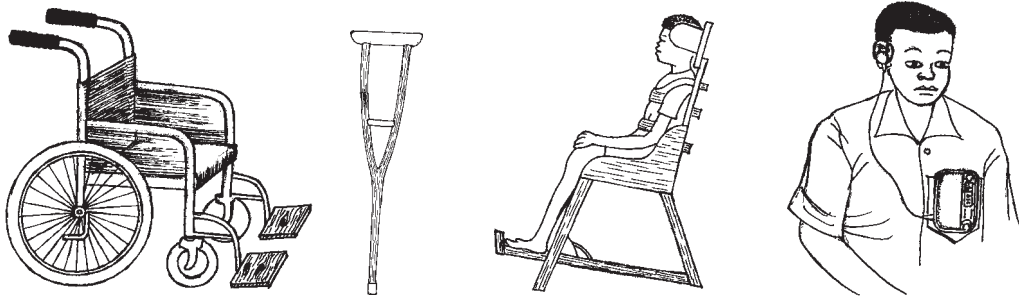
2. Conduct a group discussion about what a communication aid is and how it can be useful. The volunteers try to participate in this discussion as much as they can.
3. Invite the three volunteers to give feedback to the rest of the group about what they felt during the activity in step 2 on the following points:
  - What they would have liked the other group members to do, so that they could have participated more effectively? (strategies)
  - Which aids do they think would have helped them? (aids)

Facilitators emphasise that the discussion should concentrate on what the group members can do themselves, and not what other people like doctors and governments should do. Facilitators also help the group to distinguish between aids and strategies.

**An aid is:** something that assists you in doing something. e.g A crutch helps a man with only one leg to walk, so he can, for example, walk into his house to fetch something.

**A strategy is:** using thought and planning to achieve something e.g. having everything you need within reach if you are not mobile.

4. Group discussion about aids that group members are familiar with. Generate a list of aids. Describe each aid in terms of how helpful it is and what type of impairment it would help the most. The list may include aids for all kinds of disabilities, such as aids that encourage children with disabilities to be more mobile.



5. Continue the group discussion, now focussing on communication aids. Facilitators demonstrate different examples of communication aids using the aids made before the meeting. Ideas and examples can be found in Section 4, pages 87 - 91.
6. Facilitators and group members practise making the communication aids demonstrated in Step 5. When each aid is finished, ask group members to describe them: how helpful they are and what particular type of disability they help.
7. Invite volunteers from the group to try each aid. Ask them to feedback to the group how helpful each one was.
8. Group discussion to generate a list of useful communication aids. Use ideas presented in Steps 5 and 6, as well as any other ideas the group has.
9. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.

#### **Comment from Kilifi**

*"Now I know how to make the seat my child can rest on safely without falling and I can get on with my work. He can see what is happening and is much happier".*

## Meeting 18



**Aim:** To explore the group's understanding of epilepsy and how to manage it.

**Objectives:**

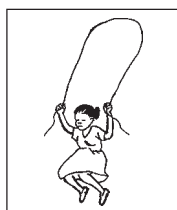
1. To explore the group's understanding of epilepsy and its causes.
2. To explore the group's understanding of different types of epilepsy.
3. To discuss ways in which to manage children with epilepsy.
4. To expose the group to what the facilitators know about epilepsy.  
Use ideas from the book 'Helping children with epilepsy in the community' by Caroline Pickering.

**Desired outcome:** The group understands that epilepsy is caused by brain damage and can be managed at the community level.

**Methods:** Focus group discussion, demonstrations.

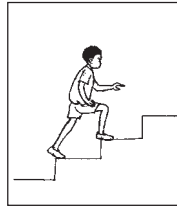
**Materials:** None.

### Introduction



### Activity

Welcome and greet the participants at the start of the meeting. Invite a volunteer to briefly remind the participants of what was discussed in the last session. Introduce the current session, saying that the group will explore how to manage epilepsy.



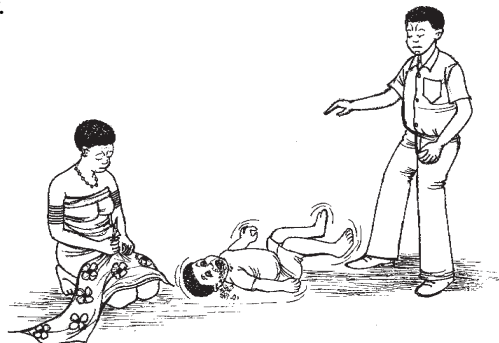
## Steps

1. Split into small groups (about 4 women per group). Discuss what epilepsy is and its causes. Each group elects a spokeswoman to report their ideas back to the whole group.

### Comment from Kilifi

*"There was a disabled child who appeared normal when born but he did not learn to sit, neither walk. He had convulsions. Nobody used to take care of him, not even his parents. He could be left alone, when he convulsed nobody got concerned. He used to eat his own stools, nobody used to clean him".*

2. Return to the whole group. Each group in turn reports back their ideas.
3. Group discussion about the causes of epilepsy. Facilitators contribute ideas from Caroline Pickering's book; "How to help with Epilepsy," from Kenya Association for the Welfare of Epileptics, or ask your own local organisation of epilepsy for information.
4. Facilitators demonstrate different types of epilepsy to the group. Emphasise that there are many other types of epilepsy apart from tonic-clonic epilepsy.
5. Group discussion about how to manage a child with epilepsy and how to discuss these issues with parents. Use ideas from Caroline Pickering's book.
6. Opportunity for further questions. Agree a time and place for the next meeting. Close the meeting.



# Notes





## SECTION 4

### RESOURCES AND IDEAS

This section presents ideas for the activities and demonstrations used in the meetings. The facilitator can select or adapt these ideas or use his/her own ideas. These ideas do not have to be used for the community action to be successful. We have included them because they worked well in our community action project. However, facilitators working with different groups in different countries, may find other ideas are more appropriate. Facilitators are encouraged to develop their own activities, searching for activity ideas using locally-available materials.

**Three manuals are available which provide very useful ideas for activities in the sessions.**

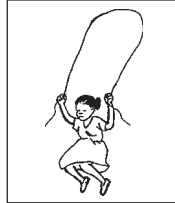
They are:

1. Disabled Village Children A guide for community health workers, rehabilitation workers and families. David Werner. 1987. Published by the Hesperien Foundation P.O. Box 1692, Palo Alto, CA 94302. USA.
2. How to help children with Epilepsy, compiled by Caroline Pickering. The Kenya Association for the Welfare of Epileptics. Printed by The African Medical Research Foundation, Wilson Airport, P.O. Box 30125, Nairobi. Kenya.
3. Let's Communicate. A handbook for people working with children with communication difficulties. WHO., UNICEF and Rehabilitation Unit. MOH Zimbabwe. WHO/RHB 97.1 Available free from WHO, Geneva.

## Meeting 1



## Activity

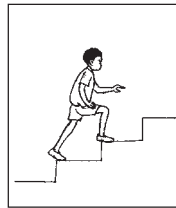


The facilitators give demonstrations of what communication is and different barriers to communication.

## Ideas

### 1. The Communication Ball

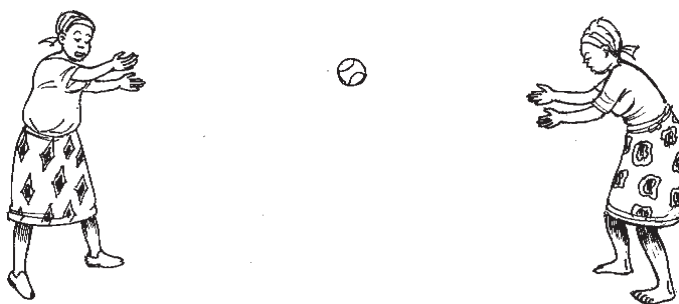
**Aim:** To demonstrate several important principles of communication through a ball game.



## Steps

**Materials:** One or two balls of different sizes.

1. Ask for two volunteers from the group.
2. Invite the two volunteers to throw a ball to each other. While they are throwing and catching the ball, the facilitator highlights the similarities between the game and the process of communication. For example, see the following picture of two women with a ball.



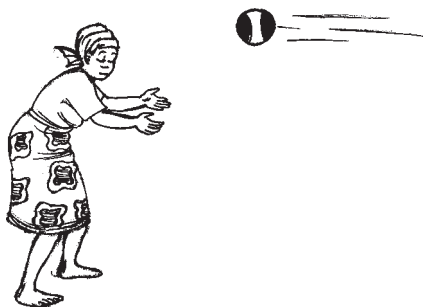
Both are turn-taking activities - one woman throwing; one woman catching. Each participant performs a different activity in turn. In communication, this could be talking/listening or writing/reading.

The next example is of two women with a ball and a third woman intercepting the ball.



What effect did this have on the game? Communication can be disrupted, for example if a person interrupts a conversation.

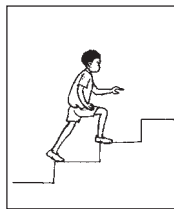
This example shows one woman trying to catch the ball with eyes closed. Attempting to play the game with an *impairment* can cause problems. Children with impairments can experience problems with communication.



## 2. Back-to-Back Communication

**Aim:** To highlight different means of communication and the importance of non-verbal communication.

**Materials:** None.



### Steps

1. Invite the participants to split into pairs. Each pair should sit back-to-back.
2. Ask one participant (partner 1) from each pair to spend 1-2 minutes telling her partner (partner 2) something the other person does not know about her (eg. what she did this morning before coming to the meeting). After 1-2 minutes, partner 2 has her turn to tell partner 1 something.
3. Ask the group to reassemble. Invite the participants to share what it was like to communicate back to back. How was it different to communicating face to face?



### From experience

**What was back-to-back communication like? Responses from Kenyan women:**

*"It feels as if you are talking alone."*

*"The person can hear but cannot see the actions so cannot understand. There should be body language."*

*"It's like communicating by phone."*

*"If I am telling her I have dug a big portion from here to there in the morning, I would want her to see my gestures."*

4. The facilitator concludes the activity by explaining that communication is *multi-modal*.

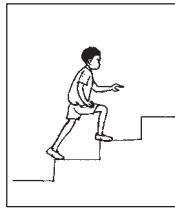
### Multi-modal

When we say communication is *multi-modal*, we mean that each time we communicate, we use lots of different ways of getting our message across. For example, facial expression, tone of voice, body language etc as well as speech. Many messages are communicated through body language and speech can play a secondary role.

### 3. Communication without speaking

**Aim:** To learn that communication is possible without speech.

**Materials:** None.



### Steps

1. Invite the participants to split into pairs. Ask one partner (partner 1) from each pair to pass a message to their partner (partner 2) without speaking or writing. Partner 2 has to guess what the message is. Partner 2 then has a turn at passing a message without speaking. The partners should begin with simple messages (eg. 'I feel hungry' or 'I have three children').
2. Ask each pair to try passing more complex messages (eg. 'Yesterday I went to the market').
3. Ask the group to reassemble. Invite the participants to share what it was like to communicate without speaking. How was it different to the way they usually communicate?

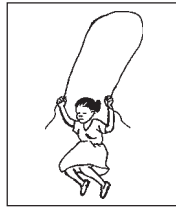
## From experience

### Observations from Kenya

- People can communicate simple messages without speech.
- Communication without speech is more difficult for most people when the message is longer, more complex or abstract.



## Meeting 2



## Activity

The facilitators give demonstrations of what can cause communication disability.

### Communication Disability

Is a response to an impairment (such as impaired hearing or seeing) together with a response to social and contextual factors (such as whether the person is spoken to or included in society). These factors interrelate with each other and the person themselves and can result in limited communication skills ability and opportunity.

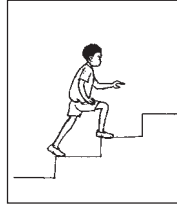
### Ideas

#### 1. Communication using inappropriate means for the communication partner

(e.g. Writing a message for someone who cannot read)

**Aim:** To demonstrate that the means of communication needs to be appropriate for the partner.

**Materials:** None.



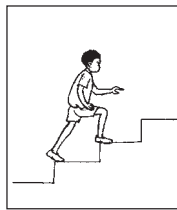
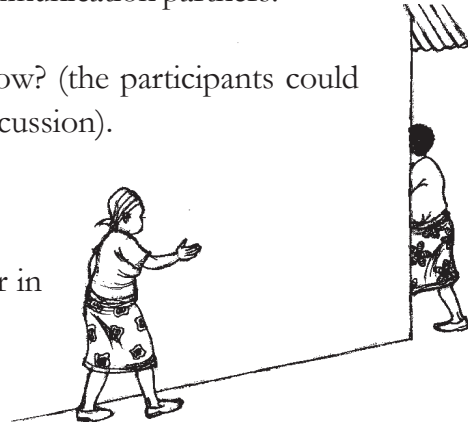
## Steps

1. Facilitator one acts as a person with a hearing impairment. Facilitator two tries to communicate with him/her using spoken language. Facilitator one cannot understand.
2. Invite the group to discuss what they think the demonstration showed. Discuss the following questions:
  - Was there a problem between the communication partners?
  - What was the problem?
  - Can this problem be overcome? How? (the participants could answer this by role play instead of discussion).
  - How do you think each person felt?

## 2. Lack of a communication partner

**Aim:** To demonstrate the need for a partner in communication.

**Materials:** None.



## Steps

1. Two facilitators act the parts of two friends. Friend one visits friend two's home. Friend one sits outside the house. Friend two explains that he/she needs to go inside for a minute to finish preparing some food. The friends have a conversation with one inside and one outside.
2. After a short while, friend two moves out of the house through the back door. Friend one doesn't realise this and keeps talking.

3. Invite the group to discuss what they think the demonstration showed. Discuss the following questions:

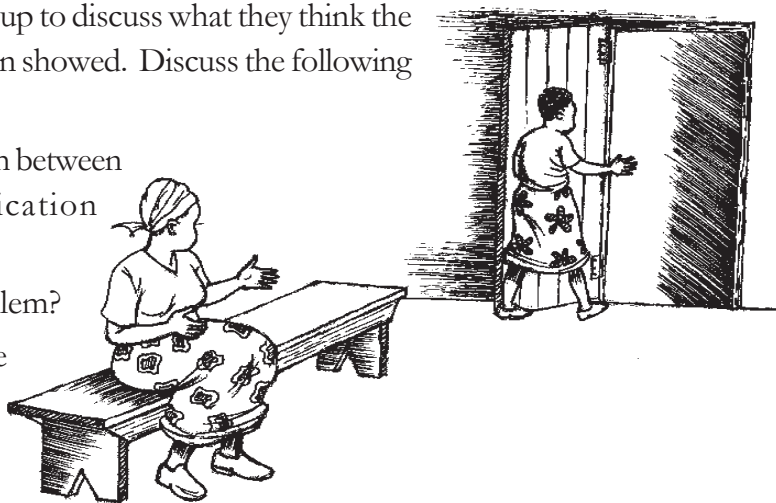
Was there a problem between the communication partners?

What was the problem?

Can this problem be overcome? How? (show by role play or discussion).

How do you think each person felt?

Other ideas for demonstrations include *not hearing well, not seeing well, not learning well or not being able to move well* (for example moving the tongue and lips for speaking or moving the hands for signing).



### Meeting 3



To change the group's mode of communication to suit people with communication impairments.

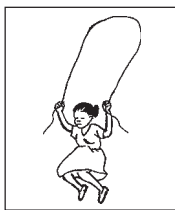
#### Ideas

##### 1. The introduction game

**Aim:** To experience an alternative mode of communication.

**Materials:** None.





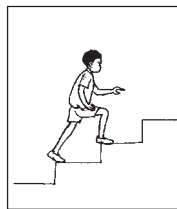
## Activity

1. One facilitator begins the game by communicating something about him/herself to members of the group for people with communication disabilities. The mode of communication should be the one that members of the visiting group normally use. We tried using signs and gestures as our visitors had hearing impairments.
2. Members of the visiting group report back what they understood from the message. Provide an interpreter, if necessary.
3. Ask for a volunteer from the women's group to try the same exercise. Then ask the visiting group to report back the meaning of the message.
4. Repeat the exercise until all members of the women's group have had the chance to try.
5. Conclude the game by asking the visiting group what made the messages easier/more difficult to understand. Ask the women's group what it was like to communicate in a different way, to what they are used to.

## 2. Communicating with signs

**Aim:** To show that signs can be simple to learn. To experience how useful signs are for communication.

**Materials:** None.



## Steps

1. Ask the guest signer to think of several short simple messages that could be communicated to the group, using signs.
2. Invite the signer to stand in front of the group and communicate one message using signs. Ask group members to work out the meaning of the message.
3. After the group has worked out the message, ask the signer to teach the signs from the message to the group.
4. Repeat steps 1 and 2 for each message.
5. At the end of the activity, review the signs that have been learned. Discuss how effective signs are for communication and how simple they are to devise.



## Meeting 4

To present facilitators examples of how negative attitudes can be changed through local songs.



## Activity

### Song lyrics from the Kilifi meeting

We should accept to live with these people who have disabilities  
They mostly depend on those who are alright,  
We should treat them just like any other human beings,  
At the moment some are taken care of while some are not,  
Some are taken to school  
Some are not.  
Dont blame God  
It will happen without our knowledge  
Even those who have disabilities don't know.  
Dont blame God.



## Meeting 5



## Activity

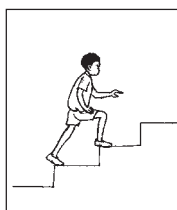
Facilitators' examples of problems faced by children with communication disabilities and their families.

## Ideas

### Example list containing ideas from Kenyan women

**Aim:** To present facilitators' lists of problems faced by children with communication disabilities and their families.

**Materials:** Paper and pens.



## Steps

1. The facilitators present a list of problems, which could include the following ideas:

### Problems faced by children with communication disabilities

- Life-threatening circumstances.
- Hidden away from visitors.
- Left naked.
- Receive little love or positive sentiment from family or the community.
- Excluded from household and community activities.
- Overworked and given no reward.
- Not given their share of food.
- Given undesirable names.
- Depression and dependency.
- Lonely.
- Frustrated and angry.
- Abused by family and community members physically, sexually and emotionally.



## Problems faced by families of children with communication disabilities

- Made to feel guilty and ashamed by others in the community.
- Cannot go for a journey or leave child unattended.
- People laugh at them.
- Feel lonely and rejected.
- Mothers of such children can be ridiculed, rejected and abused and overburdened.
- Children become aggressive.

### Comments from the Kilifi meeting

*"My father was so harsh to mum saying that it was our mother's fault that she gave birth to such children."*

*"Mothers have the burden of taking care of these children, they suffer more than the fathers."*

*"If disabled people are mis-treated or not shown love they become aggressive."*

*"Only those without disabilities are taken to school, those with disabilities are not."*

*"During meal times the crippled and dumb girl is tied to a tree away from the homestead until everybody has had their meal. This is because she drools and is disruptive."*

*"Parents are happy because there used not to be hope. Now there is hope."*

*"One deaf child ran away and walked into the ocean. He almost got drowned. Fortunately the mother found him and rescued him."*

*"Parents of disabled children are laughed at and looked down upon."*

*"These parents are so overloaded with thoughts that they are stranded. They cannot think of what to do. Therefore, it would be ideal for people to visit them and give advice on how to go about this."*

*"The main problems for disabled children are boredom, overwork, depression, fear and neglect."*

*"Some parents love these children, they take good care of them - wash them, dress, feed them well. Though they cannot walk or talk, they [the children] are not sad because of the love they get from their parents."*

*"Such children are mistreated, some parents throw away such children. This happens in this community. The fathers are often drunk and deny their children."*

## Meeting 6



## Activity



Facilitators' examples of activities and strategies that can be used to solve the identified problems, that are within the ability of the women's group.

### Ideas

- Find other families who have disabled children and meet with them and share your problems.
- Form self help groups.
- Take children to school.
- Ask the teacher to put the child in front of the class.
- Find sympathetic and understanding members of the community and talk to them about your problems.
- Talk to your disabled child.
- Offer to look after a disabled child while the mother goes shopping or visits a friend.
- Show love.
- Pair up with other children.
- Include your child in the household and community activities.
- Find a useful role for your child so that he/she becomes a contributing part of your family and community.
- Contact village elders for support over injustices.
- Make an aid such as a crutch or special chair, an ear trumpet or communication board.

## Meeting 7



## Activity



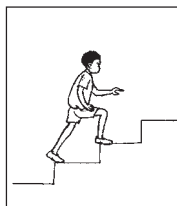
Facilitators' examples of key messages that the group can give to families of children with communication disabilities.

## Ideas

### Example list containing ideas from Kenyan women

**Aim:** To present facilitators' list of messages for families of children with communication disabilities.

**Materials:** Paper and pens.



## Steps

1. After the women have generated their own list, the facilitators present a list of key messages for comparison. This list could include the following ideas:

- All children need to be kept clean, clothed and fed.
- All children need to feel safe and secure.
- Children with disabilities need to be accepted as part of the family.
- All children need friends and the opportunity to play with other children.
- Carers can seek medical treatment for any impairment that they think is curable or can be reduced.

- Children with disabilities benefit from being included in family activities such as mealtimes, talking together or games.
- All children need to be looked after but not smothered.
- Children with disabilities can learn skills that enable them to contribute to the homestead.
- All children deserve respect as human beings.
- Children with disabilities may benefit from access to aids that help to minimise their disability (for example, wheelchairs, special seating, communication boards).



## Meeting 13



## Activity



Facilitators' examples of strategies for promoting the inclusion of children in everyday activities.

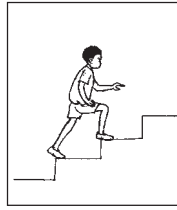
### Ideas

#### Examples of everyday activities

**Aim:** To present facilitators' examples of strategies for promoting the inclusion of children with disabilities in everyday activities.

**Materials:** None.

## Steps



1. The facilitators present some strategies, which could include the following ideas:

### Brushing your teeth



### Dressing



### Cleaning windows



### Sweeping



### Washing





## Meeting 14



## Activity



The facilitators contribute their ideas of activities and experiences that could be used to stimulate communication. They share some local toys and demonstrate the games they know. Add your own ideas suitable for your area to the ideas that follow.

### Types of play

**Aim:** To describe different types of play.

**Materials:** According to the play described.

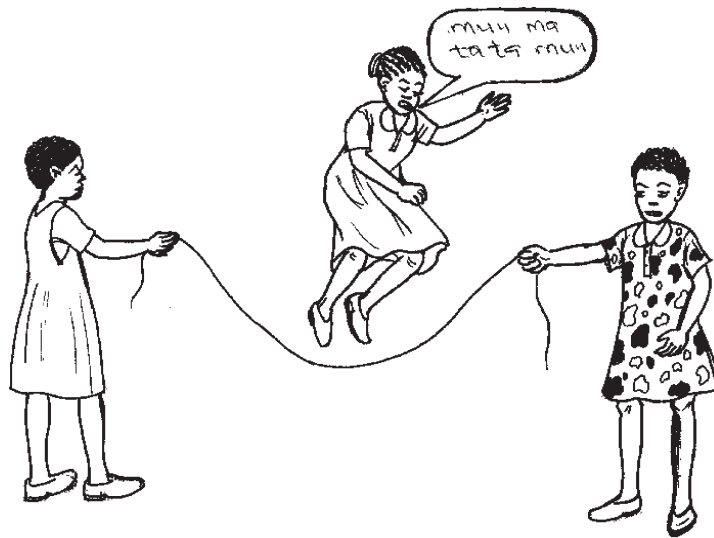


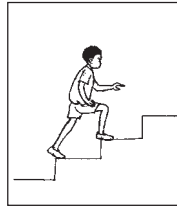
## Ideas

Using everyday objects to make toys and use them in play.

**Aim:** To present facilitators' examples of play activities and experiences to stimulate communication. To allow the group to practise using household objects as toys and for play activities.

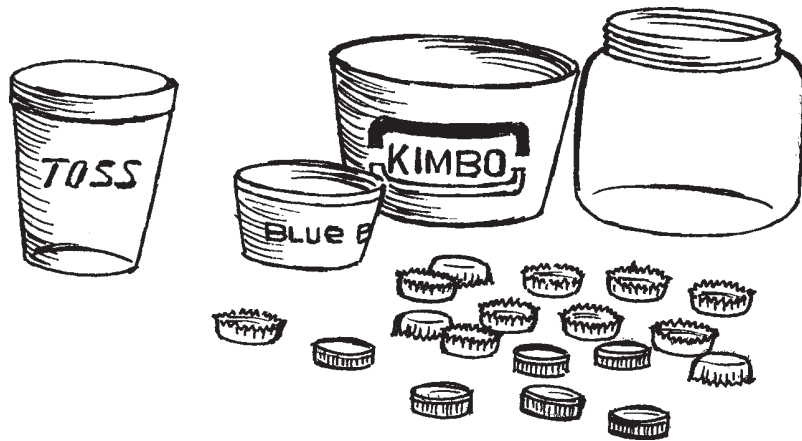
**Materials:** Household objects, such as dried beans, small stones, empty cans, jars, bottle caps, pans, spoons, string, newspapers.





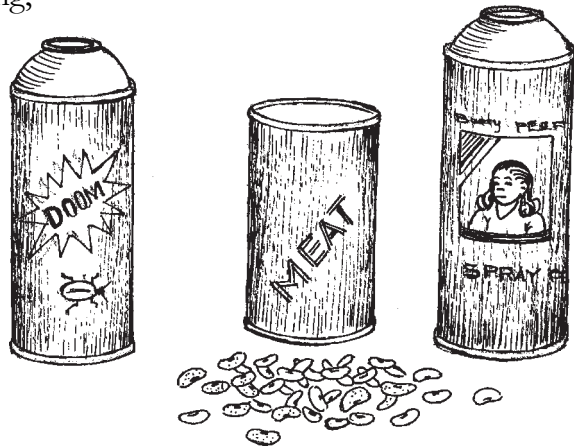
## Steps

1. Split into small groups (about 4 women per group). Give each group a set of household objects. Ensure that each set of objects can be used for at least one toy or activity. Examples of sets of objects and the toys that can be made and the activities for which they can be used, are listed below:

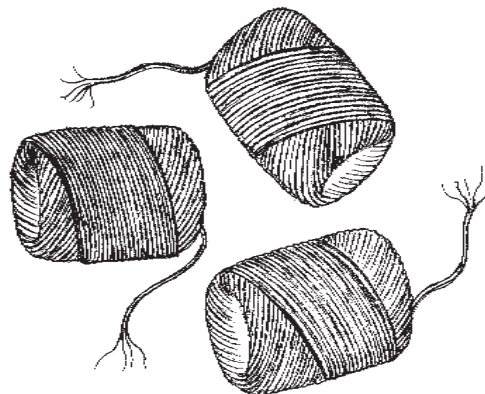
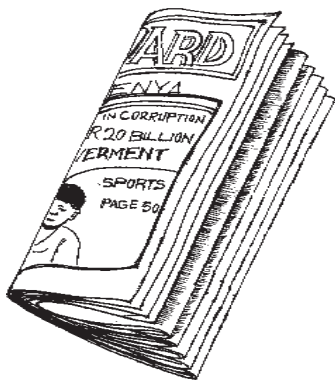


Used for building a tower,  
rolling backwards and forwards,  
making rattles.

Used for screwing and unscrewing,  
making rattles,  
listening games.



Used for banging drums and beating rhythms,  
pretend cooking.



Used for hiding games,  
making balls.

2. Ask each group to think of additional ideas. Each group elects a spokeswoman to demonstrate their ideas back to the whole group.
3. Return to the whole group. Each group in turn reports demonstrates their ideas to the rest of the group.

## **Ideas about games from Kenya**

### **1. Chinese whispers**

One person thinks of a message they want to tell another person, but instead of telling the message to them directly, they pass the message along a line of people by whispering it into the next person's ear. Each person listens to the message and then passes what they have heard onto their neighbour. When the message reaches the intended person, the final message is spoken aloud and compared with the original message. It is best to start playing this game with short and simple messages and then make them longer and more difficult.

### **2. Memory game**

This can be played with several players. The first person starts off by saying, "I went into the village shop and I bought some maize." The next person follows on by saying "I went into the village and I bought some maize and some sugar" This continues until people cannot remember all the items and then they are 'out' of the game. The person who wins is the one who can always remember all the items.

### **3. Clapping game**

Two people play this game which involves singing a local song and clapping with your partner according to an agreed pattern. The clapping is between the two partners (i.e. both hands of one person clapping against both hands of the other, or one person's right hand against another persons left etc). The challenge is to develop the pattern of clapping to fit in with the song and to achieve it as soon as possible.

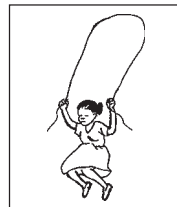
#### 4. Stone games

1. This game can be played by several people. Dig a hole in the ground and sit around in a circle. Each person has 10 stones and takes it in turns to throw the stones into the hole. The one who gets the most into the hole wins the game.

2. This game can be played by 2-4 people. Each person has 10 small stones. They take it in turns to play. There is one larger stone (Mother stone). The players take it in turn to throw out their 10 stones onto the ground, then throw up the mother stone, at the same time as picking first 1 then 2 then 3 stones etc. Their turn continues if they are succeeding. If they drop a stone or do not pick up the correct number, the turn moves to the next player. On their next turn they begin their task at the number they have reached.

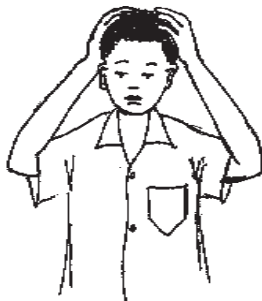


#### Meeting 15



#### Activity

The facilitators present their ideas of local signs for key words that children with communication disabilities and their families may find useful.



Wash



Hungry



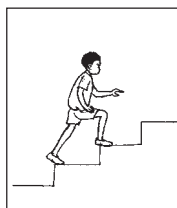
Iron

## Ideas

### Learning signs

**Aim:** To present the facilitators' list of local signs for key words that children with communication disabilities and their families may find useful.

**Materials:** Paper and pencil.



### Steps

1. Write headings on the paper of different kinds of signs that local children may find useful.
2. Include picture of the list with headings for 'people', 'objects', 'social words' and 'actions'. eg:

'People' picture	'Objects' picture	'Social words' picture	'Actions' picture
Mother	Bread	Hello	Eat
Brother	Tea	Thank you	Drink
Man	House	Yes	Sleep

3. Ask the group for ideas of words that fit under these headings that may be useful for children in everyday situations. There are some examples in the pictures that follow.
4. Write each word on the list then ask the guest signer to teach the sign to the group. The group repeats the sign after the teacher.
5. At the end of the activity, review the signs that have been learned.

Hungry



Sad



Good Evening



Drink



Sister



Truck



Brother



Happy



Father



Mother





Where



Tired



Hello



What



Good afternoon



Come



No



Yes



Go



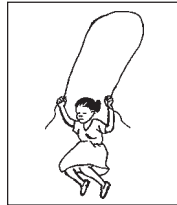
Good morning



## Meeting 16



### Activity



The facilitators present examples of communication aids made using locally available materials.

### Ideas

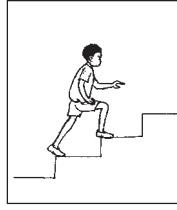
#### Communication board

**Aim:** To present ideas on how to make a communication board.

(These ideas are adapted from 'Let's Communicate' WHO/UNICEF/Zimbabwean MoH. More detailed information can be found in these manuals)

**Materials:** Paper/card, pens, pictures (from newspaper/magazine or drawn by hand).





## Steps

### Communication boards

#### **What is a communication board?**

A simple chart, made of card or word. The chart contains pictures or words that illustrate a person's daily needs.

#### **Who should be involved in making one?**

The child and his/her family and teacher. It is important that everyone supports the idea of a communication board and is involved in making and using it.

#### **When is it used?**

The board can be used by the child at all times so that he/she can communicate with his/her family and friends.

#### **How is it used?**

First, the child needs to attract the attention of a communication partner. Then, the child points to the pictures or words that express his/her needs. The communication partner should respond immediately by talking to the child.

1. Identify a child (preferably a child known by the whole group) who is unable to communicate. Identify relevant details such as:
  - age.
  - area lived in (rural/urban).
  - family size and income.
  - schooling.
  - mobility.
  - ability to point and reach.
2. Discuss the needs, thoughts and wishes the child may need to communicate. It is important that the parents of the child should be involved in this discussion. Decide which pictures (or words) would be most appropriate for the child.

3. Decide how the pictures should be displayed on the communication board. Display the pictures according to the child's physical mobility and ability to reach. Examples of displays include a tray attached to a wheelchair or a card kept in a shoulder bag. The pictures should not be displayed too close together, so it is easy to understand which picture the child is pointing at (especially if the child will use eye or chin pointing). There should not be too many pictures to begin with. Other pictures can be added when the child has got used to using the board. The pictures should be large enough to be easily recognised by the child and communication partner.
4. Decide how the child will point to the pictures on the display according to his/her physical abilities. Examples of pointing methods include pointing with a finger, a fist, the chin, a pointer strapped to the child's forehead or with the eyes.
5. Prepare the board. If possible, cover the chart in plastic to protect it. However, it is best to make sure that you are still able to change the board in the future, by being able to add new pictures or change old ones.
6. Group discussion about the usefulness of the board. Focus on:
  - the clarity of the pictures.
  - the durability of the board.
  - whether it will be easy for the child to use.
  - whether it will be easy for the child to carry around.
  - whether it will improve the child's ability to communicate his/her needs and desires.

### **Ear trumpets**

#### **How does an ear trumpet work?**

The wide, open end of the trumpet catches sounds and carries them directly to the child's ear.

#### **How do you use one?**

The child puts the ear piece in his/her ear. The speaker holds the funnel to his/her mouth and speaks directly into it.

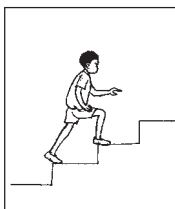
#### **Who can use one?**

Ear trumpets are most useful for adults and children with mild or moderate hearing impairments. They are not as useful for children with severe impairments.

## 2. Home-made hearing aids

**Aim:** To present ideas on how to make a simple, papier mache ear trumpet (These ideas are adapted from 'Let's Communicate' WHO/UNICEF/Zimbabwean MoH. More detailed information can be found in these manuals).

**Materials:** plastic sheets, paper, yoghurt container (or a container with a similar size and shape), mud, pen lid, glue (this can be made by mixing flour and water into a paste), a large flat-bottomed bowl (about 17cm in diameter), flat board.



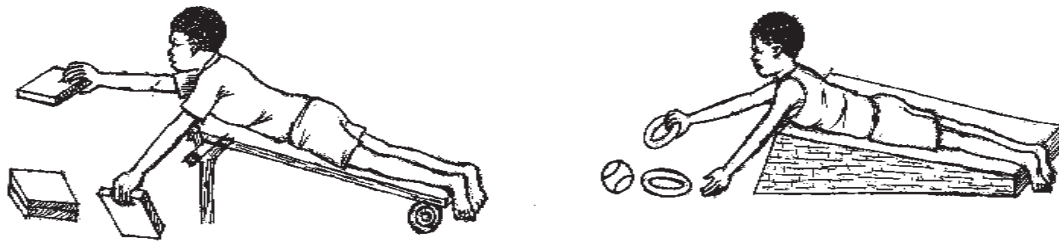
### Steps

1. Cover the board in plastic (if it isn't already plastic) to make a clean surface.
2. Place the large bowl face down on the plastic board. Place the yoghurt container face down on top of the bowl.
3. Plaster mud around the container and bowl to make a conical shape.
4. Cover the whole cone in two layers of plastic sheeting. Put one layer of sheeting on top of the other, so the mud is completely covered.
5. Tear the paper into strips. Cover the paper strips in glue. Cover the cone with these strips, making a total of five layers, as shown in the picture.
6. Gently remove the paper cast from the mud cone. Leave it to dry.
7. Make an ear piece with the pen lid. Cut the narrow end off the pen lid and smooth it. Cut the narrow end off of the paper caste so that the pen lid fits into it. Moisten the end of the cast with glue and insert the pen lid into position from the inside of the trumpet cast. The ear piece should fit tightly.



8. Cut some paper into small pieces and cover in glue. Cover the inside and outside of the whole trumpet with the paper. Leave it to dry.
9. If possible, cover the trumpet in attractive paper and varnish.

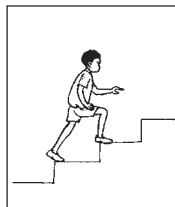
### 3. Seating aids



**Aim:** To present ideas on how to make a simple seating aid.

(This idea is adapted from 'Disabled Village Children' For many more ideas on seating, standing and walking aids please check this manual for detailed information).

**Materials:** Poles made of wooden sticks or bamboo cut to various lengths, about 1-2ins in diameter.



### Steps

1. Cut the poles to the various lengths required e.g. 4 sticks 24 ins. long, 4 sticks 20 ins. long, 6 sticks 18 ins. long, 7 sticks 12 inches long.
2. Drive the 4 longest sticks into the ground (about 6-8 ins. in so that they hold firm) to make the back of the chair.
3. Drive 2 24 ins. sticks into the ground on either side to make the sides of the chair.
4. Drive the 18 ins. stick in to make the arms of the chair.
5. Drive the short sticks into the ground to make a V shape with will separate the child's legs.

## Meeting 17



### Activity



Understanding epilepsy and how to manage it.

**Ideas:** Information based on Caroline Pickering's book "How to help with epilepsy."

### What is epilepsy?

A person with epilepsy is an ordinary human being with a medical condition. This medical condition causes a sudden malfunction of the brain which in turn leads to a seizure or fit. These often happen unexpectedly and they are frightening to all involved. The seizures or fits can be controlled by taking medicine, but the medicine has to be taken regularly, for long periods of time to be able to help reduce the number and severity of the fits.

### A person with epilepsy

Is NOT mentally ill.

Is NOT a criminal.

Is NOT possessed by the devil.

CANNOT give epilepsy to anyone else.

### What to do when a person has a seizure

#### DO NOT

Try to put anything into his mouth.

Give him anything to drink.

Try to stop the jerking movements.

## **DO**

Keep calm.

Prevent him/her from hurting him/herself. i.e. remove him from fire, water, traffic and other dangers.

Cushion his/her head on something soft.

Loosen tight clothing from around the neck.

When the fit has stopped turn him/her on his side to help breathing and recovery.

Stay with him/her to comfort him. He may be tired and want to rest.

When he feels better let him resume what he was doing.





# Notes

### **Message from the Women of Kilifi**

*"We are very thankful for this programme, we didn't know that we could learn these good lessons. The parents welcome us, we have become famous and are even called doctors: "Madaktari was KEMRI." At first we were very afraid of going to the households, we even thought of getting someone from the chief's office to guide us, but we found it was not necessary for the parents received us so nicely. Some parents even wish to be invited to our meetings."*