

Deaf Health in Scotland

Issues for Deaf People in Health Promotion

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Acknowledgements

A research project which was begun in November and completed by the following February would not normally be expected to be very broad in scope. It could hope to achieve an explanation of the issues but it would seem hardly likely to evaluate in depth. Yet the results as seen in this report show a considerable collaboration and we believe, a significant outcome.

In this project we have been particularly lucky in having together a research team who had just the right range of skills and knowledge to make significant contributions. As well as those who are listed as main contributors, we wish to thank Edith Norrman and Clark Denmark for their advice and support throughout.

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Deaf Health in Scotland

Summary and Recommendations

Deaf people in Scotland are a widely distributed group within the population and are defined by their use of sign language and membership of the Deaf Community. On the basis of an analysis of the statistical sources available, we can estimate the Deaf Community between 2,500 and 5,000 people. In setting out the characteristics of the Deaf Community we can see that there are good reasons for considering Deaf people as part of a minority group with their own language and culture. Since this language is different from English, it poses problems for the delivery of health care and for the development of programmes of Health Promotion. Health promotion

would include actions and campaigns to create a healthy environment as well as to provide health information and would in principle allow for the tackling of social causes of ill-health, as well as their symptoms. Understood in this way, Health Promotion is a mediating strategy between people and their environments incorporating both personal choice and social responsibility in health (WHO, 1986)

In this respect, Deaf people are at risk since all of our preliminary research indicates that Deaf people are marginalised and ignored. Since they are surrounded by hearing people (their parents, their children and their neighbours) they have major difficulties in access to information and services.

To date, the solutions have been limited and we found little evidence of research on Deaf people's involvement in health. There are a number of recent initiatives which have allowed Deaf people a significant role in discussing health needs, particularly in regard to women's issues, but the resourcing and the extension of these projects has been small. In a survey of Health Promotion agencies in Scotland we found a perception that Deaf people could access services and materials and that initiatives had been undertaken. This was in contrast with the views of Deaf people which was that nothing was being offered and that they avoided use of health provision because of the stresses it created, particularly in relation to communication.

Expectations of Health Promotion are that it has an underlying strength in empowering people and by doing so, making them more able to deal with their

own personal health. To date, Deaf people have been given few opportunities even though they seem like an ideal community for such work.

The research findings indicate a number of areas of work which should be explored:

- the setting up of targeted group work with elderly Deaf people, Deaf fathers, Deaf Women and Deaf young people
- training programmes for interpreters in the specialist field of health
- creation of an interactive Deaf Issues and Contacts database which can be available to professionals on-line to ensure updating of knowledge and ease of dissemination of Deaf needs and provision
- community research to focus on the changes brought about within the community as a result of the Health Promotion initiatives suggested
- research on the means of delivery of Health Promotion programmes and the resulting learning effects on the Deaf participants

In the planning for Scotland's Health, this is an important time when the needs of Deaf people can be linked to the evolving programme of Health Promotion. We believe that Deaf people can benefit greatly if they can be involved at every stage.

The Research Brief¹

The Health and Health Promotion needs of Deaf People:

Review of current Knowledge and Practice

Background

Contacts between the Health Education Board for Scotland's Voluntary Sector and Community Programme Managers and representatives of the Deaf Community have highlighted the need to address the health and Health Promotion concerns of deaf people. The Health Education Board for Scotland (HEBS) now wishes to develop a strategic approach to this area of work. This research is intended to inform the development of an appropriate strategy.

Objectives of the review

The overall objective of the review is to make recommendations about how HEBS can address the needs of the deaf people in Scotland. Specific recommendations are required about appropriate means of undertaking or supporting work in these areas:

- organisational development;
- the development of information and support networks;
- training and professional development;
- support for local projects which exemplify good practice;
- the development of appropriate information and methods of communication;
- further developmental and evaluation research

Scope of the review

1. The review will address the needs of people who have grown up or are growing up deaf, and who consider themselves deaf. The majority of people concerned are likely to be British Sign Language users. However, we do not

¹ This is the research brief provided by HEBS prior to the project and which was used to construct the approach of the project team.

wish to exclude people who use verbal language and who consider themselves deaf. The review will not address the needs of people who have become deaf or hard of hearing in older age.

2. Within the terms of this definition, information will be sought about the needs of a wide range of age groups from children of school age to older people.
3. In order to provide a context for the main body of the work, the review will ascertain what information is available about the number of deaf people in Scotland and where they live in relation to the Scottish health board areas.
4. The review will seek information about the following issues:
 - The main health concerns of deaf people throughout the UK, but with particular reference to Scotland.
 - Initiatives aimed at addressing these concerns, whether in the UK or elsewhere, and their effectiveness.
 - The advantages and disadvantages of different formats, such as leaflets and videos, for communicating health information to deaf people.
 - The advantages and disadvantages of different methods of personal communication, for example health professionals trained in BSL, interpreters or deaf people themselves.
 - Other issues which have implications for the delivery of Health Promotion and health information, for example particular cultural perspectives and concerns.

In relation to each of these issues the review should provide information about needs specific to different groups of deaf people, for example men, women and different age or ethnic groups. Formal needs assessments and evaluations of effectiveness are of particular interest. However, less formal assessments and evaluations based on experience are also of interest.

Section 1: Issues for Deaf Health in Scotland

1.0 Health in Scotland

There has been considerable attention devoted to the topic of Health in Scotland. It is reckoned generally that Scotland has a very well developed system of Health Care and has extensive and innovative training systems for health care professionals. But it has also been the subject of much debate that the health of Scotland's population is not what it should be and various theories have been put forward for its lower than intended position in the league table of nations' health. New programmes have been put in place to try to deal with this perceived problem and considerable progress has been made in recent years.

1.1 Scotland's Health

The Report "Scotland's Health" published in 1992, has created a baseline and a set of targets for the improvement of the health of the population. Some of the key points are mentioned below.

There is a general agreement that Health Care in Scotland is of a high calibre (given the relatively small population - 5.1 million) and there has been a great improvement in recent years in a number of areas; however, there has been a decline, relative to people in other Western developed countries, in heart disease and cancer. Appendix A of *Scotland's Health* contains more detailed statistics.

1.1.1 Aspects of Health

All of the points in this section are taken from *Scotland's Health*. Males born in 1990 can expect to live to the age of 71 years; females to 77 years. But this only puts Scotland into about 15th place after countries like Spain, Italy, Ireland, Belgium.

Mortality in infants declined rapidly after the war. This is matched by decline in infectious diseases - polio, diphtheria, tetanus, measles, whooping cough. However, the incidence of HIV/AIDS is on the increase and is of some concern.

In 1980, 16,793 died before the age of 65 years; in 1990, 13,600. One third died from heart, stroke and other circulatory diseases, just under a third from cancer; 14% from accidents. Men's deaths from heart problems is declining but not women's. In these areas, Scotland has the worst record in the Western world.

Although many cancers can be treated now, there is still an increase in lung cancer especially in women. Each year, 4,300 die from cancer. Breast and cervix

cancer is not improving and the main strategy at the moment is screening for all. Again it is said that Scotland has the worst record in the Western world.

There has been a big reduction in road traffic accidents. However, this is still a significant problem. In addition, there is a significant problem of deaths in the home particularly from fire, producing figures which are 80% higher than in England.

The Glasgow area has particularly serious problems for heart disease.

“These variations underline the fact that the incidence of disease reflects both environmental conditions and the behavioural patterns of the local population.” (p32)

It is estimated that 60-80,000 of the population suffer from diabetes and one third are undiagnosed. This is accounted for by non-insulin related diabetes and is linked to excessive carbohydrate consumption and obesity.

Children suffer asthma (15%) and older people have bronchitis, emphysema - mostly due to smoking.

Arthritis is increasing as more people live longer. Treatment of some cases through joint replacement is also increasing.

Stress related problems account for one third of a GP's caseload. These may present as physical problems but can be linked to life-pressures or to the abuse of stress relieving drugs - alcohol and so on. Also there is a an in crease in suicide in young men, increasingly linked to social factors such as unemployment. Serious mental illness is comparable to other countries.

Mental Handicap is seen as a problem for prevention through screening and genetic counselling to determine whether to continue the pregnancy. Sixty percent of Downs Syndrome babies can be detected by screening.

Estimates are that 55,000 of the population are suffering from Dementia (senility), with 9000 in hospital. The suggestion from research in 1975 and 1982, is that 7% of all those over 65 years suffer from this condition.

Although there have been improvements in dental health recently, the figures are still behind those of England.

1.1.2 Health Priorities

As a result of these findings, there has been an attempt to set out priorities for Scotland. Reductions are targeted in Heart Disease, Smoking, alcohol misuse, drug misuse, cancer, HIV/ AIDS, Accidents, and dental ill-health.

The broad Health Promotion perspective has been adopted as a strategy for Scotland and it includes lifestyle and environment factors. The actions proposed involve informing and then *reforming* people in habits and making them aware of the impact of their own actions. It is not absolutely clear how this can be done nor exactly who will have responsibility to make it happen - ie which professional group.

This broad approach to Health Promotion envisages actions in the areas of: housing, social work, education, leisure and sport, environmental health, water and sewerage, and roads and the services linked to these. Also included in the process are the police and the fire service.

Significant broad plans are set out in the final pages of *Scotland's Health*, and these include a Scottish Health survey.

1.1.3 The Role of HEBS and its priorities

“Good health concerns us all, old and young. It particularly concerns us in Scotland with a long record of poor health.

“The Government are fully committed to the promotion of good health in its widest sense through our social, economic and environmental policies ... for example, developments in community care, housing and environmental improvements and urban renewal are all part ..”

Michael Forsyth's foreword, 1991

HEBS was set up on 1st April 1991 with an initial budget of £5.1m. The issues were stated as:

- the promotion of good health through a combination of specific campaigns targeted at populations and problems and measures encouraging positive lifestyles
- national priorities for HE concentrating on measures to tackle:
 - coronary heart disease
 - smoking
 - alcohol misuse

drug misuse
cancer
HIV/AIDS
accidents
dental and oral health

- establishment of HEBS
- roles of health boards, local authorities, voluntary organisations, employers, mass media and public an importance of good co-ordination with HEBS

1.1.2 Recent Activities of HEBS

The priorities of HEBS were stated in their first report as:

- to reduce CHD by 30% to the year 2000. Doctors to offer consultations to patients every 3 years to all aged 16-74 years.
- Cancer to be reduced 15% by year 2000.
- AIDS/HIV programme overlap with HEA in England, but aims of HEBS to increase awareness.
- Accidents to be reduced by road safety etc.
- Smoking to be reduced 30% in 12-24 age group and 20% in the older group.
- Alcohol to be reduced by 20% of people exceeding the limits.

The target groups for work are the general public, in the community and workplace and the targeted agents were health service, voluntary sector special projects staff and schools personnel. In order to deal with these problems HEBS has focused more on the evolving approach of Health Promotion.

1.2 Medical Models and Health

A medical view has long been seen as the Western vision of health. From this perspective, health is the absence of illness and disability. It has a certain force since ill-health can be incapacitating and potentially fatal. Concern for this human state has meant a great focus on cure and then more recently on prevention. Status and power has been given to those who are able to support life by dealing with illness. This seems justified and essential to society. However, there is a temptation to see medical intervention as the panacea. Macdonald (1994) observes

“ ... the complexity of the human body and all its ills, will become understood and treatable by the applying to the problems of ill-health the sophisticated technology of medicine which science will make available. To reduce ill-health to an area susceptible of technical fixes is to ensure that health services will fail in the way they have done so dramatically in poorer countries and increasingly also in developed societies.” page 32

In this, he identifies the pitfalls of an overemphasis on what he suggests is the engineering view of medicine. He points out the lack of attention to the promotion of health and even in the atmosphere which has been engendered by the review of the *Health of the Nation*, he believes that the initiatives are fundamentally misplaced with their exhortation to apply for a “health maintenance manual.” This view agrees with Kennedy (1981) and the link between social conditions and health:

“ Very many of the people to whom we are readily prepared to ascribe the status of ill, find themselves ill because they are poor, grew up in bad housing , eat poor food, work , if at all, at depressing jobs and generally exist on the margin of survival.”
page 42

Macdonald sees the mainstays of medical approaches in the pharmaceutical industry and in the technical achievements of such interventions as organ transplants and genetic medicine. While recognising the significance of these it is important to see them as part of the area of health care and not the whole of it. This is particularly significant for our study of deaf people since often their primary aim is expressed as achieving access to this engineering and technical model (eg recent BDA, RNID campaigns which provide video versions of health information).

This medical model is increasingly seen as limiting and the Alma Ata definition of Primary Health Care as community-based and community-determined is being used increasingly. In this model the community itself uses the scientific knowledge to create appropriate services.

One of the priorities becomes what Macdonald(1992) calls a *pillar* of Primary Health Care - participation. This arises from the experience of the negative impact on health of non-participation and powerlessness. Groups which have been in the past marginalised are able to take up a role in determining health priorities and provision. The difficult aspect of this is that those who have power must relinquish a proportion of it if people are to be able to participate. The issue is to what degree the participation can be achieved, when the community applauds the system’s concept of consultation and participation more than their

own views. Often the process reaches only the level of tokenism whereby the consultation process leads to no real transfer of decision-making. Interestingly, when schemes of participation have been evaluated the results tend to suggest that the discussion is in terms of the implementation of the current model of medical practice and does not usually require a change in the model (Parlato and Favin, 1982).

As a further pillar, Macdonald(1992) discusses equity and finds it hard to imagine the real distribution of power and decision-making which would be necessary to equalise health care. This applies not only in the Developing countries but also in the Developed world. WHO put equity on the international health agenda at the Alma Ata Conference in 1978. The dominant model of health care - often medical care - failed to address disadvantage in society and sometimes exacerbates it (WHO, Alma Ata Conference, 1978, described in Macdonald, 1992). This "pillar" has obvious relevance for our study of deaf people who frequently experience the lack of equity in society and from health services.

1.3 Health Education

In considering Health Education, it has become clear that there are serious concerns about the effectiveness of approaches used so far. The notion that lifestyle can be changed without due attention to life context, turns out to be naive and a major puzzle of how people can acknowledge the correctness of health information yet retain their old lifestyle, can be explained by the roots of this lifestyle and behaviour in their home and socioeconomic context. Health education campaigns may simply become an other external force which is resisted.

A great deal of health education has tried to alter people's preferences through the media.

"The approach of social marketing may fit well the manipulation of popular choices in tobacco and soft drinks. As a health education approach, however, it has serious deficiencies. It assumes that what is called for is a technical solution to the disease problem and the means of transferring the minimal necessary message into the lives of those to be taught." Macdonald, 1992, page 147.

But it does not seem to be effective. The solution is seen to be Health Promotion.

1.4 Health Promotion

“Health Promotion would include actions and campaigns to create a healthy environment as well as to provide health information and would in principle allow for the tackling of social causes of ill-health, as well as their symptoms. Understood in this way, Health Promotion is a mediating strategy between people and their environments incorporating both personal choice and social responsibility in health (WHO, 1986) (Macdonald, 1994)

Health promotion is the process of enabling people to increase control over and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realise aspirations to satisfy needs and to change or to cope with the environment. Health is a positive concept emphasising social and personal resources as well as physical capacities. Therefore Health Promotion is not just the responsibility of the health sector but goes beyond healthy lifestyles to well-being, rooted in health enhancing environments.

A major development has been the Ottawa Charter (1986). The key issue is that people should have control over the ability to improve health. So

“... to reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realise aspirations, to satisfy needs and to change or cope with the environment. Health is therefore seen as a resource for everyday life, not the objective of living.”

There is a need for peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity if people are to begin the process of achieving well-being as so defined.

Health Promotion can easily lose its radical edge and become focused less on life context and more on the traditional focus of health education - lifestyle. It can therefore be seen as yet another measure of control (Lupton, 1995). It is important when we talk of Health Promotion with Deaf people that we re clear what kind of Health Promotion we mean. Experience of Health Promotion suggest that professionals, even well-intentioned are not ready or trained for the unexpected in community involvement and the sharing of power this demands.

The basic model will be developed in the next section. This emphasises the idea that we have to understand the individual in the social situation and in terms of personal image. If an individual does not have a strong identity or a positive social role then this will affect the ability to deal with health issues.

More recently, there has been the development of the concept of health protection. People are likely to have behaviours which are designed to protect their own health. These do not usually involve doctors. This aspect is very important and to some extent it is what links the mental health area with the general physical health.

Work presented in extensive reports (in eg Health Education Research, Health Education Quarterly, 1995) shows how topical this area is. The key words which appear repeatedly are *empowered* and *empowering*. The organisation/system can be empowering to the extent that it creates the feeling of control in people - it gives power. Whereas the individual goes through a process to become empowered and also reaches the state of being empowered.

“Empowerment refers to the development of understanding and influence over personal, social, economic and political forces impacting on life situations.” (Schultz et al, 1995, p310)

In this paper the authors highlight the relation between social stress and health. They claim a positive association between health status and chronic stressors such as poverty, racism, social living conditions. This results in increased illness and mortality. Social participation improves the situation. In particular, participation in voluntary organisations or community organisations appears to raise the level of the individual's self concept. It is now possible to measure this feature.

Clearly an extensive report on the principles of Health Promotion is necessary but it is beyond the scope of this research project. A useful summary is provided by Secker (1995).

A second paper (Freudenberg et al, 1995) sets out how the measures can be implemented. Effective intervention in Health Promotion requires the individual to be involved and in addition, the application has to be targeted and focused. Participants' concerns about health have to be linked to broader life concerns and to a vision of a better environment. Significantly, they also include the development of leadership among the participants.

All of these point the direction for the research to be described below. We need to establish quickly how deaf people see themselves in relation to society as a whole and in particular we need to get a sense of how deaf people control their lives. This can form the foundation of the intervention which might follow this report.

1.5 Developing a New Approach to Health

One of the recent examples of the new thinking on health can be seen in the Healthy Cities Project (WHO, 1986). This is a project with major social aims and which spans the whole of Europe. There are also initiatives in North America and obviously the principles are in keeping with the Health Promotion ideals which have emerged from Developing countries. A significant amount has been reported on the European work (Davies and Kelly, 1993). It is interesting how, even here the participants are not yet able to deal with the major shift in emphasis which is implied.

The Healthy Cities programme is a political programme which is about change in power relations in respect of health and illness and fundamental epistemological shift in the conceptualisation of health itself. Or at least it has the potential to be so. The problem which is implicit throughout this volume and which the exchanges at our conference were a manifestation of, is the fact that locally and nationally based policy-makers, academic researchers and community members have mostly failed to grasp the real shifts in emphasis, theory and practice that the Healthy Cities movement implies. Instead, many commentators and practitioners remain wedded to a conventional (and modernist) view that science can both liberate the human condition and provide legitimisation for the political processes of so doing." Davies and Kelly, 1993, p7.

So what do we mean by healthy city?

"..one that is continually creating and improving those physical and social environments and expanding those community resources that enable people to mutually support each other in performing all the functions of life and in developing to their maximum potential." (quoted in Davies and Kelly, 1993, p20)

This view has been recurring in all the literature surrounding this new approach to health. It is the community value of personal functioning which is significant rather than the technical definition of body functioning. The difficulty that is identified in processes such as healthy cities (ie they are not campaigns or interventions) is that results are not set in the usual pre- post-intervention, test framework. The issues which appear are that patterns are appropriate for certain settings and communities and these need to be documented rather than the short-term outcomes as seen in medical indicators.

However, even when these goals are quite clear to the project originators there are still problems in the implementation within the community. McGhee and

McEwen (1993) describe the project set up in Drumchapel, in Glasgow where the principles of Healthy Cities were taken on. Various schemes of publicity and information dissemination were used and a Resource library was set up. Volunteers were trained (although less than had been intended) and they worked within the community. However, the nature of the social needs in the area and the roots of the volunteers in the community beliefs in traditional approaches to health meant that some of the ideals could not be reached:

“... despite the project orientation which has a strong emphasis on Health Promotion, this was not identified as a suitable or desirable task by volunteers; there was much more concern over coping with problems.” page 155.

It became clear that the volunteers who were dwindling in number through some disillusion with the project's impact and the fact that there were no immediate measures of improved public health, were reflecting the predominant community and cultural values for health solutions. It might also be said that their concerns and views could have been better incorporated from the beginning. The result is that the process cannot be imposed and almost certainly has to be grown. There can be no quick fix.

The Glasgow Healthy City Project (1995) is an extensive statement of the principles of Health Promotion and is a very clear description of the inter-sectoral nature of the Health Promotion ideal. As distinct from dealing with a Health Authority, the content of the document is clearly political and social. It sets out the concerns for ill-health which are medical in emphasis but which acknowledge its roots in social deprivation and basic inequalities in life in the city. It is interesting that it does not examine the multi-ethnic and multicultural aspects of health and focuses on poverty as the key. The integrated action model which is presented has three intersecting components : economic vitality, environmental integrity and social well-being. In the overlapping areas there are concepts such as *equitable*, *liveable* and *sustainable* and only in the intersection of all these components do we see health and well-being. For the purposes of our investigation in relation to deaf people, this model is incomplete as it fails to understand the limitations of interaction among people -an inherently cultural and social aspect. While people may live well, and equally, in a safe environment, if they do not interact with one another at the human level they may not be able to achieve what could be called *community health*.

The single mention of cultural activities is in the external expression of arts - performing arts and access to them in theatres. This is of some importance but fails to recognise the inter-personal nature of culture. Nevertheless, there is considerable involvement of all services within the city and a clear expression of

the principles for action. Interestingly, the support for secure accommodation for elderly people (Eventide Homes) is mentioned - this is something of a controversial area for deaf people whose older people are more at risk of isolation.

1.6 Disability and Culture

There is relatively little written about the issues for disabled people in the topic of Health Promotion. There are generally three possible strands:

- disability as the problem - the notion that disability is a health problem or arises in the context of preventable health problems
- disability information - the need to inform people about the rights of disabled people and to improve their access to the community provision
- the actual participation of disabled people in Health Promotion

Inevitably, the thinking in health care has been focused on the first and then most recently as disabled groups became more aware, there have been developments in the second area. However, the notion of disabled people as health promoters or as designers of their own programmes has hardly been tackled. Werner (1993) describes the PROJIMO project in Mexico which had disabled people at its heart. In order to satisfy the training needs, disabled leaders were careful to avoid a dependency on outside able-bodied help and strategies of short-term training were evolved. As a result of the emerging project, social pressures were brought to bear on the community at large and access solutions were *grown*.

A linked understanding which is more commonly discussed is the need to use culturally appropriate means for health understanding. Manderson and Reid (1994) explore the types of problems which arise in cultural folklore and types of solutions to health problems which arise in the interface between medical intervention and lay beliefs. Common among these are the practices which surround childbirth in different cultures where the earliest interactions with a neonate are determined by cultural expectations and belief rather than by professionally-directed health considerations.

The need to recognise cultural differences is often clearly stated in medical approaches and there is a usual public perception that cultural differences are important. But there are still major problems of responding properly to culture. In the case of Tessa Martin (Parsons, 1990), the medical services came into conflict with a Maori family who believed she was under an evil spell. The Hospital tried to administer an experimental drug for a suspected but undiagnosed brain

tumour and the family refused since they were not receiving the information and service in which they felt confident.

“ Conflict between the child’s parents , extended family and community, doctors and the police was precipitated by the failure of the consulting physician to meet with and negotiate the treatment with he child’s family, exacerbated by media reportage which construed the family as culturally deviant believing in evil spells and black magi, and magnified by police action (reports of child abuse and the forcible removal of the child which was broadcast around Australia on the evening news). The case highlights not so much the cultural basis of the child’s illness or her care - there is no evidence of this - but presumptions of cultural difference which resulted in ‘miscommunication and conflict therapeutic mismanagement, non-compliance and dissatisfaction of both clients and health professionals’ (Parsons, 1990), Manderson and Reid, 1994, p 20-1.

Tessa died two months after being removed from her family. In this case we see the difficulties of managing culture and it is precisely this aspect which was missing in the Glasgow documents. It is precisely this area which is of significance in the case of deaf people.

1.7 Health Education versus Health promotion

This distinction has become rather significant in the discussion. Faced with increasing problems in health care, and driven by the rhetoric of medical concern, communities have tended to see their solution in an informative, health *education* - the dissemination of information from the health providers about their goals and their knowledge of how to deal with the problems. When the perception is that some people have the knowledge and the means to alter health, ie the health professionals, the community wants to share in this knowledge and acknowledges that the way for this to happen, is for them to be come better educated - ie more like the health professionals.

A system of community health has been largely to do with bringing health care into the reach of the community by providing the principles under which it operates in a form in which the individual in the community can participate. This is very much a top down approach which considers that there is a right and a wrong way to approach health.

On the other hand what has appeared is a grass-roots approach which says that individuals define their own adjustment to life according to their community circumstance and that they have to be encouraged to develop their own priorities

and solutions. In this contrasting approach, we can see echoes of the work of Paolo Freire who criticises education which uses the idea of banking knowledge or investing in people. He sees it as a top down approach which is designed to assimilate. In community education however, the individuals come together to identify their needs for information and knowledge and the skills which are produced within the community become the base for development. Empowerment is the key to this and Freire's work suggests that the only way to reduce the oppression of the minority by the majority is to allow the oppressed to develop their own systems (Freire, 1973). Freire has inspired health workers in the Community Health Movement including programmes in Scotland (Jones and Macdonald, 1994).

There are also questions about the emphasis on social means to better health. Williams and House (1991) are quite clear on the effects of social factors:

"Social relationships can improve health and reduce stress in at least three ways. First, social ties can directly improve health by meeting basic human needs for affection, social contact and security. Second, supportive social relationships can reduce interpersonal conflict and tensions, thereby reducing stress. Increases in social ties lead to improvements in health independent of the level of stress by these two mechanisms. The third mechanism is a buffer or interactive one. The buffering hypothesis holds that the mobilising social ties in the presence of stress protect the individual from the pathogenic consequences of stress." page 155

What we find in Health Promotion is the pressure for the community to devise its own means and its own goals. This has produced, as hinted at by Davies and Kelly (1993), a significant movement of workers in the health delivery field towards a *superficial* embracing of the Health Promotion ideal. This however, is still a medical science model trying to get ahead of the game. It is still an attempt to use technology and existing services to meet the perceived (and sometimes) elicited needs of the community. It is the "brown bread and jogging" approach. It probably does not meet the needs of the Health Promotionalists and is highlighted in the accounts of the Drumchapel scheme where the field workers feel their progress is insufficient and where there is disillusion that the community do not gratefully receive all the health information which is now on offer.

When Bunton and Macdonald (1990) set out the principles of Health Promotion, they were uncertain of its progress:

“A lot can be at stake during periods of change. Professional power and identities are profoundly influenced by changes in their knowledge base. The appropriateness of a medical role in Health Promotion may continue to be debated. Issues of professional co-ordination and leadership may be discussed”. page 17

We believe this only tells half the story. It is not yet clear how services are to engage with the community. Despite the clarity of goals with which services are now expected to present themselves (charters and mission statements help in this process), seldom are there devices for shifting power and for enhancing self determination. This is a key issue. It will also be seen in the research which follows that the issue of community interaction cannot be ignored and models of Health Promotion will need to address real access and integration of marginalised groups.

1.8 Health Promotion for Society

In engaging with this point, we will quickly come to see how the society must accommodate and herein lies the greatest problem for Deaf people's health. While empowerment is possible and Health Promotion from deaf roots is possible, genuine alteration of the control process is necessary. The determination of what constitutes health still resides outside of the Deaf Community. We can predict a major issue in how one can resolve the competing forces of Deaf people's awareness of their own identity with the interests which are embedded in the medico-educational framework. From our initial reading of the literature and consideration of the issues, it seems very likely that these issues will recur throughout the research reporting.

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Section 2: Some Aspects of Deafness: Effects on Health

2.1 Deafness and the Deaf Community

Within the areas of social investigation of hearing loss, the term *Deaf*, has come to signify the member of a minority group who identifies with other deaf people, who is most likely to have passed through special education for deafness and has had some access to sign language - BSL. As a generic term, *people with a hearing loss* has been used in preference to hearing-impaired, which has rather negative connotations. Those who acquire a hearing loss or are hard-of-hearing constitute another group, who are primarily hearing people who no longer hear. These are not involved in this project even though they are in the majority - for the simple reason that their problems of accessibility are rather different (See Jones, Kyle and Wood, 1987, for a detailed study of acquired hearing loss).

A Deaf person is someone who will have been born with a severe to profound hearing loss (or will have acquired it very early in infancy), will have experienced special education because of the hearing loss, will have encountered sign language at some stage in their school career (from peers or from teachers), will as adults, attend with varying degrees of frequency, a deaf club or gathering, and will tend to describe themselves as Deaf and as a user of BSL(British Sign Language).

Typically Deaf people will report a lack of access to information and services and will cite instances of difficulties in primary health care - in particular, a reluctance to use local health practices as doctors are unable to communicate directly - thus affecting the doctor-patient relation (when an interpreter or other communication means(such as writing down) has to be interposed. Research carried out in Bristol, for a promotional video on behalf of the Health Services Training Agency in England(Jones, 1990, "*Sound Advice*") highlighted a range of confusions arising from attempts to use primary health care centres.

Increasingly, information material is being made available on video in BSL - the Central Office for Information in London, in collaboration with the British Deaf Association is currently making available BSL video versions of informational materials. For example, the *Patients' Charter* is now available on video. Despite misgivings of professionals, extensive research has indicated the richness and complexity of sign language (eg Kyle and Woll, 1985). In effect, sign language like all languages develops to meet the needs of the users. As Deaf people have become more prominent and society more progressive, the domains in which

sign language can be used are increasing. The grammatical structure of the language can now support the rapid expansion of vocabulary which is needed. A similar story has occurred in the revival of modern day Gaelic. There is therefore, no reason to believe that full information on all health matters cannot be supplied through the means of BSL.

These factors coupled with the discovery of community patterns of association and cultural developments, make it most realistic to consider the Deaf Community as a *minority group* in Scotland.

2.2 Population Characteristics

So how many Deaf people are there? Although there are few direct studies of incidence coupled to social studies, which would determine the size of the Deaf population, good estimates can be made on the basis of published work. At its simplest level, we can predict that between one in 2,000 people will have a severe-to-profound hearing loss. While some of these will be in the margins, because of additional problems (the incidence of other difficulties is higher in those with a hearing loss) and because of choice not to associate with other deaf people, their numbers will be balanced by those partially hearing people who marry into the community or who choose sign language as a primary communication. A crude projection would give Scotland a Deaf population of 2,500 - 3,000 people - a more detailed analysis is given below. The age characteristics of this population should broadly match those of the hearing population - ie it is a population whose mean age is becoming older. Health issues appropriate to elderly people are becoming a bigger and bigger issue for deaf people.

Studies of deaf children (Kyle, et al, 1978) and of the Deaf Community (Kyle and Allsop, 1982) confirm the greater proportion of males as compared to the hearing population - 52% as children, 51% as adults (compared to 49% in the main hearing population). Deaf adults are less likely to marry (65% as compared to 75% of hearing people) but when they do, 90% marry other deaf people.

Deaf people occupy the lower socio-economic groups in society in terms of job and status (Kyle and Pullen, 1985) - a pattern which is repeated in Europe (Jones and Pullen, 1987) and in the USA (Schein and Delk, 1974). This is surprising insofar as Deaf people's intelligence is distributed normally; although it is compatible with the fact that deaf people achieve fewer school qualifications (almost half leaving, without a single pass at CSE - ie below O-grade level in Scotland).

Causes of hearing loss are well documented but tend to repeat the finding that up to 40% are *causes unknown*. The likelihood is that the basis is genetic but as yet

incompletely understood. Only 10% is likely to be hereditary, with varying numbers of other causes according to viral infections and to the incidence of intermittent epidemics and local environmental circumstances.

Another feature of the Deaf Community is the language which has evolved over hundreds of years.

“British Sign Language is a language of movement and space, of hands and of the eyes, of abstract communication as well as iconic storytelling, but most of all it is the language of the Deaf Community in the UK: it is not a new language, nor is it a system recently developed by hearing people; rather it is a naturally occurring form of communication among people who do not hear”.
(Kyle and Woll 1985)

Sign language evolved naturally in most countries which we know about. British Sign Language (BSL) is the language of members of the Deaf Community in the UK. The perception of the Deaf Community as a minority group rather than as a disabled group, has arisen because of its new found features eg the status of its' language.

‘For its non-academic nature and lack of emphasis on English, sign language has been viewed by hearing people as epitomising the failing deaf person’ (Kyle and Woll 1985).

However, many people now recognise that sign language, rather than being an inferior system of gestures or mime, is a language and an integral part of a culturally rich community.

The structure of the language is quite different from English. Kyle and Woll(1993) provide a summary of this showing how the lexicon, syntax and morphology are realised. The extent of the difference is sufficient to imply, quite correctly, that there is not an easy transition from English to BSL. Text and information may have to be transposed radically to preserve the meaning and intention from one language to another. Since Deaf people tend to have much less developed reading skills in English, the issue is a significant one.

Hearing aid use amongst the deaf population is difficult to determine, even though questions by our deaf researchers to deaf people, show that very few of those with profound hearing losses are continuous users. Cochlear implants are unlikely to have a large personal impact on the current adult Deaf Community at this time, but will have an impact on children and then by extension on the future adult community.

Deafness has no detectable geographical pattern of incidence in UK - it appears to be evenly distributed throughout the country. However, because of Deaf school provision, there has been some migration to the cities and there is likely to be a proportionally greater community in major cities such as Glasgow, Edinburgh, Aberdeen and so on. There is no good information on this as there is something of a catch, in that Deaf clubs grow where there are Deaf people and it is through Deaf clubs that we trace Deaf people - however, lack of appearance of a Deaf club, does not have the corollary that there are no Deaf people in that area. Finding precise figures for the Deaf Community is therefore, something of a problem.

2.3 Working with the available statistics

There are several ways in which we can achieve an estimate of the number of Deaf people in Scotland. The first is by using the predicted incidence of deafness at birth and attaching this to all the population statistics for births throughout the years which would apply to the community. This is problematic as it gives only a medical-audiological estimate of hearing loss and does not imply directly, participation in the community by those with a specified hearing loss. That is, measured hearing loss does not equate directly with community membership.

The second is to use educational statistics. This is justifiable since the majority of Deaf Community members will have gone through a school for the deaf.

In both cases there are limitations on the extent of the data available and in the accuracy of the information. We have examined statistics more widely - see section 2.3.1 below, but these do not provide a sufficient base for a meaningful estimate. A more effective estimate based on the population change and the year of birth is provided in section 2.3.2.

2.3.1 Searching for Statistics

2.3.1.1 Europe

As a first step official statistics of the EU were consulted. These tend to produce estimates which are way above what we commonly believe to be true: 33% of the adult working population have an impairment and 19% have a disability. Eleven per cent are expected to have a disability related to language, speech, vision or hearing. This reduces finally to a prediction of hearing problems for 2.65 million people in the UK. This will include those who acquire a hearing loss.

Throughout these sets of official statistics the numbers seem to be inflated and unreliable. Source: Eurostat, p137.

2.3.1.2 Educational Provision

The BATOD directory for England, Scotland and Wales has some information on schools with deaf students:

Table 2.1: Educational Provision (BATOD survey)

	England	Scotland	Wales	UK
COLLEGE	32	4	3	39
SCHOOL	29	8	3	40
SERVICE	106	19	7	135
UNIT	398	19	33	451

The above data from the BATOD directory could be considered the most up to date information available. This data was collected in January 1994.

2.3.1.3 Recorded Children

The Scottish Office Statistical Bulletin entitled `Provision of Education for Pupils with Special Educational Needs` published February 1995 shows pupils with records of needs in education authority primary and secondary schools at September 1993 in Scotland.

Pupils with hearing difficulties are shown to represent 5.7% (132 pupils out of 2,301) of those recorded with special needs in primary schools. In addition, 6.1% (139 pupils out of 2,267) of those recorded with special needs in secondary schools have a hearing problem. In total 271 pupils are recorded in Scotland with hearing difficulties. (If projected equally across the age range, this would imply 1725 people who had been recorded - ie 1725 Deaf people in Scotland's population.) This probably means that there is an under-recording of potential Deaf Community members.

2.3.1.4 Hearing Aids

The office of Population Censuses and Surveys (OPCS) do not record deaf people specifically. However they record difficulty with hearing: by gender and age, 1992.

Table 2.2: Hearing Difficulties in the Population (OPCS)

	WEARS AN AID	HEARING DIFFICULTY, NO AID	NO HEARING DIFFICULTY
	%	%	%
MALES			
16-44	-	6	94
45-64	3	17	80
65-75	11	25	64
75 & over	20	25	55
All aged 16 & over	4	13	83
FEMALES			
16-44	-	4	96
45-64	2	9	90
65-74	6	15	79
75 & over	17	24	59

Source: OPCS, 1995

The General Household Survey does not specifically record deaf people, only people who have a tinnitus problem.

2.3.1.5 Handicap

The Department of Health and Social Security published the numbers of people registered handicapped in Britain in 1970. Deaf people are covered in this survey.

Table 2.3 Handicap Register (1970)

<i>Deaf (Including hard of hearing)</i>					,000 s
	1961	1966	1967	1968	1969
Under 65	27.5	26.7	27.3	27.6	27.7
65 & over	10.2	13.1	13.7	14.3	14.6
All ages	37.7	39.8	41.0	41.9	42.4

Source: Social Trends 1995.

2.3.1.6 Screening

The MRC Institute of Hearing Research based at Nottingham University reports that the incidence of congenital deafness is 1.1 per 1000 live births for hearing losses of >40dB and 1.1 per 4000 for profoundly deaf (>95dB). This implies that 880 children will be born in England, Scotland and Wales each year with a moderate hearing impairment (40dB or greater), of whom 220 (25%) will have a profound impairment (>95dB). In addition there is acquired deafness. By the age of 5 years a further 100 children in each birth cohort year will acquire an impairment, about 60 to 80 of whom will have a profound loss. So the total number of children in each year goes up to 980 with about 280-300 of them having a profound loss. This gives a figure on the high side for the Deaf Community - 70,000 mild to profound losses in the UK and 19,000 profoundly deaf.

The MRC Institute of Hearing Research based in Glasgow, sees no regional variation of deafness in the UK once partialling out effects of age, sex and socio-economic status.

Scotland's number of hearing impaired adults are illustrated below as a function of age group, gender and regional health authority. Prevalence at 65dB HL is shown below:

Table 2.4: Estimates based on screening figures (MRC - IHR)

Age	Gender	Population (thousands)	>65dB	>95dB
18+	All	3937	77	13
18+	Female	2070	47	7
18+	Male	1867	30	6
18 - 60	All	2903	13	4
18 - 60	Female	1459	5	0
18 - 60	Male	1444	8	3
61 - 80	All	862	26	3
61 - 80	Female	488	15	2
61 - 80	Male	374	11	1
> 81	All	172	38	6
> 81	Female	123	27	5
> 81	Male	49	11	1

Source: Hearing in Adults, Prevalence & Distribution of Hearing Impairment, MRC Institute of Hearing Research National Study of Hearing: London Whurr Publications:1995.

2.3.2 Incidence Figures

Scottish Office Statistics show the population of Scotland in 1994 as 5.1 million (UK 58.2 m). Of these 2.5 million are males. The relative age distribution is shown in Table 2.5. An estimate provided by the Institute of Hearing Research in Glasgow indicates that 1.1 per thousand live births will have a hearing loss of 40dB and that of these, one quarter will have losses of over 95dB. We can insert these predictions into the population statistics.

Table 2.5: Scotland's Distribution of hearing loss by age, predicted in 1994 (proportion of the published general population figures).

Age	Distribution	>95dB	>40dB
0-15 yrs	20.2%	283	1132
16-64 yrs	64.8%	908	3632
65-74 yrs	8.8%	123	492
75 yrs +	6.3%	88	352
Total	100	1402	5608

This gives an overall figure of 1,402 profoundly deaf people and 5,608 people with a mild to profound hearing loss.

Taking the 1992 based population projections for Scotland & its regions/islands areas, we can apply the Institute of Hearing Research statistics for deaf births more accurately. Since the population of Deaf people is likely to be relatively stable throughout, we have no evidence to assume that there is a difference in incidence over the period.

Table 2.6 Scotland's Total Population by Region

	1992	1996
SCOTLAND	5,111,200	5,145,968
BORDERS	104,800	106,470
CENTRAL	272,700	274,414
DUMFRIES & GALLOWAY	147,900	148,476
FIFE	349,900	354,273
GRAMPIAN	522,400	539,698
HIGHLAND	205,900	210,236
LOTHIAN	750,600	763,864
STRATHCLYDE	2,290,700	2,278,343
TAYSIDE	394,600	397,627
ORKNEY	19,710	20,136
SHETLAND	22,640	23,232
WESTERN ISLES	29,350	29,199

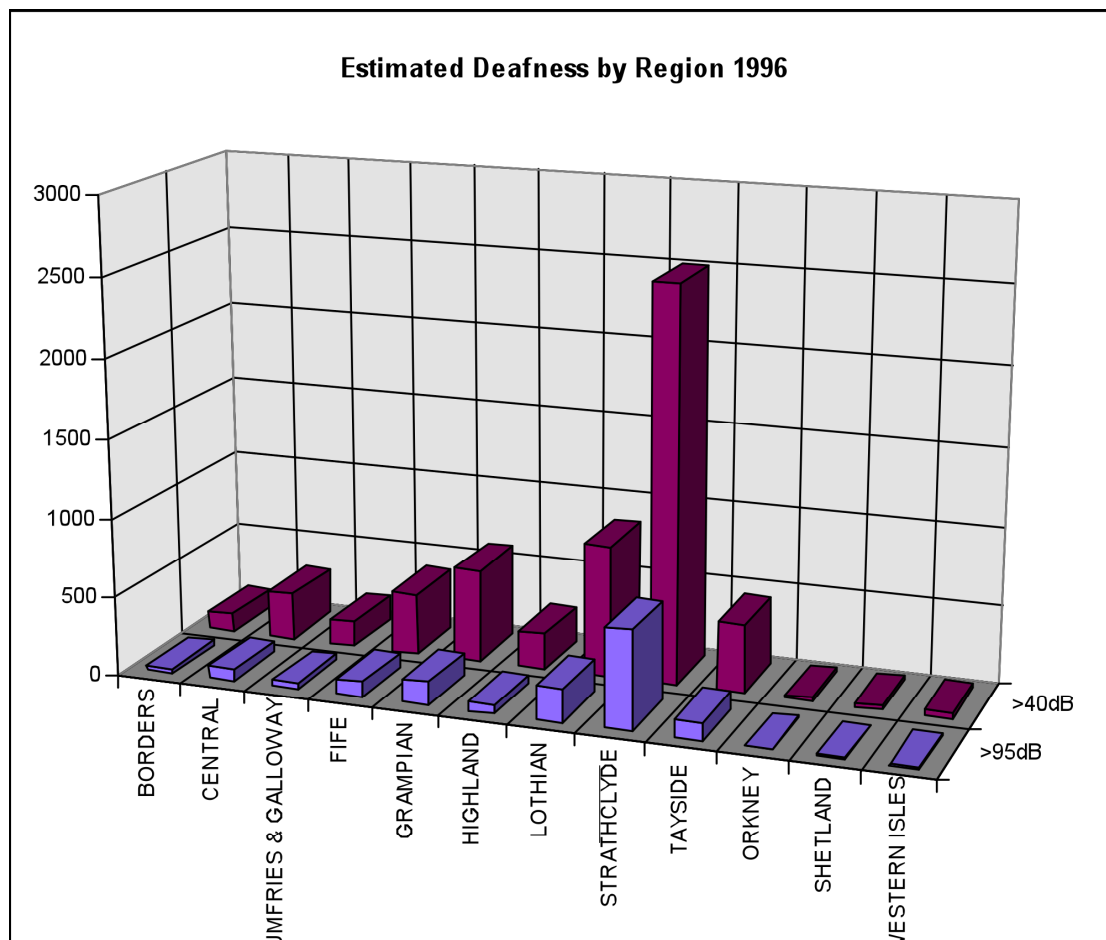
Table 2.7 shows the distribution of deaf people in the regions. These can be checked by personal contact with field workers in the smaller regions. However, we would predict a drift to the main areas of population; it is not clear if this

drift would be greater than for hearing people although the likelihood is that Deaf people may stay on in the city where their Deaf School was.

Table 2.7 *Estimated Incidence of Deafness in Scotland using IHR 1.1 per 1,000*

	>95dB	>40dB
BORDERS	29	117
CENTRAL	75	302
DUMFRIES & GALLOWAY	41	163
FIFE	97	390
GRAMPIAN	148	594
HIGHLAND	58	231
LOTHIAN	210	840
STRATHCLYDE	627	2506
TAYSIDE	109	437
ORKNEY	6	22
SHETLAND	6	26
WESTERN ISLES	8	32
<i>Total</i>	<i>1415</i>	<i>5660</i>

This table is presented graphically in Figure 2.1 on the following page. The figures imply very small populations in the outlying areas. This has major implications for services.

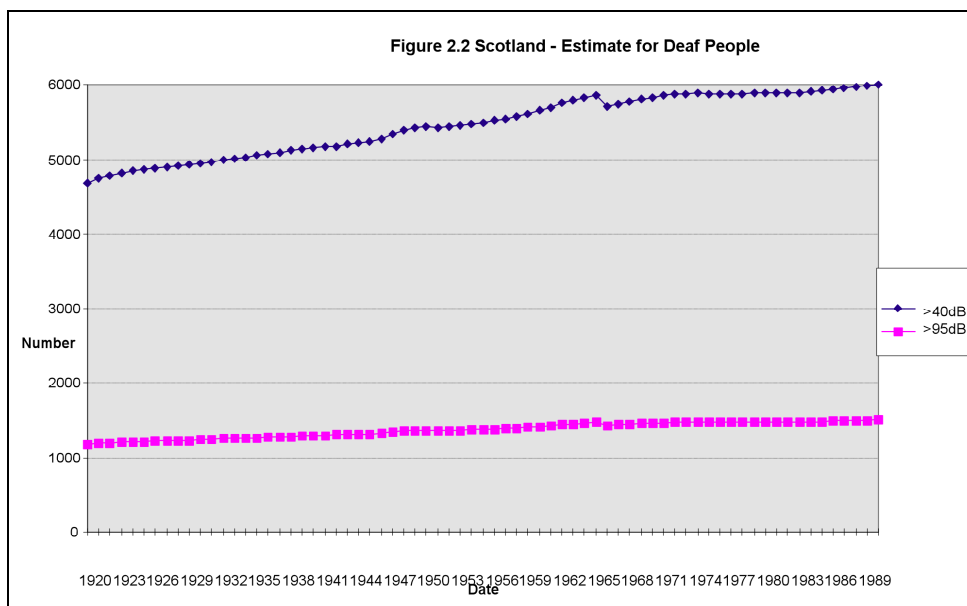


In Figure 2.1 we can see very clearly that the largest population concentration will be in Strathclyde. Although the changes to Unitary Authorities will alter this in fact, though there is no implication in geographical terms.

In Figure 2.2, the estimate of the changes in the deaf population is linked to the general population trends, showing that there has been a slow increase in the size of the deaf population. These figures are based on the same proportionate estimates of the general population. A better estimate can be obtained when we can examine the deaf school figures in terms of the age of the children. Here we can see that there is a general decline in the Deaf school population over the period from 1930. There are several gaps - the war years and also since 1982, when the DfEE stopped collecting statistics by type of problem. As a result we have no up-to-date figures for deaf children in school. Part of the decline is due to the change in policy, so that more deaf children are integrated and partly there

is better provision of hearing aids and so the partially-hearing children tend not to appear in the statistics any longer. It seems likely that the Deaf Community has become more deaf over the years although it would be very hard to obtain reliable measures of this. We are therefore left with a figure between the populations shown in Figure 2.3 This has projections across the points where we have no data and it has components estimated by taking Scotland as a proportion of the UK.

This gives an estimate consistent with the general population estimates and supports Figures 2.1 and 2.2.



The figures shown in Figure 2.3 are for people between the ages of 16 years and 76 years. If we extend this proportionally downwards to include children from birth, the total figure we obtain for Scotland is 2330 former Deaf school pupils and 4199 Deaf and partially Deaf. We can also see that this population is declining. That is although the percentage of people with a hearing loss remains much the same, there is a reduction in the number of Deaf school students and probably as a result, a reduction in the size of the Deaf Community. It is our expectation that this is not solving the problem of Deafness but that it is creating a sub-group of Deaf people who do not have the benefits of Deaf Community resources. We would expect this problem to be seen later in life in higher levels of mental ill-health.