



## HEALTH CARE: A COMMUNITY CONCERN?

by Anne Crichton, Ann Robertson,  
Christine Gordon, and Wendy Farrant

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## CHAPTER 25

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# **The Challenge of Human Rights' Policies to Traditional Health Care Structures**

In Chapters 3, 6 and 22 brief mention was made of Canada's commitment to new policies set out in the Charter of Rights and Freedoms appended to the patriated constitution in 1982. Pierre Elliott Trudeau, first as Minister of Justice and then as Prime Minister of Canada, had made the realization of the idea of equal citizenship for all Canadians one of his main aims.

The legislation relating to equality of citizenship is set down in the Human Rights Act, 1977, revised 1983. In 1983 four groups were designated as specially disadvantaged — women, native peoples, visible minorities and persons with disabilities. They were perceived to be groups whose needs for enhancement of citizenship should be given special consideration.

This chapter will follow through what these policies have meant for three groups in Canadian society — persons with disabilities, native peoples and visible minorities. There were, of course, other groups which Trudeau saw as disadvantaged (e.g., in the 1950s the Québécois and Canadian women), but these will not be discussed here as their problems of equality of citizenship are very complex and go far beyond health affairs.

### **Services for Persons with Disabilities**

Hahn (1985), has described the transition in thinking about disability policy in the 1970s as: "The shift from the medical model of disability and from the economic (rehabilitation) model of disability to the sociopolitical (minority group) model which calls for public policy changes which shape the environment from a discriminatory one to one which is open to all people. This change calls for a restructuring and reconceptualization of [ideas about] dis-

ability and disabled persons" (Pfeiffer 1992, 55). This description would seem to fit what is going on in Canada.

### **The Challenge to the Experts and the Bureaucrats on Decision Making for Disabled Persons**

By the end of the 1960s radical social movements were challenging the existing systems of service provision. The reformers were out to limit the power of "the disabling professions" (Illich 1974).

One professional group in the system which was particularly challenged were the psychiatrists in the mental health service (Czucar 1987). The interested public wanted more open government of mental hospitals (the establishment of boards), fewer technical procedures such as brain surgery and electric shock treatments, better review procedures for compulsory admissions, and review of the necessity for custodial care (particularly in the mental retardation hospitals). Although psychiatrists were active in promoting change in the way in which mental health services were structured, they came under attack. When the introduction of federal medical care insurance was under discussion the leading psychiatrists published their demands to be absorbed into the regular medical care system (Canadian Mental Health Association 1963). They wanted access to general hospital wards, acute hospital emergency department provision and payment from the medical plans for services given in their own offices.

Following this manifesto the psychiatrists worked with their American counterparts to develop a community psychiatry model of organization (Loeb 1966), but there was an angry response to the claims of community psychiatrists to be leaders of the team. Their model roused the anger of other professionals in the educational and social service field and several community groups concerned with children's welfare. *One Million Children* (Commission on Emotional and Learning Disorders in Children 1970) protested the limitations of the medical model for coping with the wide range of emotional problems of the many children who would need help at some point in their childhood.

### **Deinstitutionalization**

Slower to start but more powerful in the long run, were the challenges of the parents of mentally handicapped children to the administrators of institutions and social workers (Simmons 1982). A consumer organization, the National Institute for Mental Retardation (NIMR), engaged Wolfensberger and Nirje (1972) to clarify the concept of "normalization" in the community. Some parents and other interested individuals had already tried out community resettlement programs and found they could be successful. Since

then, the NIMR (later the G. Allen Roeher Institute) has been moving the governments beyond "normalization" to the next stage of policy development, that is, "finding the least restrictive alternative," and to demanding control over decision making and complete freedom from expert and bureaucratic dominance where the family or a circle of friends is willing to take responsibility for its own members.

There was great strength of feeling on the part of parents of institutionalized children about their disenfranchisement as parents. In the 1970s local community groups began to pressure governments to deinstitutionalize even the profoundly retarded — to transfer all the inmates of former mental retardation colonies to special care homes or group homes. Although provincial governments were committed to the general concept, the meaning of deinstitutionalization was not altogether clear. While, strictly interpreted, it implies return to the family or placement in a very small group home, in practice it may mean transfer to a more socially oriented institution.

In the late 1960s some of the traditional institutions were closed and their "less difficult" patients distributed to families or group homes (Canadian Council on Social Development 1985). Others were sent on to nursing homes or other traditional mental hospitals. McWhorter (1983) and the National Institute for Mental Retardation (1986) have described the closure of institutions in Ontario. Lord and Hearn (1987) studied the process of closure of one mental hospital in British Columbia and looked at what was happening to the ex-patients a few years later. Some were leading well-balanced lives in small group homes while others living in similar small homes in the community were still being treated in institutionalized ways. To try to deal with this matter, new guidelines for special care homes were established by parent groups (Vancouver Community Living Society 1985) or by government committees (Nova Scotia 1987b).

### **The International Year of Disabled Persons**

The year 1981 was the International Year of Disabled Persons, a year in which Canada and other countries considered how persons with disabilities were being treated by the rest of society. In preparation for this year the World Health Organization (WHO 1980) had reconsidered its definitions of disability: "In the context of health experience a disability is any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (p. 183).

The committee concerned with the definition separated out impairment, disability and handicap: "There is a distinct cleavage between disability and handicap, both conceptually and in the means for intervention [p. 41] ... In the context of health experience, a handicap is a disadvantage for a given

individual, resulting from an impairment or a disability that limits fulfillment of a role that is normal (depending on age, sex and social or cultural factors) for that individual" (p. 183).

Before 1981 only two groups of persons with disabilities were recognized as having special needs — persons with mental disorders and injured workers. Now attention was given to the rest of the group who had not been considered before, unless they were in need of long-term residential care or social assistance.

Following the report of a public inquiry by a special committee of Parliament (Canada 1981b,c), a new approach to policy development was adopted. Instead of expecting persons with disabilities to make all the adaptations to social conditions, it was recognized that society could work to remove barriers which made them dependent and unable to function optimally. Some of these barriers were social, others physical.

Throughout the 1980s great efforts were made to find out how many Canadians were impaired and what was their ability to function but as Greenwood (1985) pointed out, to know how many impaired people there are is only part of the story: "Certain dilemmas are evident in determining and providing for the needs of disabled persons: self-perceived and self-defined need versus bureaucratic standards and statistical definition: resource compensation versus resource enhancement: urban versus rural needs. Closely related to these perplexing problems are tensions in rehabilitation approaches: institutional and community approaches; individual functional improvement and environmental improvement" (p. 1241).

In 1988 a useful statement about the social model of health care for disabled Canadians was written to explain the needs of those with mental health problems (see Chart 8.2). This analysis can be used to explain any kind of chronic illness, impairment, degeneration into old age and so on equally well. This document (Canada 1988e) proposed that mental illness should be considered as posing two different sets of problems: first, coping with the disorder, and second, coping with the problems of living with the disorder. The viewpoint of that paper is summed up as follows:

The process of achieving ... health is the same for everyone — it involves removing or reducing obstacles that prevent the individual, the group and the environment from interacting in fruitful ways

Apart from the disorder itself, the obstacles may include:

- rejection by friends, family or workmates;
- the stigma of mental illness [or other visible disorders];
- inability to find or keep suitable employment;
- lack of appropriate and affordable housing;
- lack of social, recreational or educational opportunities;

- experiences of discrimination; and
- lack of needed information and coping skills. (p. 9)

Most persons with disabilities need medical help at some stage, but it is clear from this listing above that their rehabilitation will require much more from educational and employment services and housing and social welfare programs than medical care alone. And what is to be done needs to be worked out with the consumers as individuals and as a group. Advocates for persons with disabilities have made it clear that they are resentful of professionals and bureaucrats who do not respect their desire for independence and mutual support (D'Aubin 1986; Guay n.d.).

In Ottawa, under continuing pressure from Parliament, disability policy development was handed over to the secretary of state who endeavoured to coordinate the work of all ministries concerned with removing barriers and with meeting the needs of this group.<sup>1</sup> Some provincial governments set up premiers' councils to advise on policy and to work with government departments on special issues. Not all provinces have these councils; their governments may respond directly to advocacy groups or human rights' challenges. Some have interdepartmental coordinating committees within government, others do not. At the service level there are many problems of coordination between charitable, mutual aid and government organizations which provide supports.

If we accept that there has been a redefinition of health which requires that social supports as well as medical care be provided to those who need this assistance, this group of Canadians and their demands/needs for care in the community provide an example of the difficulties to be addressed in working towards a better model of care.

In discussing the shifting ideas about welfare state and welfare society we noted that in the 1980s there had been a move away from concern with the social minimum to concern with discrimination against minorities in society. But within the social minimum sector there have been major changes towards improving training for work, perceiving social assistance as being merely transitional to assist people between jobs and reducing the payments

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1 Under the Progressive Conservative government 1988-93 a Standing Committee of Parliament on Human Rights and the Status of Disabled Persons was set up which was very active in suggesting policy changes, particularly in its second report *A Consensus for Action* (Canada 1990j). In 1990 Prime Minister Mulroney established a division within the Department of the Secretary of State to look into issues affecting the status of disabled persons. This division has now been cut back in the federal civil service reductions, but it achieved a considerable amount of change in legislation before this happened.

to welfare applicants. However, the withdrawal of funding for social assistance may greatly affect the group of persons with disabilities as well as other minorities in Canadian society. Torjman (1990) has argued that the needy group of Canadians with disabilities is unlikely to easily be able to respond to the new employment oriented policies. She explained that they would find it difficult to shift out of claiming social assistance and other benefits once such assistance had been granted for their rehabilitation and support. She said that analysis of social assistance found that it effectively locks recipients into that system through a variety of economic and psychological traps. Rates of assistance fall well below the poverty line.

This issue of social program restructuring will be discussed in Chapters 27 and 29.

## Health Services for Native Peoples

### *Health Care on Reserves*

The history of medical service provision by the federal government to sub-Arctic native peoples has been chronicled by T. Kue Young (1984, 1987, 1988).<sup>2</sup> He said:

a high quality health care system is found in a region that rates very poorly in terms of its health status. ... On almost every indicator the Indians fare worse than the national population. The litany of health risks among Indians has become well known. Indices such as the birth rate, the perinatal and infant mortality rates and their components, the violent-death rate, tuberculosis incidence, and the prevalence of various nutritional inadequacies are all higher, sometimes several times so, among Indians. (1988, 125)

Young quoted Badgley (1973) who, after studying Indian health care in western Ontario, "concluded that the evolution of Indian health policy must be viewed in the broader context of the social and political development of Canada itself" (1988, 90).

The British North America Act, 1867, spelt out the constitutional powers of federal and provincial governments. While the provinces were designated as the regulating authorities for health and welfare services within their jurisdictions, the federal government took on the responsibility for Indian affairs (which included health matters).

The Medical Services Branch of Health and Welfare Canada set up nursing stations in Indian and Inuit settlements across the northern territories (O'Neil 1987). The nurse practitioners who staff these health centres are

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2 See also O'Neil (1987).

backed up by doctors (who give advice by radio telephone), and by air ambulance services which take emergency cases into hospitals.<sup>3</sup>

As well, there are Indian reserves within provincial boundaries. Much depends on geography and population mix in sorting out which authorities will provide services to these. For example, in British Columbia, the federal government has agreed to take responsibility for non-natives in sparsely settled territories (such as the Chilcotin) while the provincial government has set up public health centres on southern reserves to provide health services to native peoples who are not good at accessing traditionally organized medical services in the area. And then there are the "mixed communities," like Alert Bay, where there are Indian settlements on one side of the bay and white settlements the other, gathered around what were originally mission hospitals and Indian residential schools. Speck (1987) has indicated that in such mixed race communities the hospitals are likely to be governed by boards which lack understanding of native cultural attitudes to sickness. She has discussed a scandal over Indian deaths in Alert Bay which forced the British Columbia Minister of Health to establish British Columbia's provincial health policies for natives more clearly (McClelland 1979).

### Medical Care versus Community Development Policies

Until 1969 Indian policy was one of overt colonialization. In that year the government revised its policies (Canada 1969), and in the 1970s, Canadian consciences began to be stirred by books such as *How A People Die* (Fry 1970)<sup>4</sup> which demonstrated the failure of morale in many Indian bands when their traditional way of life was superseded. The lack of adequate economic and social development of native communities, in parallel with the strong economic development of communities of settlers in Canada, was compounded with the coming of the welfare state which established a social minimum for all. The government hand-outs to native peoples met needs for survival but not for the respect which comes through worthwhile occupation. Although (as Young pointed out) welfare state payments helped many bands to raise their marginal standards of living, these were no solution to their basic problems of adapting their cultures to the modern world.

As we have become more aware since the Meech Lake Agreement debacle, the native peoples do not think that they have had equitable treatment from Canadian governments (as compared with the immigrant peoples

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3 The services for aboriginal peoples include non-insured health benefits above and beyond the Medicare system, that is, drugs, dental care, prosthetics, etc.

4 See also Elliott (1971), Robertson (1970), Cardinal (1969) and Berger (1977).

and their descendants). However, there now seems to be more willingness on the part of governments to discuss the issues in dispute, to try to reach agreements on boundaries (land claims) and natives' autonomy within these boundaries.

It has begun to be recognized that providing medical care might not be very useful without doing something about community development, for medical care there is most needed after the violence or the disease strikes.

### **Restructuring in Cooperation with Native Peoples**

Because of the constitutional arrangements, the main changes in Indian policies have to be introduced by the federal government. In 1979 the Minister of National Health and Welfare decided to move on health policy. By giving native peoples authority over their own health services, he thought they might gain greater self respect and some experience of self government. The federal government decided to fund a series of demonstration projects to determine whether natives could administer such projects effectively. By 1983-84, thirty-one projects were operational in seven areas across the country, fourteen of which were selected for evaluation.

In the meantime, apart from these demonstration projects, there were several other important pilot programs which were showing successful organization by native peoples: the Indian Health Centre in North Battleford, Saskatchewan; the Kateri Memorial Hospital in Kahnawake, Quebec; the Alberta Indian Health Care Commission in Lethbridge, established in 1980;<sup>5</sup> and the Cree Board of Health and Social Services, established following the James Bay Agreement in 1979.

After the demonstration projects were evaluated (Indian Management Systems 1985) it was decided in 1986 to proceed to develop a transfer policy. Bands were invited to apply to the federal government to develop a plan to take over their own community health services,<sup>6</sup> environmental health services, prevention and counselling programs related to alcohol and drug abuse, the services of medical professionals presently employed on contract to the Ministry of Health, and (possibly) hospital services. The plan must

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5 Associated with the Alberta project is the Four Worlds Development Project which has put out the following publications: (1) *Taking Time to Listen: Using Community Based Research to Build Programs*, (2) *Developing Healthy Communities: Fundamental Strategies for Health Promotion*; (3) *Towards the Year 2000: Overview of the Four Worlds Development Project*; (4) *Holistic Education Evaluation* (1988).

6 Community health services may include: nursing (treatment and preventive care), community health representatives, health education, nutrition, mental health, dental services, medical and dental advice and assistance.

outline what health services are most needed, how those services will be provided and how health care money will be spent (Canada 1989a). The federal government is anxious to ensure that projects will be practical. A process of "working through" is going on.

The Assembly of the First Nations (AFN) has set up a health commission to review and report on transfer policies. And there are special issues sub-committees at work<sup>7</sup> (AFN 1988). D.E. Young (1988) has reviewed the integration of traditional and modern medicine and the prospects for the future.

Although the health transfer policies may be an attempt to empower Indian bands to take more responsibility for medical care services to Indians living on reserves, there are many social problems affecting health which need other solutions. It is generally agreed that medical care alone will not be enough to deal with the social dysfunctions of Indian bands. Drug and alcohol abuse, violence and sexual abuse are indications of deep disturbances among the native peoples.

Some would prefer to see government funds being allocated to community development before health services are transferred back to the bands.<sup>8</sup> However, a number of bands have taken up the transfer offer and are now responsible for health service development in their own jurisdictions.

## Human Resources Development

In order to develop the human resources necessary to provide culturally appropriate health services to native peoples on reserves, new initiatives have been taken in the last few years. For example, the University of British Columbia has set up a First Nations' House of Learning with a Health Care Planning Division to find suitable candidates for training in established education programs. Bursaries are available from the provincial government (British Columbia 1990b). Athabasca University established a special program for native health administrators in 1990. All this is in addition to the existing educational programs for community health representatives (e.g., Alberta Vocational Centre Service).

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7 In 1981 the International Year of Disabled Persons, the House of Commons investigated barriers to integration of disabled Canadians in society. A separate report, *Obstacles for Native People*, was published on disabled native peoples (Canada 1981c). This subcommittee continues to study the matter. Its most recent report, *Completing the Circle*, was published in 1993 (Canada 1993).

8 Some bands and some friendship centres are concentrating on implementing community development programs such as improving women's self esteem (e.g., British Columbia Native Women's Society 1990), better parenting, alcohol and drug programs (Hodgson n.d.), suicide risk assessments.

### **Problems of Indians Living in Urban Cores**

More difficult has been the development of a social policy for Indians who drift to the cities (Stanbury 1975). Brody (1971) provided an interpretation of their difficulties in becoming socially integrated into urban societies. These difficulties usually lead to excess alcohol consumption by natives in skid row areas.

Most service development for natives in urban areas is relatively recent. Friendship Centre projects have hardly begun or have not been written up (e.g., the Vancouver Pilot Friendship Project plans to open a seventy-two bed AIDS hospice and uses part of its building for a housing program). One which has been documented is the Boyle McAuley Centre in Edmonton, which has a fifty percent native Indian clientele. This centre functions as an inner city support service for a mixed local community (Edmonton Urban Core Support Network 1989). Toronto has opened a native community health centre (CHC), but Daly (1989) saw this as another blow to the CHC movement — yet further marginalization of the concept. She does not mention marginalization of the aboriginals.

### **The Métis Health**

Another major concern for the prairie provinces is the health of the Métis population (Gresco 1987). Their problems are similar to those of native peoples who have left the reserves. They have no special rights to federally funded health care and they find access to the established provincial systems presents major barriers.

### **Health Problems of Multicultural Groups**

Like the native Indians, Inuit and Métis, there are other minority groups in the Canadian culture who have health problems, and these health problems are only part of their cultural adjustment problems. It is recognized that they, too, have to be helped through community development approaches.

Yet while community development approaches may be important in the long run, in the short term it is recognized that individuals admitted to Canada with a background in other cultures will need to deal immediately with specific problems — that there is need to facilitate access to medical care, public health services and social support services.

### **Puzzled Immigrants who Need Health Care**

Consequently, governments or voluntary agencies have produced handbooks to help some of the new immigrants to find the right kinds of medical and social services (e.g., Alberta 1984; Mercer and Murphy 1981), while recog-

nizing that these will not help all of them to solve all their adjustment problems.

Alberta (Alberta 1986) undertook an immigrant and native women's health survey to identify the needs of members of special minority cultures.<sup>9</sup> The Canadian Council on Multicultural Health (1990) has also produced a list of translated pamphlets and additional materials in twenty-five languages and a bibliography about "reaching the multi-cultural community."

Waxler-Morrison, Anderson and Richardson (1990), in a guide book for health and social service professionals, presented information on the beliefs and attitudes of clients from non-European backgrounds, to assist health professionals with communication for the purposes of diagnosis and treatment.<sup>10</sup> Waxler-Morrison and her colleagues base their approach on the work of Kleinman (1980) (as do most other health policy makers working in the multicultural area). Kleinman stressed the need to understand intra-ethnic diversity and to avoid ethnic stereotypes, to appreciate the problems of resettlement in a new country, to be aware of general related issues and family adjustment problems, to accept the influence of the extended family on health care decisions, to recognize that these patients may have different expectations of health care professionals, and to give special attention to the adaptation of children and elders. Mathias (1991) has also written on the need for cultural sensitization of health workers.

### **The Social Integration Problems of Minority Ethnic Groups**

Workers in the field (YWCA 1987) recognize that these approaches will not deal with some of the major difficulties of social integration (and thus health in its wider definition) for some members of minority ethnic groups. The meaning of social integration is considered in Appendix A which discusses definitions of terms.

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9 The Alberta survey identified the following needs: learning the English language; availability of interpretation of languages in native tongue; need for services to be available where living; need for transportation; importance of contact persons; native women's issues; current access to care; immunization status, especially of children; number of children and ages (well baby implications); women in reproductive years — birth control counselling; low birth weight babies; coping with hospitalization; injuries; nutritional issues; health education resources; health practices — smoking, looking after dental caries, etc.; identifying agencies serving; relationship of health departments with these agencies; agencies' perception of health needs. Many of these are clearly health matters.

10 *The Journal of Ethnicity and Disease* is concerned with identifying racial differences in disease rates, the impact of migration on health status, ethnic factors relating to health care access, and metabolic epidemiology.

Without taking a community development approach it is unlikely that the main problems of these minority groups will be solved. Bolaria and Lee (1983), Bolaria (1985) and Bolaria and Dickinson (1988) have examined some of the barriers to integration, identifying racism as the major difficulty. However, Doyle and Visano (1988) have said: "Multiculturalism continues to be addressed as an 'ethnic issue,' packaged and retailed as a commodity to benefit ethnic communities alone. The failure to involve all interests runs the risk of trivializing government commitments and fails to involve those who need to support diversity" (p. 14).

As well, the strategies need to be changed to take account of consumer inputs, they said. Wall (1990), writing from a base in Alberta, also supports the view that groups of consumers from visible minorities should be more involved in planning services.

There is some written material available on specific local initiatives such as the work of the Committee for Oriental Problem Youth in 1990, called together by a Calgary general practitioner; on the needs of Vietnamese immigrants to Calgary, researched by a public health nurse (Lentjes 1989); and on the mental health of Chinese Canadians in Vancouver (Vancouver 1990). But Perkins<sup>11</sup> said there is much going on elsewhere which is never written down, such as work being done in the Toronto public health service on moderating lifestyle or helping to cope with the environmental problems of visible minorities.

### **Restructuring Service Delivery to Meet the Challenge of Human Rights Legislation**

This chapter has been concerned with three groups designated as disadvantaged — persons with disabilities, native peoples and visible minorities. While there is an obvious need for those wanting medical care in these groups to have access to medical services, this provision does not seem to touch the basic problems of social integration of these groups into Canadian society as a whole. Their struggles to be recognized as full citizens with equal rights are so complex that there are many evident dysfunctions within the groups themselves — dysfunctions which lead to the need for medical care but show greater basic needs of improved social organization which have to be resolved not only within the disadvantaged groups themselves but also with the rest of Canadian society.

It has become obvious that any restructuring of health and social services requires as much input as possible from these disadvantaged commu-

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11 Fran Perkins, personal communication, 1990.

nities in order to find good solutions to the needs of these groups and to bring them into a satisfactory relationship with the wants of the middle class majority who are the main policy makers in Canadian society (Mahtre and Deber 1992).

### Summary

The Human Rights Act, revised 1983, identified four specially disadvantaged groups in Canadian society. The discussion in this chapter is concerned with meeting the health needs of three of these groups — persons with disabilities, native peoples and visible minorities. The changed emphasis in Canadian society towards full acceptance of the equality of people in these groups since the early 1980s has led to reconsideration of social policies to facilitate this acceptance and to see how support should be given where necessary.

In the last fifteen years attitudes towards persons with disabilities have been changed. No longer are they expected to make all the adjustments to society. Real efforts have been made to remove physical barriers to their full involvement in working and social life as well as to reduce social stigma.

After trying out some pilot schemes it was decided to offer health transfer programs, that is, control over their own health services to Indians living on reserves. Whilst realizing that dealing only with medical care needs was not getting to the root of the social problems of Indian bands, transfers were thought to be one way to help the bands to take some independent action on one aspect of their social needs. Métis and Indians living in urban areas still have difficulties in adjusting to these cultures which are very different from their own, and as yet little has been done to assist them.

A new emphasis has been put upon multicultural health problems and efforts have been made to create an awareness of how to approach these and how to meet patients' needs more effectively, but it is recognized that it is not only better medical care but community development which is needed.

