Using community/researcher partnerships to develop a culturally relevant intervention for children with communication disabilities in Kenya

Sally Hartley, M.Ed. PhD.[1,2], **Gladys Murira, B.Sc.**[3], **Mary Mwangoma, B.Sc.**[3], **Julie Carter, M.Sc. PhD.**[1,3], and **Charles RJC Newton, MBChB.**[3,4]

[1]Formally of: Centre for International Health and Development,, Institute of Child Health 30 Guilford Street, London, WCIN IEH, UK

[2]Now at: Faculty of Health, University of East Anglia, Norwich. Norfolk NR4 7TJ

[3]The Centre for Geographic Medicine Research (Coast), Kenya Medical Research Institute P.O. Box 230, Kilifi, Kenya

[4]Neurosciences Unit. Institute of Child Health, University College London, The Wolfson Centre, Mecklenburgh Square, London, WC1N 2AP, UK

Abstract

The objective of this study is to develop a culturally relevant community based intervention for children with communication disabilities in Kenya through a community/researcher partnership. The resulting intervention is for use in a randomized control trial which will be reported at a later stage.

Using a qualitative approach, initial data was collected through focus group discussions with women, disabled people and traditional dancers. The groups examined the needs, problems and challenges faced by disabled children and their families. This generated the content and structure for a series of participatory workshops with a further two women's groups. These workshops strove to generate a culturally relevant community based intervention programme for children with communication disabilities and their families.

The content and balance of the resulting intervention was observed to be different from existing programmes described in the literature. Notably it included many culturally appropriate strategies for increasing social integration and raising community awareness. The process of generating a locally relevant community based rehabilitation intervention is potentially transferable and has particular relevance to the estimated 80% of the world where there are no formal rehabilitation services for children with disabilities and where women's groups are a strong element of local culture.

Keywords

Participation; women's groups; communication disability; Random control trials; complex health interventions

Address for correspondence: Professor Sally Hartley, Faculty of Health, University of East Anglia, Norwich. NR74 7TJ. s.hartley@uea.ac.uk Tel: 01603591672 Fax 01603 593166.

INTRODUCTION

The difficulties of introducing health and educational interventions that originate from a different culture and the tendency for these interventions to be inappropriate and therefore invalid, are well known [1]. It is also particularly problematic when the issues to be addressed are not prominent in the consciousness of the target community [2], as is often the case in relation to disability, particularly communication disability. In addition the WHO's International classification of functioning disability and health (ICF) [3] re-enforces the important role that the environment plays in creating disability. This all serves to highlight the need for appropriate technologies based on evidence collected in the region [4]. The literature also suggests that community based interventions are a good avenue for delivering services and support to people with disabilities [5] and that self help groups can contribute to improving population health outcomes [6]. The effectiveness of a community based action orientated approach has been illustrated in changing other health related outcomes such as a participatory intervention using women's groups on birth outcomes in Nepal which reduced neonatal mortality rate [7].

Communication plays a major role in every person's life. It is the means by which humans establish their own identity and integrate into their community [8]. But although the ability to communicate is considered a basic need [9], essential for an acceptable quality of life [10, 11], and a sense of wellbeing [12], services and support for the people with communication disability are rarely available in low income countries. Those that exist are usually found in urban-based institutions [13], even though about 80% of the disabled people live in rural areas [14]. Studies conducted in Uganda [15] and Zimbabwe [8] have shown that around half of children from the full range of impairment groups, have problems with communication. This is also supported by a recent study carried out in Kilifi Kenya, which shows that amongst the disabled population identified in this study 52.5% were children with communication disabilities [16].

In this area of Kenya, as in most of Africa, there is no specialist, or community based services offering support to overcome these problems. There are however, very active women's groups, whose aim is to improve the quality of life of people living in their communities. On the theoretical assumption that working with local groups generates a more valid and sustainable intervention, this paper describes the process of a partnership between the women and health researchers. The resulting intervention focuses on strategies that the women themselves can carry out to improve the communication skills and the quality of life of these children and their families.

The objective was not only to develop an intervention that would address the needs of these particular children, but also to explore the process by which more valid and culturally appropriate health and disability related interventions could be developed generally. Interventions that could be subsequently evaluated in randomised control trials.

This study is located in Kilifi, a rural community on the Kenyan coast about 60km north of Mombasa. It is the second poorest district in the country. This paper will describe one part of a bigger study. This part relates to the development of a community-based intervention arising from local perceptions of problems faced by children with communication disabilities and a subsequent partnership between the researchers and local women's groups. In this instance "children with communication disabilities" are defined as children whose ability to communicate is affected by their response to an impairment and/or social and contextual factors, which inter-relate with each other and the person themselves, resulting in impaired communication skills [9].

METHODOLOGY

The methodology involved community groups in a participatory action research approach, which is thought to be more empowering in negotiating sustainable intervention plans [17, 18]. We chose to use existing networks to benefit from local expertise and relationships, an approach which has been used and reported in other areas of health service provisions, for example by Beck *et al* in their studies on sexual health [19].

Reason and Bradbury [20] suggest 'the key components of action research are participation, a democratic process and practical knowledge, in pursuit of a worthwhile human purpose'. Generally, it is agreed that action research intends to improve the situation rather than discover universal truths. It seeks to focus on practical problems that originate in the community and follow a participatory/emancipatory approach, using educative structures, e.g. people reflect on and improve their own situations in an iterative process. The research process also seeks to develops a 'critical community', which has equality in respect to power [19, 22]. The process described here aspired to involve relevant parties in a collaborative approach to address issues that were of concern to them about the lives of children who couldn't communicate. Information from interviews of parents' of children who had problems communicating (also part of phase one but not reported here in detail), helped to inform the structure of the focus groups discussions with community groups, which in turn influenced the content and focus of the participatory workshops with women's groups. Through this process a community strategy on how women's groups could address these issues was developed.

Two data collection methods, focus group discussions (FGDs) and participatory workshops (PW/S) were used sequentially, the one informing the other. They were thought to be appropriate for enhancing the validity of the intervention through defining the relevant components, as recommended by Campbell [22]. However to avoid contamination and protect the validity and reliability of the subsequent trial in phase 3, the data were collected from community women's groups in the southern study area of the Kenya Medical Research Institute's (KEMRI) demographic surveillance system. This area is separate from the final study site, but thought to be similar, in terms of language, cultural groups and location. Information from the FGDs was used to inform the structure and content of the PW/S.

METHODS

Sampling procedure and process of data collection for the FGDs

A purposive, convenience sample of stakeholder groups was selected from the community. Purposive, in that they included representatives of the key stakeholders and convenient, in that often groups close to the research unit were selected over ones that were more remote. This was due to resource limitations in terms of personnel and finance. Although this was recognised as a limitation it was felt that all communities in the area were rural and poor and closer location to the research institute represented only limited bias.

In the first instance all community groups in the area immediately south of the research unit were identified through social services, who keep a register of such groups. There were 32 women's groups, 4 disabled people's groups and 3 dancing groups. The dancing groups traditionally travel around the area, entertaining the community with songs and dancing at holiday time and for celebrations. They were included mainly because they had a high proportion of men in their membership, whereas the other groups predominantly consisted of women. The women's groups had members who were parents of disabled children and all groups had representatives of people in community leadership roles.

Information from parents of disabled children was also used to guide selection of the community groups. This was collected from interviews with 16 parents of disabled children randomly identified from the data set of the neurological impairment study [16]. These interviews were primarily to seek feedback on the communication profile and quality of life scales being developed as outcome measures for a cluster randomised control trial, which was subsequently used to evaluate the impact of the intervention described in this paper. Information about local activities and perspectives from these interviews also served to inform the selection of relevant community groups. In addition they also re-enforced the perception that support for parents of children with communication problems needed to be located in the communities and provide support to parents who often felt they had to face the burden of disability alone.

The research team, together with the staff from the social services and a disabled community representative, discussed and decided through consensus which community groups should be included in the study. This was done on the basis of having representation from both men and women, disabled and non-disabled members of the community, parents of disabled and non disabled children and community leaders. In addition selection was based on criteria relating to the perceived activeness of the groups (more active groups being preferable), the cohesiveness of the groups (cohesive groups deemed to have more potential for collecting rich data), and the location in terms of convenience for the study. Details of the groups and the data collection methods used are presented in table 1.

Six focus group discussions were held with three women's groups, two disabled people's groups and one group of traditional dancers. This involved a total of 91 participants. As a basis for facilitating these discussions a check list of questions was developed by the research team with input from information gathered from the 16 parents of disabled children mentioned previously. (see table 2).

The FGDs aimed to explore community perceptions about children with communication disabilities, consider their possible needs, examine the challenges they and their families might face and consider what sort of interventions might be possible. The information generated was then used to develop a possible programme for the participatory workshops with the women's groups.

The meetings were held at their own meeting points, such as the local school or church. The discussions were conducted in the local language (Giriama). They were tape-recorded and a research assistant took notes for backup in case the tape failed or the conversations could not be heard due to background noise or simultaneous conversations. The tape recordings and notes were amalgamated and translated into English producing one transcript/record.

Sampling of groups and process of data collection for Participatory Workshops

A purposive/convenience sample of 2 of the 32 identified Women's groups was made in the southern district of Kilifi. This involved 35 participants. The selection was based on local knowledge of the most active and interested groups and the locations that were close to other research institute activity to minimize costs. It was recognised that this had limitations of bias against more remote communities, but thought that this would have minimum effect as even the closer communities were quite remote. Neither of the two women's groups selected had participated in the FGDs, There were eight workshop sessions with each of the two groups giving a total of 16 participatory workshops and between 450 and 500 face to face contacts.

Each group was seen separately at their groups' meeting premises. All workshops were arranged and held at their convenience by discussing with the group members and coming to

a consensus agreement. The workshops were held weekly over a period of eight weeks. This gave both the researchers and the participants' time to prepare for future activities and other relevant duties, such as thinking about more ideas, digesting those ideas already discussed, transcribing the previous discussions and seeing other groups.

A moderator with previous experience of facilitating group discussions guided the group following the eight session intervention ideas as generated from the previous FGDs. All workshops were video recorded and a research assistant took notes for backup purposes.

The four methods used for eliciting data were brainstorming, role play, story-telling and free discussions. In brainstorming, participants were asked to contribute the first ideas that came to them according to their own perceptions and understanding about a certain issue. These ideas were listed and, using the facilitator as a guide, they were discussed. Where necessary, and as appropriate, role-plays were conducted in order to enhance understanding of the issues. For example, to illustrate the meaning of communication difficulties in a more practical way, participants simulated someone who was deaf and unable to speak, trying to pass messages to a colleague without talking. After the experience they shared their feelings and perceptions about the exercise.

The use of anecdotes and vignettes were also used to stimulate a response. In this case short stories were narrated either by facilitators and/or participants in order to help encourage other members contribute their ideas in related fields. An example of a short story narrated by one participant is as follows:

> "*There were two young children in one of my neighbouring households. The youngest could not walk, neither talk. The older one used to pull him around to follow other children in plays and games. Sometimes he used to talk to his kid brother and let him repeat words after him. He would instruct him to say 'ma ma' 'ba ba' and so forth. It took a long while for the child with disability to overcome the situation. He can now say one word sentences that comprises of people's names and relations. He can try to walk a short distance, though not in a very good posture*" *(SK/WG).*

One transcript was generated by the research team which summarized information gathered from the video and the notes.

Analysis and results of the Focus Group Discussions

Themes and ideas were generated manually from the transcripts of the FGD data by the research team, using a process of consultation and consensus within the group. Participants in the FGD were not included in this initial process. The major themes that emerged from these data related to problems that these children and their family might face, such as evidence of segregation, *'They are also segregated by their families they eat separately' (J. women's group FGD)*, of abandonment '….some (disabled children) are not taken good care of, they are left to loiter around, left to beg in the streets just like streets children, they don't have food, clothing and even where to sleep'….(.N. Disabled Self help FGD), of exploitation *'…so us deaf would be forced to eat quickly and go to the shamba while the normal ones are just seated at home…' (Kibarani deaf group)* of lack of educational opportunity, *'They refused to take me to college, instead my brother told me to help his wife as he looks for a college. I stayed there for a long time but they were doing nothing'. (Kibarani deaf group),* and poor social integration, *'They used to refuse to go with me wherever they were going instead they would tell me to go to… carry water, look for firewood and cook for them…' (N. Disabled Self help FGD).* This gave rise to the proposed sessions which included a significant amount of time for the women to examine and reflect on the problems faced by both the children and the parents. Followed by discussions on

strategies for inclusion, social integration and community awareness raising. There was also many perceptions from the FGDs about what was meant by 'communication disability' *'his mind is not alright and he cannot mix with other children' (dancing group) 'but he is not deaf so we cannot be of help to him (WG/FGDs)* and what might cause these problems *'the mother was blamed and she left the homestead and never came back' (dancing group). 'the inability to hear is brought about by the fact that he cannot speak, but the moment he starts speaking he will definitely hear' (WG FGD).* It was therefore decided that a section in the participatory workshops should be put aside to explore these issues further.

Knowledge and experience about some supportive community interventions for people with communication difficulties were added to the workshop itinerary, these arose from experiential evidence of service provision in different African countries and also from the publications 'Lets communicate' and 'Hearing and Communication Disorders' [8, 23]. These ideas were selected only if they appeared to relate to the problems identified in the focus groups. For example, techniques relating to stimulating language through lived experiences (there was a lot of evidence that these children were denied expose to many lived experiences) or the processes involved in developing alternative methods of communicating other than speaking, such as communication boards, because it appeared that many of the children described had very little chance of developing speech. The process of amalgamating the evidence from the FGDs and the expertise of the researchers was done at this point by the research team. It was during the participatory workshops in the second part of the data collection that the women were consulted as to whether the items should be included in the final intervention of the programme, and if so how this should be done. The output from the FGDs was a programme of 8 sessions. These elements served to provide the structure for 8 participatory workshops with the two women's groups and are shown in table 3.

Analysis and results from the participatory workshops

The transcript/documentation generated from the videos and the field notes of the participatory workshops were examined and together with information from the original eight participatory workshops, 17 sessions were created. Some of these followed similar forms to the original version see table 3, e.g. Session 4 Awareness about causes and prevention, and some were entirely new, e.g. using traditional dancers to spread community messages. The results of the PWs indicated that the women generally found it appropriate for them to train or educate parents of children with communication difficulties on strategies that would address the needs of their children. This was based on the perception that parents are the primary caretakers, they spend the most time with their children and generally have deep concerns for their welfare, so are well motivated and would take the initiative to practise what they learnt.

Data analysis elicited observations that are presented in table 4. These ideas and perceptions of local women were then used to generate the main areas of the final intervention. This had seventeen sessions, which were based around the 15 areas listed in the third column of table 4. The evidence for the problems identified and the link with the resulting intervention is illustrated in this table.

Problems identified and possible Interventions suggested by the women's groups in the participatory workshops

For example, as a strategy for overcoming the negative attitudes towards children who could not speak or communicate, the sessions included exposure to adults who were deaf or who were wheelchair users, but also led full and useful lives. The purpose of this was to challenge the idea that disabled people are of little or no value and encourage a more

positive and optimistic approach to people with these impairments. These encounters also gave hope to the parents of children with such problems, as one mother said.

> '*I cannot believe she (a deaf facilitator) is deaf, she did so much, she is so clever*' *(WG2PW)*

Many women felt they didn't know what to do to help such children and their parents. Whilst they had the capacity to carry out many of the strategies, once their awareness had been raised, there were some ideas and approaches that required the research facilitators to share existing knowledge. For instance, the women identified the need for the disabled children to be more included in everyday events but needed to be shown existing technical strategies for constructing seating arrangements for example. These enabled children who could not otherwise sit, be helped to do so and to then be able to see what was happening in the homestead. The same applied to many ideas relating to play and cognitive stimulation. Some ideas were put forward as suggestions but only those that the women seemed to relate to, understand and approve of, were adopted.

General observation showed that role-plays were practical and increased the level of awareness, while brainstorming helped generate ideas in a more relaxed and natural way. The aspects of the intervention itself that appeared to raise the most interest and enthusiasm were the exposure to the role models of disabled people themselves and the use of traditional dancers to communicate key messages to the public. A full description of this intervention can be found in Hartley *et al* [24], a small booklet outlining the process used and all the strategies developed.

It is interesting to note that several issues emerged from the participatory workshops that had not arisen in the FGDs, such as the importance and problematic nature of children with epilepsy and also the need to learn sign language. The session on epilepsy would certainly not have been included in the intervention structure if it had been based on previous literature, or just on data collection from the FGDs. Even the desirability of learning sign language and exposing the women to disabled role models, came through much more strongly in the PWs data. Information from the PWs also added a shift in balance from an intervention that might have focussed more on strategies to improve speech and language development, to one that focussed more on changing community attitudes, promoting inclusion and communication opportunities. These strategies were observed to relate closely to the problems the women had identified and be much more likely to be within their comfort zones.

The data showed an increasing richness over time, with the later sessions yielding much more useful data than the initial meetings. This might indicate a limitation of data collected from a 'once only' encounter and put into perspective the relative value of one off FGDs and interviews.

The idea of using traditional dancers to compose songs about disabled children, the problems they face and how the community can help, arose entirely from the women, and anecdotally it is interesting to observe that after the project was completed this is the aspect that is most remembered by the community.

DISCUSSION

Airhihenbuwa [1], Hubley [4] and Boas [25] argue that health interventions should be related to their cultural and linguistic context. The WHO specifically comments that any service dealing with communication should be directly related to the life and culture of each specific community [8], since language and culture are so inter-dependent. This study

developed a method whereby the connection between the context and the intervention were realized. Thus, in this case, it is not the intervention itself that is transferable to other communities, but the process that was used. This process involved more than a cross sectional approach to sharing ideas and opinions through one off FGDs, but the development of a partnership over time which appeared to yield much richer data as the levels of understanding and trust developed.

It was observed that some suggested interventions, for example those related to knowing what 'aids' can help such children and their families, were represented in existing literature. However it was also observed that all the themes of concern generated from the FGDs, and 11 of the seventeen proposed session topics addressed factors to do with the environment and increasing participation. This focus is a clear departure from existing good practice described in the literature e.g. Wirz and Winyard [23] and WHO [8] who recommend strategies that focus mostly on functionality of the individual and increasing the capacity of activities of daily living.

Negotiating an intervention plan with community women's groups enabled the whole community to become involved, and avoided placing the entire burden on the parents of such children, as is commonly done. This shifted the focus towards the community and allowed the social determinants of disability (such as the negative attitudes of the community) to be discussed and included in the intervention to a much greater degree than would have been possible if the intervention had been focused on the child and his/her parents. This outcome is compatible with a more comprehensive model of disability such as the one reflected in the international classification of functioning and disability (ICF) [3]. Such models emphasise the very important role of the environment and participation in the dynamic of disability. In turn this suggests that rehabilitative interventions need to address all such dimensions if the level of disablement is to be reduced. Community participation provided a greater understanding of the complex contextual dynamics influencing disability, and as Kuruvilla and Joseph [26] point out, this is likely to increase the validity of the study findings.

In addition, the contextually relevant qualitative data allowed the ideas generated to be specifically tailored to this particular context. For example, the need to spread positive messages about disability was manifested by engaging the traditional dancing groups, a strategy that in other cultures might have been in-appropriate or even impossible.

As indicated previously the study described here was part of a cluster random control trial and as such is in line with suggested good practice. It supports the proposal of Riley et al [27], that qualitative evidence should inform community intervention trials at all stages of their development and be monitored by a process data monitoring committee. This is in addition to the usual and more accepted, outcome data monitoring committee. We suggest that a process monitoring committee would be in a position to evaluate suggested interventions and decide if they were sufficiently grounded in the cultural context as a pre-requisite for a future study. Our experience suggests that this committee would need representation from the target groups and in this instance would include parents of disabled children, disabled people themselves and women from the women's groups. This would help to address the ethical issues around evaluating culturally insensitive interventions and offer a process that helps to increase the validity of the interventions and therefore the chances of a successful outcome.

The approach described here resonates well with the 'realist' view described by Bhasker [28] and Collier [29], a methodological orientation with its roots in philosophy. The realist's view has an explanatory rather than judgemental focus and is described by Pawson as a

possible framework for conducting a systematic review of complex interventions [30]. Pawson offers a model of research synthesis [30], which is designed to work with complex social interventions using a 'realist' approach to evaluation. This view has many similarities to the approaches used in this study, which does not provide simple answers but a means whereby a rich and highly detailed practical understanding of complex interventions can be developed and woven into the fabric of random controlled trials. As most health and disability interventions are of a complex nature, this view is one that has resonance over the whole width and breadth of such interventions and is not confined to those relating to communication disability.

Limitations and biases

In terms of an example of participatory action research this study strives to move towards this paradigm, but there are five dimensions on which it could be strengthened. Perhaps the most fundamental limitation relates to the identification of the underlying problem by the research team and not the community. The study was designed on the basis of evidence collected from a study on Neurological Impairment in children [16] identifying a considerable number of children with communication difficulties for whom there was no service provision. Whilst this was obviously recognised as a problem by the participating groups it was not necessarily their chosen focus. Secondly, on reflection the validity of the data may also have been increased by the involvement of a parent group. It was thought that there were sufficient parents of disabled children within the women's groups, but in the eventuality this did not seem to be the case. Thirdly, whilst the level of participation of the women's groups in the development of the intervention was considerable, it could have been increased even further by increased involvement in production of the final programme. Unfortunately this would have required time and resources that the project did not have. Fourthly, in terms of selection of the community groups, this too was mainly controlled by the researchers and could have been more participatory by including community groups in this process. Finally participants could also have been used more in the analytical process.

Conclusions and Recommendations

This study shows that a participatory process changed the focus and content of a complex health intervention for children with communication disabilities from a more impairment/ activity related focus, as described in the literature, to one that targeted identified problems and related to the social determinants of disability. It did this in a way that was relevant and culturally acceptable to the target population. It is argued that this made the intervention much more valid.

The participatory process used was not confined to cross sectional FGD data, but included PWs that fostered an ongoing relationship and developed partnerships between researchers and community members. This was observed to foster rich data and contribute to the quality of the information collected.

Given this outcome, it is recommended that good practice in randomised control trials of complex health interventions should include generating and piloting interventions before the trials. Such trials should avoid the practice of exporting processes from other cultures and continents, and assuming that they are best practice in alternative settings. A participatory action research stage should be added to the research programme to make sure that the interventions they are trailing are worthy of evaluation.

Acknowledgments

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Key messages

1. Community/researcher partnerships can be used to develop interventions.

2. Such interventions are different from those imported from other cultures.

3. This process is transferable and can be part of the preparations for a Randomized Control Trial.

Table 1

Stakeholders and data collection methods

	Data collection method	
Stakeholders	**Focus Group Discussions (FGD) Number of groups (Nº of participants)**	**Participatory Workshops (PW/S) Number of groups (Nº of participants)**
Women's groups	3 (47)	2 × 8 (35)
Disabled people's group	2 (31)	
Traditional dancers	1 (13)	
Totals	6 (91)	16 (35)
Total hours of data collection	12	32

Table 2
Check list of questions to help facilitate FGD

Check list of questions:
1. What does communication disability mean to you?
2. What are the attitudes towards children with disability?
3. What are their needs?
4. How are the needs met/not met?
5. How are they treated?
6. What could you do to help meet these needs?
7. What problems do their families face?
8. How could you help the families?
9. What can we do to help you do that?

Table 3
The sessions for the PW based on suggestions from the FGD

Session 1	Introduction/ FGDs on Problems	Share idea of the project with the WGs introducing and explaining about children with communication disability through role play and discussion. Discuss some of the problems they might face. Explain what participation in the programme will involve, seek their participation but give the opportunity to withdraw at any time.
Session 2	FGDs on Problems	Explore the groups perceptions of the problems faced by children with communication disabilities and their families
Session 3	Strategies for inclusion (school, home activities, outings, Family events)	Explore strategies for including the children in everyday activities that are within the power and capabilities of the women's groups. Identify any activities that could be facilitated by input from the researchers.
Session 4	Awareness about causes and prevention	Look at local perceptions of causes and prevention. Compare their perceptions with other perceptions
Session 5	Communication skills/talking to children about what happening	Explore the process of stimulating language and communication through experiential learning. Identify the everyday activities of the local communities and relate these to communication activities
Session 6	Negative attitudes/ what can women groups do	Identify and explore the local negative attitudes towards these children and their families, discuss what local women's groups could do about these.
Session 7	Social integration.	Consider further what strategies could be used to promote the social integration of these children. Identifying which strategies might be acceptable and sustainable to the various sections of the community.
Session 8	Drawing together/ feedback on intervention	Review the sessions and reflect on what has been covered giving opportunity to revisit any section that needed further attention

Table 4
Problems identified and Intervention ideas suggested by the women's groups in the participatory workshops

Problem	(Evidence from PWs)	Intervention action
Confusion as to what communication and its breakdown involves	'what is communication in our language, we do not have a word for it… M: 1 (To understand one another) M: 3 (To listen to one another) M: 2 (To converse) M: 1(To compromise) M:4 ((To talk and to converse)' (WG1) "The problem is that when we hear of disability we just think of only those who can't walk….' Isn't a deaf person disabled?"(WG2)	What is communication? What is communication disability?
Many don't believe that disabled people can do anything good, that they are all 'stupid'	"Also there is one in our place a very big beautiful girl. There was a time I asked her to fetch some water for me she didn't look as if she was getting whatever I was telling her. Many people thought she was stupid…..I asked another person who confirmed to me that she is deaf."(WG2)	Exposure to role-models of people with communication disabilities.
Negative attitudes towards people with disability. People do not understand and are not tolerant of the problems parent's face.	"To add onto that, sometimes us mothers hide these children in case of visitors. Well he is my own child but because I know he is abnormal, I feel I should hide him for I think he will bring problems to the visitors whereas I could leave him to play with the other children he would be calm and enjoy himself. So us parents, isolate them." (WG1)	Explore people's attitudes towards children with communication disabilities and their families. Consider how they might be changed.
children who cannot communicate face lots of problems	"Those people face some problems. Let's talk the example of this child who can walk but can't speak nor hear, on the way somebody can beat him without any reason and she can't report, or sometimes they are raped, then they can't report so they just suffer, if maybe she can write it's easier she can write the name of the person and what he has done for her, but if she can't she just remains with such problems."(WG1) "Sometimes they may be refused to eat or not given food and she can't report"(WG2)	Identify and explore problems faced by children who cannot communicate and their families.
Don't know how they can help	"If we identify these parents who have such children and call them at a place like this, where we can explain to them I don't think they can refuse for it is a good way of helping those disabled children, but we need to know what to do." (WG1)	What action can the group take? Research facilitators share simple strategies that might help.
Don't know what advice to give to families	"As the parent, you feel so bad for you don't know the cause whether she was bewitched or it is God given. What we know is that God created her that way so you will not know how to help the child to either talk or communicate."(WG1)	What advice can the group give? Re Research facilitators to s share simple strategies that might help
Where are the children?	"To help them, we should call a meeting tell the parents to bring them so that we can see who they are and how we can help them."(WG2)	Identification of the children in their area.
Parents are the people to work with Aids can help but not available and we don't know how to make them	"The simple way is for us to educate one another on the ways we can use to help those children then educate the parents on those ways, so if we have agreed then us as the group and the parents can look for these ways of helping those children."(WG1) "…. this one who cant walk (athegwethegwe) completely can be taken to hospital and maybe given a wheel chair (kigari) which will make it easy to go to school and learn if the hands are	Women to contact the parents of identified children, invite to group session, share ideas. Making aids including special seating and communication boards so that

Problem	(Evidence from PWs)	Intervention action
	alright, it is only the legs and it is easy for them. For the children who cannot talk we do not know what to make." (WG2)	children can be included. Research facilitators to share information on this
Epilepsy is a big problem don't know how to help	*"Some children couldn't be talking and even walking but may get fever which results into fitting….." "….Like for my grandchild he always need drugs so as not to fit" (WG1)* *"She is fitting, maybe she has fever or not, you can just find her fitting, so you might ask yourself some questions, is this epilepsy or what type of fitting is that so you will help by pouring some water on that child". (WG2)*	Lessons on managing fits and epilepsy.
Children are not included in family events And therefore don't learn to talk.	*" That is the light. For if a child can't talk, there is not much you can do with her, you just give him food, maybe there are some activities she can do or sometimes she cant, but if she is taken to school, she can learn to understand herself and others."*	Inclusion in everyday activities for social and educational stimulation.
Children don't have anything to talk about….left to their own devises.	*"They can teach them at home like small children playing with coconut shells, when this one puts soil in the other one also does that, so they teach one another at home, that wont need money; they teach them just at home." (WG2)*	Making local toys and play local games.
Some children can sign but we cannot talk to them because we can not sign…. Or we cannot teach a child to sign who is deaf…	*"Also there is one in our place a very big beautiful girl. There was a time I asked her to fetch some water for me she didn't look as if she was getting whatever I was telling her…then I asked another person who confirmed to me that she is deaf." (WG2)* *"Even other people should be educated on how to use signs for they might in future give birth to such children; and given that they will already have the knowledge it will be easier to them to handle them."(WG1)*	Learning some local sign language
Children are excluded from school and abused.	*"Some don't take such children to school. There used to be another man called KG who had a daughter who could not talk, she was not yet mature but she was raped. People used to convince him to take her to school but in vain. Now the girl died. Some don't take them to school they keep them at home until they die." (WG2)*	Strategies for encouraging schools to include disabled children and parents to take their children to school.
Community members don't understand	*" I know a child who was drowned to death by parents and relatives because he had a disability. They thought he was curse that would bring misfortune"(WG2)*	Mobilizing community groups such as the traditional dancing groups to pass messages