

LOCATION

Kilifi district, Kenya

PARTNER

INSTITUTE OF CHILD HEALTH, UK, and KENYA MEDICAL RESEARCH INSTITUTE, KENYA
Through its innovative research and high-quality training programmes, the Institute of Child Health has created a world-class centre for the study and treatment of childhood disease and has made a major contribution to the health and well being of children and their families worldwide. The Kenya Medical Research Institute is one of the leading research institutes in Africa, encouraging research collaboration nationally and internationally to find solutions to health problems.

SUMMARY

The project is designed to increase the present knowledge concerning appropriate interventions for children with communication problems who live in low-income countries.

PERIOD OF FUNDING

October 2001 to October 2003

GRANT

£49,905

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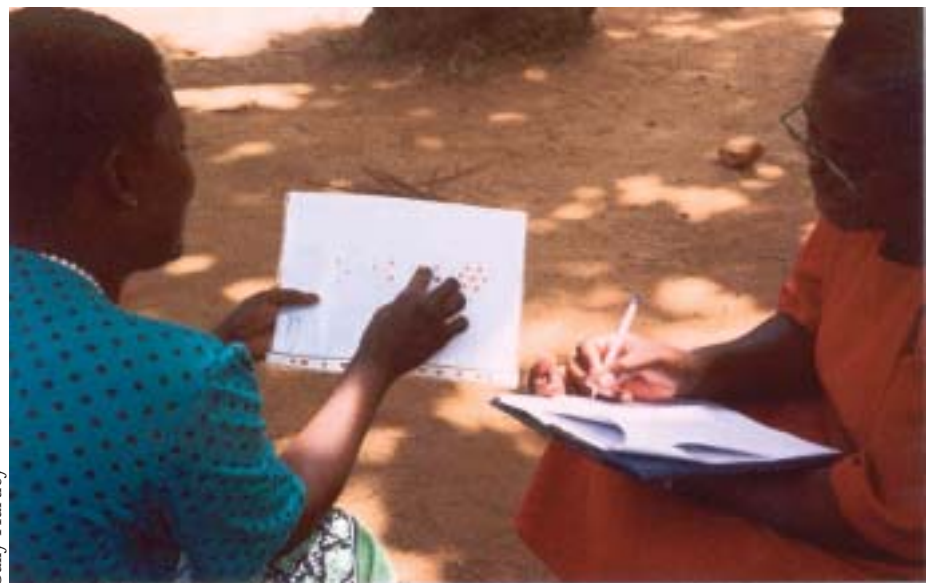
Evaluating the impact of a community-based rehabilitation intervention

BACKGROUND

Studies show that nearly a half of all disabled children in low-income countries have communication problems – approximately 20 million children worldwide and half a million in Kenya alone. Most disabled children with communication problems live in the rural areas of low-income countries and come from very poor homes. Specialist services for them are almost non-existent, so there is an urgent need to develop and evaluate alternative strategies to help this vulnerable group.

THE PROJECT

The project was designed to evaluate the impact of community-based action by local women's groups to improve the communication ability and quality of life of disabled children with communication problems. Out of a total population of 800,000 in the project area (Kilifi), there are an estimated 40,000 children with communication problems. It is hoped that if this work is successful and replicable, all these children might benefit indirectly from the project.



Sally Hartley

At the end of the study there will be:

- tools in English, Kiswahili and Giriama that can be used in Kenya and other low-income countries as a basis for evaluating communication disability and the effect this has on the quality of life
- a community-based intervention programme targeting children with communication problems that can be carried out by non-specialists and focuses on simple ways to improve children's communication and their quality of life.

The study has **four phases:**

The first phase:

- developing and modifying the **Communication Outcome Measuring Tool (COMT)** – a verbal questionnaire conducted by a trained user with the child's parent to assess the child's communication skills
- developing a quality of life questionnaire to measure children's levels of happiness, daily needs, their sense of security and self-confidence and their access to information
- piloting these tools with 30 parents (12 of whom have children with communication problems and 18 who have children who do not).

The first phase includes developing and modifying the Communication Outcome Measuring Tool (COMT) – a verbal questionnaire conducted by a trained user with the child's parent to assess the child's communication skills.

The second phase:

- identifying 334 children from an earlier neurological impairment study and assessing them for communication skills and quality of life, using the measurement tools described above.

The third phase:

- assigning approximately half of the 334 children to an intervention group and the remainder to a control group. Randomly selecting eight women's groups from the 52 active women's groups in the study area. Conducting a series of workshops for these groups, with each group working out individual intervention plans for about 20 children. The plans include:
 - respite care and support for the mothers to encourage a more inclusive approach to bringing up disabled children
 - technical advice on stimulating children and making learning aids.

The fourth phase (currently underway) is an evaluation of the intervention in terms of impact on children's communication skills and quality of life as measured by the tools described above.

Two key objectives have already been achieved: **community interventions** have been carried out and completed (December 2002), and **measurement tools** have been created, modified and developed. These have already been used pre-community intervention and will be used again post-intervention, and the results compared.

The project has been well received by the members of the women's groups, who have participated with interest and enthusiasm. They are already including mothers of disabled children and groups representing disabled people in their activities.

LESSONS LEARNED

■ Women's groups are enthusiastic about the project and some of them have started their own activities, indicating that working with women's groups may be an effective strategy for promoting community-based rehabilitation (CBR) activities.

■ In the initial qualitative part of the study, the women in the groups found it difficult to make a distinction between children with communication problems and those without, and wanted to include all disabled children in the initiative. This emphasised the fact that splitting disabled children into impairment groups is not a helpful categorisation for community work. Community-based services may be more culturally acceptable if they take a comprehensive and holistic approach.

■ In just over a year this project has begun to develop an expertise concerning the processes involved in community participation, and the research processes necessary to document and monitor this. Time for reflection and evaluation is required to develop an approach that takes into account the perceptions of disabled people and other community members, and ensures that the research remains relevant and action orientated. The present Department for International Development (DFID) funding process needs restructuring to support of this kind of research and maximise its potential impact.

FUTURE PLANS

The **Institute for Child Health** and the **Kenya Medical Research Institute** have already disseminated information about the project through the Knowledge and Research (KaR) programme newsletter and by presentations in Kenya and UK, but they also plan to document the intervention by producing a booklet *Women in Action: improving the quality of life of disabled children*. Funding for this publication is not included in the KaR grant and will be sought from elsewhere.

The qualitative data collected in the initial

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phase, which was used to develop the quality of life tool, was rich in information. For example, it showed evidence of negative attitudes towards disabled people. More time could be allocated for the analysis of this data in future projects.

The programme offers an opportunity to develop and evaluate a mechanism for establishing CBR services where no such services exist. The potential impact is significant and the mechanism for doing this has eluded CBR development to date. Applications for funding will therefore be made to other agencies in order to continue the programme's work beyond the initial completion date of October 2003.

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