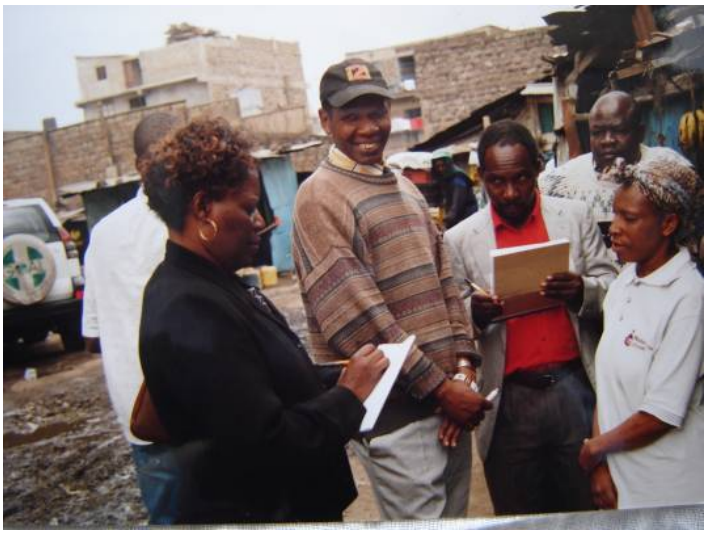
Community participation in the management of mental disorders in Kariobangi, Kenya



A Participatory Reflection and Action Project
REPORT

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Through institutions in the region, EQUINET has been involved since 2000 in a range of capacity building activities, from formal modular training in Masters courses, specific skills courses, student grants and mentoring. This report has been produced within the capacity building programme on participatory research and action (PRA) for people centred health systems following training by TARSC and IHRDC in EQUINET. It is part of a growing mentored network of PRA work and experience in east and southern Africa, aimed at strengthening people centred health systems and people's empowerment in health.

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Executive summary

Poverty, social and family disintegration and high risk behaviours such as illicit substance use present a risk profile for mental ill health in Kenya. With inadequate trained personnel and services, and reported cost barriers to health care access, studies suggest that a large number of mentally ill patients are undiagnosed and untreated in the community.

This participatory action research project aimed to explore and strengthen the community's capacity to recognise and advocate for their mental health needs, to increase the awareness of mental health problems among the community and to increase collaboration between the mental health workers from clinic and hospital level and the community in the management of mental health problems in the community. It was implemented in a socio-economically deprived urban area in Nairobi (Kariobangi) as part of a multicountry programme exploring participatory approaches to people centred health systems in east and southern Africa, through Training and Research Support Centre (TARSC) and Ifakara Tanzania in the Regional network for equity in health in east and southern Africa (EQUINET), with mentoring and technical edit from R Loewenson.

The participatory reflection and action (PRA) process was implemented between April and November 2007 involving family members of mentally ill patients, community leaders - village headman, local school teachers, religious leaders, hospital health workers, community based health workers and local clinic workers. The process drew out local perceptions and experiences on mental health and its management and identified priorities and areas for action. PRA tools were used within meetings together with transect walks and key informant interview involving the community members and health workers. After a relatively short period of implementation of the identified actions, the same group gathered to review changes and assess the new knowledge and learning generated. A pre and post intervention questionnaire assessed initial perceptions in the community members and health workers and the changes following the intervention.

The initial baseline questionnaire indicated a shared perception of relatively poor awareness of and support and services for mental health across community members and health workers. There was a difference in perception between health workers and community members of the level of family and community responses to mental health, with a more positive view from health workers than from community members.

In the PRA meetings, both health workers and community identified exclusion, isolation and poor control over life, associated with risks and a poor physical state, as features of mental ill health. The Kariobangi community was felt to experience high levels of mental ill health, with poverty a major contributing factor. The major mental disorders identified were depression, stress, poverty, lack of awareness, drugs/substance abuse, lack of essential services (mental health services), mental retardation and epilepsy.

The social mapping revealed both community and health service barriers to responses to these problems, including poor family and community support, cost barriers, inaccessible or limited services, inconvenient clinic times and poor availability of drugs for treatment of specific disorders. Low awareness in the community and the local non-government organisations was compounded by poor links between health services and these community organisations on mental health. The transect walk and key informant interviews confirmed these reported problems gave further evidence of social factors linked to mental illness such as alcohol and substance abuse. While the community preferred using local primary care

services due to easier access and reduced stigma, there were limited services available at this level. While a range of community organisations exist that were potentially able to deal with these conditions, these organisations did not perceive that they had a role in mental health, and the mental health services had poor linkages with these organisations.

Reflecting on these findings, participants suggested some areas of follow up action, including

- Helping community members identify the mental disorders and widen awareness that they are treatable.
- Improving access to services for managing mental illness.
- Supporting families dealing with mental illness

Longer term measures were identified, such as giving families affected by mental illness an initial loan to start income generating activities. As more immediate steps, the group implemented a series of follow up actions aimed at creating awareness in the community. A multidisciplinary team including community members in schools, religious leaders, and health workers, carried out public education activities amongst various social groups and non-governmental organisations. These activities were carried out over a period of three months.. A site was identified for an additional community clinic at Korogocho, and follow up was underway to address the staffing needs to enable this, and to improve availability of antidepressants and antiepileptic drugs at the clinics. Community members responded to the problem of health worker shortages by proposing strengthening self-help groups in the community, to support both health services and families affected by mental illness. A range of actions were taken within the community. Dialogue was held with authorities to reduce the outlets selling alcohol and limit the opening hours, and local non-governmental organisations engaged to extend their community centres to provide support to children with mental disabilities. While many of these activities were at early stages in the time frame of the research, there was clear evidence of increased initiative from within the community and local health services in recognising and responding in a self determined manner to what had previously been an ignored issue.

The participatory review of the intervention and the post test questionnaire demonstrated perceived improvements by both health workers and community members in the understanding of mental health (which was now rated as very high), in community support for people with mental illness, police, NGO, and chiefs support for people with mental illness, and in the management of mental health problems in the community. The PRA intervention also made both groups more aware of the shortfalls in the management of the problem by the health services, including their link to community organisations. The rating of performance fell in a number of areas relating to health service management of the problem. The participants saw the project as an opening through which they could express their needs, plan and overcome the poor coordination and communication affecting the response to mental illness. From worlds apart at the beginning of the intervention, there was evidence of a shared sense of understanding and action between health workers and communities by the second PRA meeting. The process encountered difficulties with explaining mental health concepts in local languages. Participants were initially surprised that they were expected to come up with solutions to their problems, but this expectation of a passive role diminished through the process. The intervention is still at an early stage, but the evidence suggests that the PRA approach has strengthened community roles and interaction with health workers in improving mental health care in an underserved community.

1. Introduction

Worldwide, mental and behavioural disorders affect 450 million people and account for 15% of the overall burden of diseases from all causes (WHO, 2001). Nearly two-thirds of those affected do not receive adequate care due to stigma, discrimination, neglect and poverty (Brundtland, 2001). The WHO report (2001) highlights the inequitable distribution of available resources. Only one percent of total health expenditure goes to mental health in most countries. There is a particular shortage of mental health workers and resources in the developing countries. Estimates show that there is an average of one psychiatrist for two million people in low-income countries compared to 1:10,000 in the high-income countries (WHO, 2001).

Kenya has a population of 34 million (WHO Statistics, 2006). Over 40% of people are aged less than 14 years (Central Bureau of Statistics, Kenya, 2003). Fifty percent of households live below the poverty line of US$1 per person per day and many children and young persons are in difficult circumstances because of AIDS. Due to family disintegration, many children have moved away from their families to live on the streets of the major cities and towns of Kenya. There are an estimated 250,000 street children, many of whom engage in delinquent behaviour and illicit substance use (Kenya: streetchildren.org, 2002). However, few epidemiological surveys from Kenya show the related psychiatric disorders (Acuda and Yambo, 1983).

There are only 91 psychiatrists in Kenya (one psychiatrist per four million people). Mental health services at the primary level are thus largely left to general nurses and clinical officers (Njenga, 2002, Kiima et al., 2004). These personnel readily recognise psychosis, but are less able to recognise learning disorders, emotional disorders and conduct disorders in children and adolescents (Kiima et al, 2004). Primary care staff thus refer few mentally disordered children to district or provincial outpatient clinics. The current medical system, besides being expensive, leaves a large number of mentally ill patients untreated. Kirigia and Sambo (2003) noted that the total economic cost of the 5,678 mental disorder cases admitted to Kenyan hospitals was US$ 2,351, constituting 10% of the Ministry of Health total recurrent expenditure.

This participatory action research project aimed to explore and strengthen the community's capacity to recognise and advocate for their mental health needs, to increase the awareness of mental health problems among the community and to increase collaboration between the mental health workers from clinic and hospital level and the community in the management of mental health problems in the community. This engagement of residents and primary health workers was implemented in a socio-economically deprived urban area in Nairobi (Kariobangi). The work was implemented as part of a multi-country programme exploring different dimensions of participatory approaches to people centred health systems in east and southern Africa, through Training and Research Support Centre (TARSC) and Ifakara Tanzania in the Regional network for equity in health in east and southern Africa (EQUINET).

The work was implemented as part of a mentored learning network to build skills on participatory methods. It sought to use these methods to

- increase recognition, build a more positive understanding of and reduce stigma associated with mental health problems and their causes in the Kariobangi community;
- increase awareness of mental health problems in the community among the health workers from clinic and hospital level and the health authorities in the district, including of community perceptions of these problems and community and family

roles in managing them;
- build a shared identification of follow up actions to be taken by the community and local health workers in Kariobangi urban area.

2. Methods: participatory reflection and action

A participatory reflection and action (PRA) process was implemented, carried out between April and November 2007. This approach was judged to be useful to locate the identification of problems and solutions within the community and local health workers, and to enhance dialogue between the community and local health workers. The process drew out local perceptions and experiences on mental health and its management, discussed and reflected on those perceived to be priorities for action, and identified areas for follow up action. After a period of follow up the same group gathered again to review changes and assess the new knowledge and learning generated within the process.

A group of thirty community members from Kariobangi and community mental health workers based at Mathari Hospital (the only public hospital for the mentally ill in Nairobi) were brought together across the steps of the process. The community members included family members of mentally ill patients and community leaders - a village headman, teachers from local schools and religious leaders. The community health nurses from Mathari Hospital identified these community members.

The Medical Superintendent, Mathari Hospital, Dr Nelly Kitazi gives a briefing before the first workshop
Source: Othieno 2007

A baseline questionnaire was implemented with a sample of mental health workers and community members regarding mental illness in the Kariobangi community. All the community mental health nurses from the hospital were invited for the project. The baseline questionnaire covered priority types of mental health problems and their causes in the Kariobangi community, perception of mental health and stigma associated with it, and the role of families, social groups and organisations in promoting mental health. At the end of the action research, a follow up questionnaire was implemented with the same group to assess the change in perceptions and knowledge after the process. A number of participants were, however, not able to attend this final meeting for personal reasons. Some had administrative duties to attend to while some had sick relatives that needed their presence. This meant that while trends could be shown, some statistical analyses on pre and post test findings could not be done due to small numbers.

A meeting was convened for mental health workers and community members to discuss their experiences and perceptions of mental health and the resources within communities to manage mental health problems. The facilitators included a psychiatrist (CJO) who had been trained in the 2007 EQUINET/TARSC/Ifakara regional workshop on PRA methods. The second facilitator (AMM) holds doctorate degree in social

psychiatry while the third one is a psychiatric social worker. While the team was carrying out the exercise to build experience and learning around participatory methodologies, they all had experience or work with people in the community. Mentoring input was provided at various stages by TARSC (R Loewenson).

The tools used for the PRA process were derived from regional resources (Loewenson et. al, 2006). Picture codes facilitated discussion and elicited the participants views on health in general and mental health in particular to identify the local understanding of mental health problems. Social mapping was used to explore the distribution of community resources that contribute to mental health care and the community level responses to these problems. Health workers and community health workers did the mapping jointly. The latter were involved in community visits in the area and were familiar with the social organisations operating in the community.

A transect walk was implemented by community members and local health workers to map the available community resources and their links, including to the mental health services. Non-governmental organisations, schools, faith based institutions (churches or mosques) and local administration were visited to follow up on resources raised in the social mapping and to interview the community members. Key informants from the community, local faith-based organisations and services were interviewed to obtain their perceptions of the mental health problems and the resources within the community and local services for managing them. The people interviewed were the chief, a community based health worker: a catholic nun running a local dispensary – Kariobangi Catholic Health Centre, a pastor of the local Pentecostal church and a head teacher of a local primary school.

The mental health workers and the community members after the third workshop
Source: Othieno 2007

A follow up PRA process with the participating community members and health workers reviewed these findings to identify entry points and priorities for action and actions. Venn (chapatti) diagrams were used to explore the links and strengths of the relationships between the various stakeholders and to identify and gauge the importance of the various organisations for the proposed priority actions, to explore the relationships between organisations and to identify entry points for possible action. The actions identified above were listed and priority ranking was done using beans. The three groups: community, mental health, and the primary health workers ranked the actions separately and then came together to discuss and made a final, shared, list.

A series of steps were initiated as a result of this participatory process. While this action phase was relatively short, the actions are ongoing. Using available resources, the actions taken included increasing awareness of mental health problems through public education, establishing an additional community clinic, providing adequate drugs at the clinics available, advocating for tighter controls on the sale of alcohol and providing sheltered workshops and day care centres.

A review meeting was held after three months for the community members and health workers to asses progress on the prioritised actions and to review the changes resulting from the process. A wheel chart was used for participants to visualise and discuss progress on key areas. The baseline questionnaire was repeated, as noted above. The short intervention period is noted, so these follow up processes are reported as a means of assessing participatory approaches to progress review, and to reflect on the lessons learned within the six month time frame of the intervention.

3. Implementation and results

In this section we present the findings of the baseline questionnaire followed by the findings from the steps of the PRA processes; that is the initial PRA process to identify mental health problems, the findings from the transect walk and the key informant interviews; the review of these findings by community members and health workers to identify priority actions, agreed action plans and the steps taken. The actions implemented as a result of this process are outlined. Finally the results of the wheel chart evaluation and follow up questionnaire are presented as a means of reflecting on the change produced by the process and the lessons learned on using PRA processes.

3.1 Initial views from the baseline questionnaire

Thirteen health workers and eight community members filled a baseline questionnaire before the process started to examine their initial perceptions on mental health issues. Statements were used to elicit responses that were rated on a Likert scale, scored as follows: none at all 0; very low 1; low 2; high 3; very high 4; extremely high 5. The mean scores for the various variables on the baseline questionnaire are shown separately for community members and health workers in Table 1. The term mental health was translated in the local language (Kiswahili) and examples given to enable a shared understanding of what was meant by the term in the questionnaire.

Most of the mental health workers (HW) rated themselves as having moderate understanding of mental health and mental illness, while those from the community (CM) thought that they had relatively poor knowledge. The HW thought there was more mental illness in the community than the CM, although the differences were not statistically significant. Generally health workers had a more optimistic perception of community responses to mental health than the community members: they rated community and chief's support for people with mental illness, and management of mental health problems higher than CM. HW had a statistically significantly higher rating of family involvement of care of the mentally ill than CM ($p=0.007$), indicating that perceptions between the two groups differed most widely on this issue.

Community members only rated community openness on mental illness higher than health workers. In all other areas the two groups had relatively similar ratings (See Table 1). Both groups (HW and CM) felt that the stigma associated with mentally illness in the community was high, and the management of mental illness and support for mentally ill people from policy, churches and NGO's low, although they rated health facilities as having higher levels of support and effectiveness.

Table 1: Baseline questionnaire ratings of community members and health workers

Variable	Community member response		Health worker response	
	Average	N	Average	N
Age (years)	46.88	8	41.62	13
Understanding of mental health	2.12	8	3.31	13
Level of mental illness in the community	2.71	7	3.85	13
Community concern over mental illness	1.67	6	1.67	12
Family involvement in the care of the mentally ill	0.88	8	1.54	13
Community support for people with mental illness	0.75	8	1.23	13
Church/mosque support for people with mental illness	1.86	7	1.62	13
Police support for people with mental illness	1.00	7	1.15	13
NGO support for people with mental illness	1.14	7	1.30	13
Health Centre's support for people with mental illness	2.63	8	2.31	13
Health worker's support for people with mental illness	3.00	8	2.85	13
School's support for people with mental illness	1.38	8	1.77	13
Chief's support for people with mental illness	0.88	8	2.00	13
Family openness on mental illness in the family	1.38	8	1.38	13
Community openness on mental illness	2.13	8	1.38	13
Stigma associated with mental illness in the community	3.50	8	3.46	13
Effectiveness of health services in managing mental health problems	2.50	8	2.31	13
Communication between families and health services on mental health	2.13	8	1.92	13
Rating the management of mental health problems in the community	1.63	8	2.33	12

The scores for the variables are on a scale of 0 – 5 where
0 = none at all; 1 = very low; 2 = low; 3 = high; 4 = very high; 5 = extremely high.

The findings of the baseline questionnaire do not provide an objective assessment of conditions. They do however indicate a shared perception of relatively poor awareness of and support and services for mental health across community members and health workers. There was a difference in perception between health workers and community members in the level of family and community responses to mental health, with a more positive view from health workers than from community members.

3.2 Participatory assessment of mental health problems and responses

In initial discussions, nearly all the participants (HW and CM) attributed mental illness to diseases affecting the brain. One participant, a religious leader, thought that familial causes were most important.

Participants then used picture codes to draw out their understanding of what constitutes mental health and mental illness. The picture codes are not specifically targeted to mental health, and this allowed the link between wider health and mental health issues to emerge.

Picture codes used to discuss understanding of mental health
Source: Loewenson et al 2006 © TARSC Ndhlovu 2006

In the discussions, various features were associated in the pictures with health, including

- being paid for hard work;
- being active at an advanced age;
- being happy and socially integrated.

The features associated with poor health were

- stress due to poverty
- malnutrition
- poor control over life and inability to secure basic needs
- exposed to dangers such as drug abuse, alcohol and sexually transmitted diseases.

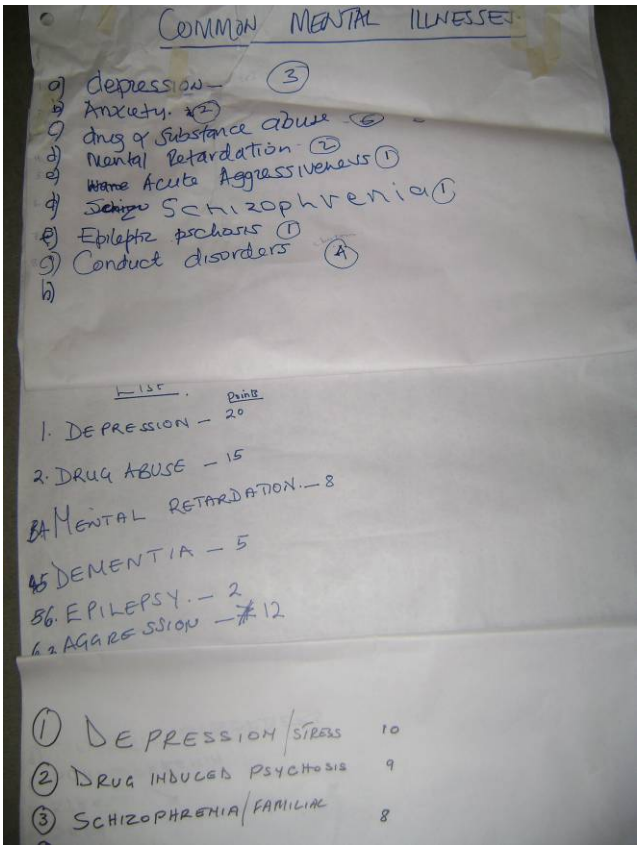
The picture with the elderly man was judged to show the strongest image of health, while the picture of the young girl with a child the strongest image of poor health. Notably the picture of the elderly person shows social integration and positive emotions, both issues for mental health. The most powerful negative image of ill health identified is one of exclusion, isolation and poor control over life, associated with risks and a poor physical state.

Both health workers and community members proposed that the factors defining good mental health included

- Feeling good about yourself
- Feeling good about other people
- Being responsible,
- Being spiritually healthy
- Absence of disease and pain
- Having a good interpersonal relationship

Both groups thus recognised the social dimensions of mental health and ill health.

In the discussion of the codes participants observed that the load of mental disorders in the Kariobangi community is high. The participants cited poverty as a major problem and felt that it contributed to the mental disorders.



List of the common mental disorders made by the community members and the health workers
Source: Othieno 2007

The participants listed the problems they felt to exist using this shared understanding of mental illness. The ranking and scoring of these problems led to dialogue around the different perceptions of the problems. Community members identified stress and depression followed by substance abuse disorders as the most important mental health problems in the community. The community members thought mental illness was rare in children, apart from mental retardation. The views of the community members were similar to those of the health workers who identified the most common mental disorders as depression, stress, drugs and alcohol abuse, psychotic disorders and epilepsy.

The major mental disorders identified as shared concerns in order of importance were depression, stress, poverty, lack of awareness, drugs/substance abuse, lack of essential services (mental health services), mental retardation and epilepsy. Some participants felt that poverty should be on top of the list since they thought that it was a major contributor to stress, depression and alcohol abuse. While alcohol abuse was recognised to link to poverty through use of cheap brews in response to stress, others pointed out, that children from rich families had similar problems.

Ranking and scoring mental health prioritiess using beans
Source: Othieno 2007

A share of the problems raised relate to social conditions in the community, and call for community and primary care level resources to respond to them. The social maps were used to explore how these problems are distributed on communities, and the resources available to respond to them. Communities mapped resources such as health facilities, social groups, schools, churches, markets, administrative camps and offices and NGOS, particularly those focusing on HIV. The social mapping also indicated resources such as electricity, water, and roads. The maps revealed the shared knowledge the participants had of their communities.

Presenting the social maps of the Kariobangi and Korogocho areas
Source: Othieno 2007

Some of the people living with mentally ill patients in the meeting cited lack of support and difficulties in buying the medications as major problems. The bus fare to the main referral hospital, Kenyatta National Hospital, which is located 20 kilometres away, was felt to be a barrier to access to medical services. The timing of the clinics was also a problem. For example, the child psychiatry clinic at Kenyatta National Hospital was held only in the morning hours and it is difficult for some patients to reach it. The participants also noted that a large number of patients with epilepsy (even those without psychiatric disorders) were going to the psychiatric clinic at the health centre and preferred to consult the psychiatric nurses. Antiepileptic drugs were often not available at the Kariobangi clinic.

In the social mapping, the HW identified several non-governmental institutions in the community that could help in promoting mental health. However, they were not aware of what mental health activities they carried out. The community members who had sick relatives also said they were not aware of their activities. There was only one outpatient clinic in the Kariobangi and Korogocho areas. There were no facilities to care for childhood psychiatric disorders. There was a high load of mental disorders according to the participants but limited facilities for managing the problems.

3.3 Results on community resources: Transect walk and key informant interview

A mapping of the area prior to the transect walk revealed that there were two main section – Kariobangi and Korogocho. Both areas were covered during the transect walk.

Verifying information during the transect walk at Korogocho. The local Pastor in the foreground. Source: Othieno 2007

Korogocho community: A number of organisations were identified in the Korogocho community that had potential to support mental health. They included a self-help community organisation for men (Maendeleo Afya kwa wote Korogocho - MAKWK); a youth group known as "I am worth defending" (IWD) engaged in various social activities including running a day-care centre for children and training youth in self-defence to combat sexual violence in the community. Another day care - Rehema day care orphan project - took care of orphans in the community.

Kariobangi community: The organisations identified were: Lea Toto: project to care for vulnerable children; Women fighting against AIDS in Kenya (WOFAK); Sinaga women/children resource centre; Kenya Widows and Orphans Support Group and Cheshire Home for the old. The organisations were all working to improve the lives of those in the community and some had privately run schools and provided free meals as well.

In both Korogocho and Kariobang the majority of the NGOs were found to be focused on HIV, with few taking on other health problems. Coordination between the various agencies was poor. Often one organisation was not aware of what the others were doing. There were no formal links found between Mathari Hospital and the community organisations. The staff from Mathari were allocated one room at Kariobangi Health Centre where they run a clinic for the mentally ill every Tuesday morning. All the key informants interviewed were not aware of the clinic. They often referred mentally ill patients to Mathari Hospital. The community members and patients who attended the clinic said that it was very helpful as it saved them the cost of travelling to the hospital. They could also attend the health centre freely without fear of the stigma associated with the big mental hospital.

Getting the views of a sister who runs one of the dispensaries in the Kariobangi community
Source: Othieno 2007

All key informants interviewed said that they considered mental illness to be a problem in the community and that the prevalence was high. Their views were similar to those of the community members included in the baseline survey. The chief said that drug and alcohol problems were very common in the community and attributed the mental illness in young men to be due to bhang (cannabis). The head teacher from the community said that mental retardation among the children was common. She attributed all the learning problems to mental retardation. She did not consider other mental disorders such as conduct disorder as a problem.

Key informants: interviewing the local chief at officer in Kariobangi; Source: Othieno 2007

Some areas were identified as not adequately tackled in public health or community level strategies. The religious leaders and the local chief said that tighter control on alcohol sale was needed. 'Khat' are twigs and leaves of a plant, Catha edulis, found in Eastern Africa that is chewed for its mind stimulating effects. The religious leaders felt this should be banned and stiffer penalties be given to those peddling drugs especially bhang (cannabis).

"*Drug abuse is common among the youth and those who had the problem are referred for help. We send them for counselling by the local pastors and those found to be suffering from other mental health problems are referred to Mathari hospital*".

Chief, Kariobangi

The head-teacher interviewed said that the children with mental retardation and orphaned children in the community needed medical and psychological care to help them cope with their schoolwork.

"*We are helpless because we do not know where to take children who are mentally handicapped or those who may be having behaviour problems*".

Head teacher, School, Kariobangi

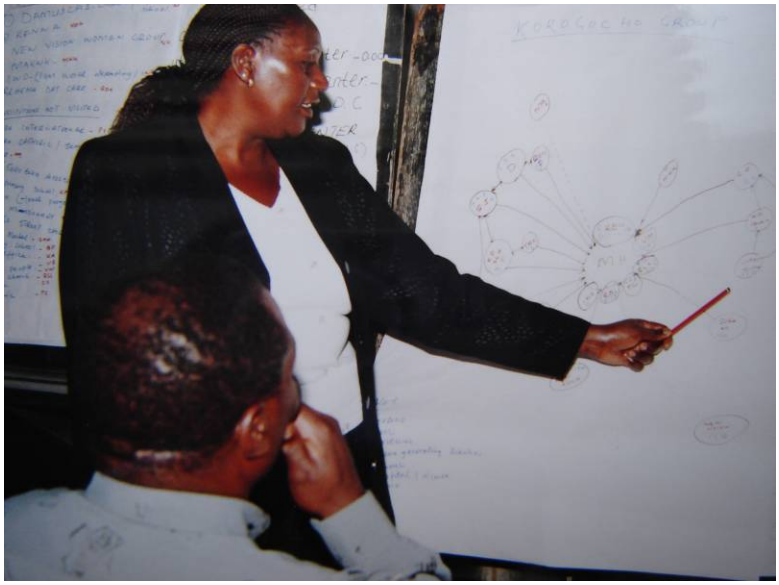
The interviews highlighted weaknesses in the service responses. The church based clinic had problems acquiring drugs for the mentally ill due to the high costs and they did not know where to refer such patients for help. The nurse running the clinic was not aware that drugs for treating the mentally ill were available at Mathari Hospital at a subsidised cost. They sometimes helped needy patients to buy the drugs from chemists since they did not stock the essential drugs for treating mental disorders. This was however expensive and led to irregular treatment and relapse of the mentally ill patients.

The staff at the clinic were also not aware that nurses from Mathari Hospital followed up patients in the community. After discussions, the psychiatric social worker suggested that mentally ill patients who were seen at the clinic and needed further treatment could be referred to Mathari Hospital. Alternatively, the psychiatric team from the hospital could visit on specific days and treat those who had been given appointments for review by the mental health team. The psychiatrist would organise this with the Mathari Hospital administration.

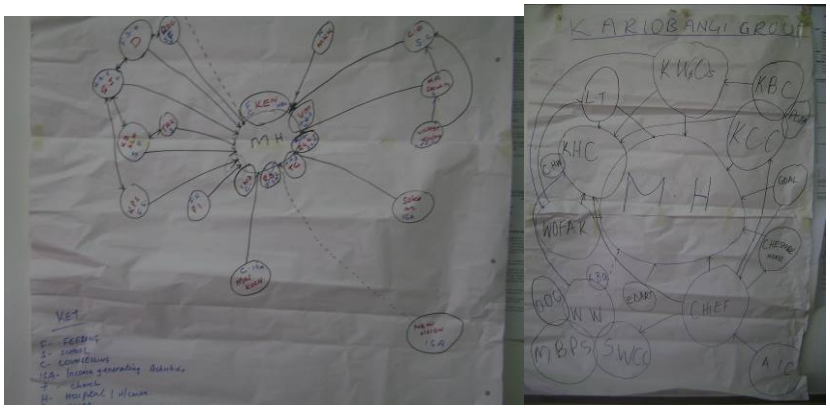
The transect walk and informant interviews gave further evidence of the social factors linked to mental illness raised in the meetings. While both approaches gave evidence of a range of social and community organisations able to deal with these conditions, they also highlighted that these organisations did not perceive a role in mental health, and that health services had poor linkages, both to these community organisations and between different levels of the health system.

3.4 Participatory reflection on actions and entry points

The results of the transect walk and interviews were discussed by the community members and health workers involved in the PRA meeting. The community resources were grouped into health facilities, schools, religious organisations, markets, security officials, social groups, and families. The participants also discussed the relative presence and importance of the different organisations and the linkages between them, using stakeholder mapping and venn diagrams. They agreed that substance abuse, including alcohol, was a major problem in the community. The participants felt that the administrative officials and security officers (chief and the district officer, the police) were very important as they had a big role to play in regulating drugs in the community and issuing licences to places that sell alcohol. Although there is a national body dealing with the control of alcohol and drug abuse called NACADA (National Campaign Against Alcohol and Drug Abuse), community members felt that their role was limited in the community. They had seen them hold only one meeting with them in the past year and the officials were not resident in the community.



Stakeholder mapping
Source: Othieno 2007



Identification of entry points using a Venn diagram
Source: Othieno 2007

The stake holder institutions identified included the Kenya Network of Women (KENWA), Women Fighting Aids in Kenya (WOFAK), City Council Dispensary at Kariobangi, Baptist Church, Marura Baptist Primary School and the Chief's office. The schools and the churches were seen as the most important stakeholders for responses to mental health. The teachers interact with many children and could easily detect the symptoms of a mental illness if they were provided with the basic information. They had already noted the presence of a number of children with learning problems, whom they said needed further treatment. The organisations dealing with AIDS related issues also had members with co-existing mental problems. The churches were also important and the pastors said they were often consulted by people with family and social problems including mental problems. Some of the churches also ran schools and had feeding programmes as well as small scale income generating projects such as chicken rearing.

Reflecting on the priority problems identified earlier (depression, stress, poverty, lack of awareness, drugs/substance abuse, lack of essential mental health services, mental retardation and epilepsy) and the resources within the community, participants suggested some areas of follow up action, including

- Helping community members identify the mental disorders and widen awareness that they are treatable.
- Improving access to services for managing mental illness.
- Supporting families dealing with mental illness

The support needed by families was noted to extend beyond health care. One family member who lived with a mentally ill husband reported that she needed material support to cope with the loss of income since her husband became ill. The health services were adding to her financial stress due to the high cost of drugs, and the cost of visiting the hospital. Efforts had been made by health services to reduce costs, but households affected by mental ill health of wage earners were very stressed: Although drugs were sold at a subsidised price at the hospital, many could still not afford them. Sometimes the nurse visiting in the community found that the families had gone without meals.

It was felt that a mobile clinic or a vehicle to facilitate the community visits could assist, but with the available resources, this was not possible. It was not also possible to provide monetary support to the families. However, it was suggested that the possibility of giving families an initial loan to start income generating activities could be explored further.

In the interim, as more immediate steps, the meeting proposed that available community-level resources identified in the PRA exercise could be used to

- increase awareness of mental health problems through public education;
- establish an additional community clinic for mental health treatment and ensure adequate drugs were provided at the clinics,
- advocate for tighter controls on the sale of alcohol, and
- provide sheltered workshops and day care centres.

3.5 Implementing follow-up actions

In follow up, various activities were taken by the community. Public education was conducted in identified schools, religious organizations and various social groups in the area through a multidisciplinary team. In collaboration with the mental health workers, the community members gave public talks on mental health to groups of teachers, religious leaders and several non-governmental organisations. The chief used a public meeting to raise the issue of the public not stigmatising the mentally ill and has discussed mental health issues with his community. Presentations were made to a group of church leaders on drug abuse. The main concern of the participants was that drugs were easily available and they blamed the government for not doing enough to control the supply. A meeting with a group of 20 schoolteachers at Korogocho discussed issues of psychiatric disorders in children, substance abuse and sexual abuse. They were informed of a gender and violence centre at Kenyatta National Hospital where they could go for help and support. The centre offered group therapies and post-rape care for victims. Preventive measures were also discussed. The education department of the hospital agreed to develop pamphlets and posters for public information. One of the social groups involved in entertainment would be co-opted in future educational activities. The community mental health team plans to follow up and sustain the public health education. The Continuing medical education department at Mathari Hospital also agreed to include public lectures in its schedules and make brochures and pamphlets on how to recognise the common mental disorders.

Discussing mental health issues with one of the women groups in Korogocho
Source: Mathai 2007

"*Here in our community the commonest cause of mental illness is mental retardation. Yes and the way we see it is because of difficult delivery and all these women here who drink a lot of 'chan'gaa' (local brew) during pregnancy*".

Women's group leader, Korogocho

Follow up was made of the recommendation that adequate supplies of antidepressants and antiepileptic drugs be availed to the clinics to cater for the large number of patients with neuropsychiatric conditions. The mental health team led by the community psychiatrist discussed this with the personnel in charge of the clinics and the medical superintendent. Drug are now available, although supplies are inconsistent.

The option of establishing an additional community clinic was reviewed by the chief nursing officer at Mathari Hospital. She identified that another clinic in addition to the one at Kariobangi Health Centre could be established in consultation with the Mathari hospital management committee. The community members and health workers identified a site where an additional community clinic could be established at Korogocho, using a room available in one of the clinics. The issue of staffing was raised, as the community nurses felt their numbers did not support another health centre. The Mathari hospital management committee was requested to post additional staff to work in the community to support the process, while participants to the process proposed strengthening self-help groups in the community, as this would support the health services and be poverty reducing. The new clinic service is yet to be opened, the main impediment being lack of staff.

The community members forwarded their views on the use of alcohol and drugs to the national body controlling the campaign against alcohol and drug abuse, recommending the reduction of outlets that sell alcohol and limiting the opening hours. They recommended that the sale of 'khat' be abolished and stiffer penalties be given to drug peddlers.

The participants found it difficult to identify adequate ways of dealing with the poverty that they felt to be a major determinant of poor mental health. There is a need to draw on wider experience, beyond the community, to inform further dialogue and action in this area. The team agreed to explore further the income-generating possibilities for families dealing with mental illness and the role of self-help groups. Community members suggested starting a mental health promotion and support group within the community. They would arrange for meetings and register the group. Individuals and family members of those with mental illness would also organise themselves into groups with the help of the health staff. These groups would identify available resources and coordinate mental health programmes within the community. Additionally, invited resource people would educate the members on how to start and manage small-scale businesses.

The occupational therapist explored the possibility of starting a sheltered workshop for the mentally handicapped in one of the local dispensaries where they can be taught useful skills for daily living. An organisation known as Star of Light and Hope cares for 50 children in one of the community centres, providing physiotherapy and education. The occupational department of Mathari Hospital would join in the care. It was also proposed to establish a day-care centre in the hospital or at one the health facilities in the area.

While many of these activities were at early stages or still being planned in the time frame of the research, the wealth of proposals and initiatives started, from community to health service level, indicated evidence of increased initiative from within the community

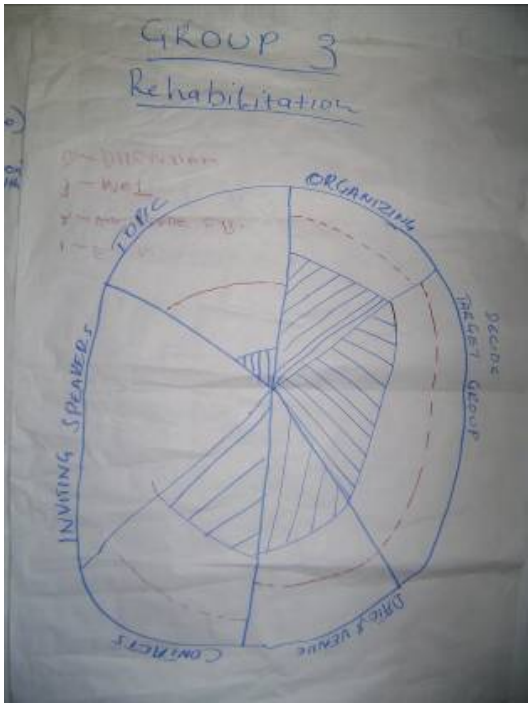
and local health services in recognising and responding in a self determined manner to what had previously been an ignored issue.

4. Reflecting on the process and lessons learned

4.1 Participatory assessment

A meeting was convened following several months of the intervention. It intended to cover the same thirty participants as the first PRA meeting, but there was some loss .as three health workers (2 postgraduate doctors and 1 nurse), two church leaders and two community members were not able to attend. The health workers were engaged in the Mental Health Week activities elsewhere.

A wheel chart was used to gauge the changes resulting from the intervention, specifically exploring changes in service delivery, establishment of new services, communication between the health workers and the community members, and communication and cooperation between the community members and the NGO in the area. The wheel chart reflected increased ratings of involvement in all areas of the planned interventions, they felt that their involvement could have been greater in deciding on the organisation of interventions, including the target groups to be addressed, topics and speakers.



The wheel chart showing the changes in activities regarding rehabilitation services before and after intervention
Source: Othieno 2007

The participants felt that the time for the action was too short to make any major changes. However they felt they had begun the process of improved communication and co-operation to achieve these changes, focused on their own shared priorities.

"After attending the workshops I'm hopeful that we can now plan more effectively on how to help the community members with rehabilitation of the mentally retarded children".

Occupational therapist, Mathari Hospital

"*Before I used to regard mentally ill people as only those with strange behaviour, who do not recognise their needs, refuse treatment become aggressive and are difficult to reason with. Now I realise that even people who appear calm may be mentally unwell. My views on mental health have changed*"

Pastor Baptist church, Kariobangi

4.2 Post test questionnaire

The participants also filled the questionnaire used in the baseline again. The responses are compared with the baseline findings in Table 2. Fewer people attended the meeting due to the timing of the meeting, so that a total of 14 responses are compared in the follow up test to 21 in the pre-test, with losses across both CM and HW.

Improvements were reported across a number of areas by both groups, including understanding of mental health (which was now rated as very high), community support for people with mental illness, police, NGO, and chief's support for people with mental illness, and the management of mental health problems in the community.

In the baseline the health workers had a more optimistic view of community resources than the CM. By the post intervention both groups felt community support had increased, (such as from the police, NGOs and chiefs), but there were still differences between CM and HWs. CMs rating of the level of mental illness had increased, while health workers had fallen, the difference between them increasing (significantly). Health workers now saw the community as significantly more concerned, although the CM did not see their concern as having changed.

The findings of the post test questionnaire suggested that the PRA intervention made communities much more aware of the problem, and made both groups more aware of the shortfalls in the management of it by the health services, including in their link to community organisations. The rating of levels of performance fell in a number of areas relating to health service management of the problem, perhaps as the exercise exposed the realities of the issue in the community and of the weak links between social institutions and health services. The rating of health worker support for people with mental illness fell for both groups; there was a small fall in the perceived rating of communication between health services and families, and a large fall in the rating of family openness.

Both the community members and the mental health workers understanding of mental illness increased after the intervention. With the intervention at an early stage, it would appear that the awareness of the scale of the problem, the range of social conditions affecting it and the possibilities for health service and social action had increased, but that the intervention was at too early a stage for improvements to be achieved in these areas. The intervention that was perceived to have had most change was in the increased community involvement in responses to mental health, with less clear improvements in the health services. Interestingly, the shared perception of some improvement in the management of mental health problems in the community is thus possibly based on this strengthening of the community response.

Table 2: Comparison of responses before and after the intervention

RESPONSE:	Average Community member (CM)		Average Health worker (HW) response		Difference combined baseline vs follow up	Difference CM vs HW	
VARIABLE	Baseline (N = 8)	Follow up (N = 5)	Baseline (N = 13)	Follow up (N = 9)		Baseline	Follow up
Understanding of mental health	2.12	2.50	3.31	4.14	ns	ns	Sig (p = 0.03)
Level of mental illness in the community	2.71	3.00	3.85	2.44	Sig (p=0.05)	ns	ns
Community concern over mental illness	1.67	1.00	1.67	2.11	ns	ns	Sig (p = 0.02)
Family involvement in the care of the mentally ill	0.88	1.60	1.54	1.78	ns	Sig (p = 0.007)	ns
Community support for people with mental illness	0.75	1.20	1.23	1.63	ns	ns	ns
Church/mosque support for people with mental illness	1.86	2.00	1.62	1.44	ns	ns	ns
Police support for people with mental illness	1.00	1.20	1.15	2.22	Sig (p = 0.02)	ns	Sig (p = 0.02)
NGO support for people with mental illness	1.14	1.00	1.30	1.75	ns	ns	ns
Health Centre's support for people with mental illness	2.63	2.40	2.31	2.22	ns	ns	ns
Health worker's support for people with mental illness	3.00	2.40	2.85	2.78	ns	ns	ns
School's support for people with mental illness	1.38	1.80	1.77	1.33	ns	ns	ns
Chief's support for people with mental illness	0.88	1.60	2.00	2.00	ns	ns	ns
Family openness on mental illness in the family	1.38	3.00	1.38	1.22	ns	ns	ns
Community openness on mental illness	2.13	1.40	1.38	1.22	ns	ns	ns
Stigma associated with mental illness in the community	3.50	3.25	3.46	3.78	ns	ns	ns
Effectiveness of health services in managing mental health problems	2.50	1.80	2.31	2.22	ns	ns	ns
Communication between families and health services on mental health	2.13	2.20	1.92	1.78	ns	ns	ns
Rating the management of mental health problems in the community	1.63	1.50	2.33	1.71	ns	ns	ns

ns = not significant ; Sig= significant
The scores for the variables are on a scale of 0 – 5 where
0 = none at all; 1 = very low; 2 = low; 3 = high; 4 = very high; 5 = extremely high.

The discussions within the second meeting reinforced this perception.

In the beginning the social exclusion faced was evident: One of the community members said in the first meeting:
"No one cares about the mentally ill. We are on our own. My husband has been unwell for a long time and I have to provide basic needs for the family in addition to looking after him. I would welcome some financial support".

A community nurse commented,
"The stigma against HIV/AIDS is being overcome faster than that due to mental health. We have to work harder".

In the second meeting, however, a community member said,
" This meeting has provided us with knowledge on mental health problems and where to refer those suffering from mental illness",
while a mother to a patient said
"If we had been doing this before, helping each other I would not have suffered the way I have suffered with my son"

4.3 Reflections on using participatory methods

Most of the participants were very enthusiastic about the project and welcomed the idea that something was being done at last. They saw the project as an opening through which they could express their needs, plan and overcome the lack of coordination and poor communication between the various social groups in the community that was leading to poor care for the mentally ill. The intervention and PRA approach made evident the interest in community members to work together with mental health workers to improve the health care in the community, with adequate support. It also indicated the support the health workers derived from a more active community involvement. From worlds apart at the beginning of the intervention, there was evidence of to a shared sense of understanding and action by the second PRA meeting.

Various difficulties were encountered. We had language problems and had to find ways to explain the mental health concepts in Kiswahili. Use of standardised translations of words such as depression into Kiswahili would be helpful in future work. The major psychiatric disorders such as schizophrenia were easily identified. However, apart from mental retardation, childhood psychiatric disorders were not considered a major problem despite the high proportion of children and their exposure to conditions that could predispose them to mental disorders. The feedback assessment showed that the community members were more aware of the psychiatric problems in the community after the intervention. However, the period was too short to record major changes.

Participants had high expectations. They were not familiar with participatory methods and were initially surprised that they were expected to come up with solutions to their problems! This problem was overcome after explanation and through use of methods that were simple and involving and led easily to participant input. As facilitators, we found the reflective discussions more difficult to manage. Participants expected facilitators to give them the solutions while they played a more passive role. We repeatedly reminded people that those affected by the situation best understood their problems and thus had to participate in finding solutions. The facilitators in turn had to

learn to listen more carefully to the participants and the community members. At first there was a great temptation to offer formal lectures to the group and to use technical jargon. However it was a learning experience for us to help the community members find solutions for their problems through reflective discussions and guidance and not provide them with solutions. In the process we found that the local health staff, teachers and other community members had valuable knowledge that could be shared with the wider group, and that the community had experience and resources from which to develop solutions to their problems. .

5. Conclusions

Further intervention is needed in this community to help the residents establish basic clinical facilities and to develop income generating activities. The community health workers also need support so that they can reach more patients in the community.
However even from a relatively short intervention, the evidence from the community meetings, actions initiated and post intervention discussions and questionnaire suggest that PRA approaches are useful to engage communities and strengthen communication between health workers and communities in improving mental health care and to putting available resources to best use. The participatory approaches helped to overcome social exclusion, mobilise more powerful people in the community to support people with mental illness and strengthen links with health services. Social interventions such as support groups provide an important means of sustaining this networking and inclusion. At the same time, there is a need to design interventions aimed at improving the living standards in the community, and to recognise and make provisions for dealing with the vulnerability of families affected by mental illness.

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Equity in health implies addressing differences in health status that are unnecessary, avoidable and unfair. In southern Africa, these typically relate to disparities across racial groups, rural/urban status, socio-economic status, gender, age and geographical region. EQUINET is primarily concerned with equity motivated interventions that seek to allocate resources preferentially to those with the worst health status (vertical equity). EQUINET seeks to understand and influence the redistribution of social and economic resources for equity oriented interventions, EQUINET also seeks to understand and inform the power and ability people (and social groups) have to make choices over health inputs and their capacity to use these choices towards health.

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