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**AN INVESTIGATION OF COMMUNITY
MENTAL HEALTH STRATEGIES**

**A CASE STUDY OF THE
BAMBAYI CARE-GIVERS GROUP**

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DECLARATION

This dissertation was undertaken in the Department of Psychology, University of Natal, Pietermaritzburg and unless otherwise stated in the text, represents the author's own work. This dissertation has not been submitted to any other university.

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December 1992

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ABSTRACT

The broad aim of this study was to explore some of the implications of the debate about psychology and its social context in South Africa. Through an examination, firstly of the role and nature of mental health care in the South African context; secondly of the two models of Community Psychology which have the most significance for clinical practice under the current conditions (the Community Mental Health and the Social Action models); and thirdly of the Primary Mental Health Care and the Community Care approaches, this dissertation makes some suggestions for an appropriate community mental health practice in South Africa. The research was located within the mental handicap programme of the University of Natal's Community Mental Health Project and examined the needs and coping strategies of a group of women caring for mentally handicapped children. Through a mental health needs assessment of the community of Bambayi and the establishment of the Bambayi Care-givers Group, the dual goals of generating baseline data from which to inform community mental health policy and service provision, and the provision of a service to the participating community were operationalized. This dual function of the research reflects the Social Action research method followed in the study. Results indicate that the community care approach appears to be the most appropriate form of care for the chronic needs of mentally handicapped African children. The adoption of transformed community care policies need to be integrated with the developmental principles of the primary health care approach. The adoption of such an approach to service delivery is geared towards meeting the urgent needs facing this country, as well as generating the data from which to develop the theoretical base for a Community Psychology appropriate to South Africa's developing needs.

ABBREVIATIONS

ANC	African National Congress
CAP	Community Action Programme
CC	Community Care
CDC	Community Development corporation
CMH	Community Mental Health
CMHM	Community Mental Health Model
CMHP	Community Mental Health Project
MH	Mental Handicap
MHC	Mental Health Care
PHC	Primary Health Care
PMH	Primary Mental Health
PMHC	Primary Mental Health Care
SAM	Social Action model
UDF	United Democratic Front
WHO	World Health Organization

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CHAPTER ONE

INTRODUCTION

Since the landmark February 1990 speech by the South African President de Klerk¹, the nature of South African opposition politics has moved away from confrontation and mass resistance towards the politics of negotiation. Within the structures of the Mass Democratic Movement there was a broad realization that it was no longer a viable strategy to simply criticize. The generation of acceptable alternatives is vital if there is to be a successful transformation away from Apartheid towards a democratic state. This move away from a primary focus on confrontational politics reflected itself within the organisations of the 'broad left', in this instance, within the progressive health and welfare sector. The following two quotes serve to illustrate the point:

" There is an urgent challenge in this final and decisive stage of the liberation struggle of formulating specific proposals, strategies and policies for the structure, organization, financing and development of health and welfare services for a truly democratic south Africa ".

Maputo Declaration of Health in Southern Africa. April 1990.

" We need to shift some of our emphasis from defiance to reconstruction and development. Tomorrow, when we are asked to suggest changes in practical terms, types of affirmative action to overcome the present inequities - where do we start...? How do we choose priority areas for development ? "

Krish Vallabjee. President, South African Health Workers congress. June 1990.

It is within the framework of social and political transition, and the recognition of the urgency for the formulation of appropriate post-Apartheid policies, that this dissertation was motivated.

The broad aim of this research is to explore some of the implications of the debate about psychology and its social context in South Africa. The underlying issues of concern are

¹ This refers to State President de Klerk's opening of parliament speech on 2 February 1990. This speech legalised the African National Congress, the South African Communist Party and the Pan African Congress; rights to political protest were in some ways restored, and within weeks Nelson Mandela and a host of other leaders of the liberation movement were released from prison. With the exception of Natal, the state of emergency which was in place since November 1985, was lifted. To all intents and puposes, the way was paved for the normalization of the political process in South Africa.

that mental health practices are bound by class, race and professional interests and are embedded in traditional Western individualistic models of treatment. It is argued that such practice is largely inaccessible to the black majority population. This has led to the exploration of two broad approaches which aim to improve the mental health of most the people in a given society - the primary health care and community psychology approaches.

It has been well documented by South African social scientists of the need for mental health care (MHC) to become more responsive to the socio-political context of this country. Dawes (1985) argues that Apartheid capitalism adversely effects the mental well-being of most South Africans through its generation of stress situations unique to this country. It is further argued that clinical psychology cannot claim scientific or moral respectability as long as it continues to take on an acontextual, uncritical position. Mental health workers can begin to redefine the role and nature of mental health care practice in South Africa and help transform the current situation through the development of appropriate research, training and practice.

Manganyi and Louw (1986), in their 1986 study of 137 clinical psychologists, reported that the majority of respondents agreed that in the future, conditions in South Africa would have changed so much that much of clinical practice will involve intervention at the systems level (family, community, organization), rather than at the individual level. In another study of 164 South African psychologists surveyed by Lazarus (1985), the majority felt that psychologists have a social responsibility in the work that they do; that as a profession they should respond to political issues, and most thought that the community psychology approach was the most appropriate for South Africa.

The study

In order to contain the scope of the study and operationalize the stated aims, the study was located within the mental handicap (MH) programme of the University of Natal's Community Mental Health Project (CMHP).

The CMHP was set up in 1987 by the Department of Paediatrics, University of Natal Medical School, with the aim of investigating the mental health needs of African township communities in Durban. The project's work involves the promotion and facilitation of primary mental health (PMH) through research and service delivery. The project was a local level attempt to counter the crisis in health service delivery as well as an attempt to counter the deleterious effects which the existing socio-political system had on the everyday lives of urban African people.

The MH programme of the CMHP included training and support of the care-givers of mentally handicapped (MH) children, stimulation groups for MH children, and involvement in the establishment of a creche for the care and training of MH children in the Bambayi community of Inanda, Natal. The intervention used in this study was the initiation of a group programme for care-givers of MH children. The group was designed to serve as a support and learning group, as well as gathering data for the CMHP.

The study aims to provide some of the baseline data needed for the development of appropriate strategies for the care of MH African children living in a peri-urban shack settlement. To do so through an examination of the everyday life experiences, coping strategies, perceptions and needs, and the social supports sought out and received by a group of women caring for MH children.

The data would thus be based upon the women's own experiences of caring for their MH children and the resources they mobilize to cope. There is very little information on the ways in which this form of community care effects the lives of the MH and on the nature of the support sought and received by their primary care-givers. Current mental health policies and practices seem to be determined more by the experiences and needs of the various agencies providing services than by the experiences and needs of the people using the services.

Freeman (1989) argues that the major problem of a primary health model in mental health is the lack of evidence that most patients can in fact be adequately treated in the community. Until such evidence exists, substantial support and actual services for primary mental health care (PMHC) is unlikely. Concerted effort and research is thus needed in South Africa to test the limits of first line MHC. At the same time, until sufficient work is done in this area, the difficulties of care by and in the community should remain an obstacle rather than a deterrent to a PMHC approach.

Since 1969 the state's policies have gradually moved towards the notion of the crucial need for an extensive national primary health care (PHC) service, and for community based MHC. Freeman (1989) argues that in reality this focus has constituted only a small part of the overall MHC strategy and has almost exclusively taken the part of dispensing psychiatric medication. This dissertation argues that adequate community care (CC) requires a much broader integrated intervention. Community care is not only out-patient psychiatric care, it does not only involve the creation of Community Mental Health Centres or day-care and other residential and training facilities. The main form of CC for

the MH in South Africa is the care provided by women care-givers in the community.

The PMHC approach and the action research methodology adopted in this study is an attempt to address the above within the parameters of a small pilot study. The work situates itself within a historical materialist framework. Its basic assumption being that the experience of individuals cannot be understood independently of the socio-economic context within which the person/family is located. From this stems a recognition of the inextricable relationship between socio-economic structures and mental health and ill health.

The above aims will be pursued along the following lines:

- * The second chapter discusses the role and nature of MHC within the South African context, assessing the impact of the state's policies on MHC services, and briefly outlines the structures of the current services, with special reference to mental handicap.
- * Chapter Three looks at the development of Community Psychology (CP) and the main principles underlying the theoretical base of the field. The chapter focuses on the two models which have the most significance for clinical practice and which have been identified as being the most relevant for local conditions - the Community Mental Health model (CMHM) and the Social Action model (SAM).
- * Chapter Four identifies two major strategies which could feasibly provide the structure for the development of appropriate and adequate MHC services in South Africa - the PMHC and the CC approaches. This chapter, in outlining these approaches with specific reference to the MH, attempts to clarify the issues by disaggregating the concepts of PMHC and CC.
- * Chapter Five sets the scene of the actual research - outlining the Action Research method; providing background information about the CMHP and Bambayi; and describing the research process, the sample and the data analysis. This chapter on context and methodology provides more detail than is customary for psychological research. The materialist perspective and the action research method demand that the material conditions of the research, and the process linking theory and method, be made explicit because the method used in generating, developing and validating theory shapes the theory itself.

* Chapter Six presents an integrated qualitative analysis of the main themes arising from the research, as well as the recommendations of the sample and an evaluation of the research by the main participants.

* The final chapter summarizes the main themes of the research, critiques the study, and presents four broad principles aimed at informing policies for the CC of MH children.

CHAPTER TWO

THE SOUTH AFRICAN CONTEXT

The role and nature of MHC in the South African context cannot be adequately explored without an understanding of that particular context. This chapter addresses the negative impact of the South African state's policy on MHC services and briefly outlines the structure of the current mental health services, with specific reference to mental handicap.

Mental health care in South Africa is in crisis. Both Freeman (1989) and Solomon (1985) argue that the distribution of MHC is highly skewed. Three broad categories of those needing care can be distinguished:

1. those who have no access to MHC at all,
2. those with access to inadequate care, and
3. those with access to a reasonable MHC service.

This broad categorisation can be further subdivided into rural and urban, rich and poor, black and white. This means that those least likely to receive adequate MHC are poor, black and largely rural people. Whilst those most likely to receive care are employed urbanites. Of those who require access to MHC, it is the African children who are least likely to gain access and receive the appropriate care.

2.1 PREVALENCE RATES

The dearth of epidemiological studies of the mental health of the South African population makes any prevalence rates of mental disorder extremely difficult to calculate. The World Health Organisation (WHO) has estimated that at any given time, approximately 1% of a given country's the population are likely to be suffering from a seriously incapacitating mental disorder, and 10% of the population is likely to suffer from a seriously incapacitating mental disorder at some point in their lives (WHO Report no:654 1975). USA statistics estimate that 15% of the American population suffer from some form of mental illness and of these some 20% receive no care of any kind. Taking the conservative estimate of 15% we can extrapolate that in South Africa approximately 5 million people are in need of MHC at any given time, with 10% of these people suffering from a seriously incapacitating disorder.

Surveys of general populations show that the prevalence of persistent and socially handicapping mental health² problems among children aged 3-15 years in developed countries is about 5-15%. As with all such estimates, there cannot be an exact prevalence rate for mental disorders in childhood. Firstly, most represent departures from psychosocial normality rather than specific diseases. Consequently prevalence figures will be affected by the cut-off point used in making a diagnosis. Secondly, disorders vary in frequency according to both developmental and social circumstances. Mental health problems tend to be more common in boys than in girls; are somewhat more frequent in adolescence than in early childhood; and at least in developed countries, more frequent among children living in inner-city areas than in small towns and rural areas. Mental health problems in childhood are thus sufficiently common to constitute a major concern in the planning of health services and to make it impractical for them to be dealt with mainly by specialist services. The nature of the problems makes it desirable to plan therapeutic services in a community setting within the context of normal as well as abnormal psychosocial development (WHO Report no 613 1977).

In terms of mental handicap (developmentally impaired intellectual functioning) as opposed to mental illness, a further difficulty in ascertaining prevalence rates is the difficulty in making a definite diagnosis of MH early in a child's life in all but a small number of cases, such as Downes syndrome. For similar reasons, neither is it possible to make accurate assessments of the prevalence across comparable age groups. Healon-Ward (1977) points out that most cases of severe MH (defined as IQ below 50) should have come to light by the ages of 15-19 years and that their total number then closely approximates the true prevalence. Three surveys in England suggest that the prevalence rate of severe subnormality is about 4:1000. Because the severely MH do not have a high life expectancy the prevalence falls as age increases and its overall prevalence at all ages is estimated at between 2-3/1000 (Healon-Ward 1977).

The international statistics quoted above are likely to be underestimations of the real situations existing in those countries. Extrapolating these estimates to the very different South African context is problematic, but remains one of the most "accurate" indicators of prevalence available.

The WHO's statistics for the severely MH vary between 3-4:1000, depending on the development status of the respective countries -with those countries in the lower limits having adequate preventative health and welfare services and those in the upper limits having poor preventative services.

² For a fuller discussion of mental handicap, see Section 4.2.

Research indicates that the most prevalent of all child and adolescent mental health problems in Southern Africa is MH, with or without epilepsy, presenting with learning and/or behaviour problems (Robertson 1988). South African estimations as to the prevalence rate of MH amongst African children varies widely. The South African government statistics estimate figures for the African severely MH at 2.9/1000 (Department of National Health and Population Development 1987). Figures for the White, Coloured and Indian population groups are estimated around 4:1000 (Department of National Health and Population Development) paralleling the WHO's figures for less developed countries.

The National Director for Mental Health regards the low South African prevalence rate of 2.9:1000 as reasonably accurate in the light of the very high mortality rate amongst severely MH African children due largely to the grossly inadequate health and welfare services (Vitus 1990). The WHO ascribes the very high incidence of mental retardation in Africa to the interrelated problems of malnutrition and the lack of cognitive stimulation in infants growing up in severely disadvantaged families (Who Brazzaville Report 1986). The Natal University Department of Paediatrics estimates a far higher prevalence rate than that provided by the state - 4.9:1000.

Taking into account the mentioned difficulties in obtaining accurate prevalence rates, the very high incidence of MH in Africa, and the Natal based research, the prevalence rate of 4.9/1000 is used as a guideline in this study. In the shack settlement of Bambayi with a population of approximately 15 000 - 30 000 in 1988, we can thus estimate a figure of 75 -150 severely MH children.

Estimates of the prevalence of all degrees of MH vary much more widely, reflecting the different criteria and the difficulty of accurate assessment. British prevalence rates range between 3-8/1000 with a mean 5.5/1000. The WHO estimates that the prevalence rates for mild retardation to be about 30 children per 1000 (WHO Report no 613 1977). No figures were available for South Africa.

2.2 RESOURCES

The resources available to cope with these numbers of MH people in South Africa are inadequate. There are a limited number of accessible and available services, a small number of specialist mental health personnel, and an extremely limited welfare system. The situation is exacerbated by the Apartheid system of racial segregation, the history of

fragmentation in health care provision and the increasing privatization of services.

2.2.1 Personnel

In 1989 there were 291 psychiatrists and 969 clinical psychologists registered with the South African Medical and Dental Council (Freeman 1989). The South African Institute of Race Relations documents that by 1983 there were only 8 black psychiatrists, none of them African (1983). The first African psychiatrist graduated in 1986. In Natal, the psychologist:pupil ratio for the black community is about 1:26000 (Brownell et al 1988). Whilst these figures have since altered, the racial breakdown of these MH professionals reflects an educational system which caters to the privileged class and race (Vogelman 1986).

There is thus approximately 1 clinical psychologist to every 3000 people in need of help. The ratio of psychiatrist to patients in psychiatric units is 1:133 (USA 1:12), only 5% of psychiatric units have access to a psychologist, 6% a social worker and 27% an occupational therapist (Vitus 1990). About 80% of the population get their care in the public sector, the state only employs about 100 registered clinical psychologists, one tenth of the total. Based on this, and disregarding a large number of frozen and empty state posts, the ratio of clinician to those in need of help is 1:24000. Assuming that psychiatrists would only deal with the seriously incapacitating disorders, the ratio of psychiatrist to patient is 1:1135.

These figures compare poorly with the USA figures of 1:80 and with English figures of 1:190 (Freeman 1989). These comparative ratios must be seen in the light of the fact that South Africa is not a first world country, nonetheless they highlight the limited 'reach' of the MH professionals.

The committee of Inquiry into Child Mental Health Care Services (Department of National Health and Population Development 1988) reports that urgent attention should be given to the training of all types of mental health professionals in view of the serious shortage of psychiatrically trained staff concerned with the mental health of children.

Social workers who play a crucial role in the care of the mentally retarded are also in short supply. In 1988 there were 6479 (1022 African, 729 Coloured, 333 Indian and 4395 Whites) social workers registered with the Council for Social and Associated Worker (SAIRR 1989). In 1986 there were 124 state subsidised posts for social workers nationwide, 35 employed in state psychiatric institutions and services (Vitus 1987). The first subsidised social work posts for blacks were developed in 1966.

The above ratios are further exacerbated by the fact that most mental health professionals are in urban based private practice or state services, whereas about 50% of the South African population is rural.

A major limitation to the care made available by the mental health workers is their training. The ethic of health and welfare practices in this country continues to be influenced by prevailing Western/Eurocentric mental health practices which are within certain situations and communities, often inappropriate to the South African situation. Training is based in tertiary educational institutions and biased towards high-tech, urban-based, curative practise, with an increasing shift towards the privatisation of care provision.

Psychologists for example, are trained in modalities which tend to be individualistic and intrapsychically focussed, labour intensive and long term. Whilst this may be appropriate for those who can afford private sector care it is inappropriate to meet the needs of the majority of South Africans who have access only to public sector health care, if at all. Because of their training, many psychologists feel best equipped to enter private practice and thus do so. Another factor which loads the concentration of psychologists in the private sector, is the lack of any real attention given to the primary health sector as a whole, and particularly to the structure and function of public and primary mental health care services. This neglect of PMHC provision is reflected in the training received by MH workers, especially the psychologists, and consequently on their practice. Preventative services compromise only 4.5% of all professional activities of registered psychologists in South Africa (Freeman 1989).

Current South African personnel trends favour specialist workers within the mental health sphere i.e psychologists, psychiatrists and social workers. Trends both in developed and developing countries show that the broader the training in diagnostic, treatment and referral skills, the more cost effective and appropriate the ultimate health care provision. The continuation of existing training and personnel trends are at the expense of developing more broad-based practices. The Committee of Inquiry into Child Mental Health Care Services strongly recommended that:

" Instruction in the mental health of children in the form of courses and in-service training should be given to primary health care staff...Primary mental health care services in respect of children should have a high priority for development by health authorities."

(1988:ppix)

2.2.2 Economic Resources

The result of the above coupled with the government's policy of privatization has resulted in a situation where the private health sector which cares for only 20% of the population, consumes nearly half of the countries health resources. Medical aid schemes cover approximately 20% of all private patients, of whom most are white. These 20%, consume 56% of medical services, with the 80% of indigent patients sharing the remaining 44% of the services. Medical aid schemes cover 68.8% of Whites, 33.8% of Indians, 30.2% of Coloureds and only 5.5% of African people (Sunday Times 2-06-91). Thus for the South African first-world patients with jobs and medical aid membership, conditions today are still good by international standards.

According to South African welfare policy, an individual is primarily responsible for their own welfare, thereafter family members are expected to take responsibility, followed by the community and finally the state. Vitus writes that:

"Although this may be conceptually commendable it is only likely to operate effectively in small, homogenous, self-motivated communities. In practice most people do not automatically know what is good for their own welfare. This means that in places like South Africa, everyone sits around doing nothing until a crises occurs - then everyone gets involved at the same time... The state should finance the total cost of those who are indigent, and between 30 and 70 percent of the cost of those who can pay, depending on means. At present, welfare organizations spend up to 40 percent of their time and energy in raising 60 percent of the money required for essential services. Especially given the absence of tax incentives, this makes no economic sense."

(1990:34)

At present South Africa spends about 5.6% of its Gross National Product on health care. The 1988/89 health budget was R454 million, a decrease of R187m, or 29% over the previous year's budget of R641m (SAIRR 1988/89). This is high relative to countries with similar GNP per capita, but low compared with the USA's 14% and England's 7-8%. It is possible that this figure may rise, but it will most likely be constrained by the need to get the saving/investment pattern in shape to support economic growth, and by other demands on public resources for the development of education, housing, etc (Sunday Times, 2-06-91).

Mental health has received minor attention vis-a-vis physical health. Mental health received 0.96% of the health budget -R43 940 00. The demands for better physical

health care are likely to increase in the New South Africa, whereas the demand for improved MHC is unlikely to receive priority with predicted shrinkage in any future budget allocations (Freeman 1990).

Further wastage of resources occurs because of the neglect of preventative and promotive strategies in MHC. The current focus on psychotic disorders, private practice and on the curative approach has resulted in restricted and expensive services limited to a relative few. The lack of attention to non-psychotic disorders which have a far greater prevalence, means that a large number of people with mental health problems are not cared for. In fact the prevalence of non-psychotic problems are likely to be relatively greater in a country like South Africa where political oppression and economic deprivation predisposes to a range of non-psychotic problems (Freeman 1989).

Furthermore it is estimated that around 20% of all people presently at out patient health departments with physical symptoms have underlying psychological causes and unless health personnel are trained to recognise this, patients will be inappropriately investigated and treated, becoming chronic repeating patients in their search for relief, thus generating a cycle of excessive and unnecessary expenditure (WHO Brazzaville Report 1986). Such neglect results in personal and economic strain and ultimately results in overburdening in the health services.

The WHO estimates that as many as 50% of mental health problems could be prevented by appropriate public health strategies and efficient PHC services (WHO Brazzaville Report 1986). In South Africa only between 1% and 2% of the mental health budget is allocated for prevention and promotion and only about 7% on primary care, education, community services, prevention and promotion. The balance is spent on hospital care with about 50% of the mental health budget going towards the academic hospitals (Freeman 1989).

The need for a more efficient PHC system in South Africa illustrated by widely quoted data on the occurrence of preventable disease among black people. For example, in 1987 the number of infant mortality rates outside the homelands, according to the number of deaths per 1000 live births in the first year, were: 63 for Africans; 41 for Coloureds; 16 for Indians, and 9 for Whites. The limited state spending on PHC is often cited as a cause of racial inequalities in health care provision. PHC is seen as the most appropriate form of care for socio-economically disadvantaged, peri-urban and rural communities - which in South Africa are overwhelmingly black. Where state PHC services are provided, they often experienced as insensitive to communities' needs (Kelly 1990).

2.3. APARTHEID POLICIES AND MENTAL HEALTH CARE

" In South Africa the mental health movement arose because of a need for a home for mentally retarded women. At a drawing room meeting in June 24, 1913 called by the Child Life Protection Society in Cape Town to discuss vagrancy and prostitution among mentally retarded young women, the South African society for the care of the feeble minded was formed."

(Vitus 1987)

"The State has never provided facilities specifically for black mentally retarded children or adults. Until 1962 all its efforts in that direction were aimed at whites. The opening of Westlake Institution marked the first efforts by the state to provide facilities for "coloured" retards. A small percentage of black mental defectives have nevertheless been accommodated in state mental hospitals"

(Solomons 1980)

From their earliest days, the development of the South African health and welfare services have been characterized racist state policies - by the racial inequality in the distribution of resources and facilities, by overcrowding in the black facilities and by the regional and racial fragmentation of South Africa.

The present government itself recognises that:

"As far as the other population groups (ie black people) are concerned there is still a considerable shortage of institutional and community facilities and services... the expansion of all services and facilities for intellectually handicapped children (is recommended) so that parity can be achieved for the different racial groups"

(Department of National Health and Population Development 1988)

In Natal, the lack of beds for severely MH children is critical. Durban Mental Health Society has at any one time an average of 5 severely MH African children urgently requiring placement (due either to abandonment or difficult family circumstances) with no facilities available for their care. There are no centres providing residential care for severely MH African children in the greater Durban area. Three centres exist in the whole of Natal: Ekuhlengeni Sanatorium, Umbogintweni (200 beds; Montebello, Dalton (38 beds); Thembaletu, Harding (20 beds). Moreover, because of overcrowding and pressure, many of the patients are discharged before they are able to cope in the

community, or without adequate care available for them by their community.

There is one special care centre providing day care for severely MH Africans over the age of 6 years in Pinetown, with no such services in the rural areas. The shortage of day-care centres is a crucial one as this means of care has been identified as one of the mainstays of community-based PHC. The transportation of children to and from these day care centres continues to be a huge problem.

There are 3 state-aided "special care" residential and day-care centres for White children between the ages of 3-18 years in the greater Durban area, and 7 in the rest of Natal (National Council for Mental Health 1987). A study by the National Council for Mental Health (1988) found an oversupply of White special-care facilities in Natal and the Orange Free State, while facilities for Africans catered for less than 10% of their needs in these provinces. The voluntary mental health movement provided for approximately 10 000 people in various projects across the country in 1990, of these only 1800 were Africans (Vitus 1990).

Apart from services for white children, there is a serious shortage of training centres for MH children. There are 3 training centres for African children between the ages of 3-18 yrs in Durban (2 for Whites), and 3 in the rest of Natal (6 for whites). The age range for White children attending these centres is 3-18 years, thus providing more extensive care to a very vulnerable age group and to their families. These centres are not residential, thus de facto limiting such care to those with access to transport in the urban areas.

The facilities and services for severely MH people over the age of 18 years are inadequate, and provision is not made for people in the transitional phase between childhood and adulthood. There is therefore a large gap between training centres and employment opportunities. There are 2 protected employment workshops for africans over 18 years in the greater Durban area (2 for Whites), and 1 in the rest of Natal (3 for Whites). No specific provision is made in township development for the erection of facilities for the MH, consequently there is a shortage of building sites (Department of National Health and Population Development 1988).

A critical factor in the care of the MH and in any community care services, is the provision of subsidies and disability grants. The maximum disability grant given to Africans is R150 per individual per month as well as a per capita subsidy for institutional care of R100 per month, White people receive R251 and R468.90 respectively - a total of R250 versus R719.90. Indian and Coloured people receive a disability grant of R200

per month. Furthermore, subsidies for residential care for specialised schools are made to Whites only. Schools for the MH in KwaZulu do not receive subsidies for their running costs, only for the teachers salaries.

There are minimal facilities and services for the evaluation of children with MH. There are no facilities in the greater Durban area which provide consistent and comprehensive assessment of African children with intellectual disability, especially in the moderate form. Follow-up services are also not available.

2.3.1 Fragmentation and MH Services

Compounding these stark examples of state racism, is the regional and racial fragmentation of the South African state into 4 provinces, 4 "own affairs" state departments and 10 ethnic African homelands. There are 14 departments of health, each with its own infrastructure. The health services in Natal are run by the Natal provincial administration, the KwaZulu Ministry of Health, the House of Delegates, the House of Representatives, the central government and city municipalities. A situation which renders the administration, planning and coordination of services in the fields of education, social welfare and health almost hopeless.

A massive bureaucratic structure has been entrenched to administer this system, which even by the states own admission, does not cope:

"Service fragmentation presents serious problems for psychologically disabled persons in that it permits gaps in the service system and such persons can easily be dropped unless a comprehensive and well co-ordinated service is provided..."

(Department of National Health and Pop Development 1987)

The voluntary MH movement deals with 28 authorities in the fields of health and welfare on the national level alone. In addition the National Council consults with numerous other government departments and statutory bodies, many of which are still "duplicate" racially stratified bodies. There are also a myriad of voluntary welfare organizations that deal one way or another with the mentally handicapped. The state and the voluntary welfare structure is too complex to outline even briefly, suffice to say that the co-ordination and liaison between the different state, statutory and voluntary structures seem to be slowly grinding to a standstill because of an ever-increasing maze of red tape and confusing policy directives (Vitus 1990).

Policies governing practices differ from region to region, within and between different racial and provincial structures. This system is filled with anomalies and makes

intervention very difficult. For example, if a social worker applies for a disability grant on behalf of a client living in Bambayi, she has a choice of going to two magistrates courts:

- the Verulam magistrates court which deals with the northern Durban and KwaZulu Townships including parts of Inanda within which Bambayi may be included;
- or the magistrates court which deals with the South African townships around Durban, including parts of Inanda within which Bambayi may be included. Inanda being an area rather arbitrarily split between SA and KwaZulu.

The SA and KwaZulu disability grant forms are different, as are the court procedures. The administration and granting of the grants rests within the powers of the judiciary. The National Council for MH is currently appealing for standardisation between SA and the Homelands, and for the power of administering the grants to be invested in the welfare services.

The South African states current practice in the allocation of resources and in the statutory fragmentation of the health and welfare services, significantly compromises mental health care delivery. These "compromises" are viewed as being rooted in Apartheid ideology and as signifying a lack of direction in national policy. Re-organization of MH and psychiatric services and doing away with wasteful fragmentation and multiplication of bureaucracies will make more money available for treatment of the average person in need of care. But this in itself will not be enough without material upgrading. Strong motivations must continue for MH services to be provided at all levels to meet population numbers.

2.4 SUMMARY AND CONCLUSION

A number of the obstacles to adequate MHC in South Africa have been discussed. Obstacles to the effective delivery of MHC include: the fragmentation of services, the neglect of a primary mental health care approach in favour of a more limited curative approach to MH, the specialization of MHC skills and services, centralization and concentration of resources, increasing privatization, and the subjugation of MHC services to Apartheid ideology.

A further compromising factor is the stigma of mental handicap within society in general and within the welfare, and particularly the mental health and medical professionals. The area of intellectual and related physical disability is a much neglected, even ignored one in the training and practice of these professionals.

The consequences of these obstacles are inefficiency, lack of co-ordination and racial

inequalities in access to MHC services, limited and often inappropriate trained MHC personnel. It is argued that substantial improvements would result if the present structure was replaced by an integrated and united policy and planning body in mental health. As well as the development of a whole new approach to MHC delivery in South Africa, namely the PMHC approach based on the following three principles:

1. Recognition of the inextricable relationship between social and economic structures and MH
2. The need to emphasize prevention and promotion
3. The need to provide everyone with access to competent care.

CHAPTER THREE

COMMUNITY PSYCHOLOGY

3.1 INTRODUCTION

The previous chapter attempted to illustrate the deleterious effects that the current state policies have had on welfare and health care in this country. Suggestions made over the years by practitioners, consumers and organizations in the field, is that the present health and welfare system be replaced by an integrated, PHC orientated, national body guided by a broad-based policy forum. Such changes could only stem from economic and political changes strong enough to pressure the current state into fundamentally changing it's social policies and consequent powerbase.

Changing the political climate and the present health structures would not necessarily solve the problems mentioned. The urgent need for accessible MHC - especially in a society characterized by endemic racism, huge disparities between the haves and the have-nots, and rapid socio-political change - and the relative scarcity of resources to meet the need, demand the development of a new approach to MHC delivery in South Africa. This demand has immediate as well as long term implications. Whilst political and social obstacles are overcome and new policies decided upon, mental health workers need to deliver a crucial service whilst at the same time transforming the process and content of this service.

In MHC, as in health care in general, the PHC approach is widely regarded as the way forward. This chapter in laying the groundwork for the development of this approach within MHC, will discuss the development of the field of community psychology (CP). The paradigm shift brought on by the ongoing developments within this area of psychology are seen as crucial to the development of MHC in this country.

In order to approach a clearer understanding of CP and to clarify the theoretical base informing this study, the first section of this chapter (3.1) aims to historically examine conceptual developments relevant to the area of inquiry.

The following two sections discuss the more recent history of CP, namely developments during the 1960's in the USA. Section 3.2 deals with the Community Mental Health

Movement which formed the basis for the Community Mental Health Model (CMHM). This model represents the first theoretical and practical articulation of CP as a distinct sub-discipline within psychology. Section 3.3 deals with the Social Action Model (SAM) which developed partially in response to perceived inadequacies of the CMHM, whilst being greatly influenced by the CMHM.

Two other influential models exist within mainstream CP - the ecological and the organizational models. This dissertation focuses on the CMH and the SA models because of the influence of the former on MH practices in South Africa; and because the latter is considered to offer the most appropriate perspective for a South African CP (Lazarus 1985). Space does not permit an analysis of the important influence the broad, process-oriented and context-centred ecological approach has had on community development strategies within psychology.

3.2 CONCEPTUAL ROOTS

The official beginnings of the CP movement are correctly attributed in the literature to developments in the USA during the civil rights era of the 1960's. This era signalled a growing concern with both the lack of resources and treatment facilities to deal with mental health problems, and the impact of social systems on the human psyche (Mann 1978). However to date the CP movement, which is seen as heralding a major paradigm shift in the field in general, to North America in the 1960's seems ahistorical and poorly theorized.

There has been a gradual development within the theories of science and society of the recognition of the influence of social forces on the development of theory. This acknowledgement of context led to the recognition within the social sciences of the individual-society dialectic, and a need for models to conceptualize this relationship. Community psychology can be seen as one of the trends within psychology of an attempt to theorize this mediation and operationalize theory through the development of appropriate research and intervention strategies.

The emergence of a more critical and socially responsive psychological theory and practice may be seen as the culmination of developments within the philosophy of science and society. With the beginnings of the social and human sciences in the mid-19th century, came two philosophical critiques from the physical and natural sciences which pre-date the social and human sciences by over one century, namely the idealist and positivist critiques. Historical and dialectical materialism - the work of Marx and Engels,

developed in the mid-19th century and began to critique the idealist and positivist positions. The early 20th century saw the emergence of realist perspectives within the philosophy of science which have more recently been applied to the social sciences. The current debates within the philosophy of science and society seem to be a working together of realist and materialist positions (Hayes 1983).

An outcome of these critiques on the theory and practice of the natural and social sciences, has been a clearer understanding of the subjectivity of theory and knowledge. Namely that the pursuit of knowledge and the practical applications of that knowledge are value-laden, social activities firmly rooted in the prevailing socio-economic order and cultural life of any given society.

" If it is true that human societies are in part a product of the social theories and historical beliefs held by their citizens then society is not an independent reality that can be thought of as standing wholly outside a science of society"
(Harre 1988:189).

Whilst not the only contributor in this sphere, a particular influence of Marxist philosophy has been the recognition of the need to contextualize theory and praxis within the broader social relations. The Marxist position in the context of this study and upon which this work is grounded, has two basic principles:

Historical Materialism: which asserts that in terms of human activity, the present is critically influenced by the past, individual experience is critically influenced by wider social relations, and mental processes are reliant on physiological processes. Thus in the context of this study, the individual experiences of the care-givers of the mentally handicapped cannot be understood independently of the broader socio-economic, cultural and political context of South African township life.

However as Cornforth (1952) asserts, the focus of social science is not only to explain and contextualize the problems of individual actions and motives. It also involves examining the changing social relations and material conditions within which individual and social life occurs. The laws which govern these changing interactions are contained in the method of Dialectical Materialism. This concept attempts to understand things as they are (materialism), and in their actual inter-connection and movement (dialectics). Dialectical materialism sees the world not as a system of ready-made things, but as a system of processes in which all things go through an uninterrupted change of coming into existence and then passing away (Cornforth 1952).

Dialectical materialism views psychology as a dynamic interactionist science, recognizing

that individuals exist within their historical and social context as biological and psychological subjects (Timparno 1975). It views human nature as one that is constantly transformed by human action and as such ahistorical. Thus the rules/coherent tendencies in history apply to psychology as well. This materialism in no way reduces human nature to a determined passivity, but it does not deny the pressures that individuals are born into.

Examples of materialist instances in psychology include: Vygotsky's work on conceptualizing language and thought as interactional entities (*Mind in Society* 1978, *Collected Writings* 1930-1935); Reich's exposition of psychoanalysis, socio-political movements and the role of the family (*The Mass Psychology of Fascism*, 1933); Fanon's work on the relationship between racism, colonial exploitation and personality development (*The Wretched of the Earth*, 1967).

Such examples in the history of psychology are important because they are attempts to break from the individualist mode of a psychology dominated by positivism and idealism, and as such have strong political implications. These theorists attempt to provide some conceptual bridges across the gulf between micro theory and macro accounts of people's subjective experiences. The idea being that such concepts should provide analytical tools for beginning to tease out the impact of wider social forces such as the state, the economy, the family on the everyday life of the ordinary person. The materialist approach thus requires the development of a theory of mediation incorporating a conceptualization of the dialectic in an examination of the individual-society interface.

Leonard, for example, uses Marx's materialist theory of history as the basis for an exploration of:

"...the nature of human consciousness, how it is constructed within specific historical conditions, how it is manipulated in the interests of particular class, gender and ethnic groups, and how such manipulation might be more effectively resisted." (1984:2)

Leonard locates his work against what he terms the "gap" in Marxist theory. Sartre has also referred to this conceptual "gap" in Marxist theory as the problem that:

"Marxism lacks any hierarchy of mediations which would permit it to grasp the process which produces the person and his product inside class and within a given society at a given historical moment."

(1963:56, in Leonard 1984:5)

This study does not propose to generate the theory of mediation to close this "gap".

Rather, it is hoped that the accounts of the experiences of caring for mentally handicapped children in Bambayi, together with the researcher's experience of using the action research approach, could be used as a data base from which to develop principles that could act as a guide for a "grounded theory" (Glaser & Strauss 1967) underpinning a model of PMHC/CP in South Africa.

The research process is located within a materialist framework in an attempt to:

1. Locate the subjective accounts of the individuals in the sample within a framework that is sensitive to the wider structural relations and changing social forces within which this experience takes place
2. To self-consciously locate this researcher's method of inquiry within a theoretical framework which will allow for an examination of the relationship of the action researcher/psychologist to the research process and to the "sample" community.

3.3 THE COMMUNITY MENTAL HEALTH MODEL

The sources of the emergence of community orientated approaches in psychology developed as a result of the aforementioned theoretical developments, and more specifically, in response to developments within the social history of the USA during the 1950's - 1970's. The civil rights era of the 1960's saw the emergence of the CMH movement. President Kennedy's call for a "bold new approach" to the care of the mentally ill and the passage of the Community Mental Health Centres Act in 1963, ushered in a new era of MHC and service delivery (Robin & Wagenfeld 1982). Namely, the extension of psychiatric services into the locale of the illness rather than treatment in mental hospitals only, ie: community based treatment with the community being geographically defined.

The CMH movement was not only a creation of the optimism of the sixties. It arose from a convergence of a series of developments within the mental health field, advances in psychopharmacology, and the economic prosperity of the time.

Psychologists began to take into account the effects of social variables like poverty, alienation, sexism, racism and violence on mental health, and to question the philosophy underlying the conception and treatment of mental illness. This conceptual shift in emphasis, influenced by similar developments within the philosophy of the social sciences, led to a radical reappraisal of the dominant intrapsychic model in psychology. This model was criticized for its elitist nature in that it does not seem to address the

needs of most people. The CP *modus operandi* stresses issues that pertain to the community and its collective destiny, rather than those of the individual subject only.

The CMH model, which developed out of the CMH movement, is an attempt to conceptualize a strategy for influencing human behaviour, largely within the setting of the CMH centre. The basic aims and objectives of the model are threefold:

1. Control of mental health problems through prevention, with preventative programmes directed at reducing the incidence of mental illness.
2. A focus on positive mental health. Rather than merely redressing deficit and pathology, it focuses on the development of competencies and coping skills. Plans for the expansion of training and research to refine and develop the existing knowledge-base and to increase the number of skilled personnel to keep abreast of ever-increasing mental health problems.
3. An increased understanding of the social and environmental context in terms of its influence on the definition of mental health problems and their treatment. With an attempt to transform MHC to provide a wider and more efficient range of mental health services over a broader area to a larger number of people in need (Mann 1978).

The preventative emphasis stemmed in part from the clinical psychologists disenchantment with attempting to undo psychological damage once it had passed a certain critical point. And in part from epidemiological studies indicating that the latent demand for services far outstripped the manifest demand. The critical personnel shortage also led professionals to seek alternative intervention models and solutions to the supply and demand inequities.

The CMHM definition of mental health did not simply equate mental health with the absence of mental illness, but moved beyond individuals to take account into their total personal and social environments. As Seedat et al (1988) point out, promoting prevention requires a conceptualization of mental health that moves beyond a mere semantic shift. This model does not undermine the role of the individuals psyche and trauma. It asserts that mental illness is the product of an interaction between individuals and their environment, thus pathology is likewise located at this interface. Preventative efforts are made at various ecological levels (small groups, organizations, entire communities) in an attempt to deal with issues like racism and poverty which are not only seen as evils in themselves, but also as causes of mental illness and intellectual disabilities. The strategy was that through CMH centres, mental health education programmes and through consultation with community leaders, statutory change would

be brought about (Mann 1978).

Typical interventions characterizing this model are the development of adjustment and coping skills, eg: crisis intervention, life skills training, mental health education; and the reduction of environmental stressors, eg: mental health consultancy and training, altering the environment to improve mental health. Research plays an important part of the CMHM. Epidemiological research is seen as particularly relevant as the focus on prevention is on the reduction of the incidence rates of mental disorders. Epidemiological research thus looks at the etiology of mental disorders; attempts to establish base rates for mental disorders, and acts as a means of evaluating programmes.

The role of the psychologist in this setting is that of a professional rendering expert services to a client population through direct service, consultation, education and activism. In this approach the client population is broad and includes the training and expansion of the roles of natural caregivers (parents, teachers, childcare workers) in an attempt to systematically develop grass-roots forms of CC.

A large number of people saw the emergence of the CMH movement as providing the opportunity for the CMH centres to act as agents for social change. It was envisaged that in addition to treating those already ill, these programmes would prevent mental illness in much the same way as community health programmes eradicate and prevent infectious diseases. Calls were made for those in the CMH centres to assume the additional role of social activists. For Robin and Wagenfeld (1982), such calls fitted in well with the prevailing reformism of the 1960's.

3.3.1 Evaluation of the Community Mental Model

Starting in the early 1970's, articles assessing the impact and direction of the CMHM began to appear (see Mann 1978; Hunter & Riger 1982; Robin & Wagenfeld 1982; Rappaport 1977, 1980). Underlying the critiques of the model is the acknowledged reality of the changed socio-economic climate of the 1970's in the USA. The downward swing in the economy and conservative political trends resulted in revised economic policies and in the reduction of funds to community based programmes. The changing role of the central state was reflected in the state viewing itself as an agent of social change on behalf of the poor and disadvantaged.

Three broad critiques emerged:

1. The first was critical of the model's strategy of social activism. This position

asserted that the CMHM, in its pursuit of the "chimera of activism" (Robin & Wagenfeld 1982), had lost a good deal of its impact in terms of direct service provision.

2. The second position argued that the CMH movement failed because activism was not a deviation from the movement's main cause, but its *raison d'être*. Thus the CMHM failed because it did not fulfil its promise of social activism, change, and reform. Robin and Wagenfeld (1982) write that this failure can be ascribed to the persistence within the theory and practice of the CMHM of the medical model, the latter seen as too narrow and antithetical to community involvement and activism.

The CMHM is viewed essentially as a reformist strategy aimed at making modifications and improvements to existing social institutions and environments. Prevention programmes do not in fact constitute a major focus of the CMH centres. Control is firmly vested with the experts who render professional services to the clients - a direct emulation of the hierarchical therapist-patient relationship in individual psychotherapy. Concepts of community participation and control are not dealt with by the model. The importance given to care givers and the value afforded to clients in the consultation process, are a limited form of participation which does not challenge the professionals position. Although the model makes provision for accountability to the community, especially in its stress on evaluative research, the potential system of demonstrating preventative impacts has not been established (Mann 1978).

Freeman (1989) suggests that the typical interventions of the CMHM engender a false sense of personal empowerment and foster individualism - in fact promote the socio-political status quo by masking oppression and exploitation. An example of this is the Witwatersrand Council for Mental Health's "Life Skills Training" for (mainly black) youth. "Personal empowerment" skills necessary for "change management" such as effective communication and change management are taught. The course promotes conflict resolution through discussion only, any other means of dealing with racial and economic conflict between those in power and those oppressed, is viewed as "unreasonable, irrational and mentally unhealthy" (Freeman 1989).

3. The third critique, closely related to the second, argues that CMH never really existed. The CMHM emerged in large part as a reaction against professionalization and institutionalization. However professionally and organizationally it moved into the community without a clear rationale and

conceptualization for its programmes. Thus although the professional ideology changed, professional practice was so entrenched that business went on as usual.

Hunter and Riger (1982) ascribe this disjuncture between theory and practice to the fact that the concept of community was a borrowed and inadequately understood model. They argue that the notion of geographically defined communities as a locus of care for the CMH centres, set limits on the number of people to be served. Relying on this as a core concept for the development of CMH centres resulted in an inability to extend MH services as widely as was envisaged. As well as in a failure to provide an adequate theoretical base for the understanding of the interaction between individuals and society in terms of the development of psychopathology and the influence of this interaction on human behaviour and on social change. Such an understanding, crucial to the development of the model, needs to be based on a clearer analysis of the concept of "community".

The Concept of Community

Contemporary thinking about the concept recognizes the multi-dimensional nature of community. There are different types and dimensions of community that need to be examined and understood in terms of their inter-relatedness.

Research indicates that individuals interact within different types of communities on a daily basis, eg: the communities within which people demographically fit, within which people live, where people work, study, pray and play. Different dimensions exist within which individuals relate to the types of communities with which they come into contact. Hunter and Riger (1982) have identified three critical dimensions:

1. The ecological community refers to the physical and spatial organization of people going about their daily routines of meeting their sustenance needs from their environment - how and where they get food, work and shelter.
2. The social interactional and institutional realm of the structure of social relationships - the networks of individuals interacting within various formal and informal groups, organizations and institutions as they attempt to realize individual and social goals.
3. The socio-psychological and cultural dimensions are linked and are understood as representing the experience of the "sense of community" by the members of that particular community structure ie: the symbolic identification of and with communities by their inhabitants.

Significance is given to the independence of these types and dimensions from each other,

as well as their crucial inter-relationship. Problems may be identified in one dimension, but because of their inter-relatedness, solutions may be found in another dimension. Likewise, programmes designed for one dimension may be inappropriate at other levels where different approaches may be better suited. This understanding opens up a much broader range of potential intervention strategies.

Individuals relate to these various types and dimensions in varying degrees. The "Theory of the Community of Limited Viability" (cited in Hunter & Riger 1982) holds that community commitment is likely to be variable across both individuals and communities. This theory postulates that individuals limit the costs of their behaviour and their psychological, social, even their economic investments in a community, in proportion to that community's capacity to provide commensurate rewards. The question of community becomes focussed on the fit between individual needs and community capacities. This fit becomes the basis for judging both individual and community mental health.

The implications of this theory for CMH programmes is important in directing attention not simply to individual needs or community capacity, but rather to the relationship between the two. The study of community commitment, the implications for theory and practice in this context is an important, barely explored field.

Berger and Luckmann's "Social construction of Reality" (1966) has been influential in the notion of the social construction of community. Community is not seen as a received truth, something out there to which individuals simply relate. Rather, a community is what people define it to be. This perspective stresses that notions of community are embedded in and emerge out of interaction in communication networks and information flows that serve to structure and restructure that definition. These networks may be informal (family, friendship networks), formal (the media), local and national.

The definition of communities as weak or powerful, safe or unsafe, disintegrating or cohesive, rich or poor are the result of interactive labelling processes. These processes are important in giving the community and its residents an identity. Community identity is a critical ingredient in producing an image of the area for those who belong to it and for those viewing it. Not to be sensitive to a community's social construction of its identity and to impose views of the causes and location of social problems on a community, are traps that community psychologists may fall into in their (often top-down) attempts to assess communities and establish intervention programmes.

By not recognizing the complexity of the concept of community, the CMHM undermined its future development. It did so by not heeding its own call for a focus on the implications of the dynamic interaction between individuals and their environment. The results of this are:

1. That the model does not provide a theoretical base for understanding pathology as located at the interface of the interaction between individuals and their environment. It thus remained with traditional explanations of mental illness based on the individual model. Without a theory of pathology it is inevitable that the core of "community based" treatment strategies are conventional crisis intervention, consultation and a reliance on psychopharmacology.
2. It does not contribute towards a greater understanding of the expert/professional -client/community interface, and consequently of the role of the psychologist during collective intervention.
3. Following on the above, the model does not have a clear conception of the aim and purpose of community based development. As a model it is thus unable to provide broad principles, policies and strategies of community development appropriate to the promotion, prevention and treatment of mental health.

Mann (1979) states that the tendency to hang on to the tradition of a focus on individual history and to give less attention to social history, seriously limits the model as a model in and of the community. It has failed address and anticipate the question of community change at the social level, and as such has not provided sufficiently for the generation of a transformed knowledge and training base.

Criticisms of the model are necessary for its development and act as a boost for the development of future models. The aims and objectives of the CMHM stand as a landmark development in the history of psychology.

3.4 THE SOCIAL ACTION MODEL

The Social Action Approach, with it's foundations in the "War on Poverty" strategy, evolved during the late 1960's in the USA. This broad-based social programme was an attempt to counter cutbacks in state spending and to address the distribution of income which had steadily become skewed with the poorest receiving the least (Mann 1978). This approach aimed to equalize opportunities for upward mobility; sought to make available more social resources to the poor, and attempted to alter the social and psychological characteristics of the disadvantaged so that they could participate more fully in society (Mann 1978).

The centre of these efforts was the Community Action Programme (CAP) which tried to stimulate local responsibility and participation in programmes dealing with social problems. The concept of community action/organization was not a new one or one peculiar to the USA. In the field of CMH however, this community-based, bottom-up approach to policy development and problem solving was a radical departure from previous models and programmes.

The guiding principle of the Social Action Model (SAM) is community development and a focus on an analysis of the fundamental structural causes of social events. In associating economic problems with social and psychological conditions, underlying causes of poverty were identified which required a multi-dimensional problem-solving approach aimed at social change. Within this conceptual framework MH, is seen as inextricably linked to the structures and working of society and not to the individual psyche alone.

The core assumption underlying this model centres around the dynamic relationship between the individual and the broader society. As with the CMHM, the SAM criticizes traditional psychology's individualist orientation which locates pathology solely within individuals. It locates the causes of problems of living within the social arrangements of society; proposing that social inequities, economic exploitation, and political powerlessness may be the roots of social and mental health problems.

Reiff, in his opening address as the first president of the Division of Community Psychology of the American Psychological Association, outlined three broad dimensions of the SAM:

"...as the first dimension, ...we have to shift our perspective away from the individual to the social structure. The second dimension is our value system. We have to shift from individual values to social values; that is, define problems not in terms of achievement, competition, and success, but in terms of freedom, distributive justice, and other such values. Closely linked to the problem of values, is the third problem of social ideology; that is, what is our ideological position with regards to our professional body of knowledge? How do we define problems? It is easy to talk about internal conflict,...But rarely do we hear anybody in psychology say that this is a class society where people exploit each other on a class basis as well as on a psychological basis. We cannot deal with the problem as a psychological problem only, for it is not just a psychological problem... I believe that this is a class society, that we exploit each other, and that exploitation produces human misery. For me that is an organizing principle."

(Rieff 1967:47, in Iscoe, Bloom, Spielburger, eds. 1977)

Reiff's (1967) assertion that CP include within its domain an analysis of the conflict between the structural organization of society and human needs, encapsulated the conceptual shifts occurring within CP. The SAM set out to operationalize the social systems approach advocated but not developed by the CMHM. Thus expanding its level of understanding to include a perspective in which the primary object is an aggregate of people and the factors which affect their usual behaviour. A body of knowledge about how social systems effect psychological reactions, as well as a knowledge of the operation and modification of social systems themselves (Mann 1978).

The CMHM proposes reformist preventative strategies to help individuals better cope with social and psychic stressors. The SAM aims at radically challenging the roots of these "stressors" within a programme of social action aimed at effecting social structural changes. The shift is thus from prevention to empowerment.

Rappaport (1981) asserts that empowerment should be "the call to arms". He argues that prevention programmes aimed at the so called high-risk populations, especially under the auspices of established social institutions, became a new area of colonialization where the poor had no alternative but to consume the goods and services provided by the "alternative" CMH workers, thereby providing them with jobs and money. Prevention programmes undertaken by CMH workers tended to add to, rather than change the prevailing social institutions/status quo. Within this framework, the role of the MH professional remained largely unchallenged - they tended to operate as consultants, not to people, but to agencies, schools and other sanctioned social agencies. Their role relationships to individual people never changed.

The needs-based CMH approach with its practitioner/expert in the forefront was the logical outgrowth of the strictly medical-model approach to MH care. The SAM of personal and community empowerment is based on the dialectical relationship between rights and needs, thus developing the ideas of the CMHM and reflecting the trends within the philosophy of the social sciences. As Rappaport phrases it:

"What use is the right to treatment if treatment is neither available nor good? What good is the right to be in the community with no role, no respect and no resources?...By empowerment I mean that our aim should be to enhance the possibilities for people to control their own lives."

(1981:20)

Thus the ethic of the empowerment strategy is to release the potential of existing

competencies which are unable to function because of power imbalances and lack of resources.

By including power within its explanatory model, the emphasis shifts from "blaming the victim" to implicating the social structure. This means that a pre-requisite for empowerment is a redressing of social inequalities. The SAM conceptualizes community groups and inter-group relations in terms of conflicting interests between groups. Since the dominant group have vested interests in maintaining political and socio-economic inequalities, differences are not easily reconcilable. Social action promotes the mobilization and organization of an "appropriate constituency" to exert pressure on the ruling elite (Seedat et al 1988).

Thus unlike the CMHM which confines its preventative efforts within the catchment area, the SAM locates the causes of the "problems of living" to be within the broader social arrangements of society and aims to change those structures through community-based programmes. Rappaport (1981) goes as far as to say that in order to advance such programmes of socio-political change, CP should be a social movement rather than a professional enterprise.

The focus on being community-based is not a simply political one aimed at meeting the needs of a particular constituency. It impacts on the politics of creating theory and praxis. Mann (1978) writes that rather than presenting a systematized theory, the model makes assumptions about the nature of the theory that is required, and admitting that an adequate theory is not at hand, suggests a pursuit of knowledge about the relevant concepts through participation in and analysis of elements of social policy. Emphasis is placed on how the definition of the problem effects subsequent interventions, and on the applicability of "participant-conceptualization" to generating the required knowledge (Mann 1978). This way of conceptualizing issues impacts fundamentally on the research methods used, with typical action research centring around the development of community based and controlled programmes.

As part of its intervention strategy, the SAM capitalizes upon natural support systems. Rappaport's (1981) notion of empowerment has a particular bias towards the neighbourhood as being the unit of analysis and the catalyst for effective social transformation. For the disempowered, the area where they can best effect change is at the neighbourhood level. The implications of this for national policy development is the networking relationship between the various levels of organization from the national to the micro-level. With problem definition, strategy formulation and resources moving

between the community base and the relevant state structures along unfettered channels, with the onus being on a public policy of mutual accountability and local-level empowerment (Rappaport 1981).

This framework, with its more textured understanding of the concept of community, locates its programmes within many diverse local settings, thus extending the concept of empowerment to include the possibility of different local rather than centrally controlled solutions. This strategy may generate solutions based on different assumptions in different settings. The criterion thus shifts from a single, one-sided standard of competence to recognition that social problems have many solutions as well as answers (Rappaport, 1981). Rather than a top-down approach to social policy, the SAM advocates a bottom-up approach which starts with local-level structures and works backwards to tell officials which direction to look at when developing social policies and programmes.

Social action programmes address themselves to the issues of finance, increasing and redistributing resources, establishing a power base, developing grass-roots support, public education, action research and community development. To help develop self-determination and community control, the model works towards developing strategies to foster a sense of power and community participation, eg: increasing community morale, tapping community resources, generating opportunities for promoting local leadership, developing social skills.

Interventions are organized around two fundamental strategies: - the development of members of the target population as service workers in the new programmes - the "indigenous nonprofessional",
- the organization of the consumers of services to control the activities of the programmes - community control (Mann 1978).

It was assumed that the local nonprofessionals would be more sensitive to community issues and needs and could be able to provide valuable input for programmatic planning. In as much as it was known that the intended recipients of these services were not inclined to use such services, it was assumed that these local workers could liaise between the professional services and the community in order to encourage the use of services. Such a system involved education and training and created employment opportunities, eg: direct service providers (tutor, teacher, nurse, case-work aides); community workers/organizers; facilitators who serve to link up clients with the appropriate services.

North American mental health projects found that these workers provided informal support and information for the clients, and performed the invaluable function of language and cultural translators for the professionals who were removed from/not of the community they worked within (Mann 1978). They also found that the use of nonprofessionals created some interpersonal and role problems within the projects, which caused these agencies to examine themselves more critically.

To foster community control, the mental health programmes of the CAP were located within various multi-purpose, locally controlled, community development corporations (CDC) which were established in ghetto and rural areas around the USA. Bower (1973, cited in Seedat et al 1988) reports that functioning on a non-profit basis, these CDC's have been able to promote economic and social development, as well as some degree of political power. Through their civic programmes they are able to provide a permanent source of income and collective power for some of the ghetto residents and the community as a whole. The CDC's that have been able to sustain themselves are those who have become part of a broader social movement, feeding off the political and financial support of these structures.

The role of the psychologist within this model is seen as that of "collaborator", of community mobilizer cum conscientizer. In an attempt to democratize the professional-community interaction, it was envisaged that the psychologist would typically find him/herself involved in the conflicting roles of service provider and community activist. A situation which may be seen as typical of the dynamic tensions involved in the formulation of a new theory and practice of community psychology.

3.4.1 Evaluation of the Social Action Model

The SAM is regarded as CP's first attempt to theoretically and practically locate itself within its social context; address the individual-society and the psychology-society interface; self-consciously politicize the research process and the role of the psychologist, and redress social ills. The ambitious nature of this programme stems from the SAM being conceptualized as a programme for social change and attempting to radicalize the conceptions of social problems.

In attempting to meet the above aims, the model makes a distinction between community psychology which focuses on understanding and responding to social inequities, economic exploitation and political powerlessness which are seen as playing a crucial role in the creation of mental health problems; and community mental health with its

focus on the mental health of individuals and service delivery. Intervention is directed towards the mental health of all, with the intention being that the incidence of mental problems will decrease and that the mental status of the population in general will be improved by the envisaged changes in living conditions. The SAM takes up the challenge within psychology of moving away from an individualist conception of what constitutes mental health, by incorporating socio-political variables with the aim of empowering communities.

The individual-social dialectic

Whilst the SAM is recognized to hold a particular perspective, it lacks a unified conceptual base and a clear theoretical framework. Its aims, while radical in some respects, do not fundamentally question the capitalist society of which it is a part and do not offer a systematic theory of intervening in social change, ie: how psychological emancipation may be achieved through the process of political liberation and empowerment (Lazarus 1985).

Although the SAM attacked poverty, racism, sexism and injustice, this approach was also part of the USA's state approach during the late sixties and the early seventies. The economic order and class structure of the society (which in large part can be seen to be responsible for many of these problems) were never at issue except for calls made by some of the followers of the model (see Reiff 1967). It can thus be said that although the model is concerned about the victims of the system, it does not in fact fundamentally question the capitalist system of which it is a part. The SAM does not talk about political liberation, rather it talks about communities empowering themselves within the existing order in order to gain better access to the free market. The CAP's were thus regarded by many as part of the strategy to co-opt the working class into the prevailing socio-economic order.

This lack of critique towards class oppression and the capitalist system points to the lack of debate between this model and other critical theories within the social sciences, particularly those with a marxist perspective, as well as highlighting the SAM's essentially humanist approach. Driven by its belief in social change resulting from placing and strengthening the locus of social control in individuals, the notion of empowerment - the development of personal power together with access to political and economic power - becomes paramount to the model's multi-level strategy for change.

This strategy calls for a need to work at the individual and social levels simultaneously. CP approaches the individual-society relationship with its predominantly interactional

systems approach, stressing the effects of the environment on the individual (Heller et al 1984) and providing strategies for individuals to control their environment. This approach does not examine the socially constructed nature of the individual, and as such offers an essentially one-sided approach to what is regarded as a dialectical problem (Mann 1978).

The SAM tends to underplay the individual's subjective experiences, focusing instead on the conflictual nature of the interaction between different groups in society. It does not examine the specific ways in which psychopathology develops and so does not offer a comprehensive theory about the origins and process of mental illness. By making an ideological shift away from the dominance of the medical model, and viewing mental health problems as essentially social problems, it seeks the solution of these problems from within the social domain. It assumes that in the process of empowerment problems like manic-depression and sexual abuse would be eradicated. Organizational and psycho-social strategies to deal with the problems of living are put forward, without offering more psychologically orientated strategies to deal with the intra-psychic problems which develop within individuals as they interact with elements of the social.

Duveen and Lloyd (1985, in Seedat et al 1988) contend that this problem will never be solved as long as the individual and society are seen as separate "immutable givens". As psycho-social categories they are not independent, because there is no "pure individuality" which can be understood separately from social relations. The dualism in theory and practise which results from this situation, impacts on the intervention strategies developed by the model and raises questions about the "therapist-patient" relationship, in this instance, that between the professional and the community.

The professional-community relationship

The second major challenge taken up by the SAM is to develop intervention methods that will liberate the "patient" from "psychological oppression" (Seedat et al 1988). The model tends to limit its view of the community to the working class/poor/disempowered community arguing that mainstream psychology with its individualist focus does not, and cannot ever serve "the community". The implication being that CP, as a separate branch in the field, is constructed to serve "the community".

Advocates of the SAM claimed that mental health workers should play the role of collaborator/social activist/advocate in the process of social change. They are seen as having the duty of involving themselves as social change agents in furthering community struggles, work which became synonymous with preventing mental disorder and fostering psychological health. The distinction between CMH care and community

organization became deliberately blurred. The fact that most of the skills needed in this broader conception of MHC were not those traditionally associated with the discipline, was seen as an advance rather than a disadvantage (Freeman 1989).

This strategy was clearly aimed at democratizing the professional-community interaction and is generally seen as an advance in the field. The dilemma of role of the "expert" is not unique to CP, and much needs to be theorized and operationalized in this area. By declaring themselves as collaborators in community struggles against "the oppressors", the issue of the differences in skills, status and access to power is not clearly dealt with. These issues may in fact be obscured in the rhetoric of community control, political relevance and comradeship. Rather than effecting the transfer of power from the experts to the community, the "knowledge" and "action experts" continue to appropriate these social conflicts into their field of expertise. Thus in the process of taking part in another community's struggle, another field of practice was created for these professionals, as well as maintaining the status-quo (dependency relationship) between the "experts" and the "community".

Disco (1979, in Seedat et al 1988) maintains that the contradictory class position of the "community experts"/intellectuals enables them to show support to the oppressed while continuing to enjoy the privileges of the class that they are helping to maintain.

The danger implicit in this development is that professional interests are closely tied up with the interests of the ruling elite, and in the service sector, although increasingly challenged, the state continues to control the delivery and quality of services. The control that the professionals manage to extend through the community strategy, increasingly serves to extend the control of the state deeper into the everyday life of ordinary people. Possibly leading to the further disempowerment of communities:

"The popular tradition of self-reliance has, in effect, been converted into esoteric knowledge administered by experts, which has helped the growing belief that everyday life is too complex and lies beyond the reach of everyday people."

(Lasch 1982:226)

The above critiques are not aimed at devaluing the expert skills of the psychologist. The issue is rather at finding out ways in which the skills of the professional can be both extended and applied in such a way that they can act as a resource which is available to anyone, rather than as a body of knowledge defined by and accessible only to a few. On the issue of deprofessionalization, Swartz argues that:

"...to reject the 'professional' title, in keeping with the rhetoric of equality, is to

accept a very particular view of professionalism as the only one. In the long run, it may be more fruitful to explore how the concept of 'professional' in itself needs to be transformed."

(1986:19)

Professional skills are generally highly regarded by the population as a whole. In a study conducted by Berger and Lazarus (1987) enquiring from community organizers what they thought the role of the community psychologist should be, the participants felt that expert knowledge and skills were crucial, but felt that the problem lies with the monopolization of skills by an elite and the resultant dependency of the non-expert community. They recognized however that this was reinforced by clients who tended to view professionals as advice givers and problem solvers. They also suggested that professional services should be integrated into broad-based community support networks which would break down the demarcation of specialist functions and the mystique surrounding professionals. It was pointed out that psychologists who wanted to work for social change needed to seriously examine their own position and priorities in relation to the communities that they wished to work with in this respect.

The call from "below" is thus for psychologists to further develop their skills within a socially responsive paradigm and to democratize accessibility of knowledge and care, rather than to take on the exclusive role of a (political) social activist. Freeman (1989) argues that there is an arrogance in the social action approach which suggests that mental health practitioners will succeed in changing society where the organized working class and community organizers have failed. This is not to say that the skills and activism that MH professionals can contribute will not further any struggle against oppression and exploitation, but that these professionals do not, and should not, have a privileged position in the struggle for social change, as the SAM sometimes implies.

The need for specific MHC skills cannot be brushed aside by the SAM proponents assertions that the paradigms of individual psychology fail as a basis for community change. Hayes (1986) argues that this is a reductionist analysis because it conflates the concept of an individualistic conceptualization of the person, with working with individuals. This analysis, based on a flawed understanding of "community", fails to recognize that mainstream clinical and therapy-based psychology does in fact service a community - it evolved to meet the needs of bourgeois society. Community psychology, in arguing that working class problems are social and not individual problems which are amenable to therapy, falls into the trap of implying that working class people do not need skilled intervention to deal with their problems. It perpetuates the myth that

oppressed/working class people do not have psychopathological problems and turns working class individuals' psychological problems into social ones (Hayes 1986).

Working with individuals may often remain the primary focus of clinical intervention. However this need not be practised within an individualist framework, what is relevant is that individual problems are contextualized and the client-mental health worker relationship is appropriately democratized. Berger and Lazarus argue that "involvement in the struggle for a new social order does NOT preclude the need to address people's more immediate problems" (1987:20). Within the South African context, the SAM advocates believe that the removal of Apartheid oppression is the prerequisite for improved MH in South Africa. Alignment with this position, and using one's psychological knowledge and skills to further the aims of this position, is by definition a political activity.

Mental disorders occur in every society, regardless of it's social structure, thus transforming social conditions is not going to automatically result in the end of psychiatric and psychological conditions. Contemporary society is not geared for the incorporation of the mentally ill, if already scarce MH resources were to be used in social action rather than in direct MHC, it could lead to a situation of neglect and chaos.

The Community Control Strategy

Mann (1977) sounds a note of caution to the uncritical adherence to the community control strategy. The SAM tends to limit its definition of a community to the politically oppressed communities within which the CAP's operated. The model values participation of a limited constituency and emphasizes accountability to it, but tends to ignore participation in and accountability to the larger social system. The SAM provides a framework for intergroup relationships within the community social system, but it defines these relationships in adversarial terms rather than from the perspective of an overall social system.

This grass-roots organizational focus of the model is fundamental to the radical shift it made from previous mental health strategies. However this separatist strategy, whilst resulting in increased levels of "in-group" cohesion and autonomy, does not lead to integration with broader political and economic social structures. Pettigrew (1968, in Mann 1978), in his research of racial integration, points out that community control without control of the tax base is no control at all. Pettigrew advocates integration into the mainstream of the social system as the only viable route.

The isolationist vs integrationist strategy is the central paradox in the community organization strategy that the SAM does not solve. That is, the possibility that it could survive better within the normative structure of the broader community, aware that it would then be placed in conflict with some of its own constituency who would see such a move as a sign of accommodation with the opposition. This is an issue of much debate amongst community organizers in South Africa during the socio-political transitional phase of the late 1980's and early 1990's. This transitional phase has by definition, witnessed fundamental challenges to the monolithic structure of the state. Challenges to the unilateral nature of the undemocratically elected central state policies are in turn a challenge to the groupings that are in opposition to the government. Opposition politics are moving into the sphere of the politics of negotiation and reconstruction. Political strategies which demand, at least in the short to medium term, a critical and equal participation in existing state structures, as well as strategic alliances with other groupings with complimentary goals.

3.5 SUMMARY AND CONCLUSION

The examination of the CMH and the SA models show a serious attempt by psychologists to clarify the nature of mental health, the role of the psychologist and the role and nature of mental health services.

Debates around the nature of mental health, whilst inconclusive as to the relationship between psychopathology and social structures, broadened the definition of mental health as being not just the absence of disorder, but moving beyond individuals to take into account their total personal and social environments. The work of MH workers was seen as encompassing the prevention of mental illness as well as the promotion of mental health. These developments within CP shifted the terrain of the MH worker away from an exclusive focus on the treatment of diagnosable syndromes, towards the promotion of mental health.

These 'shifts' are of seismic proportions in terms of the nature and practice of psychology, having the type of impact on theory and practice that can lead to a paradigm shift in the field. The area of CP is still 'work-in-progress'.

The practice of mental health intervention in South Africa is still rooted in the treatment of diagnosable disorders within the parameters of private and medically-based treatment environments. This situation reflects both the reality of the MH field in general, as well as the local conditions. In South Africa, the need to address seriously incapacitating and

disruptive behaviour coupled with minimal MH resources and the individualistic orientation of MH, has often meant that a narrow definition of MH has been practised.

It was argued in Chapter Two that substantial improvements would result if the present system of MH, both in terms of the education and training of MH workers and the structures of MH care, was replaced by an integrated and united policy and planning body in MH. However changing the structure would be a partial solution. The great need for MHC and the scarcity of resources to meet the need, demand the development of a whole new approach to MHC delivery in South Africa (Freeman 1989).

The progressive health and welfare sector as well as the state have recognized that in MHC, as in health care as a whole, the PHC approach appears to offer the best way to meet this country's health and welfare needs. Freeman (1989) outlines the main principles of PMHC:

1. Recognition of the inextricable relationship between social and economic structures and MHC
2. The need to emphasize the prevention and promotion
3. The need to provide everyone with access to competent care
4. MHC should be administered by appropriately skilled personnel
5. MHC should be community based and controlled.

The WHO argues that whilst there are practical and political obstacles which exist to adopting the PHC approach, the principles underlying PHC offer the best potential framework from which to deliver MHC in a developing country such as South Africa. The WHO's definition of MH encompasses the main principles of PMHC, as well as being complimentary to the CMHM and the SAM:

" Mental health encompasses the notion of the optimal development and functioning of the individual allowing the realization of aspirations and satisfaction of needs as well as the ability to cope with the environment within the context of family, social, cultural and community parameters"
(WHO, Alma-Ata 1978)

Summarizing from the CMHC and the SA models and drawing from the principles of the PMHC approach, the tasks facing MH workers struggling to define the role of a more socially responsive MH practice, are:

1. To adopt a holistic approach to MHC, where MH is not just related to the presence or absence of psychopathology, but also including areas such as job satisfaction, a harmonious family life, access to political power, etc.

2. Integrative care - MHC should be multi-disciplinary with well co-ordinated input from people at a number of levels eg: psychiatric nurses, community workers, psychologists, etc.
3. Adequate MHC should be non-discriminatory across race, class, gender, geographical location, etc.
4. The delivery of MHC should be non-hierarchical in the sense that the people most readily available with appropriate skills be given more responsibility, rather than necessarily ascribing to the medical hierarchy of the doctor as leader of the team. The dominance of psychiatrists, doctors and to a certain extent psychologists, is seen as problematic in terms of hampering the functioning of other team members.
5. To transform therapeutic skill to be of relevance to, and available to different communities.
6. To view the prevention of disorder and the promotion of MH as necessary to achieve MH for all, and to design training and intervention programmes that integrate a PMHC approach into theory and praxis.
7. Wherever possible MHC should be community based rather than institutional. Members of communities should be encouraged to accept, integrate and support people with MH problems and to reduce ostracization. Community based clinics should operate to assist communities in caring for such individuals.
8. To participate in the development of a service structure that provides direct MH services in the short and medium term, thus laying the infrastructural groundwork for MHC services in the long term and contributing to the further development of the country's resources as a whole. The Alma Ata declaration is clear that not only is socio-economic development crucial for good health, but conversely that health is fundamental to development:

"the promotion and protection of the health of the people is essential to sustained economic and social development and contributes to a better quality of life..." (WHO Alma Ata 1978).
9. As such, MHC needs to gain more "influence" within state health and welfare policy, with more priority given to developing and funding MH. This should be channelled primarily to community based services eg: clinics and education.

CHAPTER FOUR

COMMUNITY MENTAL HEALTH CARE STRATEGIES

Within the MH field, the concepts of PMHC and CC are used liberally, often in an indiscriminatory manner, and often interchangeably. This chapter shall look at PMH and community care, with particular reference to caring for MH children.

Chapter Three identified two major strategies which could feasibly provide the structure for the development of the quantity and quality of CMHC services in South Africa - the PMHC approach and the CC approach. Both approaches emphasize the same core principles, that:

1. Mental health occurs within broader social parameters
2. Promotion and prevention are cornerstones of mental health
3. Where possible, CC is preferable to institutional care
4. Community participation and empowerment are crucial in mental health provision.

Both approaches aim to change and expand health services at all levels of care to include mental health. There is one major difference however, and that is that CC is not necessarily based in or through health structures. This difference does not make these approaches mutually exclusive, in fact it is proposed that a combination of the two approaches could provide a feasible MH service approach for South Africa.

4.1 PRIMARY MENTAL HEALTH CARE SERVICES

Current and proposed CMH services in South Africa are following the international move towards the adoption of the PMHC approach. PHC ideas have been introduced in South Africa over the past 40 years, with pilot schemes being established principally by independent organizations and mission hospitals. University medical schools have gradually integrated the approach into their teaching and research, and many have established community health units or schools (Lund 1987).

The state authorities and the professional bodies previously resisted the adoption of PHC as the basis of national health policy. A change came when it was built into the Health Act of 1977, and it forms the basis of the National Health Services Facilities Plan of 1980 (Lund 1987). More recent policy proposals propose the devolution of health

administration to local communities, with PHC entrusted to local authorities (Sunday Times 2-6-91). It has thus been officially accepted as an appropriate form of health service for South Africa's needs. However as discussed in Chapter One, serious obstacles lie in the way of the policy being translated into practice. The present government is still advocating privatization as the economic solution to health services, and calls for the rationalization and consolidation of public health services into a single health department have not been heeded.

Within the current CH services, mental health is the most neglected and underdeveloped. State MHC is concentrated in large custodial mental institutions, in psychiatric beds in some general hospitals, and through a community service usually managed by psychiatric nurses. These services do not meet the MH needs of the population they are geared towards - namely the needs of the chronically mentally ill, and the general MH needs of the population - without coming close to meeting the needs of the mentally handicapped.

Within the state PMHC services, adequate and appropriate mental handicap services of any quality do not exist. Despite the proclamations on the appropriateness of PHC, there exists a serious shortage of state run community based residential and social facilities, assessment, counselling, special education, rehabilitation and occupational services. Moreover, the waiting lists for the institutionalization of severely handicapped children runs into many thousands.

The care needs of MH people are chronic and thus by definition community based. The focus on curative MHC services at the primary, secondary and tertiary levels are not appropriate for the needs of the MH. The fact that those bodies which deal most with the MH and their families, namely mental health related welfare services and sections of the voluntary sector, are not integrally involved in PHC further compromises the care of the MH. The virtual abdication of services catering for the MH to the voluntary sector by the state, with limited state subsidies, can be seen as callous neglect. The state's lack of commitment to community care is illustrated by the fact that in 1988, 93% of the MH budget was spent on hospital care and only about 7% on community care. The latter figure included prevention and promotion (Freeman 1992).

PMHC services for the MH are slowly materializing. Such state services where they exist, are generally integrated within existing health structures and use health care, welfare and educational workers to deliver a MHC service to the MH. An example of such a service is The Learning Disorders Clinic which is part of the Child, Adolescent and Family Unit of the Department of Psychiatry at Medunsa/GaRankuwa Hospital. One

of the clinic's programmes will be discussed as a brief illustration of the problems of PMHC service delivery.

The clinic is a referral diagnostic and therapeutic facility for children who present with poor school progress. Because MH is one of the causes of poor school progress, the clinic deals with children presenting with mild to moderate MH. The clinic in an attempt to offer a service based on PHC principles, functions on three very basic principles (Schoeman 1988):

1. Interventions must not make the community dependant on the hospital. The clinic thus attempts to use available decentralized resources, and where these do not exist staff attempt to make knowledge and skills available on a community level. At the same time, it is realized that it would be unwise to burden a community with problems for which it is not equipped to deal with. Thus the hospital and the clinic try to remain available as a backup referral diagnostic and therapeutic facility.
2. One cannot work effectively with a child outside the context of the family and the school. Programmes try to involve the broader educational setting of the child.
3. The training of adequate numbers of MHC personnel forms a corner stone for the long term solution of the present problems.

The clinic uses specialized mental health professionals to diagnose and treat children at the clinic, using mainstream "western" diagnostic instruments and therapeutic techniques, some of which have been adapted for black South African's. These professionals (clinical psychology interns) also run "mother groups" at the hospital, during which mothers give mutual support to one another. These groups have found that a rather didactic, learning theory approach has proved the most useful.

The clinic tried to initiate an outreach remedial teaching programme from the hospital using members of the catchment community. This was in the form of pre-prepared structured exercises from which appropriate activities for each individual child were selected. The child's care-giver (nearly always a female relative) was taught how to use the exercises at home. Follow-up sessions were arranged at the clinic during which the child's progress was monitored and further exercises given.

From an overall point of view the outreach programme was not effective. On the whole, the care-givers did not implement the activities and stopped coming to the follow-up clinics. Schoeman (1988) outlines the following reasons for the failure of this particular

programme:

1. Often both parents worked and had to commute for long hours between home and work with little spare time to do the exercises with the child.
2. The child was often cared for by different people who did not know the remedial programme. There was thus no consistent supervision and motivation and the programme was not carried through.
3. Often the child was cared for by an illiterate person who could not implement the language based, school-oriented activities.
4. It is not practical to implement a remedial programme from a centralized hospital setting. Parents had to take leave to come to hospital, older children had to stay away from school in order to bring a younger sibling. From more distant areas, transport costs of R5 for a pensioner or someone who earns R120 per month, is a prohibitive amount to pay.
5. Language difficulties posed an enormous limitation. The programme was based on school adaptation activities and since most learning at schools is language based, the intervention placed a heavy emphasis on language. There are many structured language programmes available in English, but few in the black languages. The clinic staff felt that to develop such exercises they needed the expertise of an educational psychologist, to whom they had no access.

The outreach programme did not fulfil further PHC principles in terms of the corner stones of primary care - equity, accessibility, affordability and appropriateness:

1. By centralizing the programme at the hospital, not only was accessibility compromised, but the developmental task of building up CMH points in local clinics or other facilities was not done.
2. Following from the above and contradicting the clinic's stated principle of reducing the community's dependency on the hospital, this intervention may have served to increase such dependency.
3. Professional staff administered the programme at each of its stages, from diagnosis to follow up. A central principle of PMHC is that MHC should be administered by appropriately skilled staff - not by either over or under-skilled personnel. A number of studies from the Third World indicate that some MHC functions can be adequately taken over by "general" health workers eg: community psychiatric nurse, staff nurses, community health workers (see Freeman 1989). To make the best and most responsible use of resources, upgrading of skills will be necessary.
4. The involvement of educationalists in at least the planning phase of this programme would have been optimal, as would the implementation of a remedial

programme in the schools of the area.

5. The use of highly specialized personnel to design the programme, carry out the initial assessments and the follow ups at the centralized hospital setting, serves to further entrench the dominance of specialized, hi-tech mental health interventions. This direct service model coupled with a small number of trained MH personnel is time consuming, reaches out to only a few and tends to remain an assessment service with little opportunity for therapeutic intervention and follow up support.

6. Apart from the use of care givers to do remedial work with the children, there is no evidence of any other community participation in the programme. Whilst seen as central to the success of any primary care initiative, studies indicate that it is very difficult to mobilize sustained and informed community participation in mental health (Mann 1978).

7. Following from the above point, it is not reported whether the clinic staff were involved in promoting this particular programme as well as broader mental health issues to the people who use the hospital. Prevention of mental ill health and the promotion of mental health should form an integral part of MHC and are important in mobilizing community support and participation.

8. The reliance on language based and "hi-tech" remedial interventions was inappropriate for the needs of that particular group. It is reported that the clinic is developing remedial activities based on common experiences in the child's environment. These include the recording of songs in the local language (such as the Tswana equivalent of "one, two, buckle my shoe...), games which involve the manipulation of numbers (such as "dipeko", card/dice games and marabaraba), and nursery rhymes (Schoeman 1988).

The clinic's efforts are a move towards a model based on the principles of PHC. The location of the MH clinic within a general hospital allows for a potentially more integrated and holistic approach to all health problems. This situation makes referrals between the different levels of health care easier and less expensive for all the parties involved. A closer relationship between the different health workers could come about. This set up could result in far more MH problems being diagnosed and treated at the PHC level. Studies show that about 20% of patients who present at general health points do so as a result of MH problems (WHO 1984). The current infrastructure for PMHC is negligible, by integrating into the health services the PMHC approach offers a viable, cost effective and currently available structure for the provision of MHC.

The problems with the service illustrate the difficulties faced in PMHC as well as some of the arguments against the PMHC model. Probably the main argument against the PMHC

model is that by situating MHC within the health care structure and system, MHC tends to be dominated by the powerful medical paradigm with its emphasis on individualized, curative treatment by specialized staff in a medical setting. Experience shows that workers and intervention strategies which are not part of the relevant medical and psychological fields tend to be side-lined.

4.2 COMMUNITY CARE SERVICES

The community service which is most lacking is that which is most needed by the mentally handicapped - a comprehensive locally-based CC service which is part of a broad PMHC strategy, but without being dominated by the still medically biased PHC structures. Like many policies, CC sounds attractive and means many things to different people. This chapter shall examine three separate meanings of the term as they pertain to the MH:

1. CC as an alternative to institutional or hospital care;
2. CC as an alternative to segregated specialized services;
= care in the community
3. CC as care by the community.

All three meanings of the term tend to be confused, leading to many of the problems of existing CC strategies and in policy formulation.

4.2.1 Mental Handicap and the Voluntary Mental Health Sector

MH related welfare services, namely the government CMH services and the voluntary mental health movement, are largely responsible for CC facilities in South Africa. The bulk of the everyday care of the MH that is not done by families and "informal" care networks, is carried out by mental health related welfare services and the voluntary mental health movement.

The voluntary mental health movement, which in 1990 consisted of the National Council for Mental Health, is made up of 19 mental health societies and 85 other affiliated bodies. These bodies carry out a supplementary service to that rendered by the government, mainly the provision of formal support systems to mentally ill and MH people in the community.

The National Council liaises and consults with the government and statutory bodies in connection with mental health policy, it offers staff training and conducts research and service development. The Council monitors and supervises mental health social work services subsidized by the government, develops and co-ordinates national publicity

campaigns in the field of mental health promotion, psycho-social rehabilitation and mental handicap, as well as offering assistance to communities in the establishment of new mental health services (Vitus, 1990).

State welfare and voluntary sector services are not incorporated into any PHC structures, they tend to operate independently of state health and are more closely aligned with the state welfare services. As mentioned in Chapter One, overall liaison in policy planning and service delivery is lacking between health, welfare, the non-government and the government subsidized organizations.

The state policy of privatization of the health services further compromises the situation. It is argued by the government that privatisation is a rational revenue saving attempt. Freeman (1992) provides the counter argument that this is an attempt on the part of the state to avoid responsibility for their apparent inability to provide health and welfare for the whole population. Whatever the political dispensation and the economic situation in the future, one of the main priorities for the mental health movement is to market its services to the public more adequately and thereby ensure a larger slice of the financial cake.

Despite the rather dismal situation outlined above, considerable advances have been made in South Africa in terms of the management of the MH since the van Wyck Commission's investigation was published in 1967 (van der Westhuizen 1990). Advances which have been largely brought about by the families of the MH and by the voluntary sector, and which to a large extent are limited to the more affluent living in the larger urban centres.

4.2.2 The notion of "Mental Handicap" and the development of services

The different meanings and types of CC reflect the historical processes which have shaped the social construction of disability (including MH). The past two decades have seen the development of alternative perspectives to the medical model of MH. Mercer (1973) has identified two separate perspectives on MH: the clinical perspective and the social system perspective.

The clinical perspective is based on the medical model which adopts an individualist perspective to MH. MH is classified as a handicapping condition whereby the limiting consequences of deficits and problems within each MH person restrict them in participating fully in society. In opposition to this view, the social systems perspective looks at the social aetiology of disability and classifies MH as an acquired social status

defined by its location in the social system in relation to other social statuses, and by the attendant role prescriptions expected of those holding that status. This position views MH as a form of social oppression, because full participation in society is not prevented by personal limitations but by the social restrictions imposed upon by the rest of society.

The social perspective analysis rejects the standard definition of MH: sub-standard general intellectual functioning coupled with deficits in adaptive behaviour manifesting during the developmental period (Kaplan & Sadock 1981). Mercer (1973) argues that the social systems approach postulates that MH is a convenient category created under the guise of medical science for the purpose of controlling those people who do not conform to societal norms. In order to legitimize the control of deviant persons, the 'social problem' is transformed into a 'medical problem' and the person is labelled as 'sick'. The concept of MH is largely regarded as a social construction which exists in the minds of professionals (Lea 1990).

The implications of this view is that, as far as possible, individuals should not be labelled as MH. This issue of categorization is an unresolved one even within ardent supporters of the position. In general however, the greater the degree of MH, the less controversy surrounding the classification.

This challenge to the dominant view of MH illustrates the doubts that have existed about MH throughout history, even amongst those who view it as a valid category. Witness the changing labels given to the MH, eg: idiot, moron, mentally retarded, intellectually handicapped, developmentally delayed. All labels, which have changed over the years in an attempt to soften the impact of stigmatization whilst still conveying that these people are in a negative way, different from the norm.

Research indicates that the children labelled as MH are aware of the negative evaluations others have of them, they experience the stigmatizing effects of that label whether or not they internalize the pessimistic connotations (Gibbons 1981, in Lea 1990). Mercer's American based (1973) research found a significant relationship between social class and labelling. Children with the same skills but different social backgrounds could be labelled and treated in very different ways. Generally, the closer the child's background was to the dominant WASP (White Anglo-Saxon Protestant) culture, the less likely was that child to be labelled MH.

A factor compounding this discrimination is that existing diagnostic patterns, especially I.Q. tests, tend to discriminate against minority groups. Mercer argued that labelling and

classifying the MH should not be based upon a single assessment such as the I.Q. test but should be based upon a variety of procedures. The concept of "pluralistic evaluation" was adopted by the Californian legal system in 1971 based on extensive research indicating that it halved the number of children classified as MH and reduced the social discrimination against minority groups (Mercer 1973).

Studies indicate that the effects of labelling and stigmatization can to a certain extent be ameliorated by involvement in certain interventions and support structures. The overwhelming body of research however, indicates that people labelled as MH suffer acutely from that negative label, even if they manage to resist internalizing a negative sense of self (see Lea's excellent review of the literature 1990).

The growing recognition of the human rights of people with MH has contributed to the "recognition" that MH people must be involved in determining their own lives. This notion of self-advocacy lies behind the principle and practice of normalization.

The principle of normalization first emerged in Denmark in 1959 and has since developed into an internationally influential human service paradigm (Lea 1990). The basis of normalization is that MH is not a static and lifelong condition necessitating long term institutionalization, but a dynamic condition affected by the type of service provided. The different definitions of the concept all attempt to move the principle from the theoretical to the practical. The MH are not viewed as a homogenous group which must be given special treatment in isolation, opportunities and services must be developed according to individual need, and not simply because that person is MH. It is hoped that this perspective will enable MH people to live in ways which are as enriching and culturally normative as possible.

Flynn and Nitsch (1980, in Lea 1990) provide a six-stage framework with which to evaluate the adoption of the normalization principle in any part of the world:

1. The adoption-in-theory phase
 - conceptualization
 - initial acceptance
 - legislative legitimation
2. The adoption-in-practice phase
 - resource (re)allocation
 - widespread implementation
 - societal institutionalization

They outline five adoption modes depending upon the different conditions which may

prevail in any particular region: complete, partial, temporary, faddish and no adoption.

Lea (1990) used the above framework to assess the status of normalization in South Africa. Her research indicates that normalization seems to be located in the conceptualization stage of the adoption-in-theory phase. The reasons put forward for this are that the field of MH was neglected until the 1967 van Wyck Committee Report was published, and developments have since then been hi-jacked by other "struggles". Lea (1990) postulates that mental health professionals and laypersons involved in the area have been "consumed" by other sites of struggle (eg: to increase the quantity and quality of services available), leaving them little time to consider the relevance of the principle of normalization.

Lea (1990) hypothesizes that a pattern of partial or no adoption may emerge. The legacy of Apartheid policies and the state of underdevelopment in sections of the South African population may mean that the normalization of attitudes and service delivery may be adopted and applied to the more affluent members of society living in the urban areas only. Thus where services are well developed normalization may be adopted and practised, and where services are underdeveloped, the provision of large-scale and more traditional services such as institutions may remain entrenched on the grounds that they are able to cater for a large number of people.

Another scenario could be that the policy will never be adopted. The deeply embedded principles of segregation and conservatism may, for the foreseeable future, ensure that traditional modes of service in this neglected and cash-strapped field will remain entrenched (Lea 1990).

The issues of labelling, self-advocacy and normalization not only highlight some of the changes that have occurred in the field of MH, they also serve to reinforce the relationship between the principle of normalization and the struggle for human rights. It is put forward in this thesis that **service development cannot take place outside of a national policy of development which is in turn based upon a national charter of human and civil rights.**

4.2.3 Community Care and The Mentally Handicapped

As mentioned above, the recognition that much more than custodial care should be developed has resulted in a change of attitude and service provision amongst sectors of the population. Although this awareness is still in its infancy in South Africa, it has meant that the MH are increasingly less stigmatized and hidden, with the result that services

supporting the care of the MH within and by their communities are being developed.

4.2.3.1 Community care as an alternative to institutional care.

One of the earliest meanings associated with community services and CC was the development of small residential units in the community, as opposed to the provision of residential facilities in large isolated institutions. This development was associated with the criticisms and dissatisfactions of care within the large scale institutions and hospitals, especially criticisms based on Goffman's concept of the total institution. Large scale institutions came to be viewed as intrinsically damaging to inmates and as creating the very problems they were supposed to be solving. This conceptualization has been a major influence within the official policy statements of the British government (Ayer & Alaszewski 1984).

4.2.3.2 Community Care as Integration of the MH within the community.

Ayers and Alaszewski (1984) write that this development of CC in the community also started with a critique of large scale institutions, but from the perspective of the role of institutions in society. Institutions are seen as segregating the normal from the abnormal and in some way creating abnormality and deviance. Thus even the development of the small scale residential units in the community mentioned above, are seen as being damaging to individuals because they continue enforcing the segregation of the MH from the rest of society and are associated with the provision of inferior services.

This position, based on the principles of integration and normalization, stresses that MH people have the right to individuality and to enjoy normal patterns of life in the community. MH people should not be excluded from the services received by the rest of the population, but should benefit from these services. Specialized services and organizations should be provided only to the extent that they demonstrably meet or are likely to meet additional needs that cannot be met by the general services. Such services should facilitate rather than hamper integration.

It is argued that MH children could and should use the same educational and residential facilities as other children. The integration would give MH children access to the superior facilities of ordinary children and would help the MH children to live and be accepted in a normal environment:

"For the handicapped child, integration offers the opportunity to gain self-confidence and social skills for dealing with the outside world and non-handicapped people...Integration should offer a more normal environment, and more relevant and wider social experiences...It should also enable the MH to feel

part of, and be part of, their local n/hoods.

(Kendall & Moss, 1972:41, in Ayer & Alaszewski, 1984)

This interpretation of CC proposes that it is not just the removal of barriers to the use of services that defines CC - a determined attempt to integrate the MH within the community is necessary. Much research needs to be done in this area, especially on the impact of normalization programmes.

Human Rights and Normalization in South Africa:

In South Africa, CC services located in the community have tended to remain locked into the categorical, segregated model of MH. In terms of residential facilities, the government offers the "special care centre". A special care centre is defined as a "day or residential centre catering for those persons falling into the profound and severe lower range of intelligence" (van der Westhuizen 1990:125). Children and adults placed in these centres are deemed "ineducable" or "untrainable". These centres range from being large institutions, which cater mainly for black people, to smaller day and residential centres run along institutional lines.

People falling outside of the categories of severe and profound MH, and whose needs are not accommodated by mainstream society, have generally no access to accommodation outside of their family home. Some of these people are catered for by the "training" and "work and occupation centres" which by virtue of the fact that they offer activities which occur during the day, act as day care centres. As stated in Chapter One, there is a dire shortage of residential facilities, especially for black people.

Vitus (1990), writes that much money has been spent on bricks and mortar and comparatively little on grass-roots community services. There are a limited variety of facilities available in South Africa, and most of these were built some 20 years ago according to rigid structures prescribed by the government. Huge institutions - schools and residences - have been built in the urban areas, while little has been done to help MH people to adjust to their environment. Vitus (1990) points out that the main function of these institutions should not be take over the responsibility of relatives, and to provide "activities" for the MH, but to train people for specific functions in the community so that at least some MH people will be able to be placed in the open labour market and achieve some social mobility. Job creation schemes for the MH have not been initiated in the rural areas.

Normalization has barely been explored in South Africa. Vitus writes that:

"In the late 1970's some movement was attempted in this direction, but ceased in the light of errors made overseas. Total mainstreaming of children is probably not a realistic ideal in South Africa, but the introduction of special classes is probably more cost-effective and less disruptive than large specialized special schools. There are many different models of mainstreaming and partial mainstreaming, which ought to be investigated."

(1990:92)

The advocacy movement in terms of the MH, has not taken hold in South Africa. This is hardly surprising in a country which is yet to adopt a bill of human rights which would protect the rights of all South Africans, least of all the rights of the MH. This fundamental lack of protection increases the vulnerability of the MH with respect to their right to live where, how and with whom they so choose.

The government has fairly rigid standards for subsidy schemes which apply to all MH people regardless of their individual capabilities or needs, thus limiting accommodation options and the subsequent right of MH people to live where they want.

Vitus (1990) reports that despite the many problems involved in the issues of sex and marriage, it seems as if it is becoming more acceptable to allow MH people to marry and form sexual relationships, as long as the sexual relationships are of a permanent nature. However some organizations have a very conservative attitude and if they are in the position to do so, enforce a policy of strict sexual abstinence. Sexual urges are suppressed by the use of tranquilisers and other drugs on the grounds that the MH are "hypersexual".

These attitudes and prescriptions have a fundamental impact on the CC of the MH. For if basic human rights are so rigidly prescribed by the state, they tend to limit rather than to protect. Consequently limiting the creation and adoption of programmes facilitating different forms of institutional care and normalization programmes.

The National Council for Mental Health submitted a memorandum to the South African Law Commission regarding the human rights of Mentally ill and MH people in 1987 (Vitus 1990). Two main issues were raised:

1. It was recommended that provision be made for the appointment of curators at state expense for mentally ill and MH people without means, who live in the community. This would create the machinery necessary to safeguard the interests of these people. The Law Commission prepared a draft bill in 1988 dealing with

this issue.

2. The creation of the position of Ombudsmen to whom the mentally ill and MH could turn if they believed they were ill treated or unjustly deprived of their rights. No consumer movements exist in South Africa to advocate on behalf of the mentally ill and the MH. Although a formal mechanism existed for complaints at most homes and institutions, the Council was of the opinion that communication channels were often blocked because of vested interests and for other reasons. Furthermore many MH people are exploited within their own families and have no one to turn to. Ombudsmen would have the power to inspect the work done by curators. Vitus (1990) writes that this matter has been shelved pending the possibility of the adoption of a general bill of rights in South Africa.

4.2.3.3 Community Care as care by the community.

This approach defines CC as care by the community, where support for the MH and their families comes from the community, relatives, friends and neighbours. Ayer and Alaszewski (1984) in their review of the literature, write that sociological studies have shown that neighbourhoods in industrial societies are not only made up of strangers, and that they can and do provide networks of social support. The rates of social interaction can be very high within neighbourhood based social networks, contributing to a cohesive group with a system of mutual obligations. Indeed more care and support can be provided by these networks than by formal state agencies.

Studies of social supports and networks have mushroomed in the past 20 years or so (Caplan 1974, Barrera 1983, Maforah 1988) as the social sciences, and state policies, have shifted their orientation to the analysis of "everyday life" and the subsequent provision of "community" services to meet some of the needs, and allay some of the aspirations, of the underclasses .

One of the first large-scale community studies of this type was conducted by Young and Willmott (1957, in Ayer & Alaszewski 1984) in East London. A major study of family and kinship in a traditional working class area, Bethnal Green, and in a new housing estate, Greenleigh. They identified two key elements in maintaining the cohesiveness of the community:

- the role played by women, and
- residential stability.

The three-generational relationship between mothers and daughters, where the old as

well as the young both give and receive services, is seen as the mainstay of mutually supportive networks. **Indeed, community care by the community can be said to be care by the women.**

Young and Willmott (1957) argue that migration breaks traditional community ties and relations, dislocating the structure of family relations and therefore impairing the caring capacity of the community. As relatives are displaced by neighbours and strangers, so lives outside of the family are no longer centered on people, but on the house. Their research indicated that when the three-generation family structure is disturbed, the task of caring for dependants at both ends of life - one of the indispensable functions of any society - becomes much less manageable.

Research indicates that whilst social support networks exist in industrial societies, they tend to be restricted in size and function, and in the nature of support given and received. Some people could draw on better networks and some neighbourhoods are more supportive. These networks need to be reinforced and systematically fostered in order to maintain and enhance the caring capacity of the community. In some very far reaching recommendations, Young and Willmott (1957) recommended that planners should not disrupt traditional communities. Existing houses should, as far as possible, be refurbished otherwise communities should be rehoused en bloc so as not to disturb social relations.

Sociological studies identifying and examining social networks, such as the one mentioned above, developed alongside epidemiological surveys which studied the nature and distribution of health problems within social groups. This research reinforced the sociological studies by stressing the importance of the community in the creation and management of health problems. Whereas community studies indicated the nature and possibility of changing and improving local communities, epidemiological research indicated the importance of controlling disease by controlling the community (Caplan 1974).

Curtis (1979, in Ayer & Alaszewski 1984), in writing about the future use of social networks in mental health theory and practice, points out that the collapse of traditional networks of support has resulted in group structures dominating social networks, rather than primary relationships. With regard to the problems of MH and mental illness, the institutions and the new community services begun to replace the caring function of the family member/friend/neighbour/local health worker.

Curtis (1979) writes that the existing pattern of health development does little to enhance the caring capacity of the community because services are dominated by professionals who only treat the individual who presents with the problem. The social networks to which these individuals belong are not considered. This narrow response to problems is found in the new community services as well as the traditional institutions. He argues that the development of community services has merely created a parallel system of care based on the same assumptions and competing for the same scarce resources as the more traditional forms of institutional care.

This argument echoes the one made in Chapter Two, where it was put that community care services in not fundamentally challenging the conception and treatment of MH, act as yet another variable controlling the lives of those dealing with these issues, at the same time providing yet another avenue of employment for mental health and social service workers.

Curtis (1979) argues that the emphasis of intervention should shift from the person who presented the problem to the whole network of friends and relatives. If social networks could be viewed and used as partners in the healing process there could be at least one other person to work on the issues at stake. Curtis (1979) emphasized self-help and mutual-help in the community which could be fostered and enhanced by professional support. The MH person should be maintained in their community as long as possible, and if this was not possible, then a network of mutual support was to be created, eg: small group residences within a geographic area, co-operative flats, foster or adoptive parents.

The principles that MH people need extra help from the communities in which they live, and that these communities could provide the understanding and support which professionals cannot always provide, are ones whose implications have still to be accepted by the South African state. The point of departure for most existing CC services seems to be that the "community" must supplement the services offered by the official services, rather than supplementing the caring capacity of families and the community within which the MH person operates. The implications of this position in societies characterized by conflict and social dislocation, are that the state has to engage in social engineering or community development to create the "right" sort of community. A British report on local state services states that there is a :

"... need for the personal social services to engage in the extremely difficult and complex task of encouraging and assisting in the development of community identity and mutual aid, particularly in areas characterized by rapid population

turnover, high delinquency, child deprivation and mental illness rates and other indices of social pathology. Social work with individuals alone is bound to be of limited effect in an area where the community environment itself is a major impediment to healthy individual development... A clear responsibility should be then placed upon the social service department for developing conditions favourable for community identity and activity."

(Report of the Committee on Local Authority and Allied Personal Social Services, Camden, 3703, H.M.S.O., 1968:para.476, in Ayer & Alaszewski, 1984)

CC by the community is by default the main form of care for the MH in this country. This aspect of CC, can be seen as the most fundamental, not only because it is where most of the care of the MH takes place, but also because any "enhancement" of CC by the community has a long term impact on the lives of the MH and on the impact they have on their community. Declarations by the relevant government departments that PHC and CC are the way forward, have still to translate themselves into concrete proposals for mobilizing the "community" in a systematic way for the care of the MH. Most policy proposals are limited to viewing CC as care in the community only, and community services for the MH tend to revolve around community psychiatric services, subsidy schemes, residential and training facilities.

CHAPTER FIVE

METHOD AND CONTEXT

This chapter deals with both context and method. The way in which the research occurred and the context within which it occurred, is described in more detail than is customary for psychological research. The materialist perspective outlined in Section 3.2 and the action research method, demand that the material conditions of the research and the process linking theory and method, be made explicit because the method used in generating and validating theory, shapes the theory itself.

5.1 THE ACTION RESEARCH METHOD

Lewin describes action research as that done in the actual context, aimed at being socially useful as well as theoretically meaningful (1979). Typical action research centres around the development of community based and controlled programmes. Mann (1978) writes that the participative approach, emphasizing joint investigation by the researcher and the participants, is considered particularly important in socially useful research because of the following criteria:

1. The need for the problem under investigation to be relevant to the community
2. The necessity to gain sanction for conducting the research
3. To provide an opportunity for the participants to learn skills and develop their competencies.

The central idea is to involve the people living in the area where the research is to take place in community schemes which match their own perceptions of need, and to translate these schemes into action with their participation, assisted and evaluated by techniques of social research. Within this framework, the social scientist does not provide a detached assessment of the situation, but makes a specific contribution to an exploratory process of organizational change through a joint working relationship with the field workers, administrators and community members. The researcher has the dual responsibility of contributing towards structural improvement as well as studying the process (Lees 1975), of collaborating in the production of new frameworks as well as solving problems. The aim is thus to improve as well as to understand the situation.

In participatory research compared to other types of research, the researcher is more dependant on those from whom data comes, has less unilateral control over the research

process, and has more pressure to work from other people's definition of the situation. In challenging the role of the "intellectual", this position brings with it problems of role definition and objectivity/partisanship.

The action research method is not a homogenous one, and different motives can inspire action research projects. Such as the need for developmental planning, the interests of the theoretical social scientist, political tactics of bringing attention to or diverting further resources from a particular problem, and the hope of producing substantial outcomes in a particular social context (Lees 1975). This research project has a developmental planning focus in that one of the proposed outcomes is a set of proposals for application on a wider scale by the CMHP and, if appropriate, by other mental health and social service agencies. Thus one of the functions of this research is policy development and the action is seen as a pilot for future action plans.

In terms of this research, the problem area - the development of appropriate services - was explored by a needs and competencies assessment based on the community's own perceptions of need, in order to specify the dimensions of the problem in its particular context. On the basis of this information, working solutions were formulated and operationalized with a view to solving the problem. The working solution in this case was the action research programme aimed at gathering the data in an attempt to contribute both to the practical concerns of the people in the immediate problematic situation, as well as to the goals of this dissertation. This dual aim of improving/intervening in, as well as understanding/researching the situation, is viewed as one of the defining features of action research. The issue of whether these dual aims are compatible within a single research framework will be discussed in Chapter Seven. Evaluation procedures were then used to evaluate the effectiveness of the action taken.

Action research programmes postulate this kind of action plan as a continual process of problem solving which combines the knowledge and research techniques of social science, with efforts to promote desired change. Consequently, action research can be presented as appropriate vehicle for developing new initiatives in social policy (Lees 1975). It is assumed that an exploratory approach using social science methods of inquiry and evaluation as a built-in support for social action, constitutes a useful addition to the more traditional ways of undertaking socially useful research and tackling social problems. Action research can be seen to be developing a new relationship between social science and social policy - where there is a commitment to inquiry instead of the more traditional top-down approach adopted by those in politics, administration and research.

5.2 SETTING THE SCENE: BAMBAYI AND THE COMMUNITY MENTAL HEALTH PROJECT

5.2.1 The Community Mental Health Project

In 1987 a group of health and social service professionals and representatives from various communities in the greater Durban area, decided to establish a community mental health project. This decision was made largely in response to the extremely high levels of political and social violence in the greater Durban area, and the hypothesized impact that this situation might have on the mental health of the people living in these areas. This project also aimed "... at not merely filling gaps in the present mental health sector but rather at developing an alternative progressive approach to mental health care" (Loening 1990:1).

Children were identified by the above grouping as the main target group for intervention because the mental health status of African children was perceived as being under great stress in the face of the rapid social changes occurring in contemporary South Africa, and the socio-political and economic pressures bearing on families within this context.

The shack settlement of Bambayi was targeted as the area for intervention largely because the University of Natal, Medical School had established and ran a clinic in the area, the Mahatma Gandhi Clinic, thus providing at least the infrastructural basis from which to run a community based mental health service. Bambayi is also a fairly contained area geographically, thus facilitating community work and service provision. The decision to target the community by the University 'intellectuals' was not made in a vacuum. Extensive meetings were held with key people in the community and a survey was conducted by the CMHP in Bambayi which explored the need for mental health service provision.

The administrative locus of the CMHP was based in central Durban. The project operated out of the Gandhi Clinic whilst in Bambayi. The project was initially staffed by a senior social worker and two students from the University of Natal's Community Services Training Programme³. The students remained in the team after completing their studies. The need for specialized clinical skills was identified, and in 1989 a clinical psychologist was added to the team.

³ The Community Services Training Programme is an independent unit based on the Durban campus of the University of Natal.

The four main objectives of the CMHP were stated as:

1. Education of the community around mental health issues
2. Training of personnel, including people from the target community
3. Service provision in terms of assessment, programme planning, therapeutic intervention, referral, follow-up and evaluation of individuals, groups and the different communities within Bambayi
4. Research: epidemiological studies, intervention strategies, service utilization.

A preliminary survey was conducted in 1988 in Bambayi to gather baseline data from which to inform the structure and function of the Community Mental Health Project (CMHP). The results of this needs assessment survey showed the most common manifestations of stress and disorder amongst 5-15 year old children in the Bambayi area to be:

- | | |
|----------------------------|--------|
| 1. frequent headaches | -28% |
| 2. bed wetting and soiling | -22% |
| 3. unusual fears | -18% |
| 4. backward or slow" | -16.7% |
| 5. disturbed sleep | -14% |

The key informants from the community who were interviewed in the needs assessment survey, identified the following factors as contributing to disturbed mental health amongst children:

1. inadequate school and special education facilities
2. lack of recreational facilities
3. poverty, unemployment and poor housing
4. inadequate technical training facilities
5. police and vigilante harassment.

Developmental delay was selected by the CMHP as the primary issue for intervention as it was identified as a key community concern and seemed to be a problem of enormous proportions. Furthermore, it was chosen as a point of entry for the CMHP because MH was viewed as a "neutral"/non-threatening area. The objectives of this focus were to:

1. Identify children with apparent MH, epilepsy, speech and hearing defects and/or behaviour problems
2. Assess the degree of impediment, detect any associated physical problems and refer where necessary
3. Assess the family functioning
4. Establish supportive structures for the primary care-giver

5. Introduce individualized stimulation programmes.

The point of entry for this researcher into the CMHP and subsequently into the Bambayi community, was through research. The original (rather grandiose) idea for this dissertation was to investigate the development of a South African mental health policy which was based upon the broad principles of CP and PMHC, through an investigation of the needs of the people using the mental health services. Through a series of discussions with people involved in the CMHP, it was decided that a theoretical discussion of CP would aid the aims of the CMHP, and furthermore, that the initiation of an intervention programme would provide some of the information necessary for the development of the CMHP's services to the Bambayi community.

The dissertation's focus on MH and the needs and competencies of the care-givers of MH children, stems from the CMHP's needs assessment of the mental health problems in the community.

The function of this researcher's study was threefold:

1. To provide further baseline data to inform the structure and function of the CMHP
2. To design appropriate interventions for the primary care-givers of MH children in Bambayi as identified by the CMHP's need assessment of the mental health needs of the area, namely the initiation of educative and supportive structures for the care-givers
3. To fulfil the requirements of a Master's Degree.

5.2.2 Bambayi

The research for this dissertation took place in 1989. The history and socio-demographics date from that time. The community profile is drawn from interviews conducted by this researcher with key informants - community and social workers based in the area, nurses from the Mahatma Gandhi Clinic, members of the CMHP, university staff working with the project and the clinic. Further information stems from the CMHP's research which includes further key informant interviews, namely with a womens' group, teachers, traditional healers, parents, children and clinic nurses. Secondary data dealing with the socio-demographics of the area was also used.

The community profile includes the following:

1. History of the Bambayi community - past events that have influenced developments in the community

2. The environment - eg: the geography, general patterns of relationships, community spirit, recreational facilities
3. The residents - eg: population density, housing, employment, values and traditions
4. Community resources - eg: human and material resources, service organizations
5. Organizations - eg: civic, local government, community, political, youth, women
6. Problems existing in the community - eg: violence, drugs.

Bambayi is a peri-urban informal shack settlement situated between Ekuphakameni (Shembe Village) and Phoenix in the Inanda area, on the northern edge of Durban (see map, Appendix A). The area includes the 100 acres of the Phoenix Settlement Trust lands - on which Gandhi's original house as well as the Gandhi Memorial library and museum, the Gandhi Primary school and the Press building stood until they were destroyed in 1986. The rest of the land is owned by absentee African and Indian landlords. Population estimates range from 10 000 - 30 000 people, giving Bambayi one of the highest population densities in the area.

Up until 1985 most of the land was occupied by Indian farmers and African landowners, two groups which had co-existed without violent conflict for 50 years. The conflict between the Indians and Africans in the area in 1985 appeared to have stemmed from two main roots:

1. The race and class conflict between the two groups. In 1985 Chief Gatsha Buthelezi, leader of Inkatha, made a statement to the effect that African people have the right to settle anywhere in the area because no Indians own land in the Inanda area.
2. The conflict between the African National Congress (ANC) aligned United Democratic Front (UDF) and the ethnic Zulu nationalist organization Inkatha.

The violence in August 1985, which resulted in the destruction of the Phoenix settlement, was sparked off by the assassination of a prominent UDF lawyer, Victoria Mxenge, by unknown attackers. The reaction of the UDF supporters resulted in violent clashes between the UDF and Inkatha. Richard Steele, who was the curator of the settlement before it was destroyed, described the situation leading to the attack:

"...Inkatha-inspired Zulu nationalist elements took advantage of the unrest situation to single out Indian property for attack. At the end of it, forty-seven Indian shops had been burnt down and 500 Indian families forced to flee. The

police did very little to prevent these attacks. The government had already given these families and traders notice to leave Inanda because of the Group Areas Act, so it was in their interest not to intervene" (Steele 1985:17).

The above situation resulted in an influx of African shack dwellers into the area. The resident community of Bambayi is to this day characterized by groupings which tend to make up the most marginalized sections of the population:

1. People who, for various reasons, do not qualify for township housing elsewhere
2. Political/ethnic refugees
3. "Second families" made up of the family groups of the unofficial second wives and girlfriends of men who have "official" families in the homelands or in other areas of Durban.

Bambayi also serves as the catchment area for Pondo's and Bhaca's⁴ in Natal, communities which initially settled in the area because of the 1984 Pondo-Zulu conflict in the Umbogotwini area.

In 1989 Bambayi was divided into two sections, a split reflecting the political divisions between the local Inkatha leadership, and between the relatively old residents and the newcomers. "Old" Bambayi was populated largely by Pondo and Bhaca people (traditionally ANC sympathizers) and a few Zulu's, whilst "new" Bambayi was predominantly Zulu, and said to be an Inkatha base.

Services in the settlement were virtually non-existent. The road was not tarred. There was no piped water except to the clinic. Water was acquired from communal taps at 5c per litre. There was no refuse collection and no adequate sewerage system, pit latrines were used. There was no electricity, except for powering a few street lights and some of the businesses. There were no parks, gardens or recreational facilities, bar some stony soccer grounds. Virtually every inch of ground was rented out by landlords. Public transport, whilst servicing most of Inanda, did not operate within Bambayi. There were a number of spaza shops in Bambayi which were largely owned by business people not resident in Bambayi. There was no trading store. It was alleged that this area was the centre of the dagga trade in Durban.

Facilities available included the Mahatma Gandhi clinic which was established by the Department of Paediatrics, University of Natal. The service provided was both curative

⁴ The Pondo and Bhaca are two Xhosa speaking groups from the Transkei.

and preventative service, as well as having a maternity section. At the time of the research, the medical staff consisted of two qualified nursing sisters. Traditional healers provide a service to the community. Social workers based at Inanda Newtown only go into Bambayi if a case has been referred to them. The settlement had one school, Themalibhe Primary School (class 1 - Std 5), with 1087 pupils and 15 teachers, 3 of them qualified. It was estimated that only 59% of the children attended school. There was one community hall which was also used as a Sunday school, and one church.

The material conditions under which people lived was extremely poor. Most of the houses were poorly constructed shacks, there is not much privacy, dwelling densities (buildings and people) are very high - the average household size was 10.8 with an average of 4.1 rooms per dwelling. Shack rentals were approximately R20 per month. The levels of unemployment were high - about half of the economically active population was unemployed (estimates from Sutcliffe & Wellings 1985). It was estimated by the key informants that about half of the economically active residents were working, most as unskilled workers in and around Durban.

Mike Seneka, the Phoenix Trust community worker, described three broad tenure categories operating in Bambayi:

1. Trust land (mostly in New Bambayi) inhabited by shack dwellers who did not initially pay rent. "Faceless"/"mock" landlords have since allocated sites and draw rent
2. Rent payers living on privately owned farms in Old Bambayi
3. Tenants living in shacks and sub-letting from other shack dwellers.

There is confusion over the jurisdiction of the area - parts of Bambayi fall under the Kwa Zulu government, parts belong to private landowners, to the Durban City Council, to the Department of Development Aid and to the Phoenix Trust. The possible removal of the residents due to the proposed upgrading of Inanda adds to the confusion. These factors, as well as the different land tenures, can be seen to complicate and retard development in the area especially in terms of the development of democratically elected civic structures. It was reported that many of the residents do not in fact know whose land they are living on (Sutcliffe & Wellings 1985).

The civic organizational structure of Bambayi involved the following structures:

1. Two "elected" unofficial councillors who were Inkatha officials, and who were involved in an elaborate feud at the time. The councillor of the new Bambayi however, was willing to work with the trust with it's UDF and Natal Indian

Congress links

2. A Residents' Association whose main duty was to promote and serve the "social" interests of the community. The residents association had three standing committees:

2.1 The school committee

2.2 The security committee, which included a community court and defense unit

2.3 The Inkatha committee

A UDF aligned Inanda Civic Organization, formed in 1984, was trying to organize in Bambayi at the time of the research and it was reported that this group was concerned with securing political dominance in the area.

Other organizations operating in the area were: an embryonic womens' organization affiliated to the ANC aligned Natal Organization of Women; a new youth organization which was a breakaway from the ANC aligned Inanda Youth Organization; the Zenzele club, a women's self help group; the Phoenix Trust, whose main objective was the promotion of Gandhian principles and maintaining a presence on the hilltop, and the Bambayi Interim Steering Committee, a new group aimed at co-ordinating the new school project and made up of a number of diverse community representatives. This latter group was starting to get involved in dispute resolution in the community.

(Some of the) Political dynamics

The UDF-Inkatha war and the related Pondo-Zulu disputes in Natal impacted enormously on the character and development of the area.

Inkatha had made a concerted effort at ruling Bambayi, and the two (unelected) councillors were Inkatha members. Bambayi was politically strategic for various reasons:

1. The community was very vulnerable to Inkatha because it was the major Pondo and Bhaca enclave in Natal. The Pondo people have a long history of resistance to domination and have strong links to the ANC
2. It was said that the Bambayi hilltop was an important strategic location for Inkatha and the UDF because it was the best springboard for launching offenses into adjoining areas like Kwa Mashu.

It was indicated by the key informants that despite the Inkatha control of the unofficial "local government" type structures, Inkatha had poor "real" support in Bambayi. Examples given to substantiate this assertion, were Inkatha's inability to establish a Women's Brigade and a Youth Brigade in the area. The existing women's and youth

groups in the area were UDF affiliates. UDF structures at the time were embryonic and it was difficult to gauge levels of support.

In the midst of the UDF-Inkatha war in the area, tentative reconciliatory steps were made during the time of the research by the local leadership. The local UDF and the Inkatha leader of Old Bambayi, facilitated by representatives from different groupings in the area (the school, clinic, the Phoenix Trust), were trying to establish a democratically constituted, community based, interim steering committee with the goal of establishing a permanent democratically elected residents association. Bambayi and the areas surrounding the settlement however, remain one of the most violent in the country.

The conflict between the Pondo's and the Zulu's was seen as a particular problem in Bambayi. The conflict appeared to be threefold:

1. Conflict over scarce resources of which the Zulu's have greater access
2. Conflict between the traditionally ANC supporting Pondo's and the Inkatha leadership.
3. Long-standing ethnic conflicts

The question of ethnicity was a difficult one to research. It seemed however that ethnic differences were used to further political conflict, particularly as Inkatha was an ethnically constituted organization. The ethnic issues were also played out at a very grassroots level, a level which seemed to exist regardless of the dynamics of the current political situation. An example of where ethnicity became an issue was in the classroom, where teachers had difficulty translating into the different languages, creating tension between some of the parents and the school authorities.

Difficulties organizing in the area:

A major problem identified by the key informants was the difficulties they faced organizing in the area. Their concerns centred around three key issues: the stresses impacting on the families in the area; the culture of division and violence which appeared to be endemic in Bambayi, and the lack of leadership and organizational structures. These issues impacted on the research process as well as being fundamental to the suggestions arising from the research.

1. Families in crisis:

The urban African family unit has experienced enormous pressure and undergone changes in its form and structure in contemporary South Africa (Cock et al 1986). The effects of the socio-political and economic forces on the family unit which were briefly

outlined in Chapter Two, have resulted in a disorganization of the traditionally well ordered and tightly structured family structure of the African family.

Burman and Reynolds (1986) identify the beginning of the process of the breakdown in family structure in the urbanization process where the transition from rural communities to squatter camps often resulted in the expertise and wisdom of the adults becoming redundant to younger generations. Research indicates that the traditional roles defining appropriate behaviour between different generations and family members are eroding with no clearly defined norms with which to replace them. This process has been greatly exacerbated by unemployment, political conflict and violence as well as the effects of years of discriminatory social engineering. The consequences of this for individual mental health and social organization are severe.

The families of the women making up the sample were all organized as family groups rather than as the traditionally structured family units. Households were made up of family members who did not constitute a nuclear or extended family system. Sutcliffe and Wellings (1985) write that households in the area are often made up of a number of (usually adult) people brought together to be within easy commuting range of Durban. Social support between family members was not always forthcoming in the face of often severe economic, religious and socio-political tensions.

According to the key informants interviewed in the CMHP's needs assessment survey, the following psycho-social factors were seen as weakening the primary social bonds between family members and between friends and neighbours: the high levels of crime, marital conflict, family violence, sexual abuse, drug and alcohol abuse, child neglect and teenage pregnancies. It was generally perceived that single parent and "second" family structures were very stressful. The increasing levels of crime committed by children was viewed as a way of relieving stress, as well as a means of economic survival. The involvement of children in political activity, was said to have increased as socio-political and economic tensions increased. This was seen as occurring because children were often forced to join political groupings, as well as the fact that joining a political organization was seen as a means of addressing perceived difficulties.

Parents reported that they were finding it difficult to discipline their children, particularly as traditional authority structures were becoming increasingly undermined. Parents also reported that they were becoming extremely worried about the fact that they were often forced to leave their children unsupervised for long periods of time.

Teachers reported that physical ill health, drug abuse, behavioural problems and stealing were on the increase amongst the school pupils. Nurses at the Gandhi Clinic reported that violence related injuries, sexual abuse, sexually transmitted diseases and unwanted pregnancies were on the increase.

The CMHP members reported that residents of the area saw psychological problems and behavioural disorders as a necessary outcome of the high levels of stress experienced because of the material and socio-political situation.

Burman and Reynolds (1986) have identified four disorganizing factors which affect the cohesion of the family:

1. Divorce and desertion which place psychological and support burdens on the family
2. Illegitimacy may result in family tension which affects cohesion
3. Overcrowding and high density rates can result in frustration and tension because of the lack of privacy for couples and teenagers, the lack of space for children to play, and the difficulty of having visitors
4. Influx and Labour control Laws which resulted in millions of men and women having to live far away from their homes had a tremendous effect on relationships and family structure, as well as impacting negatively upon social and mental health.

Familial relationships and the family structure were crucial elements in the women's (as in the sample group) way of perceiving and relating to their MH child. Despite the tensions mentioned above, all of which effected each of the women, family ties in some of the families were remarkably strong, and most of them clung to the stressed and altered family system as their main source of support. Two of the women in the sample had strong family ties and reported a strong support system. Two of the women had cut what they reported as problematic family relationships and did not turn to relatives for support. It was reported that families with mentally ill and MH members are often looked upon with suspicion and in derision, with little social support offered by family members and the broader community.

Attempting to research and intervene with families under such strain, especially the single-women households, was experienced by this researcher and by the key informants as extremely difficult. Family members tended to have little time, money or energy to spend in activities other than household tasks, child minding and income generating activities. Some family members were involved in political and criminal activities,

substance abuse, or caught up in the debilitating apathy and fear which may accompany unemployment and destabilization.

2. Culture of Division and Violence:

Residents were divided along the following lines, even though most of them were bonded by poverty and race:

1. Political divisions: UDF -Inkatha
2. Ethnic divisions: Pondo - Zulu
3. Stratification: landlords - tenants; formal and informal entrepreneurs and the marginally employed and the unemployed
4. Criminal: warlords, drug barons and dealers, gangsters and com-tsotsi's - the non-criminally involved community.

Bambayi was not a homogenous community. Apart from the divisions outlined above, most of the residents were made up of refugees not living in the area by choice. Thus the desire to integrate with others and develop the area, especially in terms of organizing permanent structures, was slim. At the time of the research there were only about three or four built houses in the area, the rest of the dwellings were shacks. The war raging in the area, together with the uncertain land tenure and the possibility of removals due to planned upgrading of the area, bred great insecurity, minimal community spirit and a general lack of trust between residents, between residents and the authorities and the neighbouring communities.

Non-residents were viewed with particular suspicion. According to community workers in the area, locals tended to label "outsiders" in terms of the following categories:

1. Political labelling, namely UDF or Inkatha. Bambayi residents were frightened of the consequences of associating with somebody who was politically "identifiable" for the fear of being seen as partisan to a particular faction and thus vulnerable to attack;
2. People who offer concrete material aid and advice (eg: social and church workers), and those who do not. Locals are sceptical, they had seen enough attempts at research and intervention come and go without tangible results and ongoing support.

The real threats to people's lives arising from the socio-political dynamics outlined, mitigated against participation in communal and organizational activities. Residents feared political labelling, the political/ethnic tensions within community organizations and the dangers of travelling to and from meetings.

The political and criminal conflict and violence in the area constantly threatened any research and organizational activity. The social and political violence was particularly acute during the period of the field research - August to mid-December 1989 (see news reports, Appendix B). Heavy rainfall coupled with non-existent drainage and no ground cover, resulted in extensive flooding of the area surrounding the clinic. The flooding was particularly damaging to the flimsy shack structures.

The above factors impacted negatively on the research process, in terms of access to key informants and often to the clinic itself. Official statistics estimated that the "1989 Christmas Offensive" in Natal claimed the lives of 46 people in the Durban area in October and 62 people in November. The first two weeks of December saw 70 people dead and hundreds left homeless as people left their homes because of the war raging around them (Daily News 14-12-89). This was said to have been the highest death toll due to political violence in the city's history, with 31 deaths in Inanda alone (Daily News 14-12-89). Hundreds of shacks were torched in the period October - December 1989. This episode of violence was said to have been the worst since the 1984 conflict.

The clinic was closed on seven occasions during the field research because of the violence. The following "body count", as described by the women in the Care-givers group, will give an indication as to the proximity and extent of the violence. On Sunday 10 December, a woman was stabbed and set alight whilst she was still alive. Her shack was then torched. This incident occurred at 6pm and was witnessed by one of the care-givers as it was her next-door neighbour. On Wednesday morning 13 December, the day of our final group session, the burnt body of a man who had been tied up with wire was discovered a couple of metres from the clinic by one of the women in the group. On the same day a body of a man who had been stabbed to death was found in the school which is adjoining the clinic; the body of a child that had been killed was found across the road from the clinic; the "roasted" bodies of two young men were found in the vicinity of the clinic, and smoke was billowing in two places in the near distance as shacks were being torched during the day.

The clinic was inaccessible for 5 days because the flooding caused the bridge accessing the clinic to collapse. Several of the shacks surrounding the clinic collapsed and most were flooded out. The weekend of the flooding (Thursday 30 - Sunday 3-12-89) was also a weekend of violence in the area and in the region, with official reports estimating 11 people killed in Natal over the weekend (Natal Mercury 4-12-89).

The women, whilst conscientious in their commitment to the programme, were often exhausted and distracted by these events. Needless to say this researcher was also "distracted" by these events. Access to the area was hampered by the violence and then by the floods. On several occasions, access was granted only if I brought in some of the clinic's medical provisions in my car. The situation was further complicated by the theft of my car during this period which meant that access and arrangements were further compromised.

3. Lack of leadership and organizational structures:

Access is vital for any intervention. There existed no democratically elected, broad-based township structures. Leadership figures were difficult to publically identify, locate and integrate into any consultation process. The existence of multiple leaders further contributed to the confusion and insecurity of the area. Key informants stated that residents did not appear to be aware of who the community leaders were in the area, of how they were elected, and of what authority these figures had over the residents and community issues.

It was thus difficult to know with whom to communicate, and through what structures and individuals to gain legitimate entry into the community. This process was complicated by the fact that the two functioning and seemingly legitimate structures, the school and the clinic, were sorely stretched and under threat by the criminal and political violence and by limited finances.

Organizers in the area reported that the residents had little working knowledge of democratic practices (eg: tolerance, accountability) and organizational procedure (eg: meeting procedures, attendance). People tended to operate individualistically and were not used to group efforts and skills. The climate of endemic suspicion, conflict and violence, the break with traditional communal structures and practices, the lack of civic structures and resources, and the constant battle and competition for scarce resources, mitigated against communal participation.

The lack of "free" and communal space, meant that there were few focal points where the residents could gather voluntarily and in relative safety. The lack of street lighting and transport contributed to this state.

5.3 RESEARCH PROCEDURE

The case study approach using the dual strategy of a community profile and a needs assessment and intervention programme using a small sample of four women, was considered adequate for the fulfilment of the objectives of the study. That is, to explore in detail, and in context, the process by which women care for their MH children and how this impacts on service development and delivery.

The Sample

A sample of four women living in Bambayi and caring for young MH children were chosen to participate in the research process. The women were referred to the CMHP by the clinic staff, but none had yet participated in any of the CMHP's activities. The sample was not drawn from the general population but from users of the Gandhi clinic. There was thus an element of bias in the sample in that certain resources had been identified and used by the sample.

Six women were originally selected, but two dropped out before the intervention programme began. The remaining four women completed the Baseline Interview Schedule and were consistent participants in the group programme.

The women's biographical data matched the socio-demographic profile of the "typical" Bambayi resident as outlined in the community profile. The average age of the women was 37 and a half years and their average educational level was a Std. Three. Two of the women were Zulu, one was Bhaca and one was Pondo. Two of the women were living with their partners, one woman was single and one was a second wife with only sporadic contact with her estranged partner.

Two of the women were in informal employment: one worked as a half-day domestic worker and one woman worked in the family sheeben. The other two women were unemployed, working as washer-women when they had work. The average total income was R274 per month. Three women lived in their own households, and one lived with relatives. The household size was an average of six people residing in one and a half rooms.

Three of the women were the mothers of the MH children, and one woman was caring for her daughters MH child. The focus on women only in this research, does not reflect the position that women ought to play a dominant part in caring for children or any dependant members of a household. Rather it reflects the reality of the situation where women, mostly mothers, play the dominant role in caring, receiving support in varying

degrees by other household members.

Research Design

The following research design was used to elicit the necessary data and provide the framework from which to conduct the intervention programme:

1. COMMUNITY INVESTIGATION

- Community Profile

2. NEEDS AND COMPETENCIES ASSESSMENT

- Baseline interview schedule

3. INTERVENTION

- Group programme

4. EVALUATION

- Sample group evaluation
- CMHP team evaluation

5. DATA ANALYSIS

5.3.1 Community Investigation

The community profile outlined in Section 5.2 of this chapter was an attempt to contextualize the reason for conducting this research, as well as describing the material conditions impacting upon the research process and the women who participated in the Care-givers Group.

As previously mentioned, the community profile is a composite picture elicited from data generated by the CMHP's 1988 needs assessment survey of the area, from this researcher's interviews with some key informants on Bambayi, and from the collection of secondary data dealing with the socio-demographics of the area was also used. The key informants interviewed by this researcher were drawn from the community and social workers based in the area, nurses from the Mahatma Gandhi Clinic, members of the CMHP, university staff working with the project and the clinic. Further information stems from the CMHP's research which included further key informant interviews, namely with a womens' group, teachers, traditional healers, parents, children and clinic nurses.

5.3.2 Needs and Competencies Assessment

Once the need for services aimed at MH children was identified by the CMHP through their needs assessment, a more detailed (albeit very limited) needs and competencies assessment was undertaken by this researcher. The bulk of this assessment was done through the administration of an interview schedule to the sample group. However the community investigation and the group programme also played an important data gathering function.

The needs assessment was seen as necessary because often the needs identified by official statistics and professional perceptions do not necessarily reflect the way problems are perceived by those for whom the services are designed. This disjuncture is particularly acute in South Africa for the reasons outlined in Chapter Two.

Encouraging local people to define their needs for themselves is not the answer to the above problem. This approach may result in an inadequate measure of "real" need, in that it may be limited by the definers' perceptions of what is possible, or by their unwillingness to admit personal difficulties (Lees 1975). The identification of need is a complex process involving various approaches. It is hoped that the multi-method approach of this research will cover some of the dimensions of need identification.

The needs assessment was not viewed as a method on its own or as just another attempt at local level consultation. Rather it was viewed as part of an ongoing process of consultation and planning around the issues under investigation.

Baseline interview schedule (Appendix C)

An in-depth interview was used because scant descriptive baseline information was available on the topic under investigation. There was thus a need to formulate definitions and categories in this area.

The semi-structured interview schedule was administered individually to each of the four women before the group intervention. It includes socio-demographic data and explores the following themes:

1. Initial recognition of MR and explanations given, initial support sought and received
2. Everyday care: problems, needs, competency strategies, household support
3. Informal support outside of the household
4. Role of formal and "traditional" services
5. Participation in co-operative coping strategies

6. Recommendations for services/interventions.

The themes were aimed at providing a way of exploring with the care-givers the reality of their situation; including their past experiences, current problems and coping strategies, and the type of support sought from and received from other members of their household, from family and friends and the formal services. This included an examination of the generation of and participation in co-operative coping strategies, eg: self-help groups.

The support categories used in the interview schedule were categorized along what Barrera calls "a conceptual typology of social support functions" (1983:135). A typology which Barrera derived from an extensive analysis of descriptions of social support, and which serve as a basis for an empirical analysis of the structure of supportive behaviours (Barrera 1983).

The six categories are:

1. **Material Aid:** Providing material aid/tangible assistance in the form of money, shelter and other physical objects
2. **Physical Assistance:** sharing of tasks through physical labour
3. **Intimate Interaction:** interacting in a non-directive manner such that feelings and personal concerns are expressed. That is, traditional non-directive counselling behaviours such as listening; empathy; providing reassurance, respect and trust; unconditional availability; physical affection
4. **Guidance:** Offering advice and guidance; information or instruction
5. **Feedback:** Providing individuals with information about their behaviour, thoughts or feelings; discussion of ideas and plans
6. **Social Participation:** engaging in social interactions for fun, relaxation and diversion from demanding conditions.

The schedule was based on a review of the existing literature, and on two principal sources: Ayer and Alaszewski's (1984) survey of 120 mothers with severely mentally handicapped children in North Humberside, England; and Barrera's (1981; 1983) work measuring the structural and functional dimensions of the social support construct.

To facilitate more objective data collection, the baseline interview was conducted by a trained researcher independent of the CMHP team members. The latter were involved in the intervention programme and took on the women's cases on completion of the research.

The interview schedule was written in English, whilst the interviews were conducted in Zulu. Research indicates that a small sample and a rigorously briefed and trained interviewer yields more valid and reliable data than the meanings lost in repeated translations and interpretations of the same data (as per consultations with the Centre for Social and Development Studies UND).

Sessions were held with two CMHP workers and the interviewer translating the interview schedule into Zulu to establish consensual meanings of the Zulu terms whose usage was anticipated during the interviews. It was not anticipated that precise meaning and understanding of terms and issues would take place, either in the interviews and in the group intervention. It is believed, as Mischler writes, that "an adequate understanding of interviews depends on recognizing how interviewers reformulate questions and how respondents frame answers in terms of their reciprocal understandings as meanings emerge during the course of the interview" (1986:52). Thus it is only through the repeated mutual reformulations and specifications that an acceptable level of shared meaning can be achieved. It can thus be said that it is in this way that terms used take on a specific and contextually grounded meaning (Mischler 1986).

It was hoped that the element of repetition inherent in the research measures used, would act as a measure of internal validity in terms of the measures used and the data collected.

5.3.3 Intervention

The four session Bambayi Care-givers Group programme was held at the Gandhi clinic over a four week period in November and December 1989.

The aim of this intervention was threefold:

1. A research function - data gathering, a further measure of needs and competencies assessment, development of theory and method, service and project development
2. Education and skills training - to serve as a support and learning group for the care-givers and the CMHP team members
3. An empowerment and developmental function - to lay the basis for the development of an independent, on-going, self-help group.

The groups were run in an attempt to fulfil the aims outlined above, as well as to give something back to the participants and the broader community who aided the research through their co-operation. This latter component to the research process is integral to

the action research approach.

This particular group intervention strategy was used because a social situation existed which was seen to be responsive to a group approach due to the following factors:

1. The existence of a common problem
2. The potentially beneficial use of the emotional, social and networking supportive function that such a group could generate
3. The opportunity to improve the use of informal and formal sources of aid
4. The opportunity for didactic input, peer learning and comparative problem solving strategies within a supportive environment.

Peer group support programmes for parents are increasingly regarded as an effective way to enhance child rearing practices and roles, especially amongst parents experiencing stresses associated with their children. Powell (1987) writes that parent groups can provide an opportunity to share feelings and experiences, explore new perspectives and ideas, form important friendships, and develop a reference group regarding child care attitudes and practices.

The sessions took place in a large, mostly undisturbed room in the clinic. The two hour long sessions took place on Wednesday afternoons from 1.30 -3.30pm, for a period of four weeks. The decision to use the clinic premises for the intervention was taken on the basis of accessibility and the high rates of utilization of the clinic services by the surrounding communities. As well as the fact that the clinic was recognized by the key informants at least, as a legitimate community structure.

The group was made up of the four care-givers and two group facilitators. The two group facilitators were CMHP workers. The CMHP social worker was the group facilitator, and the 'outside' researcher who conducted the Baseline Interviews was the co-facilitator and documenter. This researcher did not participate in the groups because of her inability to speak Zulu, the language in which the groups were held. A preparation meeting was held by this researcher and the two facilitators before each session, and a feedback, evaluation and planning meeting after each session.

The group programme was semi-structured as well as group determined. This was done in an attempt to fulfil the aims of the group intervention which attempted to cater for the needs of three parties - the care-givers, the CMHP team and the researcher. The group programme included an discussion of the effects of the violence on the women's lives. The need to discuss this issue was identified during the Baseline Interviews and added to

the programme. The group programme was intended to incorporate six sessions. The war and floods in the area during the research meant that the programme had to be rescheduled and redesigned to constitute four sessions.

The programme content (see Appendix D for an outline of the Bambayi Care-givers Group Programme) followed the same themes as the Baseline Interview Schedule, incorporating a built-in evaluation function:

Session 1: Theme - Introduction

- Introduction
- Group goals
- Group expectations
- Contract
- Discovering the MH
- Initial contact with the CMHP
- Closure

Session 2: Theme - Problems and Coping Strategies

- Perceptions of causes of MH
- Main problems experienced
- Social support
- Coping strategies
- Closure

Session 3: Theme - Self-help Strategies and Skills

- Suggestions as to what women can do to help themselves
- Skills needed
- Views on participating in collective programmes
- Closure

Session 4: Theme - Evaluation and Termination

- Verbal discussion based on the care-givers group evaluation form (Appendix F)
- Discussion of the effects of war and violence
- Final closure

5.3.4 Evaluation

The main participants in the research process -the care-givers group and the CMHP team - were involved in the evaluation of the research programme. Their evaluation was a

partial one however, focusing upon the Bambayi Care-givers Group only.

CMHP Team Evaluation

The team evaluated the group programme after each session and filled in an evaluation form after completion of the programme (Appendix E).

Bambayi Care- Givers Group Evaluation

Session Four of the group programme included an opportunity for the four women to evaluate the group programme (Appendix F).

5.3.5 Data Analysis

The participant's accounts of their experiences was considered to be of prime importance for the purpose of data collection. This research approach, focusing upon first hand experiential recollections, has been championed as respectable and essential (Harre 1978). The value of qualitative explorations such as the remembered experiences of participants has been emphasized (Argyle 1978, cited in Lazarus 1985). Criticism has been levelled at the validity and reliability of such qualitative research, however as Armistead (1978, cited in Lazarus 1985) states, one can acknowledge the limitations without serious effects upon the method.

In an attempt to overcome the biases and problems inherent in this method, a multi-method measurement procedure was designed, with regular evaluation and feedback measures.

The results from each measure will not be presented and analyzed separately. An integrated, qualitative analysis of the results of the interview, group and evaluation methods was attempted. It was felt that the aims of the research, in terms of the exploration of the experiences of the care-givers and the generation of baseline data, lends itself to such an analysis. A critique of this approach is offered in Chapter Seven.

CHAPTER SIX

RESULTS

6.1 INITIAL DISCOVERY

6.1.1 Dimensions of handicap

Since the problems of caring for a MH child are likely to be related to the extent of the child's disability, and since the range of disabilities amongst MH children is extremely high (Ayer & Alaszewski 1986), it was felt that an objective assessment of the children's handicap, in terms of their specific disabilities and their IQ levels would not be appropriate. A general assessment of the nature of their disabilities was done by asking the care-givers to discuss their child's ability to perform specified everyday activities within the context of their own home (Q's 37-48, Appendix C). This process facilitated an understanding of the competency levels of the children in terms of their everyday care, and the problems and coping strategies of the care-givers group.

The following very general criteria were used to 'measure' the children's disabilities:

1. The ability of the child to attend to the most immediate physical needs of her body, including feeding, washing dressing and personal hygiene
2. The ability to move around effectively in her home environment
3. The ability to occupy her time appropriate to gender, age and culture, including play activities
4. Participation in social relationships with other household members.

This method draws on Ayer and Alaszewski's (1986) research which adopted the social systems perspective by using the mother's perceptions of their children's disabilities in order to better understand the meaning of handicap within the specific context of the home.

Two of the children, a two year old girl and a five year old boy appeared to be severely disabled. Their caregivers reported that they were unable to cope with basic tasks and required constant help and supervision. Both of these children seemed to be severely mentally and physically handicapped.

One of the children, a five year old girl, appeared to be deaf and did not speak. She had not been formally assessed in terms of these factors. Her ability to cope with most

everyday tasks, namely dressing herself, bathing and eating, was good. She was able to occupy herself in play activities but seemed a very anxious child, constantly clinging to her mother and suffering from disturbed sleep and "screaming dreams" of which her mother says: "...I suspect are from seeing something fearsome". She did not appear to be MH, but from her mother's report, seemed to be a deaf and an anxious little girl.

The remaining two children, two brothers aged five and eight years, only begun talking with relative fluency at age five. Their mother reported that they had difficulty comprehending and carrying out instructions. The examples she gave were of going shopping and of dealing with money. She said that the children were unassertive, very easily frightened, suffering from nightmares and sleep walking episodes:

"Their screams which are strange because they don't look safe. They scream, wake-up and walk away, especially at night. They are frightened and eat their teeth at night".

The brothers experienced some difficulty dressing and bathing themselves. Their mother reported that they were able to feed themselves and occupy themselves in play activity, requiring occasional supervision. The boys seemed to have difficulty coping with everyday chores and social interactions and appeared to be very anxious children. It was difficult to assess their levels of handicap, but from their mother's report it seemed as if they were experiencing some form of learning difficulty, with possible aphasia and that these difficulties were exacerbated by high levels of anxiety.

6.1.2 Initial awareness

The initial recognition and acceptance of their children's disability was a gradual process for the women. The grandmother of the group was aware of her granddaughter's handicap from the child's lack of response to stimulation from a very early age. The remaining mothers allowed their children different amounts of time to "fail" to reach significant developmental milestones before they started seeking or being receptive to explanations of their child's condition.

The recognition of disability seemed to involve two processes:

1. One of gradual awareness on the part of the care-giver as she understood that certain signs exhibited by her child meant the possibility of delayed development, such as the child not responding "clearly" to her surroundings; not coping and progressing at school; being constantly bullied by other children; late developmental milestones; physical disabilities, being unable to talk and not coping with simple tasks

2. Discussions with family, neighbours and officials (teacher and non-medical clinic staff) who interpreted the child's problems as possibly related to some form of disability.

All of the women sought medical advice before accepting that their children were developmentally delayed in some way.

6.1.3 Initial and current explanations of MH

On the whole, the care-givers initial beliefs as to the cause of their child's disability was that ancestral anger had befallen their family because the necessary rituals were not carried out when the child were born. The following explanations were given:

1. A child born out of wedlock caused ancestral anger because no lobola or damages were paid to the child's mother's family
2. The necessary rituals were not properly observed when the child was born
3. The child's father did not attend the customary rituals after his child was born.

The women were asked how they currently made sense of the situation: "From what you now know, what are your current explanations of the child's condition ? ". One of the women was clear about the fact that she had always attributed her child's condition to MH. Two of the women reported that they were only convinced that their children's disability had a physiological 'origin' after no change occurred with their children despite observing the rituals and consulting with isangoma's. The remaining woman was a sincere believer in ancestral causation. All the women reported that their family's believe in the ancestral causation of their children's disability.

None of the women had actually met with traditional healers to discuss the child's problems. Elder male family members or parents dealt with this issue.

6.1.4 Initial support sought and received

Informal support

The people that the women first approached to help them make sense of the situation can be divided into two categories:

1. family members, and
2. people who they felt would know more about the situation, eg: 'knowledgable' neighbours and friends, the child's teacher, clinic workers.

Support received from these sources was:

1. guidance and advice
2. family members also offered material aid in the form of money and food;

physical assistance with household chores; intimate interaction in the form of emotional support and concern, and social participation. As one of the women reported : "My sister is always with me to keep me company and to talk".

Formal support

The first formal support sought was from:

1. traditional healers, and then
2. the Ghandi clinic

The women approached these sources first on advice from family and people they had first spoken to about their child's problems.

The women found the help received from the clinic more practically useful than the consultations with the Isangoma's.

The help received from the clinic was guidance and advice about the child's disability and referrals for more specialized assessment and help. Consultations with the Isangoma's were however viewed as non-negotiables in the view of the past lapses in the observation of traditional practices described above.

All of the women followed the advice given by the clinic which was mainly in the form of referrals to King Edward Hospital and to the CMHP. The main problem encountered seeking help was financial constraints and transport difficulties and, in one instance, a father not giving permission for treatment. They overcame these problems by asking for support from family members and through sheer persistence:

"I stuck to all the advices from the different people, and went through successfully"

Follow-through from support sources

Team members from the CMHP were reported as being the only support sources to get back to the women after they had been approached by the women for help.

6.1.5 Discussion

Because the initial assessments of the children pointed to the fact that their respective disabilities indicated MH, all of the women believed that their children were MH regardless of the levels of disability and emotional disturbance involved. The very brief and gross disability assessment made by this researcher indicated that at least one of the children was physically disabled rather than MH - the deaf girl. This experience makes very obvious the dangers of hasty and ill-informed diagnoses which fundamentally alter the status of a human being in the eyes of those who know of their so-called MH. This

might alter the very course of that child's life, because the mother and other care-givers may not, for whatever reasons, seek further assistance and so gain further clarity on their child's condition.

The families in the sample were uncharacteristically small, with the women not having any other children after they became aware of their child's handicap. This trend may have surfaced in this (very limited) sample because of the biased nature of the sample in terms of it being a group of women who had already sought out and received support for their problem. This help seeking behaviour could be related to the fact that smaller families made it easier to seek and receive resources. This is an issue which needs to be further investigated.

6.2 CARE IN THE FAMILY

This section assess the impact of a MH child on family life and especially on the primary care-givers. The work associated with caring for a MH child, the allocation of caring within the family and the levels of support received by the primary care-giver will be examined.

6.2.1 Daily care in the home

Everyday care in the household was categorized into three main areas: child care, child minding and household tasks. The women reported that they received the least support from family members when it came to doing household tasks. Family members were more willing to aid in child care and child minding activities. The women's other children played an important child minding role. The other children did not want to be left alone with their disabled sibling because the child needed constant supervision and could not participate properly in play activity.

The most difficult part of the day was at night (6pm - midnight) when the women had to do household tasks, deal with their tiredness, their disabled child and the rest of the family. The early morning hours (midnight - 6am) were also experienced as extremely difficult to cope with in terms of caring for a troubled child and coping with one's exhaustion.

6.2.2 Caregiver's coping strategies

The responses the women gave when asked how they coped with the problems involved in everyday care centered around emotional and spiritual strength and support. The most important qualities for coping were patience; love; the willingness to sacrifice their time,

and the humbleness to receive and follow advice. One of the woman said:

"It was all patience and following all the advice from people, and love for my grandchild".

The guidance, intimate interaction and social participation offered by friends and family was experienced as spiritually uplifting:

"...and the encouragement from my boyfriend who accepts everything as is, that is the thing tha makes me cope".

Mutual support and reassurance from others in the same situation was seen as hugely helpful and reassuring:

"I do not know people around me with the same problem as myself. But when I go to King Edward and see other people with the same and worse problems than me, that helps".

Religion was cited as a source of comfort and assurance:

"When I am in church I forget about my problems".

All the women used the group discussions as a means of normalizing their situation and of gaining mutual support. The women were not sure of their ability to cope and used the group discussions to air their doubts and seek support: "Sometimes I just refuse to think about this problem, I don't know if this helps".

The difficulties experienced were also discussed:

"Sometimes I just can't cope with the problem and I hit the child. One day I lost my temper and hurt the child". The women found it difficult to express anger and frustration towards their disabled child.

The following comment released a floodgate of anger, bitterness and sadness:

"I am forced to to leave the infant with other children so that I can manage to look after him. I am forced to but this big boy on my back always to stop him screaming and acting strange. I am forced never to go anywhere by him".

The women were categorical about their duty as the primary caregivers:

"I cope because I am a mother of a child and have no alternative".

6.2.3 Support sought and received from household members

All of the women had spoken to other members of the household about their problems in

caring for a MH child and had sought support. The most common support sought from household members was material aid, physical assistance and guidance. The most common support received was physical assistance in terms of child care and household tasks and guidance in terms of advice on how to cope. Social participation - talking and laughing - was experienced as "lightening the load".

The women found other household members co-operative without always freely volunteering their services. The household members who offered the most support were those closest to the women: the male partners of the two women who were in supportive relationships; and the older women in the household - sisters, mothers and daughters. However, whilst available and offering support, the fathers and informal step-fathers of the children tended to offer reluctant support with child care and minding, and very rarely helped out with household tasks. The women were more likely to receive support from their own blood relatives than from their husband's relatives.

Despite the difficulties mentioned, household members offer the most available support to the women. Problems in seeking support were experienced mainly by the two women who did not live in an extended family household. Both these women felt very alienated and unsupported, expressing the notion that they:

"must be self sufficient or (I) will loose hope, because others will start ridiculing me if they hear me talking about my problems all the time".

6.2.4 Impact on the care giver

Impact on physical and mental health:

All of the women felt that they were carrying the load of caring for their child and one of their strongest concerns was their ability to cope, especially in the long term. The overwhelming emotions expressed were those of guilt and frustration with their perceived inability to care for their children as they would like because of their lack of skills, time and money.

The women cited that these feelings of frustration and inadequacy; the fear of harm coming to their vulnerable disabled children; the exhaustion associated with caring for a disabled child and the strain of requiring support from others to cope, had affected both their physical and mental health. The women reported that they find themselves "thinking too much about him". One of the women reported what appeared to be psychosomatic symptoms of stress:

"My brains are always badly and heavily occupied that I sometimes feel dizzy and have a heavy headache".

They were unhappy about leaving their children with child minders who were often inconsistent or incompetent - generally their own older children and other family members. The following two comments sum up their situation:

"I do not have all the means of helping her. I don't have enough time to stay with her because I am working"

"I feel very unhappy because I cannot successfully leave my child with anybody for more than a day"

The women felt that their homes were un-hygienic and that their neighbourhoods were dangerous places for a MH child.

All of the women reported feeling very stressed by their general circumstances. Caring for a MH child exacerbated that stress greatly because of the burden it placed on the mothers and on families struggling to exist in terms of basic subsistence.

The women felt that the main thing that they had learnt from caring for a disabled child was "love and patience". On the whole however, they felt that "some of their life had been wasted by caring for a MH child" and they had not benefited in any significant way from the experience thus far.

Impact on "own time"

Caring for a MH child fundamentally affected the women's "own time". The women were restricted in any case because of the violence and by financial and time constraints, but their extra responsibility meant that, as one woman put it:

"I cannot go anywhere I like. The only solution is taking her with me which is very difficult because she is now big."

Impact on employment

The women reported that having a MH child restricted their ability to find and keep work. The major reasons being time and child minding:

"You have to spend more time on her than on other children"

"...nobody to look and understand my child except myself".

One woman stated that her job options were restricted because:

"Although I'm working, but I can't move from this job because of fears that other employers might not accept my problems like the present one".

Relationship with child's father

The women stated that they felt very angry with the children's fathers for leaving them to carry the load. However when asked whether caring for the child had affected their relationship with the father of the child in any way, two out of the three women for whom the question was appropriate (the forth being the grandmother), stated that their relationship remained "unaffected".

This apparent contradiction could be because their relationships were estranged and so the father's did not play much of a role in the child's life in any case. Another reason could be that despite their bitterness at the father's lack of concern, they might not have expected these men to play a role in caring for these children. The question about "carrying the load" seemed to have elicited a more direct expression of their emotions than the subsequent question about the relationship being "affected".

The third woman, the "second wife", reported that the child's father reacted very badly to the child's disability, blaming her for it's condition and eventually leaving her when the child was two years old. She legally sought maintenance, and he pays R100 per month. She is a washerwoman and he lives in a hostel in the neighbouring KwaMashu township.

Relationships with other children, friends, neighbours, work colleagues

The women gave the same response of "unaffected" and unchanged relationships in relation to the impact of caring for a MH child on their relationships with their other children, other household members, friends, neighbours and work colleagues.

Their positively loaded answers in the interview schedule contradicted their group responses in Session Two of the group programme. During the group the women discussed both the negative and the positive impact of caring for a MH child on their relationships with others. A reason for this contradictory response could have been that all of the women interpreted the question asked in the interview schedule in the negative and did not feel open enough to discuss this issue. The phrasing of the question in the Baseline interview Schedule may have misrepresented or simplified a complex issue (see Q's 64-69, Appendix C).

On the whole, the women reported that the lack of support received from neighbours and friends, both volunteered and when requested, and the generally prejudiced attitude of others, had made them wary of discussing their situation or exposing their children to other people. One of the women said that:

"Others do not understand this, they are fearful or they mock and are hasty with these children. This makes it very difficult to ask others to mind the children"

The harsh material deprivation coupled with the stigmatization of the MH, appeared to make some of the women very sensitive to their situation, to the extent that they projected their feelings onto others. For example, one of the women who reported generally conflictual relationships with her family and neighbours, stated that her neighbours:

"...find me being the most sufferer and the poorer woman with children who are mentally retarded. So they find themselves better and me poor".

Whilst this statement may be a bitter projection, the harsh competition for scarce resources which occurs between the very poor and the very marginalized within the politically divided community, means that people often compete rather than co-operate with each other.

6.2.5 Impact on the household

Adjustment of other household members

All the women stated in the interview schedule that other members of the household had adjusted positively in an effort to cope with living with a MH child. The adjustments made revolved around:

1. Acceptance:

"It was just to accept my child and to swallow all the problems as theirs since this is a family"

2. The allocation of extra time for child minding and chores:

"They have given themselves time to be home in order to help me".

One of the women poignantly describes how her 10 and 8 year old sons "...wake up early every morning to help me in the house before they go to school".

The group discussions reflected a more complex situation where other household members were often resentful and reluctant to offer support in the form of material aid and physical assistance because it was boring, tiring, limited their activities and stretched their resources to the limit.

Impact on household plans and activities

Three of the women stated that general household activities were not affected. One of the women stated her that her MH boys affected where her family lived, largely because of the financial burden on the family and the need to be close to medical care. It was generally perceived that the MH children had restricted the social life and mobility of the

other household members.

Impact on the development of other children in the household

All the women stated in the interview schedule that the other children were not restricted or enhanced in any way. This issue was not directly explored in the group, but this response contradicts previous sentiments expressed about the added load in terms of child care that older children had to bear, the restriction of the mother's time spent with her other children, as well as the extra financial load on the family. There was never any mention made of the other children benefitting positively in any way.

Impact on finances

The women stated unequivocally that their disabled child/ren placed an enormous extra financial burden on the household. All the categories provided in the interview schedule (Q's 81-83, Appendix C) were seen to have required extra cost, that is: medical fees, transport costs, loss of earnings, extra clothes and laundry, food, child minders and special education.

All of the women felt that they should receive financial assistance, and that it was the state's responsibility to provide such support. One of the women felt that the responsibility should be shared amongst the state, community groups and the private sector.

6.2.6 Experiences of Violence

At the time of the research, violence was part of everyday life in Bambayi. The violence was not only in the form of the more obvious acts of political violence described in Chapter Four, it had permeated into all dimensions of social life. More "ordinary" criminal violence was also on the increase. The key informants noted that the incidences of drug related violence, sexual and domestic violence, were rapidly increasing.

The women reported that both they and their families were affected by their experiences of violence. They felt especially vulnerable because of their particular lack of physical and financial mobility. The ability to run away and to move out of one's home at a moments notice was often the only form of 'defense' people had against attack.

"We do not have peaceful nights at this area. We sometimes wake up in the middle of the night to hunt for our safety because of the wars taking place around".

One of the women stated that she felt especially stressed by the violence because:

"I live in a sensitive state. My life demands peace of mind and good relaxation because of the health of my child"

The women reported that the children's levels of anxiety and coping were "made worse by all this feelings of fear around them". The women stated that this latter factor was one of the main reasons for them wanting to leave the area. None of the women however, had any concrete plans to leave.

6.2.7 Visions of the future

The future care of their children was one of the uppermost concerns of the women. They did not have concrete plans for their children's future other than the hope that relatives would be able to take in the child. This hope appeared to be a tenuous one however, with the women having little faith in the ability and/or willingness of their relatives. The women were pessimistic about their child's future, when asked what would happen if they were ever unable to care for their child, they all answered that their child would suffer.

The women did not envisage an independant future for their child, regardless of the child's levels of disability. The women's hopes for their children were that they would somehow receive education and training. They felt that the way to acheive this would be through institutionalization or attendance at a special school, and by working 'hand-in-hand' with the appropriate organizations.

The women's lack of faith in the ability of society to care of their child seems to be a very realistic one, based on one hand the lack of community care and other services; as well as on their feelings of powerlessness in terms of meetingr for their needs and effecting change. They mentioned that they felt very threatened discussing this issue and that they tended to avoid even thinking about the future. They said however that it was a great relief to discuss worries and plans about the future within the supportive atmosphere of a group of people dealing with the same issues:

"I was going mad with no idea what to do, where to start. Thinking about what he is going to do as a man is too much. I had stopped thinking. The group has calmed me and armed me with positive thoughts for the future"

6.2.8 Discussion

The women's main concerns were with making enough money to support their dependants; with protecting their families against the violence; with protecting their children against careless child minders, unsympathetic, prejudiced people and making provision for their child's future. Their daily problems with coping, earning a living and

dealing with their exhaustion and anxieties almost seemed to be taken for granted as part of their lot in life. There was a lot of evidence of stress and they described a life of hard work, social restrictions and sacrifice.

Cock et al (1986), write that given the disorganization of African family life in contemporary South Africa, mothers are often forced to go back into wage labour soon after the birth of their child. The inadequacy of creches and other formal child care arrangements means that this is done at enormous physical and emotional cost. It involves a cost to the mothers who are subjected to considerable strain and anxiety. As well as to the children who are often left with ill-equipped and/or expensive child minders.

The data suggested that it was the women themselves who made the major adjustments, as well as taking on the responsibility for attempting to protect the rest of the household by taking on the main burden upon themselves. Abandonment of their disabled child never came up as an option, although three of the women made serious queries about the possibility of institutionalizing their children.

The extra work created by caring for a disabled child appeared to be absorbed into the women's existing workload with only limited support from their partners. Male partners sometimes helped with child care, offered guidance and provided social interaction, offering very little support in household tasks and the more physical aspects of care - the latter which seemed to be viewed as "women's work". It seems as if fathers had the power to legitimately avoid those tasks they found less interesting and rewarding. The women, despite their resentment, seemed to generally accept this low level of participation as natural and normal.

This asymmetrical allocation of tasks reflects the traditional concepts of the division of labour in the family, and persisted regardless of the extra work created by their child's disability and the employment status of either partner. It appeared to be taken for granted that the women would provide for such care, and the women themselves were prepared to accept this situation and did not rely on support/relief from within or outside the family. A similar assumption appears to underpin the policy of CC for the chronically ill, which appears to be based on assumptions about the ability of families to meet the demands placed upon them, which in practice usually means the willingness of the mother to carry the burden of the care.

Ayers and Alaszewski (1984) write that such a concept of community care tends to

stress the interests and the needs of the child but fails to give equal cognisance to the interests and needs of the family and especially the mother. They argue that the reliance on the family as a cheap and continuous treatment resource is exploitative and short-sighted. The South African CC scenario with its lack of the most basic assessment, psycho-social, institutional and educational CC for the MH does not serve the interests of the child, never mind its immediate support structures.

6.3 CARE BY THE COMMUNITY

This section examines the availability and use of informal support outside of the household. This informal support network is seen to include friends, neighbours, work colleagues and employers. Perceived attitudes of the Bambayi community are also explored.

6.3.1 Support sought and received by informal support network

The last time the women sought support from their informal support network was within the last month of the actual research. The most common form of support sought and received from friends and neighbours was social participation followed by guidance and feedback. Material aid and physical assistance were not sought because the women did not expect their friends and neighbours to offer such support. It was reported that friends and neighbours, the latter in particular, were poor and could offer little material aid and physical assistance. Neighbours who were not friends, were perceived as generally unhelpful and often expected to be paid for any assistance.

The employers of the two women in paid employment were described as very accommodating, offered material aid in the form of food, clothing and extra money. One of them allowed her to bring in her child when child care arrangements broke down.

The women stated that they would turn to their household members and families at short notice for support in any crisis. The women rated their households and family members as the most useful support resources, and friends as the least helpful. The latter assessment is somewhat contradictory considering the value the women placed on the emotionally supportive role of their friends. Their negative rating could possibly be related to high levels of disappointment at the disjuncture between expected and actual support received from friends.

The issue of whether friendships changed or were lost due to the birth of a MH child was not explored. None of the women had become friends with another care-giver of a MH

child.

6.3.2 Perceived attitudes of the Bambayi community towards MH children

When asked in the interview schedule: "What is your perception of the Bambayi community's attitude towards MH children ? ", three of the women stated that the community has a positive attitude and generally accepted these children.

The women seemed to interpret "community" as "community organization", because when elaborating on just how positive the community's attitude was, the work of the Interim Steering Committee (re setting up day care facilities for MH children) was perceived as representing the Bambayi community's attitude. Whilst this is the mandate of the committee and a very positive interpretation on the part of the women, it may not reflect the more negative attitudes expressed elsewhere in the interview schedule and in the group discussions.

The group discussion reflected a more negative attitude on the part of the general community towards MH. The following statement by one of the women reflects the sentiments of the group discussion:

" (the community) do not really accept such children because I have seen them in fear of these children, and I have seen them mock these children".

6.3.3 Discussion

The research indicated that the women who lived in households which included members other than the women's immediate family, had the access, the support, the time, the energy and the resources to develop a more varied and less conflictual support network. Both groups of women however, were very restricted in the variety of support systems they could draw upon. This was not only a function of the restricting effect of caring for a MH child, but also a function of their poverty, the material deprivation and the war in their area.

Thus although informal support exists, it tends to be fairly minimal and does not aid the women in the areas which they have identified as needing the most assistance, that is, in practical and financial support. Thus the concept of care by the community which rests on the assumption that the primary care-giver and the family group can draw on a variety of supportive social supports, can be seen to be invalid, at least in the deprived, marginalized Bambayi community.

6.4 CARE IN THE COMMUNITY

This section looks at how and in what ways organizations, professionals and formal agencies supplement the caring capacity of the care-givers, and the extent to which the women found these services accessible and useful. This assessment is done through an exploration of the women's perceptions, based upon their experiences of service utilization.

Organizational membership was also explored in an attempt to assess the women's participation in, and opinions of co-operative coping strategies.

6.4.1 Support sought and received

On average, the women approached seven organizations and formal services for support. The most common formal support sources approached were the Gandhi clinic and the CMHP staff, namely the CMHP social worker and the clinic and community nurses. Followed by church members, Isangoma's and community organizations.

The type of support received from the health and welfare agencies was predominantly in the form of guidance as well as in the potential receipt of material aid in the form of welfare grants and applications to special schools for their children. The help received from the welfare agencies was guidance and material aid in the form of money, food and clothing.

Satisfaction with the support resources was fairly high, especially with the direct and very relevant support received from the CMHP and the motivation and positive feedback received from the different community groups. The least helpful support source was cited as the Isangoma. The women did not receive much aid from the other support sources mentioned, but they seemed particularly disappointed in the work of the traditional healers because it seems as if their personal expectations of change were dashed, and the traditional healers promised a change which did not occur.

It seemed as if the women had recently embarked on the "formalized" help seeking trail, thus their knowledge about where to seek support tended to correlate with their first contact who directed them to their first support source outside of the household and informal support networks (see Section 6.1.4).

Problems with seeking support centred around time, transport and money. The women reported that by painstakingly following the advice given, they were able to follow

through with most of the guidance received. One of the women mentioned that one of the difficulties in following through was the fact that there was no internal consistency within the formal support agencies with regards to records and personnel. She found it difficult dealing with different people every time she went to deal with her welfare grant application.

6.4.2 Care-givers perceptions of what the formal support resources could best offer

Two of the women misunderstood this question, thinking that they were asked to comment on how these resources had already helped them. The response of other two women are listed below:

1. The women conflated the support which nurses and doctors could offer, that is to "improve health" and provide medical treatment. Thus illustrating an indirect but significant perception that nurses are primarily involved in medical treatment and are not viewed as more generalist health workers.
2. Hospitals and clinics: guidance and to provide health care.
3. Social and community workers: motivation and advice, and to help "build institutions" for MH children. All of the women would like to have "my own" community or social worker, a keyworker who would look after their case.
4. The government: financial support; build schools, institutions and homes, as well as "to show concern". The latter point was emphasized. This comment indicates that if the state would show concern and be more accountable to the plight of the poor and especially the African poor, the women would be more motivated and have more hope for the future. This assumption is made by comparing the women's perceptions of the attitude of the state to that of the community organizations - the latter who did not provide much in material aid, but offered hope and encouragement which was greatly valued by the women.
5. Community groups: guidance and motivation.
6. Schools: education and guidance.

6.4.3 Attitude of the formal support personnel

All the women reported positive and helpful attitudes from the teachers, doctors, nurses, social and community workers and community groups that they had been in contact with in regards to how they could best care for their disabled child. None were able to comment on the attitudes of the traditional healers because these people had been approached by other family members, generally the men in the family. The attitude of the government was mentioned above.

6.4.4 Organizational membership

Three of the women stated that they belonged to an organization. One woman was a member of the South African Domestic Workers Union, one was a Member of the "Comrades" and one was an Inkatha member.

The trade union membership was fairly straightforward - she got involved because she wanted assistance and the advantages of her involvement were that the trade union promised to protect her represent her interests as a worker. She didn't know what she wanted to change or develop in the organization in order for the trade union to better meet her interests. Her difficulties in involvement were in struggling to find the time to attend meetings.

The other two women described their involvement as coming about because: "I am living in the Comrades area" ; and "We are forced to be (Inkatha) members since we stay in this area". They reported that they received no advantages from their forced "involvement" and felt powerless about changing the organization.

6.4.5 Organizing for the MH

The women stated that they had not thought of getting together with others caring for MH children and of finding ways of co-operatively helping each other.

The women believed however that there could be advantages in starting and belonging to such a group in that:

"I would understand and know more about such children"

"...because we will share problems and ideas of how to handle and cope with handicapped children".

The women put forward three main obstacles to initiating such a venture:

1. They did not feel knowledgeable and powerful enough to start such a group:

"I had no experience of it"

" (I) do not know how to tackle the subject with others because I still cannot help myself over it"

"We have no way. There are our superiors to deal with such problems to solve".

2. Financial difficulties in that they would have to "...undergo a study of it which

would need a lot of money before going ahead"

3. Political opposition:

"No ways with Inkatha around. They don't want others to organize outside of their things".

It was mentioned during the group discussions that in their opinion, people tended to view group initiatives that offered them no material advantages as a waste of time, time which they could be using to earn money for themselves and their family.

6.4.6 Discussion

The mothers had come into contact with a limited number and variety of formal support resources. This is not surprising considering their material constraints, lack of access to information and the fact that services for MH African children are in general very scarce.

Another factor inhibiting their search for appropriate support was the fact that the health workers they had come into contact with at the clinic and the hospital, appeared to have little or no training in child development, MH and disabilities such as deafness and learning difficulties, and little notion of the implications of such disabilities. The fact that the group included two women with five and eight year old children with serious disabilities who had not yet received specialist help despite repeated attendance at health points, is an indictment of the health and welfare services.

It was hardly surprising that the CMHP social and community workers were perceived as the most helpful. Their knowledge and support was relevant; the team were not overloaded as other health and welfare workers tend to be and followed up their cases; they included an educational and emotionally supportive component to their service, and their service to the care-givers was focused, geared to local conditions and issues, accessible and free of charge.

Experience and research (see the Who Collaborative Study on Strategies for Extending Mental Health Care 1984) indicates that the social and community mental health worker with training in issues related to MH and other disabilities appears to be the most appropriate key service provider. They seem to be the person best placed to assess the needs of the household and to maintain a continuing relationship with the child's family unit; to mobilize the necessary resources, and to ensure that the efforts of the different resource agencies are properly co-ordinated.

However the reality of the situation is that few social workers have the necessary expertise and knowledge in MH and in networking to carry out the above functions. As well as the fact that social workers dealing with African clients tend to have enormous case loads and cannot carry out home visits which have been identified as a crucial support for the care of the chronic client. Social workers are not supported by state services which is oriented towards a supportive, CC health and welfare policy which includes realistic and accessible financial support. These problems are compounded by the rapid turnover of people in these stressed and poorly compensated positions.

A general but extremely pervasive and debilitating handicap that the care-givers of the MH face, is the prejudice against the MH and the low status given to this type of work by the "helping" professions.

Voluntary associations have been described as playing an important role in the care and support of the MH and the disabled. Such associations did not exist in Bambayi and although they operate in township communities, the women did not appear to be aware of their existence, nor were they pointed in the direction of such resources in their search for help. Ayer and Alaszewski's (1984) study indicated that women found that these associations played an important part in reinforcing their ability to care for their children by providing psychological and social support and information about resources. These associations did not act as self-help groups for the English mothers, but rather as facilitating contact between the families and other service providers. As in Bambayi, the professional helpers tended to inform the women only about their own services and not about any other support sources.

Another glaring gap was the complete lack of day care or creche facilities for MH children. Not that there existed any such services for other children. However the need for protection and more specialized care is more acute for chronically disabled children. This need was in the process of being addressed by the CMHP and by the Interim Steering Committee. It was identified as an important and relatively easily obtainable goal in terms of community need (very necessary and politically strategic), venue (part of the destroyed school) and funding (attractive issue to fund raise around).

Short term care has been identified in England as a key part of CC. By this it is meant that agencies with residential facilities - like MH hospitals, children's wards at general hospitals, assessment centres - can help care-givers by taking the child into care for short periods. This relieves the women from the continual burden of caring, and can be used as an opportunity for observation, assessment and review of the child's progress, so

that specific stimulation and training programmes could be designed (Ayer & Alaszewski 1984). Such care has been found to enable families to keep their child in the home and out of long term institutional care.

This aspect of care in the community which would have been invaluable to the women because of their great need for their children to be properly assessed, for information and for child care, is totally lacking in the greater Durban area and is generally not available in South Africa.

Thus the notion of care in the community applies in a very limited way in Bambayi because of the existence of the locally based, non-governmental clinic and the CMHP. This CMH pilot project was the only one of its kind operating in the greater Durban area. Other than that, state and non-governmental services for the MH and the otherwise disabled operate minimally, if at all. The women in the study took the main responsibility for caring for the MH child in their care, and their main support system was the members of their household, followed in a very limited way by other family members, friends and the locally based clinic and CMHP.

6.5 RECOMMENDATIONS FROM THE GROUP

The theme of the third session of the group programme was "Self-help skills". Suggestions from the care-givers as to what they could do to help themselves, where:

1. To get involved in self-help groups organized around teaching and income generating activity
2. To organize themselves properly as care givers and not only as 'mothers'. That is, to learn the specific skills needed for the care, education and training of MH/disabled children
3. To get involved with the other members of the community who were attempting to establish a creche for MH children
4. To start an "under 10's" group for MH children based on the same lines as the stimulation group for older children that was run at the time by a member of the CMHP team.

The women felt that the skills they needed to achieve their aims were:

1. A background knowledge of MH, eg: genetic, medical, psycho-social especially child development, educational
2. Practical skills needed to care for the children's physical and psychological needs, eg: how to exercise and stimulate the children

3. Income generating skills for care-givers, eg: pattern cutting, alterations, sewing. Sewing skills were seen as preferable to knitting because the former has more variety and requires less of a capital outlay.

The women's strongest recommendation was that groups organized around mental health issues and targeted towards care-givers who had "bad work and little food for their children", needed to include a self-help/skills training/income generating component to their programme. The consensus amongst the group was that "the people of Bambayi" would not be motivated to attend because "people look at this as time wasting because they miss out on earning money to go to a group discussion".

The group valued the focus on generating and strengthening social support ties between care givers of the MH and saw this as an excellent way "solve our problems together". They felt that the educational aspect of the programme "filled in empty spaces in my head". They were adamant however that future groups needed to be **concrete and problem centred in their approach and include income generating skills in the programme.**

6.6 EVALUATION OF THE GROUP INTERVENTION PROGRAMME

Lees (1975) states that the function of action research in the social services should be to increase the practitioner's ability to provide an effective service. However, whilst the immediate concern of the action research process in this context is problem-solving, this should not undermine the principles and procedures of rigorous research. The skills of the social scientist must be retained in the identification of problems, the formulation of action strategies and the evaluation of their effectiveness. Evaluation in this context means the making judgements about problem situations, and the effectiveness of the action strategy adopted. Followed by a re-assessment of the situation with the view to implementing additional and modified action strategies if considered appropriate.

Cox et al (1984) write that at best, the impact and effectiveness of community practice programmes are hard to demonstrate. The basic criteria used to evaluate this study are based on the following, as outlined by Solomon (1984):

1. What difference did the programme make ?
2. Who was affected by the change ?
3. Why did it happen this way ?
4. How consistent and widespread is the change ?
5. Were there some unforeseen side-effects ?

The evaluation of the impact and effectiveness of the group intervention programme was done through a structured discussion with the group of care givers, and by a separate discussion with the members of the CMHP team. The format of these two discussions was adapted from an evaluation questionnaire given to a mother's group (see Douglas 1986).

The discussion included an examination of expectations; of the levels of trust and loyalty to the group; the clarity and achievement of goals; satisfaction with knowledge gained and support received, criticisms and recommendations. The CMHP team members were asked to evaluate the role they played in the group programme and whether they felt the group was useful for the CMHP.

6.6.1 Feedback from the Care-Givers Group

The women reported that they felt "very happy" about having been part of the group programme. Their expectations of the group centred around the education and skills training goal of the group. That is, to share "ideas on overcoming the problem", and to "get help on what we needed concerning our problems". The women felt that their expectations were met because:

"the variety of thinking and opinions made it different from what I thought it was going to be. I learnt more from the group than the little I had in my mind".

The empowerment and developmental function of the group in terms of social support and the development of an on-going, self-help group were not mentioned in the evaluation. Although as mentioned in Section 6.5, the women stated that they valued the focus on generating and strengthening social ties, they felt more positive and better motivated to tackle their problems.

The women found that the most helpful aspect of the group programme was the diversity of opinions which emerged during the group discussions. All of the women were keen to participate in future groups dealing with similar issues because they hoped to "better the life of such children by becoming more knowledgeable about the problem".

All of the women found it a problem to come to the group sessions because of the lack of time and the transport expenses incurred. Below are suggestions they made about the group process and structure:

1. Meeting time: it was suggested that the groups be held latter in the afternoon, from 3.30 - 5pm, in order to facilitate taking time off from work.
2. Length of sessions: all of the women felt that the sessions were too long - one

hour would have been adequate.

3. Meeting place: whilst the women stated that their own homes would be the ideal place to meet as a group, they felt that the clinic was the most convenient place to meet, in terms of location as well as the presence of other services in the building. They emphasized however that alternative venues should be found in the event that the violence in the area escalated to such an extent that the clinic was inaccessible - as was the case during the research process.

4. Transport: the women stated that they would have liked to have had transport provided to and from the groups.

5. Meals and refreshments: all of the women felt that food should be provided, especially to the children accompanying them.

6. Child-minding during the session: this was viewed as a necessity, something which would encourage attendance and commitment to the programme.

7. The group structure with a leader and co-leader/recorder: all of the respondents stated that they were happy with the arrangement. They felt that it was important for there to be a "well informed leader and a person who can write down our ideas".

8. Other practical suggestions: this question was not explicitly phrased in terms of group structure and process, and was interpreted as asking for any other practical suggestions as to the care of their children. The women's answers reflect their pressing concerns for the need for day-care, for their children to receive education and training and for the children's future to be secured by state-sponsored schemes.

The women were given a choice as to whom they thought should take part in similar groups - mothers, care-givers, fathers, the children themselves, family members, teachers and others. All of the women quite categorically chose the first two options - mothers and care-givers. This response was not explored any further. It can be hypothesized however, that since it is the care-givers who actually care for the MH children, the women felt that it is to this group that the resources must be allocated.

Following from the very strongly voiced recommendations written in Section 6.5, the care-givers felt that the following activities and discussions should be prioritized in any future groups. In rank order:

1. Income-generating skills
2. Education programmes on what is MH, how to live with and train a MH child
3. The establishment of day-care facilities: A group for MH children where they can be looked after, educated and trained during the day

4. A self-help group to discuss problems as care-givers of MH children and to solve these problems together
5. When asked for "any other ideas", there was another misinterpretation of the question and the women responded by stating what else is required to care for a MH child - LOVE: "The only thing is to love your child and to give it plenty of time to grow and love itself".

Despite the top ranking of the need for income-generating skills, the women felt that any future group programmes should start off with education (of MH), followed by income-generating skills, self-help and day care.

6.6.2 Feedback from the CMHP team members

The team members (the social worker and the two community work students) correctly identified the group goals in terms of those set down in the proposal, but felt that the goals were not altogether clear. This perception appears to be borne out by the fact that the care-givers expectations centred around the educative and not the social support function of the group.

The CMHP team members felt that the information-gathering aspect of the group was met in that "useful information was gathered". "Useful contributions were made" in terms of the planning-for-the-future function of the groups. The team members felt that the goal which was the least achieved was the support function of the group in that "minimal to average attempts at support were made between group members".

It seems that despite the stated aims, the group operated primarily at a didactic, information-gathering level. This seems the most realistic scenario, a four session programme is hardly likely to engender social support networks. The CMHP team members felt however that the women were "friendly" and that there was "considerable trust and openness in the group", although the group members did not get very "close". Subsequent feedback from the CMHP indicates that three of the women have kept contact with the CMHP and one in particular, is very active in the stimulation groups which are run for MH children.

The team members were "somewhat happy" about the role they played in the group programme. They were pleased with the fact that the group allowed them to practise their programme planning, research and group work skills; that the group was a continuation of the work previously done by the CMHP, and that the group allowed them to better understand one of their crucial target groups. The team members were

disappointed that the group programme did not go as planned because of the floods and the violence. It was mentioned that these factors undermined attendance and participation in that current events often dominated the discussion, "deviating from the planned programme".

The team members felt that the group programme was "useful" for the CMHP because it helped the CMHP to plan and evaluate its own programmes, it provided group work experience and brought care-givers with the same concerns together:

"The participation of the group members and their contribution has been useful and can help in formulating an action plan. A bond was formed between group members and this will help in networking".

"...because it has shown us that people are happy about our work and our work is useful to them, and they have also told us what are their expectations from these group sessions. I have found out that some people are practicing what we have told them".

With regards to the group process and structure, the team members concurred with the care-givers, but debated the issue of whether the women should be subsidized for participating in somebody else's research. The consensus appeared to be that food and child minding was necessary, but that paying people per interview and per session could prejudice their involvement and commitment. The team members were undecided as to whether people's own homes or the clinic were the best venue. From the discussion, it seems that the function of the groups would play a deciding factor in determining the venue. It may be more appropriate for a self-help/social support group to meet in the women's homes, and for an educative/skills learning group to meet in a venue with more resources like space, tables, a telephone.

The team members felt that any future groups should be made up by the care givers as well as other family members. The team's suggestions as to what future groups could concentrate upon reflected their prioritization of the community's needs. In rank order:

1. Day-care and creche facilities
2. Income-generating skills
3. Self-help/social support group; educative input on MH.

CHAPTER 7

CONCLUSION

7.1 SUMMARY

The broad aim of this study was to make some suggestions for an appropriate CP practice in South Africa. The discussion of CP focused upon the two models most pertinent to clinical service provision and to the South Africa context - the Community Mental Health model and the Social Action model. This discussion indicated that these models, and in particular the SAM, should serve as a guideline for the development of CMH practice in South Africa, rather than being adopted wholesale as the models or model for the psychology of the 'New South Africa'.

It is felt that the theoretical debates raised by the two North American models are important for the conceptualization of the challenges facing psychological theory and practice in South Africa. Namely the disaggregation of the concept of 'community'; the relationship between the nature of human consciousness and individual psychopathology and society; a focus on the psychological processes of power, oppression and liberation; the professional/expert - client/community relationship; the role of the psychologist/mental health worker in community work and in social change; the mechanisms of social change; the development of new and the transformation of existing therapeutic techniques and policy strategies; the notions of community participation and control.

However these debates are as yet unresolved, this is work-in-progress for local and international mental health workers. The above models lack a unified conceptual base and a clear theoretical framework. Advocates of the SAM state explicitly that rather than presenting a systematic theory, the model makes assumptions about the nature of the theory which is required, and admitting that an adequate theory is not at hand, suggest a pursuit of knowledge about the concepts that are relevant through participation in and analysis of elements of social policy. Emphasis is placed upon how the definition of problems effects subsequent interventions, and on the applicability of "participant-conceptualization" to generating the required knowledge (Mann 1978).

It is at this juncture, and from the perspective of service provision, that this research was located. Because CP theories are undeveloped, it is suggested that South African mental

health workers use these models as guidelines, and work towards developing working principles on which to base mental health theory and practice. It seems most appropriate within a developing country that these core principles be based upon the general principles of development. In the context of the social services, this means an adaptation of the principles of PHC into psychology and MHC.

Local and international studies have suggested that crucial to the development of a more appropriate practice, is the development of community based MHC services. The focus of this study was thus to explore the concept of CP through an examination of the development of a CMH care service - the Bambayi Care-Givers Group Project.

The dissertation examined the context of mental health services in South Africa in an attempt to set the scene for the theoretical discussion of CP, as well as to contextualize the examination of the development of the care-givers group within the MH programme of the University of Natal's CMHP.

The examination of the state of the mental health services and the discussion of CP, strongly suggested the adoption of transformed CC policies, guided by and integrated with the PHC approach, as the most appropriate for the care of the MH in South Africa. The challenge is thus to create services for the MH which will integrate forms of PMHC with the secondary and tertiary levels of health care. This would include the creation of humane and stimulating residential, day-care and training institutions as well as community-based programmes aimed at transforming the current ad hoc forms of CC and empowering the care-givers. In other words, a holistic strategy incorporating the formal as well as the informal means of support.

7.2 COMMUNITY CARE FOR MENTALLY HANDICAPPED CHILDREN

7.2.1 Changing attitudes towards community care

The reality of the situation in South Africa is that due to limited resources and the neglect of the MH the care of MH children invariably means care of these children in and by the community. The 'community' in this instance means mothers and female care-givers. This research confirms this local and international trend. There is no substitute to the care and involvement that women provide.

A feminist critique of CC shows that CC is not care through, by or in the community but by individual women living at home and coping largely by themselves. Women provide the unpaid labour which greases the wheels of CC. Their loss of career and work

opportunities tend to be easily disregarded. The women in the study cared for the children largely on their own, support by other members of the community was minimal. This state of affairs appears to be a universal one and exists because women are expected to carry a heavier load than might be expected of a man in comparable circumstances. In fact British research indicates that male carers receive more informal and formal support than do their female counterparts (Ayers and Alaszewski 1984).

Caring for MH and otherwise disabled people is often seen as 'second-rate' work or a 'labour of love'. Either way, this work is accorded low status and low rewards. It can be argued from a feminist perspective that only when caring for the MH is considered as 'real' work and adequately supported materially and emotionally as such, will CC become a viable and respected alternative.

Finch and Groves (1983) argue that CC only appears to be cheaper than institutional care because it involves a transfer of costs from the state to the woman. These women experience two types of costs which tend to be overlooked - the loss of earnings which includes both actual earnings and lost opportunities, and the emotional costs in terms of psychological well-being. Brown and Harris (1978), in their study on depression, show that women who care for dependant relatives have higher levels of morbidity than women who do not have that burden. Ayers and Alaszewski (1984) point out that it is possible that the long term costs of providing therapeutic and health care to these women may turn out to be greater than the long term savings.

Thus any changes in CC policies, especially those which seek to extend the provision of informal care, will invariably have a greater impact upon women than upon men. What this research is advocating, is that this form of care will remain the main form of care of MH children in the future whatever reforms take place. What is needed therefore, are CC policies which are explicit about what CC is, who the main care-givers are, and what rewards and supports will be received by the primary care-givers to decrease their burden of care as well as to empower their ability to provide quality care. The needs of carers must be seriously addressed.

Informal⁵ CC needs to be officially recognized and promoted through national policy research, the allocation of state resources, appropriate training for social service workers and the promotion of national and locally-based CC programmes.

⁵ Informal community care by members of a community needs to be distinguished from the 'formally' recognized types of community care. For example, psychiatric out-patient community care, Community Mental Health Centres, the various day-care and residential facilities.

7.2.2 Empowering the care-givers of the mentally handicapped

A guiding principle of PMHC and of CP in general is that of community participation. 'Community participation' is a term almost as broad and abused as that of community. The concept includes the 'community' participating in all the stages of service provision - from the identification and conceptualization of the issue at hand, to the participation in treatment modalities and management structures.

This research did not focus explicitly on the issue of community participation and control. However, as in the SAM, the notion of empowerment was viewed as a fundamental part of the intervention strategy. That is, the empowerment of the care-givers in terms of information, 'hard' skills and the enhancement of their ability to utilize support systems. As well as empowering the women's confidence in themselves through information and social support.

The notion of providing the care-givers, through a community-based group programme, with education and training to enhance their support networking and care-giving skills, was based on the premise that this knowledge would spread faster to more people in the community than would be the case using the individual client-visiting-the-clinic model. Another factor was that this model may also result in more co-operation between people dealing with the same problems because of its emphasis on experiential learning and support and networking skills in the group. One of the aims of the group intervention was to lay the basis for the development of an independent, on-going self-help group amongst the participants.

The above aim was far too ambitious considering the very limited duration of the group programme and the fact that the primary aims were the generation of baseline data. The group did not coalesce into a neat self-help group. The group did not set out to recruit and train 'indigenous non-professionals' (as in the SAM). However one of the four women participating in the group continued her association with the CMHP. She received training in caring for MH children and was hired to work for one of the Project's stimulation groups for young MH children.

The group intervention programme illustrated that care-givers of the MH are willing, in fact are desperate, to gain more skills in caring for their children. However the economic circumstances of the care-givers, meant that unless the groups include a clear material aid and guidance component as well as an income-generating skills programme, the possibility of attracting and sustaining commitment appears to be slim.

7.2.3 Enhancing the caring capacity of the broader community

The women in the study used informal supports, namely their family systems, to a far greater extent than the formal support structures. This did not mean however that the women were on the whole antagonistic towards the formal support structures, the fact was that they had not properly utilized the health and welfare services because they were so inaccessible.

Research based in developing countries indicates that few people with functional psychiatric disorders, MH and epilepsy 'spontaneously' go to existing primary health facilities for help (WHO Report No 698 1984). In fact people usually approach mental health professionals for help only as a last resort, even though they are often satisfied with the help received (Maforah 1988). The first stop in the help seeking behaviour for people with mental disorders and for the carers of the mentally ill and handicapped, are family members.

The role of family, friends and neighbours is integral to the care of a MH child and enhancing the caring capacity of the child's immediate community is crucial to good CC. Informal social support, particularly the quality of the emotional support and material aid received, is seen as a crucial factor influencing how an individual copes with and survives life problems (Caplan 1974).

The women in the study reported that the support they received from family members was crucial to helping them cope, however the support received from other sources of informal support was minimal. A group programme teaching networking skills and facilitating informal support between the participants through self-help initiatives is a strong suggestion arising from this research. This recommendation reinforces the core principles of primary health care - appropriateness, accessibility and affordability. As well as providing a core fund of knowledge within a residential community which promotes the principles of mental health and acts to prevent mental ill health.

Maforah (1988) lists a further three functions of 'natural' support systems which echo the principles of the SAM: to provide a broad range of low cost, easily available social service; to act as a source of information and help for people with personal and health problems; and to mobilize residents for community action.

7.2.4 Contextualizing community care into a broader care strategy for the mentally handicapped

If CC is viewed in isolation as the prominent, most convenient and cost effective form of

care for MH people, it would undermine the efficacy of this form of care. This research indicates that unless formal support in the form of state subsidies, education and training facilities, day-care and residential facilities and accessible and appropriately trained workers are available, whatever the quality of the informal support received, the carers tend to buckle under the strain and the children and their families suffer.

Community care has not provided an alternative grand design to the other forms of caring for the MH. It needs to be seen as a crucial aspect of care which incorporates the principles of PHC, normalization and human rights. It needs to be incorporated at the primary health and community welfare level into a broader national care strategy for the MH. The question of whether CC programmes and facilities are run by the government CMH services, or the voluntary mental health sector is one which needs to be worked out at the local level depending upon the resources available and on who can provide services to the most people most effectively. What must be guaranteed however, is that the relevant state departments give a firm commitment to providing funding, staff and appropriate training programmes and facilities for social service workers.

7.3 CRITIQUE OF THE STUDY

This research was viewed as an exploratory pilot study, aimed at generating information and ideas that could be used in policy-making and that other studies could develop. However the enormity of the aims and the breadth of the exploration meant that the study often lost its focus and certain important areas were not investigated. In particular areas like the role of the mental health worker in community work and in social action; the expert/professional - client/community interface; community participation and control.

The ambitious nature of the stated aims meant that the aims were not directly linked to the research design which had a dual focus:

1. The gathering of baseline data needed for the development of appropriate strategies for the care of MH African children living in a peri-urban shack settlement
2. The design of an intervention programme which would aid the participants as well as generating research material.

In particular the central aim of exploring the development of an appropriate CP practice in South Africa begs for a more explicit in situ evaluation of the SAM and the Social Action Research model, this has not occurred, especially at the conceptual level. As an

exploratory study the focus was upon offering suggestions in terms of the process of how to get to a 'grounded' theory, rather than on offering solutions.

The research design was characterized by a mixed discourse of research methods and the dual focus outlined above, ie: primary and secondary research; a group programme which was a mix between intervention and information collection; assessment, description and evaluation. Whilst this resulted in a 'fuzzy' design, and diluted a more focused examination of both the theoretical and the practical issues, the research process attempted to remain faithful to the principles of action research which are based upon the premise that the researcher must attempt to 'improve' as well as to understand the situation.

The mix between studying the process and contributing towards structural improvement (Lees 1975), as in the group intervention programme, introduces numerous independent variables to the research process, particularly in terms of the participant's motivations and the role of the researcher. The significance of this latter point is enormous to the issue of appropriate practice. The issues of training, therapeutic techniques, the role of the mental health worker in community work and social change are a whole new area which will not be explored in this dissertation.

An enormous amount of both descriptive and analytical data was generated by the use of a variety of methods which made the analysis and evaluation of the results difficult. Despite the quantity of information generated and the fact that a number of people participated in the community profile, the research was essentially a case study due to the geographical focus and the small number ($N=4$) of participants in the Baseline Interview Schedule and the care-givers group intervention.

The data analysis and the evaluation were broad and often descriptive, no systematic methods of analysis were used. This meant that some important factors were not rigorously assessed, for example the impact of the intervention, including a measure of the transfer of skills/of empowerment. To do this a more rigorous before-and-after design would have had to be implemented. It was felt however, that this would have imposed a framework on this particular study, which would have deviated from the broad aim of exploring the experiences of the care-givers.

The evaluation conducted with the CMHP team members and the care-givers was only a partial one examining the participant's perceptions of the Care-givers Group intervention. A more comprehensive evaluation examining the whole research process and the role of

this researcher was not done. This limited evaluation undermined the research and deviated from the action research process which stipulates ongoing evaluation.

Another factor which needs to be taken into account is that of bias. The materialist perspective, the bias of focusing on the historical and socio-political context was made explicit at the outset. Nevertheless, this perspective orients the very nature of the investigations and the theoretical frameworks used in the study.

And finally, the very process of the Action Research model was undermined by the duration between the actual field research and the final presentation of the written document. Even though the CMHP received a detailed analysis of the research and the recommendations arising from the work, the results have not been disseminated to the women participating in the research and to the Bambayi community in any systematic way. I accept the irony of submitting a written study more than three years after the field work was completed, when the same study exhorts social researchers to deliver findings punctually to the participants in their research.

7.4 CONCLUSION

Whilst these limitations are recognized, the research appeared to have made a valuable contribution to the CMHP.

The care-givers group, with a core of five committed members, continued at their own request till June 1990 until they joined the self-help⁶ group run by the CMHP. The work of the group centred around planning for and starting a training and stimulation group for MH children, and on learning how to care for severely MH children. The women thus operationalized the main recommendations arising from the initial group, that is: to learn some of the skills needed to care for, educate and train a MH child, and to establish day-care facilities for the children in their care.

The subsequent group thus focused largely on practical training and service provision. The CMHP also took a decision to get involved in skills sharing and training for people interested in working with care-givers in the surrounding area. The support generating function which was one of the motivations for the initial group was explored in terms of the guidance and feedback aspects of support. The intimate interaction and social participation functions of social support were not explicitly focused upon in the on-going group programme, although it is assumed they were important to the group process and

⁶ The self-help groups run by the CMHP were involved with bag making, organizing 'Wonderbox' demonstrations through community and women's groups in the area, and in Family Planning awareness.

played a significant role in the commitment of the group members to the group.

One of the women in the initial group joined the CMHP and assisted in running the children's 'Mental Retardation Group'. She went on a week's training course with one of the CMHP team members and received payment for her work. The Mental Retardation group was started in April 1990, and the creche in June 1990.

The discussion of the nature of MHC services in South Africa revealed a situation riddled with obstacles to the effective delivery of appropriate services catering for the diverse needs of the population. Whilst the insecurity and violence of the political and socio-economic situation in the early 1990's is undoubtedly impacting negatively on the mental health of all South Africans, the potential for improving mental health services in South Africa has improved substantially in the past couple of years. A number of factors discussed in this dissertation have contributed to this perception:

1. At a very broad level, the possibility of a democratic social order promises respect for human rights and a more equitable socio-economic situation which could result in better care for all, as well as more of that neglected and most crucial ingredient - 'peace of mind'.
2. The current state's recognition of the importance of primary health care and assurance of the re-orientation of resources towards this sector, is an enormous improvement on the past. Even if these assurances remain largely at the level of rhetoric, it is hoped that this official recognition will act as an impetus for change at the levels of attitudes, training and service provision, rather than stagnating and acting as a red herring preventing more fundamental restructuring.
3. The development of "alternative, progressive" social service and health organizations since the early 1980's have played a significant role in bringing together health, welfare and mental health workers who had the shared vision of a transformed health and welfare service geared towards the provision of better care for all. The impact of these organizations⁷ was more in the organizing of these health and welfare professionals and in the intellectual debates generated within these organizations and reported in some journals⁸, rather than in the actual provision of widespread alternative services. The effects of this has been

⁷ OASSA - Organization for Alternative Social Services in South Africa; NAMDA - National Medical and Dental Association of South Africa; SAHWCO - South African Health Workers Congress; HWO - Health Workers Organization; CSW - Concerned Social Workers; SABSWA - South African Black Social Workers Association.

⁸ The journals which carried these debates were mainly *Psychology in Society* and *Critical Health*.

the development of South African critiques and alternatives to the theory and practice of, in this instance, mental health in South Africa, and the dissemination of this knowledge to a substantial number of people working within, allied to, or interested in this field.

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Two die in deluge which is forecast to continue today and tonight

NON-STOP RAIN SWAMPS IN ATL

Daily News Reporter

MASSIVE downpours with falls of more than 200mm in some areas have swept across Natal, claiming two lives in the Durban area and washing away homes as traffic authorities warned of blocked roads and more rain to come.

At Botha's Hill a 52-year-old man, Mr Tom Gates of Botha's Hill, was drowned after his car was washed downstream as he struggled unsuccessfully to open the door.

At Durban North a man was killed when his car skidded in the rain.

The West Riding suburb of Hillcrest was swamped by heavy rain which left one house in Lesley Drive reportedly on the verge of collapse. The owners were evacuated last night.

Durban's rainfall of 300mm so far this month is only 83mm short of the 1962 record of 383mm.

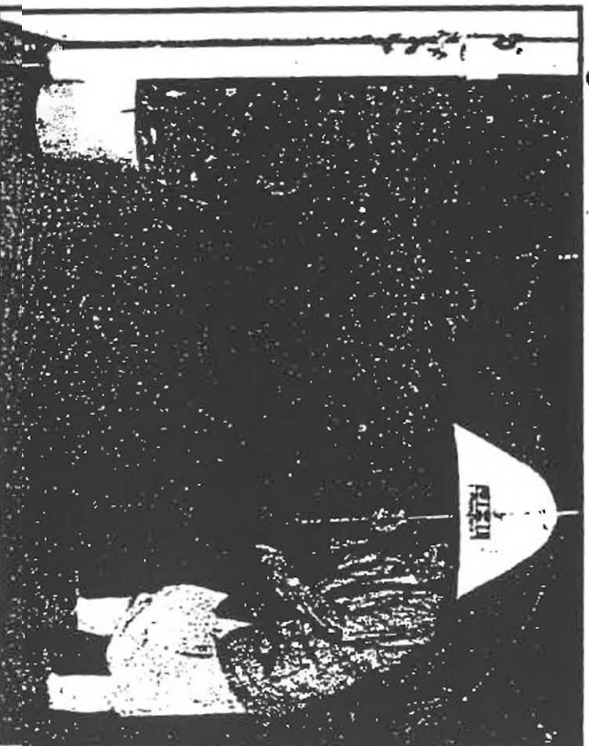
Hardest hit by rain in the Durban region were the Klood, Gillits and New Germany areas, which all had between 240mm and 260mm overnight.

Weather forecasters in Durban said the rain would continue today and tonight, with moderate to heavy falls on the coast and inland in the already waterlogged northern parts of the province and in Zululand.

In Northway at Durban North early today, a young man died when his car skidded in the heavy rain and hit a lamp-post.

The Indian man has not been identified. Spokesmen for Dur-

Daily News 30-11-69.



MORE than 200mm of rain fell at Klood. Mrs Shirley Bloomfield was one of the lucky ones who kept out the rising water.



NEWSPAPER CLIPPINGS

APPENDIX B

SURVIVING THE ²⁸ NIGHTS OF FEAR

Sleep is a luxury with gangs stalking the streets of Inanda Newtown

SLEEP has become a valuable commodity to many of the residents of Inanda Newtown — because these days too many of them are going without it as they survive nights of fear.

Take the case of a typical Durban worker. About 3.30pm every day he checks his watch and realises he will be going home to Inanda Newtown, north of Durban, in half an hour. And in about 2½ hours dusk will signal that residents of this township should keep indoors and try to prepare for a peaceful night's sleep.

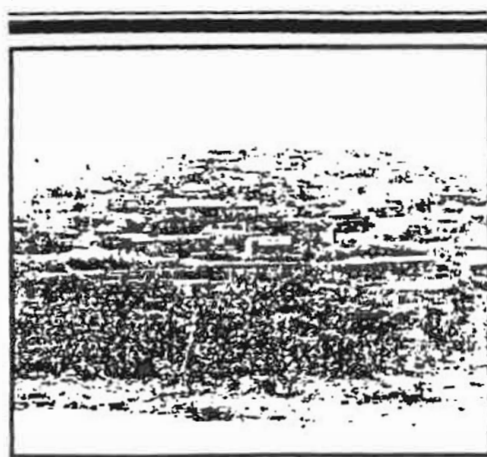
However, "peaceful sleep" can be enjoyed only by the residents of nearby Phoenix township. At Inanda Newtown it went out the window sometime last year when the first ideological clashes between the United Democratic Front and Inkatha began, according to "Stimela".

Interviewed this week in the small factory where they work in central Durban, he and his friend "Bhongoza" said the disruptions in the townships of Inanda and Inanda Newtown were getting to the point where they were interfering with their work.

"How can you get to work on time when you haven't slept all night?" asked Stimela.

They said the clashes in these townships began last year with varying intensity, but they were not as serious as at present. Now groups of marauders patrolled the dark, dirty streets and

IN the violence-ravaged township of Inanda Newtown, sleep has become a luxury as ideological clashes between Inkatha and UDF supporters take their toll. Daily News reporter IRVIN SITHOLE talked to two men who work in Durban about the difficulties they face. Their real names have not been used for their protection.



PART of the sprawling township of Inanda Newtown.

paths of the townships every night.

"Every night groups of armed people knock at our door. If you open for them they then ask you where you belong — UDF or Inkatha.

"But they don't say where they themselves belong. It then becomes difficult for you to answer them because if you say you are an Inkatha member you could be saying that to 'amaqabane' (Comrades) and you could be killed.

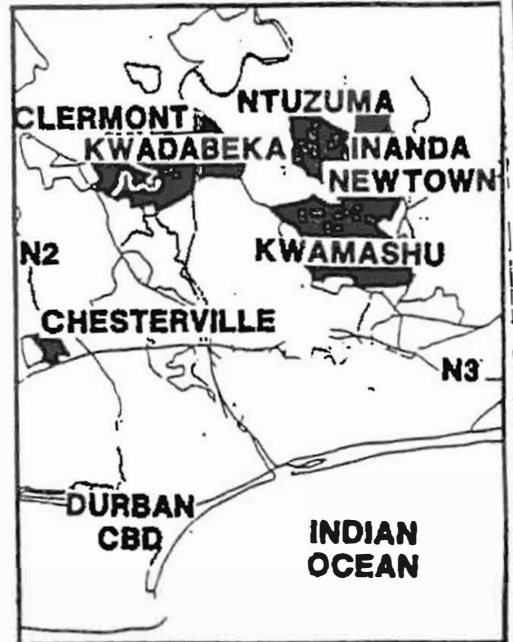
"And if you say that you are a Comrade you could be confessing to members of Inkatha — and you could also get killed. If you say you are not a member of either of the organisations then you are committing the worst crime," said Bhongoza.

goza.

He said that in Inanda Newtown people had to be either UDF or Inkatha; not neutral. Should one say to the group of questioners that one was neutral, they then claimed you were fooling them and were hiding your affiliation.

Stimela recalled the time when the faceless patrolers visited him at night. They knocked at his door, but he did not open it. They then shouted at him, saying that if he did not open the door he should give them some money through the window or they would burn his house.

Faced with these two options, Stimela opted for the first. However, this did not mean he had



MAP showing the relationship of Inanda Newtown to the Durban CBD.

a peaceful sleep after that: "I stayed awake the whole night, not knowing if they would come back. I listened attentively to their noise as they left my house until I could hear their voices no more. But still I could not sleep."

Bhongoza said they had become helpless victims of a vicious circle in townships where they were not expected to report anything to the police, even a house that was broken into.

If one brought the police to the scene, one was then inviting the locals to unleash their wrath.

Stimela said the situation had become so serious that he had been forced to live in the township alone: "I sent my wife and my children

to go and live with relatives on the farm in June. I'd rather be alone so that if anything happens and I'm forced to jump through the window and run, I know that I don't leave my wife and children behind."

Stimela has even warned his employer that he might be killed one day.

Asked if he were considering leaving the township, Stimela said: "If there were a place around Durban which I thought was better than Inanda, I would consider moving."

"But at the moment I can't think of any better place," he said.

So he stays on in Inanda Newtown. And sleeps fitfully.

DAILY NEWS 8-11-89

Woman shot and se alight, two men killed

VIOLENCE broke out once again in the strife-torn township of Inanda near Durban at the weekend.

After this latest spate of incidents, the tally of people killed now stands at 110 and more than 250 houses have been destroyed.

Police spokesman Capt Coert Marais said investigations were being hampered by the lack of roads in some areas, which made movements extremely difficult.

He said the killings took place in isolated incidents and appeared to be retaliation between different groups.

Mercury Reporter

A woman and two men were killed in sporadic violence in Natal at the weekend, according to the latest police unrest report.

On Friday, at Kwa Masbu near Durban, a black woman was shot by a group of blacks and her body set alight.

On the same day, a police squad fired tear-gas at a group of blacks who had erected a road barricade in Inanda. When the crowd dispersed, the police found the body of black man on the scene.

Another black man was fatally stabbed in Inanda after he was

robbed of his private gun.

At Imbali, near Pietermaritzburg, a black man was arrested after a group of blacks fired shots into a home.

At Inanda yesterday, a private vehicle was set alight and four squatter huts were destroyed in the ensuing fire.

At Kwa Masbu, shots were exchanged between a policeman and a crowd of blacks who had surrounded his house. The group dispersed after slightly injuring a woman by stabbing her with a knife.

At Lindani, Durban, a squatter hut was extensively damaged after it was set alight.

Eleven die in Natal unrest incidents

NATAL Mercury Reporter 4-2-87

ELEVEN people — including a policeman — had been killed in unrest-related incidents in Natal this weekend from Friday to late Saturday night, according to the official South African Police unrest report.

The report said a man was killed on Friday at Imbali, near Pietermaritzburg, when he stopped to return the fire of about 15 black persons who shot at his private vehicle.

'The motive for the killing is unknown and no arrests for the killing have been made.'

At Kwa Masbu outside Durban a train carriage was extensively damaged when seats were ripped out and it was set alight. No arrests were made.

Gutted

On Saturday police found the bodies of five black males at Hammarsdale, all with knife wounds. Seven other blacks, also with knife wounds, were in the vicinity. No arrests were made.

Also in the Hammarsdale area, six 'kraals' were gutted by fire. No one was injured and no arrests were made.

'At Nhlanzeni near Camperdown two groups of about 50 people each, apparently representing Inkatha and the UDF, attacked each other at approximately 10 20 a.m.

'Several shots were fired and one man was fatally wounded. Two policemen drove them apart. One pistol and ammunition was found at the site. No arrests were made.

'At Imbali near Pietermaritzburg a special constable was fatally shot in the head. The motive for the killing is unknown and no arrests have been made.

'In the Durban area there were several petrol bomb attacks.

'At Kwa Masbu a KwaZulu police vehicle was burnt out while the members investigated a shooting incident. No arrests were made.

'At Kwa-Makutha near Durban the bodies of two black women and one black male were found. No arrests were made.'

Meanwhile, a number of illegal marches and demonstrations occurred in the other three provinces.

'At Athlone in Cape

Town on Saturday morning, a crowd of about 53 coloureds gathered at the Avondale cricket grounds under the leadership of Saco to disrupt a cricket game.

'Police told them to disperse. One policeman was injured when he was run down with a motorcar. The driver of the vehicle was arrested on a charge of attempted murder. All 53 were arrested and later released.'

In central Cape Town 36 people were arrested on Friday when they refused to stop an illegal march in Victoria Road from Community House to Industria House.

At Ugie in the Border area two groups of about 30 people each converged and sang freedom songs on Saturday night.

'Both these groups were dispersed with tear-gas. One person was arrested on a charge of public violence.'

At Kirkwood in the Cape on Saturday morning a protest march against social injustices, organised by the Kirkwood Youth Congress, took place. About 3 000 people took part. No police action was taken.

In the Transvaal on Friday about 100 people who took part in an unlawful march were dispersed by police with tear-gas, at Tokozo on the East Rand. No arrests were made and no one was injured.

Disrupted

At Diepkloof near Soweto 24 people were arrested when they refused to discontinue an illegal gathering.

At Mohlakeng, near Randfontein, municipal police fired shots with a shotgun at a crowd that threw stones at municipal officers. The people were apparently incensed when the power supply was disrupted in a thunder storm and municipal officials could not supply candles. No one was injured and no arrests were made.

On Saturday at Steynsburg near Middelburg a policeman was injured when he was stoned by a group of people. He opened fire and four black men were arrested. The policeman was slightly injured.

At Thokoza an illegal gathering was dispersed by police with tear-gas.

Death toll rises to 15 as faction battles continue to rage in Natal Havoc as criminal enter township wa

ANIL SINGH

AS fighting in the trouble-torn Inanda and Ntuzuma squatter settlements continued to rage today, some residents claimed that criminal elements were jumping on the bandwagon to wreak havoc in the areas.

The death toll has risen to 15, with 55 shacks and four houses gutted in one of the worst outbreaks of violence seen since the outbreak of the 1984 Inanda unrest.

Hundreds of residents of Inanda and Ntuzuma stayed away from work today and armed themselves to protect their families and possessions in the latest bloody power struggle raging between different factions fighting to take control of the area.

Residents today reported that armed men were parading on the streets and a pall of black smoke was hanging over the townships. Fighting was continuing on a much bigger scale than at the weekend.

Police reported that at least 15 people had been killed in the trouble-torn areas of Inanda and Ntuzuma yesterday and 55 shacks and four houses gutted.

DP figures show 70 dead in 12 days in townships



NATAL MERCURY
12-12-89.
By NICOLA CUNNINGHAM-BROWN

SEVENTY people have been killed in the black townships surrounding Durban in the past 12 days, according to the latest unrest figures released by the Democratic Party.

Some township residents feared that violence could intensify once major industries close for Christmas.

Last night Mr Roy Ainslie, co-ordinator of the DP's unrest monitoring group, said that 37 people had died in Ntuzuma alone since December 1.

Inanda's death toll for the same period was 13, and the Inchanga area 11. In KwaMakutha four died, in Kwa Mashu two, and one each in Richmond Farm, Molweni and Shongweni.

He said the DP's investigations into the specific incidents in Inanda and Ntuzuma indicated that there had been concerted attempts by vigilantes in the Inkatha-dominated areas of Emahlangeni and Lindelani to move into UDF-dominated areas, particularly Inanda Newtown section A and Ntuzuma.

Their objective is to politically neutralise these areas.

He said there were a number of general causes for the Natal violence, which many believed was mainly due to increased rivalry between supporters of the UDF and Inkatha.

The appalling socio-economic conditions in many of the affected areas... have given rise to "isotism" and criminal activities.

There has also been a challenge to the traditional authority of the chiefs. The ambivalent role of the security forces has also played a definite part, as have the unchecked activities of vigilantes.

And a perception in some of the townships that the legal system has failed victims of the violence, has given rise to people taking the law into their own hands.

Meanwhile, Ntuzuma and Inanda residents said yesterday they had been threatened with further violence by residents from Lindelani, Inanda Newtown and various outlying squatter areas.

Sporadic fighting continued yesterday.

Vital services such as electricity and telephones have been out of operation in some areas since last week.

Police said yesterday they were evaluating the situation daily, and more SADF units would be sent into the strife-torn areas if necessary.

The SAP's Natal Regional Commissioner, Maj-Gen Johann van Niekerk, said the violence was mainly a conflict between Inkatha and the UDF.

It is also known that criminal elements take advantage of this situation.

Withdrawn

Vagrancy, unemployment and squatting is a great contributory factor, especially in the Inanda/Newtown area.

Maj-Gen van Niekerk said a large number of Defence Force members had been deployed in Mpumalanga to aid the S A P.

No reported incidents of violence have occurred there since the SADF reinforcements have been withdrawn.

It must be made clear that law enforcement and subsequent arrests and detention is purely the responsibility of the S A P, tasks which cannot be undertaken by the SADF. Maj-Gen van Niekerk said.

Ring of fire and blood around Durban

Sam Sole

DURBAN was ringed by a chain of fire and blood this week as the Natal unrest reached its worst level this year.

While carefree holidaymakers streamed to the coast, township residents and security forces steelled themselves for a "festive season" termed "relative calm" as what has been grimly dubbed the "Christmas offensive" got underway.

The last few days have been unlike anything we've seen before," said Roy Ainslie, head of the Democratic Party's unrest monitoring group in Durban. "It's war out there."

Mr Ainslie said there had been serious fighting in KwaMakutha, Kwa-Mashu, Ntuzuma, Richmond Farm, Inanda and Inchanga.

He said factions had been preventing young people from going to school and forcing them on pain of death to join the fighting.

A new phenomenon of widespread looting had surfaced.

He said the attacks in Inanda and Ntuzuma this week appeared to be a co-ordinated assault, some allegedly directed by well-known warlords. "In Ntuzuma about 100 houses were attacked and 16 people killed in the space of two days this week."

Hundreds of women and children had sought refuge in the local Catholic church while dozens of families were moving to safer areas.

Comrades and Defence Committees were patrolling roads and preventing people from going to work, ordering them to stay and defend their houses.

"There are roving bands all over the place and sporadic fighting continued on Friday."

In KwaMakutha (near Amanzimtoti) 15 people had died since November 18, said Mr Ainslie. "Funeral vigils have been attacked in a bizarre cycle of violence. Security forces have also broken

Christmas offensive rages in townships

SUNDAY TRIBUTE 10-12-89.

lional gatherings.

The amaSenyos gang — a band of thugs with no real political ties — had "virtually taken over" K-section of Kwa-Mashu, said Mr Ainslie, and there had been numerous reports of murders, looting and rape from the area. "In two streets 24 houses were attacked. The attackers are becoming brazen, attacking people in the middle of the day and demanding protection money."

Mr Ainslie said he had learned the two men killed on the Durban beachfront last month had been members of the amaSenyos who were recognised by comrades and attacked. "Two killings on the beachfront and we get a top level visit, increased policing and a great fuss — meanwhile the townships are bleeding."

since mid-November. "Over 48 hours this week there were four vigilante attacks on Newtown section A, repulsed by local residents and the SADF. Comrades attacked an Inkatha stronghold called Emangweni, killing an unknown number and gutting the house of the local KwaZulu councillor."

Mr Ainslie said Mpumalanga appeared to be quiet this week under a strong SADF presence.

Meanwhile ripples from the wave of trouble have been reaching into white homes and businesses. Countless employers had domestic and formal staff stay away because of the unrest, and many have heard harrowing stories of chaos and bloodshed. It is understood that one of Natal's biggest employers, Tongaat-Huig, held

SIPHPIWE'S FLIGHT FROM TERROR OF INANDA

Barry Martens

GUNSHOTS, houses aflame and people fighting with pangas were all too terrifying for the young sons of Siphiwe Kunene (7) and Zipho Ndela (8).

So Siphiwe grabbed up his two-year-old sister Cindy, and Zipho took his brother Joshua, also only two, and they fled for safety.

The escape of the four children from strife-torn Inanda a few days ago is one of the heart-rending — and also gratifying — stories to come out of the recent eruption of violence in black townships around Durban.

Armed with only a piece of paper with the address on Durban's Borneo where their aunt, Mrs. Violet Sithole, worked, they went in search of her.

They had no money at all.

But thanks to the kindness of two bus drivers they were eventually delivered almost to the doorstep of the house where Mrs. Sithole worked.

For the four small people — none of whom speaks English and for whom the big city is a strange place — it had been an awesome experience.

With violence breaking out all around them, they fled the home of their aunt in Inanda and found



SAFE — thanks to a brave little boy, Siphiwe Kunene (7) with his two-year-old sister Cindy, whom he brought out of strife-torn Inanda.

DAILY NEWS 13-12-84

To Page 3

Police move in to township

A STRONG contingent of policemen assisted by soldiers moved into Inanda in a major "door-to-door" operation today and have so far arrested 11 men and confiscated handguns, home-made shotguns and also two stolen motor cars.

Lieutenant-Charles du Toit, head of the South African Police Public Relations Division in Natal, said a large number of police and security forces moved into the township and surrounding areas at 1300am.

The police blitz is the direct result of the bloody violence which has wreaked havoc in the squatter settlement, which has left at least 30 people dead and hundreds homeless.

Fierce fighting broke out at Inanda and neighbouring Nxumama on Fri-

Daily News Reporters

day and police reported more than 60 shacks being destroyed by arsonists.

The violence is the worst in Natal since the outbreak of the 1994 unrest. Supporters of Inkatha and the United Democratic Front have clashed openly and criminal elements have also seized the opportunity to terrorise residents.

Hundreds of residents have fled their homes with their children and are seeking refuge in Durban and surrounding areas, in many cases with white and Indian families.

Colonel du Toit said police and security force members were going door-to-door and search-

ing premises.

Since 1300am, we have arrested 11 people and recovered six home-made guns.

"In F Section, police arrested two men for theft of motor vehicles and found two handguns and a large quantity of .38 bullets," said Colonel du Toit.

Colonel du Toit said one man was shot and wounded when he attempted to escape.

Meanwhile a five-point plan for Christmas peace in the townships in the Greater Durban area has been proposed by Democratic Party MP, Mr. Peter Gasmoe.

Today he called for calm as rumours flared that "wholesale war" is to break out after the factories close on Friday.

Political violence toll

Marin Challenor
Political
Correspondent

Four killed each day in November: report

MORE than four people a day were killed on average in the political violence in Natal and KwaZulu during November, according to the monthly figures released today by monitoring groups in Pietermaritzburg and Durban.

In November 52 people were killed around Durban in the violence, according to the Democratic Party's unrest monitoring group, while 64 people were killed in the inland area monitored by the Centre for Adult Education at the University of Natal in Pietermaritzburg.

Since the beginning of 1987, when these two organisations began monitoring the fighting, they have recorded 2 100 deaths.

The Durban figure was the highest monthly total yet and was made up of Inanda (21 deaths), Kwa-Mashu (12), KwaMashu (12), Ntuzuma (12), St Wendell's (12), Durban (two), and being the two men who were killed on Durban's beach front after being identified as alleged members of the AmaSawera vigilante gang that is plaguing KwaMashu.

Both one, Amantsohi and Port Shepstone one, and Pietermaritzburg one.

This took the 1989 Durban figure to 415 deaths, and the total since 1987 to 745.

The Pietermaritzburg figure included 27 deaths

in Mponatanga, and took the centre's 1989 figure to 580. The number of deaths lodged since 1987 stands at 1 655 deaths.

In a statement yesterday, Dr. Mageshulu Buthezi, Chief Minister of KwaZulu, said the violence in Inanda and Nxumama over the past few days was clearly not political in the sense of a conflict between Inkatha and the UDF/Conasa.

"There has been a lot of conflict and competition for territory amongst certain community leaders which has nothing to do with the UDF/Conasa-Inkatha conflict. There has also

been a criminal element involved in the violence," Buthezi said.

The conditions which people in these squatter areas face, the high unemployment and the lack of basic services have exacerbated problems of this

kind.

He was extremely

pleased to watch

escalation of

violence around

Durban. "The prob-

lem compounded by

the attitudes of the

community have

worried the S.A.P.

and the KwaZulu

Police who

are the only insti-

tution available

for the enforce-

ment of law and

order and for the

restoration of

peace," Dr Buthe-

zi said.

APPENDIX C

BASELINE INTERVIEW SCHEDULE

PARASKEVI STAVROU

**Department of Psychology
University of Natal
Pietermaritzburg**

SURVEY INFORMATION

1 a. Survey Number :

1 b. Interviewers Name :

1 c. Date :

Name

Date

Checked

Coded

Punched

Filed

DEMOGRAPHIC DATA

133

CAREGIVER DETAILS

1. AGE _____ yrs
*** raw figure
2. SEX _____
1 female 2 male
3. RELATIONSHIP TO THE CHILD _____
1 mother 2 stepmother
3 grandmother 4 aunt
5 sister 6 other _____
4. MARITAL STATUS _____
1 single 2 married
3 divorced 4 widowed
5. EDUCATIONAL LEVEL _____
*** raw figure
Sub A, Sub B, Std 1 to 10, Postmatric qualification
6. EMPLOYMENT _____
1 unemployed not seeking employment
2 unemployed actively seeking employment
3 retired / pensioner
4 employed informal sector
5 employed formal sector
7. OCCUPATION _____
*** specify actual job
8. RESIDENTIAL STATUS _____
1 with father of the child
2 own household
3 child's father's parents/ relatives household
4 own parents / relatives household
5 spouse / boyfriend - not child's father
6 other _____
9. PLACE OF BIRTH _____
*** specify actual location
1 urban / peri-urban area
2 rural, white farm
3 rural, tribal area
4 shack land

HOUSEHOLD DETAILS

134

10. NUMBER OF FAMILY MEMBERS RESIDING IN YOUR BAMBAYI HOUSEHOLD

TOTAL

1 pre- and non school going children (under 16)

2 scholars at school/college (all ages)

3 pensioners (men over 65, women over 60)

4 women (16-60) unemployed-not seeking work

5 women (16-60) unemployed-seeking work

6 women (16-60) working-wage labour

7 men (16-65) unemployed-not seeking work

8 men (16-65) unemployed-seeking work

9 men (16-65) working-wage labour

11. NUMBER OF PEOPLE IN YOUR BAMBAYI HOUSEHOLD EARNING OR RECEIVING THE FOLLOWING TYPES OF MONTHLY INCOME

1 wages, formal

2 informal sect.

3 pensions

4 remittances

5 maintenance

6 other

12. HOUSEHOLD MONTHLY CASH EARNINGS TOTAL ALL HOUSEHOLD MEMBERS NOTED ABOVE, Q11

1 wages, formal

R _____

2 informal sect.

R _____

3 pensions

R _____

4 remittances

R _____

5 maintenance

R _____

6 other

R _____

BAMBAYI

135

13. LENGTH OF RESIDENCE IN BAMBAYI
*** raw figure
14. LENGTH OF RESIDENCE IN PRESENT HOME
*** raw figure
15. STRUCTURE OF HOME
- 1 no. of independent structures
- 2 no of rooms with doors

CHILD DETAILS

16. AGE
*** raw figure
17. SEX
- 1 female 2 male
18. EDUCATIONAL LEVEL
*** raw figure
Sub A, Sub B, Std 1 to 10, Postmatric qualification
19. PHYSICAL DISABILITIES / ILLNESSES

INITIAL AWARENESS

20. When did you first begin to realise that something was different about the child ?

******Probe:*

childs age, delayed developmental milestones, problem behaviour, others comments.

21. When you first noticed something different about your child, what was your explanation ?

MAKING SENSE OF THE SITUATION

22. Who did you first speak to about the child ?

23. Why did you approach them first ?

24. Did you contact somebody else, or an organization/agency (eg.clinic,hospital) ?

1 yes

2 no

25. Who was it / were they ?

137

26. How did you know to seek this person / agency out ?

27. What type of help were you given by the people you spoke to ?

*** *list specific examples*

1 material aid

2 physical assistance

3 intimate interaction

4 guidance

5 feedback

6 social participation

7 other

8 none

28. Did you follow through any of this advice ?

1 yes

2 no

29. If not, why not ?

138

30. What problems did you encounter seeking help ?

31. How did you overcome these problems ?

32. Did anyone get in touch with you about the child's care, after you had approached them ?

1 yes

2 no

33. Who approached you about the child's care ?

34. From what you now know, what are your current explanations of the child's condition ?

35. Does anyone in your family / household have different explanations to you of the child's condition ?

1 yes

2 no

36. What are these explanations / how do they differ from your's ?

EVERYDAY CARE

37. Is able to dress and bathe him / herself ?

1 yes

2 no

38. Is able to eat by him / herself ?

1 yes

2 no

39. Is able to sleep with little problems ?

1 yes

2 no

40. What problems do dressing and bathing create ?

41. What problems do mealtimes and eating create ?

42. What problems do bedtime and sleeping create ?

43. How do you cope with all these problems ?

140

44. Does general behaviour such as screaming, rocking, acting strange, being very slow and such, create any difficulties at all ?

1 yes

2 no

45. What would you say these difficulties are ?

46. How do you cope with these difficulties ?

47. Can the child occupy/play by itself ?

1 yes

2 no

48. What level of supervision does the child require ?

1 constant
2 occasional
3 very little

49. When present, does the father help with any of the child care ? 141

*** *always = 1* *sometimes = 2* *never = 3*
never present = 4

1 child care _____
 2 child minding _____
 3 household tasks _____

50. When present, do any of the other household members help with any of the child care ?

*** *always = 1* *sometimes = 2* *never = 3*
never present = 4

1 child care _____
 2 child minding _____
 3 household tasks _____

51. Whom in your household do you receive the most help from ?

<i>Head</i>	<i>1</i>	<i>Spouse</i>	<i>2</i>
<i>Son</i>	<i>3</i>	<i>Daughter</i>	<i>4</i>
<i>Son-in-law</i>	<i>5</i>	<i>Daughter-in-law</i>	<i>6</i>
<i>Parent</i>	<i>7</i>	<i>Grandparent</i>	<i>8</i>
<i>Grandchild</i>	<i>9</i>	<i>Brother / Sister</i>	<i>10</i>
<i>Other relative</i>	<i>11</i>	<i>Lodger</i>	<i>12</i>

52. In what area do they give you the most support ?

1 child care _____
 2 child minding _____
 3 household tasks _____

53. Which aspects of daily care would you want more help with ?

1 child care _____
 2 child minding _____
 3 household tasks _____
 4 other _____

54. Is there any part of the day that is the most difficult to cope with ? 142

1 yes

2 no

55. Which part of the day is most difficult to cope with for each of the following tasks ?

1 morning 06 - 12

2 afternoon 12 - 18

3 evening 18 - 24

4 night 00 - 06

1 child care

2 child minding

3 household tasks

4 other

IMPACT ON CARE GIVER

56. Do you think that you are carrying the load of caring for this child ?

1 yes

2 no

57. How do you feel about this ?

58. Have you ever spoken to anybody in your household about the problems of caring for a mentally handicapped child ?

1 yes

2 no

59. If yes, what type of response have you received and from whom ? 143

<i>Head</i>	<i>1</i>	<i>Spouse</i>	<i>2</i>
<i>Son</i>	<i>3</i>	<i>Daughter</i>	<i>4</i>
<i>Son-in-law</i>	<i>5</i>	<i>Daughter-in-law</i>	<i>6</i>
<i>Parent</i>	<i>7</i>	<i>Grandparent</i>	<i>8</i>
<i>Grandchild</i>	<i>9</i>	<i>Brother / Sister</i>	<i>10</i>

1 material aid

2 physical assistance

3 intimate interaction

4 guidance

5 feedback

6 social participation

7 other

60. If not, why ?

61. What are the difficulties in talking about your problems ?

62. Has caring for the child affected your relationship with the father in any way ?

1 yes

2 no

63. If yes, how has your relationship been affected ?

64. Has caring for the child affected your relationship with your / the other children in the household ?

1 yes

2 no _____

65. If yes, how has your relationship been affected ?

66. Has caring for the child affected your relationship with other household members ?

1 yes

2 no _____

67. If yes, how has your relationship been affected ?

68. Has caring for the child effected your relationship with your friends in any way, your neighbours or work colleagues ?

1 yes

2 no _____

69. If yes, how have these relationships been affected ?

70. Has caring for the child effected your (physical & mental) health in any way ?

1 yes

2 no _____

71. If yes, how has your health been affected ?

145

72. Do you think that caring for a handicapped child restricts you in getting a job more than a normal child would ?

1 yes

2 no

73. If yes, how has this restricted you from getting a job ?

74. Has coping with the child effected your "own time" in any way ?
(eg: church activities, crafts, women's groups)

1 yes

2 no

75. If yes, how has your own time been affected ?

IMPACT ON HOUSEHOLD

76. Have the household members adjusted in any way to cope with living with a mentally handicapped child ?
(eg: sibling waking up earlier to help)

1 yes

2 no

77. If yes, how has your household adjusted ?

146

78. Does having a handicapped child effect any household plans or activities ?

1 yes

2 no

1 where you live

2 relationship with friends

3 relationship with neighbours

4 leisure activities/socializing

79. Do you feel that the development or activities of the other children in the household are restricted or enhanced in any way ?

1 yes

2 no

80. If yes, how has this development and/or activities been affected ?

81. Does having a handicapped child mean an extra financial burden on the household ?

1 yes

2 no

1 medical fees

2 transport costs

3 loss of earnings

4 extra clothes and laundry

5 food

6 child minders

7 special education

82. Do you think there is a need for financial help for families caring for mentally handicapped children ? 147

1 yes

2 no

83. If yes, who do you think should provide support ?

1 community organization

2 civic organization

3 state organization

4 private sector organization

FUTURE

84. What are your thoughts about the child's future ?
*** probe - fears, hopes

85. Do you have any plans for the child ?

1 yes

*** elaborate

2 no

1 training

2 education

3 institutionalization

4 relatives

86. What do you think will happen to the child if your are too old to care for her/him ?

148

87. What would you consider as the best solution ?

88. Do you have any idea of how to go about solving that solution ?

1 yes

2 no

89. What are these ideas ?

INFORMAL SUPPORT IN THE COMMUNITY

149

90. Have you become friends with anyone who has a mentally handicapped child ?

1 yes

2 no

IF NO SUCH FRIENDS PROCEED TO Q94

91. If so how did you meet ?

92. How often do you meet and have a chance to talk / support each other?

- 1 at least once a week
- 2 at least once a month
- 3 at least once every three months
- 4 at least once every six months
- 5 not more than once a year

93. What types of support do you receive from such friends ?

*** *list specific examples*

1 material aid

2 physical assistance

3 intimate interaction

4 guidance

5 feedback

6 social participation

7 other

8 none

94. Have you ever spoken to other friends (not just ones with mentally handicapped children), neighbours, work colleagues about the problems of caring for a mentally handicapped child :

1 yes

2 no

95. What type of support did you seek ?

*** list specific examples

1 material aid

2 physical assistance

3 intimate interaction

4 guidance

5 feedback

6 social participation

7 other

8 none

96. What type of support did you get ?

151

*** *list specific examples*

1 material aid _____

2 physical assistance _____

3 intimate interaction _____

4 guidance _____

5 feedback _____

6 social participation _____

7 other _____

8 none _____

97. When was the last time you had to turn to someone for support ?

1 within the last month _____

2 within the last three months

3 within the last six months

4 within the last year

5 other _____

98. Who would you turn to at a short notice / in a crisis for assistance ?

1 family/relatives _____

2 friends

3 neighbours

4 other _____

99. Please rate the following groups of people ?

152

1 very helpful

2 somewhat helpful

3 not helpful

4 not applicable

1 family/relatives

2 friends

3 neighbours

100. Would you prefer to live in Bambayi or in another community ?

1 yes

2 no

101. If yes, why ?

102. If no, why not ?

103. What is your perception of Bambayi community's attitude towards mentally handicapped children ?

104. What do you think the attitude towards mentally handicapped children is of people outside of Bambayi ?

105. Have you ever approached any of these individuals and / or organisation for help and how did you find them to be ?

*** *helpful* = 1

not helpful = 2

didn't approach = 3

1. psychologist, psychiatrist
2. social worker
3. medical doctor
4. clinic nurse
5. hospital nurse
6. community nurse
7. school teachers/principal
8. priest
9. fellow church members
10. traditional healers
11. sangoma, nyanya
12. magistrate
13. the police
14. community organisations
15. health
16. women
17. self-help
18. mutual aid societies
19. civic
20. political
21. family, relative
22. household
23. friends
24. neighbours

106.

What type of help were you given and from whom ?

154

*** multiple response

1 none

2 material aid

3 physical assistance

4 climate interaction

5 guidance

6 feedback

7 social participation

8 other _____

1. psychologist, psychiatrist _____

2. social worker _____

3. medical doctor _____

4. clinic nurse _____

5. hospital nurse _____

6. community nurse _____

7. school teachers/principal _____

8. priest _____

9. fellow church members _____

10. traditional healers _____

11. sangoma, nyanya _____

12. magistrate _____

13. the police _____

14. community organisations _____

15. health _____

16. women _____

17. self-help _____

18. mutual aid societies _____

19. civic _____

20. political _____

21. family, relative _____

22. household _____

23. friends _____

24. neighbours _____

107. How did you get to know about seeking help from these organisations / 155 individuals ?

108. What are the problems in seeking help from some of these organisations / individuals ?

109. What has the attitude of the following been towards mentally handicapped children ?

1 doctors

2 nurses

3 social and community workers

4 hospitals and clinics

5 traditional healers

6 community groups

7 schools

110. How best do you think these organisations / individuals can help you care for the child ? 156

1 doctors

2 nurses

3 social and community workers

4 hospitals and clinics

5 traditional healers

6 community groups

7 schools

111. Would you like someone that you could see regularly ?

1 yes

2 no

1 community worker

2 nurse

3 social worker

4 health visitor

5 support group member

6 other

112. How do you think the government can help households caring for mentally handicapped children ?

113. Do you belong to a group / organization ?

1 yes

2 no

IF ANSWER IS NO, PROCEED TO Q119

114. If yes, what group / organization do you belong to ?

115. How did you get involved in the groups activities ?

116. What advantages do you get from being a member ?

117. What would you like to change in the group and / or develop so that the group can better meet your needs ?

118. What are the difficulties in being involved in such a group ?

119. If not a member, have you thought about getting people together to discuss¹⁵⁸ the problems of caring for a mentally handicapped child and to find ways of helping each other ?

1 yes

2 no _____

120. Have you ever discussed this idea with anybody ?

1 yes

2 no _____

121. If not, why not ?

122. If yes, what was the response ?

123. What would you think would be the advantages of starting and belonging to such a group ?

124. What would you think would be the difficulties starting and belonging to such a group ?

125. What have you learnt from caring for a mentally handicapped child ? 159

126. Do you think that some of your life has been wasted by caring for a mentally handicapped child ?

1 yes

2 no

127. Do you think that you have benefited by caring for a mentally handicapped child ?

1 yes

2 no

128. Is there anything that you would like to add ?

1 yes

2 no

129. If yes, what would you like to add ?

130. Are there any questions that you would like to ask me ?

Interviewer Comments

APPENDIX D

THE BAMBAYI CARE-GIVERS GROUP PROGRAMME

Session One: Theme - Introduction

1. Introduction
2. Discussion and clarification of group expectations and goals
3. Establishment of group contract: commitment, dates, time, venue, child-care, group structure and content
4. Discussion of the initial recognition of the child's MH
5. Initial support sought and received
6. Discussion of first contact with the clinic and the CMHP
7. Closure and discussion of next session.

Session Two: Theme - Problems and Coping Strategies

1. Discussion of MH and the care-giver's perceptions of the causes of MH
2. Main problems experienced: financial, emotional, social
3. Social support sought and received: family, friends, neighbours, employers, traditional healers, state and community organisations
4. Other people's attitudes towards MH children and their reactions to the care-giver's need for support
5. Coping strategies
6. Closure and discussion of next session.

Session Three: Theme - Self-help Strategies and Skills

1. Suggestions as to self-help strategies
2. General discussion of skills needed
3. Discussion of the care-givers views on how CMHP group programmes can meet these particular needs
4. Care-givers views on how to organise members of the Bambayi community around issues of MH, attitudes of the Bambayi community towards collective programmes
5. Closure. Request from the care-givers that the group discusses the violence in the area and how it is impacting on their lives.

Session Four: Theme - Evaluation and Termination

1. Discussion on group evaluation form (Appendix F)
2. Discussion of the war and violence and the effects on the lives of the women and their families
3. Final closure.

APPENDIX E

THE COMMUNITY MENTAL HEALTH PROJECT TEAM EVALUATION FORM

1. What do you think the goals of the group programme were ?
2. How clear were the group programme's goals ?
 1. no apparent goals
 2. goal confusion, uncertainty
 3. goals mostly clear
 4. goals very clear.
3. How effectively were the following goals met by the group programme ?
 - (a) Information gathering function of the group
 1. not met
 2. a little information gathered
 3. useful information gathered
 4. very useful information gathered
 - (b) Support function of the group
 1. not met
 2. minimal attempt made at support made between group members
 3. average attempts at support made between group members
 4. group members very concerned with supporting each other.
 - (c) Future planning function of the group
 1. not met
 2. few useful contributions made
 3. useful contributions made
 4. very useful contributions made.
4. How much trust and openness was there between the members in the group ?
 1. distrustful of each other
 2. a little trust
 3. average trust and openness
 4. considerable trust and openness
5. How much loyalty and sense of belonging was there amongst the group members to the group ?
 1. members had no group loyalty or sense of belonging
 2. members not close but some friendly relations
 3. above average sense of belonging
 4. strong sense of belonging among group members.
6. Do you have any comments about the following:
 1. meeting time
 2. meeting place: clinic, own homes, other
 3. length of group sessions
 4. transport to and from group sessions

5. the provision of meals and refreshments
 6. organized child-minding during group sessions
 7. group structure, ie with a facilitator and co-facilitator/recorder
 8. any other suggestions ?
7. If the CMHP runs groups like this in the future, who do you think should take part ?
1. care-givers
 2. mothers
 3. fathers
 4. the children themselves
 5. family members
 6. teachers
 7. others.
8. What sort of activities and discussions should be included in future group programmes ?
1. What is mental handicap ?, how to live with and stimulate/train a mentally handicapped child.
 2. Support group for care-givers to discuss their problems, to share ways of coping and solving their problems.
 3. Teaching income-generating skills, eg: sewing, handicrafts.
 4. A day-care stimulation and training group for mentally handicapped children.
 5. Any other suggestions ?
9. If the CMHP decides to carry-on with such groups, which of the above ideas do you think the Project should start off with next year ?
10. How do you feel about the role that you played in the group programme ?
1. unhappy
 2. somewhat happy
 3. very happy.
11. Could you please elaborate on your answer to Q10, with suggestions for the future.
12. Has the group programme been useful for the CMHP ?
1. no
 2. a little useful
 3. useful
 4. very useful.
13. Could you please elaborate on your answer to Q12.

APPENDIX F

THE BAMBAYI CARE-GIVERS GROUP EVALUATION FORM

1. Before you came to the Bambayi Care-givers Group, what did you expect it to be like ?
2. Was the group different from what you expected ?
3. How do you feel about having been part of this group programme
 1. not happy
 2. somewhat happy
 3. very happy.
4. Did you find the group sessions:
 1. not helpful
 2. somewhat helpful
 3. very helpful.
5. What was the most helpful about the group for you ?
6. Has it been a problem for you to come to the group sessions?
 1. Yes
 2. No.
7. If yes, in what way has it been a problem for you ?
8. Do you have any comments about the following:
 1. meeting time
 2. meeting place: clinic, own homes, other
 3. length of group sessions
 4. transport to and from group sessions
 5. the provision of meals and refreshments
 6. organized child-minding during group sessions
 7. group structure, ie with a facilitator and co-facilitator/recorder
 8. any other suggestions ?
9. If the Community Mental Health Project runs groups like this in the future, who do you think should take part ?
 1. care-givers
 2. mothers
 3. fathers
 4. the children themselves
 5. family members
 6. teachers
 7. others.
10. What sort of activities and discussions should be included in future group programmes ?
 1. What is mental handicap ?, how to live with and stimulate/train a mentally handicapped child.

2. Support group for care-givers to discuss their problems, to share ways of coping and solving their problems.
3. Teaching income-generating skills, eg: sewing, handicrafts.
4. A day-care stimulation and training group for mentally handicapped children.
5. Any other suggestions ?

11. If the Community Mental health project runs groups like this in the future, which of the above ideas do you think they should start off ?

12. If another group were to start in the future, would you be interested in participating ?

13. What would you expect to gain from being a member of such a group ?