King's Fund

Linkworkers in Primary Care

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King's Fund
Publishing
11–13 Cavendish Square
London W1M 0AN

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Published by
King's Fund Publishing
11–13 Cavendish Square
London W1M 0AN

First published 1998

ISBN 1 85717 224 8

A CIP catalogue record for this book is available from the British Library

Available from:

King's Fund Bookshop
11–13 Cavendish Square
London W1M 0AN
Tel: 0171 307 2591
Fax: 0171 307 2801

This report has been produced to disseminate research findings and promote good practice in health and social care. It has not been professionally copy-edited or proof-read.

Printed and bound in Great Britain

Contents

Acknowledgements
Executive summary 1
Introduction 5

Part 1: The current state of knowledge 7
Methodology 7
Terminology 8
Role definitions – activities undertaken by linkworkers 10
Roles and professional boundaries 26
Why linkworker projects were established 28
Funding 32
Recruitment, training, support and development 35
Management, supervision and accountability 40
Administration and organisational issues 42
Evaluation of schemes 44

Part 2: Looking to the future 45
Making the most of linkworkers in primary care 45
The development of linkworkers in primary care – whose responsibility for the future? 48
Integration or independence – a continuing dilemma 51

Part 3: Linkworkers in primary care – a checklist for commissioners and providers of primary care 53

Bibliography 58

Appendix 1: The literature review: about the search strategy 63
Appendix 2: Interview schedule 66

Acknowledgements

Many people have helped with this project. Dr Steve Gillam commissioned and edited the work. Janice Robinson and Barbara Vaughan gave help throughout the project. Susan Elizabeth and Juliet Beaven in the Grants Unit made available information about relevant grant-funded projects. Thanks are also due to Lucy Johnson for advice and assistance in identifying material for the literature review, and to Hayley Hutton and Clare Brown for their administrative support.

Thanks are also due to the following people who gave information or took part in interviews and discussions, and who must take credit for many of the ideas in Part 2 and Part 3 of this paper: Balvinder Basra, Akgul Baylav, Elizabeth Brasnett, Maggie Cairney, Patience Caseras, Jeff Chandra, Andrew Gill, Dr Paramjit Gill, Dr Iona Heath, Shamem Jamal, George Leahy, Dr David Jones, Kate Jones, Dr Raj Khanchandani, Robina Mir, Neil Mortimer, Moosa Patel, Hansa Pattani, Jean Stafford, Bhagiwanti Sukhani, William Vineall and Rachel Wells.

Executive summary

Introduction

This paper examines what is known about linkworkers, using information derived from a review of the literature and from interviews with those working in the field. It discusses how linkworkers might make a contribution to primary care in the future, and considers some of the organisational issues that will need to be addressed. Finally, it includes a checklist for commissioners and providers of linkworking in primary care.

Part 1 - The current state of knowledge

1.1. Methodology

The methods used were:

a) A review of the literature

b) Interviews

c) Information from King's Fund grant-funded projects

1.2. Terminology

There are many terms in use for "linkworkers" and the word denotes many different roles. This problem makes it difficult to compare linkworker schemes.

1.3. Role definitions - activities undertaken by linkworkers

Linkworkers undertake a variety of roles, and are employed by a range of organisations. Roles within the NHS include dealing with language, cultural and communication issues; advocacy; promoting better health and making health care systems accessible. Although many linkworker schemes were developed to address communication difficulties, many have extended their remit to take on other important roles. There is a recent upsurge of interest in ways of overcoming language barriers that use remote (telephone) interpreting systems, rather than linkworkers, but opinion is mixed on the usefulness of these schemes.

1.4. Roles and professional boundaries

There is commonly tension about roles and professional boundaries, with some suspicion from health care professionals. These tensions are best avoided by careful negotiation in establishing projects. Professional boundary disputes tend to resolve over time, and are alleviated by the inclusion of linkworkers in the wider primary care team.

1.5. Why linkworker projects have been established

Linkworker schemes have been established for many reasons, often as a response to language and communication issues and to promote advocacy and outreach. Some schemes respond to issues raised by local research, whereas others have been more loosely based on perceived needs. Some schemes have been established opportunistically, in response to a funding opportunity, or as a result of local pressure. Few were a response to formally assessed needs.

1.6. Funding

Information on costs and sources of funding is patchy and comparable, national data were not found in this study. Funding for linkworkers has usually been short-term and this has been a serious restricting factor. Charities have been significant funders, but schemes have experienced difficulties moving into the mainstream. Linkworkers are usually on low Administrative and Clerical (A&C) salary grades; this lowers their status.

1.7. Recruitment, training, support and development

The issue of linkworker recruitment cannot be wholly separated from their training and qualifications, or from their ongoing need for support and development in their roles. Many schemes have tried to recruit linkworkers with relevant knowledge of communities, and their training has been designed to reinforce and supplement their existing knowledge. However, many people consider that linkworkers are insufficiently trained. There have been some attempts to make training more

systematic, linking it in with accredited courses and access to higher education. These initiatives may avoid the perpetuation of unequal opportunities for black and minority ethnic health care workers, who might otherwise be denied equal access to health care careers with more status, pay and opportunity for career development.

1.8. Management, supervision and accountability

Opinion is divided on whether linkworkers are best managed from within the NHS or by an independent body. There are ways to develop hybrid forms of management which build on the advantages of each model. Whichever structures are chosen, the involvement of local communities in the management of linkworker schemes is desirable.

1.9. Administrative and organisational issues

There is room for improvement in the administration and organisation of linkworker schemes. Most services offer a nine-to-five service, which usually falls short of meeting need.

1.10. Evaluation of schemes

There are many methodological difficulties in evaluating linkworking. The short-term nature of projects and lack of funds for evaluation pose particular difficulties. The research base is therefore weak.

Part 2 - Looking to the future

2.1. Making the most of linkworkers in primary care

There are aspects of primary care where linkworkers can make a particularly valuable contribution, including at new patient health checks; at health promotion, screening, immunisation and advice sessions; in disease management; women's health and mental health.

2.2. The development of linkworkers in primary care - whose responsibility for the future?

Health Improvement Programmes offer Health Authorities the opportunity to adopt a more strategic approach to the development of linkworking in primary care. Primary Care Groups are likely to vary in their capacity to commission linkworking. There is a continuing need for development funding, but short term funding poses problems.

2.3. Integration or independence - a continuing dilemma

Those who see themselves as potential funders of projects tend to favour a high degree of control over the management of projects. However, if linkworkers are to work effectively in primary care, models of management must be explored that encourage hybrid models of management building on past experience. Such models would locate linkworkers more firmly in the mainstream of the NHS, while retaining community involvement in the governance of linkworker schemes.

Part 3 - Linkworkers in primary care - a checklist for commissioners and providers of primary care

This section contains a checklist of questions to be addressed by commissioners and providers, under the following headings:

- Strategic framework
- Assessing need
- Defining the linkworker's tasks
- Management and supervision of linkworkers
- Funding
- Monitoring and evaluation
- Recruitment and selection of postholders
- Training
- Administration and support

Introduction

The contribution of linkworkers to the NHS goes back over 20 years. Growing awareness of the particular needs of health service users from minority ethnic groups during the 1970s and 1980s triggered the piloting of various linkworker schemes across the country. An extensive descriptive literature testifies to the success of these schemes in a number of urban settings with a large number of largely Asian minorities. In different settings, the role has encompassed interpreting, advocacy, health education and health promotion.

The changes to the GP contract introduced in 1990 encouraged Family Health Service Authorities (FHSAs) to reimburse the salaries of a widening range of ancillary workers. Linkworkers were seen as a potentially valuable cultural bridge between doctors and patients in areas with large ethnic minority populations. The evolving debate about skill mix in general practice has intensified interest in this area. Increasing demands on primary health care teams, coupled with the problems of medical recruitment, have renewed interest in extending the role of the practice nurse. "Nurse practitioners" in their turn, are seeking to delegate some of their functions. The White Paper *The New NHS - Modern Dependable*[1] is likely to promote continuing review of skill mix and further diversification of roles in primary care.

There are many descriptions in the literature of individual linkworker schemes giving details of their establishment, training and activities undertaken. Although broadly positive, few have systematically considered their impact. For health service managers and GPs thinking about setting up linkworker schemes, there is a lack of clear guidance with no recent or definitive overview of the subject. This document attempts to fill that gap and preliminary work has been undertaken at the King's Fund to synthesise the information and to draw out lessons from the past that may be relevant

[1] HMSO. *The new NHS - modern - dependable.* Cm 3807 December 1997

to the future. In particular, we have tried to consider the contribution that linkworkers might make in a society that is culturally diverse, in a policy context where primary care is extending its scope and in a political context where there is a renewed focus on tackling inequalities in health.

In this report we look first at what is known about linkworkers, using information derived from a review of the literature and published papers, and from interviews and discussions with those working in the field. The literature contains a considerable amount of material about linkworkers in settings other than primary care, but inferences have been drawn where possible to relate material to primary care settings. Ways in which linkworkers might make a contribution to primary care in the future are then considered, with particular reference to the roles which they might fulfil, and the organisational issues that will need to be faced in order to maximise their contribution. Finally, there is a checklist of issues to be addressed by commissioners of linkworking in primary care and by providers.

PART 1

THE CURRENT STATE OF KNOWLEDGE

1.1. Methodology

This paper is based on the following information sources:

a) A review of the literature

A search of the literature on linkworkers was carried out, and the search strategy is detailed in Appendix 1.

The depth and quality of the published material varied greatly. It included academic studies which had been published in peer-reviewed journals, evaluations of local schemes and particular projects, academic theses submitted for higher degrees, papers written for Health Authorities, journalistic accounts of linkworker schemes, accounts that were apparently designed to give information about linkworker schemes and/or to make out a case for their continuation and articles that discuss linkworker roles in a wider context of health care needs for ethnic minorities. The literature was largely descriptive and seldom attempted to assess outcomes. There was relatively little information available on detailed costings.

b) Interviews

Interviewees were selected in order to give a range of perspectives from linkworkers, their managers, GPs and Health Authority commissioners. They came from a range of geographical locations, and sources in London, Leeds, Bedfordshire and Birmingham ensured that varied experience across the country was taken into account. Interviewees were also known to have an interest in primary care, ethnic minority health and (in most cases) in linkworking. However, this was a small, exploratory project, and no claim can be made for the representativeness of interviewees. Rather, their valuable insights brought to life many of the issues explored in the literature, and added some lively speculation on future developments, which are not to be found in published

material. Many of the issues draw on the insights of one or more interviewees. Since there was a convergence of views on a number of issues, it would be tedious to ascribe all views to sources. However, where a view seemed to be unusual, or to reflect a particular professional or organisational perspective, this has been acknowledged.

Interviews were conducted with ten individuals and, in addition, two group discussions were held. The interviews were mostly conducted face-to-face, and three were conducted by telephone. A semi-structured schedule of questions was prepared (see Appendix 2).

c) Information from King's Fund files on grant-funded projects

Files of relevant projects funded by the King's Fund were consulted. These were useful in confirming the diversity of schemes and management and financial arrangements, but did not yield much additional evaluative material.

1.2. Terminology

KEY POINTS

- **There are many terms in use for "linkworkers"**
- **The word "linkworker" can denote many different roles**
- **These problems make it difficult to compare linkworker schemes**

An immediate problem that faces a researcher in this area is the problem of terminology. There are many alternative terms used alongside "linkworker" and the word is used to cover a multiplicity of roles, some of which are common to many "linkworkers" and some of which are rather less common. Roles evolve over time, even within one site and within one post holder's job. Passionate arguments take place over the appropriate terminology, as each nomenclature carries or conceals a set of assumptions about the role and status of the post holders.

> ***There is no agreement about what bilingual workers do. Furthermore, there is no indication about what they do from their job titles, many of which are used inter-changeably.***
> **(Baxter et al 1996)**

Common alternative terms in the UK include advocate or health advocate, bilingual worker or bilingual health worker, bi-cultural worker and lay health worker. This is in addition to interpreters, whose task, strictly speaking, is to interpret from one language into another where the parties lack a common language. However, in practice, many interpreters have acquired a broader function that has features of linkworking as part of an enhanced role. Although the American literature has not been comprehensively reviewed for this paper, the issue of terminology is even more complicated in the USA, where over 30 terms are used for lay health advisers (Eng and Young 1996).

Within this report, we take an inclusive view, and consider many aspects of linkworking, whatever title may be used by the personnel who perform the various tasks. For ease of reference, we use the generic term linkworker throughout, except where a scheme is described that uses an alternative designation for its workers, or where we retain the particular terminology that is used in the literature. The common strand in our use of the term is that all the "linkworkers" we consider contribute in some way to the effective communication of patients from ethnic minority communities and health professionals in the NHS, and/or to improving access by patients from ethnic minorities to health services.

It should be noted that some "linkworkers" may work primarily in a local authority setting. Although their roles may have much in common with those whose work focuses on the NHS, we have not included them within our remit.

1.3. Role definitions - activities undertaken by linkworkers

KEY POINTS

- **Linkworker roles are very diverse and linkworking can mean many things to different people. Roles can be grouped into the following categories:**
- **Language, culture and communication issues**
- **Advocacy**
- **Promoting better health, including participation in disease management**
- **Making health care systems accessible**
- **There is a recent upsurge of interest in ways of overcoming language barriers that use remote interpreting systems, rather than linkworkers, but opinion is mixed on the extent of the usefulness of these schemes**

Box 1 Roles of linkworkers

Among the various roles of linkworkers in the UK are the following:

- Interpreter
- Cultural ambassador
- Outreach worker
- Advocate
- Patient's representative
- Social supporter
- Health advisor/educator
- Health promoter
- Lay health worker
- Source of feedback to NHS planners and providers
- Route for communication on consultation
- Educator of health professionals
- Community change agent
- Counsellor
- Messenger

These roles are performed by workers employed by a variety of organisations.

Box 2 Who employs linkworkers?

- NHS Trusts (Acute, Community, Mental Health and Integrated Trusts)
- Health Authorities (formerly FHSAs)
- GP practices
- Charities
- Community organisations
- Local authorities

In this section, we examine the various roles of linkworkers and allied schemes. Their roles have been grouped into broader categories, where appropriate. In many cases, the schemes covered several different roles, or changed as they progressed. Aspects of particular schemes have been used to illustrate particular roles where the written material is particularly useful for the purpose.

Language, culture and communication issues

Virtually all the schemes that are described in the literature share a commitment to improve communication between those who work in the NHS and those who need to use NHS services, but do not speak fluent English. However, the role of linkworker has, from its inception, been seen as wider than simply interpreting from one language to another (although that may be the limited ambition of some NHS staff).

There is widespread recognition that simple interpreting may omit the opportunity to access a great deal of information about the patient that would be useful to a doctor or nurse. For example, body language will be impossible to assess in a remote interpretation situation (e.g. a telephone interpreting service). Even an interpreter who is physically present may not be called upon to assume the wider role of suggesting the meaning of body language and gestures, or to explain the meaning of health beliefs and concepts to the parties for whom they are interpreting.

Both the literature and the interviews indicate that effective communication in health care relies on a common language, but also on culture, class, beliefs, trust and many other factors. Baylav notes that lack of a common language is the most common cause of communication difficulties but other issues co-exist.

> ***Issues around medical jargon and confidence using it, unfamiliar body language, different cultural values and different expectations from the consultation and treatment also play an important part.***
> **(Baylav 1996)**

Baylav also emphasises that bilingual workers from the same community and culture as the patient can give explanations and point out misunderstandings.

Interviewees in Camden and Islington had a broad understanding of the diversity of roles that both linkworkers and advocates perform, but saw the main point of linkworkers as facilitating access to mainstream services. As one manager put it:

> ***The key thing is that when people turn up at a surgery, they should get language input but not a replacement service.***

Box 3 Options for patients when there is no shared language and culture:

- Avoid making use of the NHS except in emergencies
- See health care professionals and use gestures to communicate
- Go privately to an own-language doctor
- Take relatives (often children) along
- Pay people to help at consultations
- Try to get to those few doctors/hospitals who have professional health advocates

(Baylav 1996)

In practice, interpreters in primary care, and particularly linkworkers who see their role more widely, play a major role in mediating between parties about the significance as well as the meanings of words and gestures. In some instances, cultural gulfs can be very obvious. An interpreter who simply relays that a Chinese patient is suffering from "excess heat", is unlikely to advance the understanding of a doctor who has been trained exclusively in Western medicine. Sometimes, the cultural gulf may be less obvious, but none the less important. A linkworker may be able to use knowledge of a community to allay fears or encourage communication about subjects that are difficult to talk about. She can explain advice in terms that are more compatible with the patient's values, beliefs, knowledge and assumptions (as well as explaining the patient's concerns in terms that are more consistent with the health care worker's values, beliefs, knowledge and assumptions!).

Nevertheless, the need for interpreting is paramount in the minds of many GPs when asked to consider the aspects of a linkworker's role that they consider most valuable. Mutual incomprehension on account of language renders all attempts to offer a reasonable service near impossible, and makes all other considerations secondary.

The demand-led nature of general practice poses a particular problem for GPs. Also, there is a clear difference of view between those who work in areas of relative cultural homogeneity, and those in more culturally heterogeneous areas. For example, in the London Borough of Camden there are many languages spoken and moreover, "language needs change daily".

Similarly, a GP who practices in an inner city practice in the London Borough of Haringey, felt that while there is an idealised perspective that a patient from another culture always needs a trained intermediary to translate or advocate, this is only feasible in areas of high concentration of a particular ethnic group.

> ***In one session, an inner city GP may see one Somali, two Kurds and one French speaker etc.***

Even in areas where it may be possible to identify and predict most of the need for interpreting, there are usually other smaller ethnic minorities whose needs can easily be overlooked

The perceived need for linkworkers to act as interpreters may also reflect the insights of health care workers who speak the patient's language, and know something of the barriers that obstruct access to health care for particular communities. As there are more GPs in Britain who speak a range of languages spoken on the Indian sub-continent than, say, Kurdish or Somali, some communities may have more powerful champions for overcoming communication problems within the medical professions than others.

Box 4 Communication and wider aspects of linkworker roles - an illustration

The Asian Mother and Baby Campaign (AMBC) is an early example of a scheme where language and communication issues were prominent, but were just a part of a wider set of aims.

- to encourage early diagnosis of pregnancy and uptake of maternity services, including education in parentcraft
- to improve communication between mothers and health professionals
- to help health professionals gain the co-operation of Asian families
- to help Asian families become more fully aware of the services available and of the reasons for using them
- to ensure that the services provided were accessible and acceptable

(Bahl 1987)

AMBC's linkworkers were trained to act as interpreters, cultural ambassadors, representatives of patients and staff and as health educators
(Rocheron et al 1989).

Those who see interpreting as the main focus of linkworking recognise that the linkworker may need to follow up patients after a consultation in the surgery, to help them navigate through other parts of the health care system, and that this assistance almost inevitably extends their role beyond interpreting. A qualitative study of three linkworker and advocacy services (Warrier and Goodman 1996) found that the role of linkworkers/advocates was multi-faceted, often covering many different roles, of which interpreting is just one. They observed that linkworkers/advocates in maternity settings not only eased communications, but also provided information on childbirth and infant care, and interpreted instructions and information from health professionals. They reduced dependency on family members for interpreting and made professional consultations effective. They also facilitated parent education sessions and encouraged uptake of such sessions. In addition, they offered women emotional reassurance.

Different approaches to overcoming language barriers

It is debatable how far language barriers can be separated from other aspects of communication and to what extent language and communication needs can be met by interpreters who are not physically present. Telephone language lines and interpreting services enable consultations to proceed that would otherwise be hindered by mutual incomprehension. As technology develops, there is growing interest in the possibility of using the services of interpreters who are not present during the consultation, but who assist via a hands-free telephone line.

One randomised control study in the United States (Hornberger et al 1996) assessed the quality of communication, interpretation and level of patient, interpreter and physician satisfaction in two language services used at the first post-partum visit by mothers and their newborns. For one group, the interpreter was linked from a remote site to headsets worn by clinician and patient. In this service the interpreter translated simultaneously, ("remote simultaneous interpretation"). The control group used a more traditional method where the interpreter was physically present and interpreted for the physician and patient after they had each spoken ("proximate consecutive interpretation").

The remote simultaneous interpretation was shown to be more accurate and more effective in encouraging "utterances" than the control model of proximate consecutive interpretation. The study claimed that mothers and physicians preferred the remote simultaneous service, but that interpreters preferred the control service because they could perform tasks beyond simple interpretation such as assessing gestures and facial expressions, and elaborating to the clinician on a symptom that may represent a unique cultural expression of the patient's illness.

In Britain too there is current interest in different methods of interpreting in primary care.

> ***The gap in service provision for the non-English speaking patient presenting acutely to the general practitioner or to other health professionals is a source of real danger for the patient and adds significantly to the stress experienced by the clinician and the informal interpreter. If we are really committed to a multicultural society and equal access for we must close this gap.***
> **(Jones and Gill 1998)**

In this context, the authors state:

> ***Health care professionals then must choose between several imperfect alternatives..... Clearly more research is needed into the effects of remote interpreting, and we need to explore how various combinations of remote and physically present interpreter services might best meet needs at an affordable cost.***

Advocacy and acting as the patient's representative

Spearman (Spearman 1991) contends that bridging a gap between service providers and patients from ethnic minorities requires more than linguistic and cultural communication. She argues that challenge to the medical model of health is required. She also notes that in the absence of such change, health advocacy is necessary, although there is also a danger that health advocates may become versed in the bio-medical model and may lose sight of the patient's point of view. It is this particular emphasis on seeing things from the patient's point of view and starting from a conviction that there is unequal power between health professionals and patients that is particular to advocacy.

Advocates often also find that the needs of their clients transcend agency boundaries. While some advocates are based in health care settings, they may need to advocate in other settings if they are to enable their clients to achieve better health. As one Health Authority manager put it:

> ***We have a medical model of care in the midst of an area where it is social factors that make people sick, but they are surrounded by excellent medical services.***

Advocacy has sometimes developed alongside other initial aims in linkworker schemes. Some schemes, including the AMBC, appear to have been rooted mainly in a paternalistic value system, that gave prominence to the need to educate a disadvantaged ethnic minority group, and to gain their co-operation in what was primarily an agenda driven by professionals. However, in practice, AMBC linkworkers found that the problems of the women whom they saw were wider. In some sites, such as Brent, issues of racism were seen by the community as critical, rather than the more limited communication issues that prompted the project to begin. Thus advocacy often develops out of the need to be responsive to the needs of clients, rather than the needs of professionals, or the ways in which professionals perceive clients' needs.

As we see throughout this report, advocacy is a major component of many schemes designed to improve access to services for people from ethnic minorities. The Multi Ethnic Women's Health Project (MEWHP) provides one of the most explicit illustrations of independent advocacy as a primary purpose of the scheme (Winkler 1985 /1988; Cornwell and Gordon 1984). It is by no means coincidental that MEWHP's workers have never been known as linkworkers, but always as advocates. They have also been amongst the most assertive in challenging individual and institutional racism in the NHS.

Most schemes, whether they are explicitly advocacy schemes or not, have found that in the nature of their activities, bilingual workers have become involved in trying to bring about changes in service delivery and in the attitudes of health professionals. Thus, while the MEWHP is explicit about its campaigning role in relation to obtaining better access to women doctors, better food for ethnic minority communities etc., other schemes, such as the Haamla[2] project in Leeds (Mir 1996) also seek to challenge discriminatory practice.

Many schemes use the expertise of linkworkers to educate and inform fellow health workers about cultural and religious practices and beliefs. This is another aspect of advocacy, making the case to colleagues for a more sensitive service to people from ethnic minorities.

In the primary care setting, particularly where linkworkers may work with the same GPs on a regular basis, it may be that advocacy will assume yet another form. Linkworkers who work with the same members of a primary health care team often find that they advocate for the needs of a community as much for individual patients.

If we assume that advocacy consists of a role where the advocate works to help patients or clients achieve their rights and obtain the very best that they can get from services, some GPs will wholeheartedly support such a role. Others will see the linkworker/advocacy role as existing in order to serve their needs, as well as the patient's needs, and may be less enthusiastic about supporting a patient-focused model of working. It has also been suggested that some GPs work under such great pressures that they may not want to hear what is really going on for their patients, in the wider sense, as they do not have time or resources to deal with it.

Interviews indicated that there is also some suspicion among clinicians and managers that in carrying out the advocacy part of the role, workers may sometimes pursue their

[2] Haamla is an Urdu word which means pregnant woman.

own agenda. Some primary care practitioners and health care commissioners also harbour a suspicion that some linkworkers may be from a different social class or ethnic group than the patient, and may not, in fact, be able to be empathise adequately with the client.

However, these pessimistic views fail to take into account that trained advocates, working to a clear brief, should be able to demonstrate that they would, indeed, be able to work as professionals on behalf of the patient or client, to further their clients' own wishes in relation to their health care. It would be as unreasonable to dismiss the potential benefits of advocacy in primary care on the basis of the postulated shortcomings of under-performing advocates as it would be to dismiss primary care because some GPs are less competent than others.

A more difficult aspect of advocacy in primary care is where to draw the line around what workers should do on behalf of their clients. Many people have problems that transcend the boundaries of statutory organisations, and a single person may require a linkworker/advocate to assist in interactions with the primary health care team, with local authority departments, and with the Benefits Agency. From a client's perspective, the needs are inter-related and may appear to be indivisible. While many primary care practitioners and health commissioners are sympathetic to that view, some are uneasy about being responsible for such a broadly based service, particularly if it makes a call on their own budgets.

Promoting better health

Box 5 Evaluating linkworkers' effectiveness in promoting better health

It is difficult to obtain evidence on linkworkers' effectiveness in promoting better health for a variety of reasons, including the following:

- Most linkworker schemes have been too short term to assess the real benefits of linkworker activity, particularly since human behaviour may change slowly.
  Most linkworker schemes have been inadequately evaluated, if they have been evaluated at all. Few have included outcomes in health promotion or disease management among their measures.
- Even in the rare attempts at randomised control trials (e.g. Hoare 1996), there is a substantial possibility that information received by those who had linkworker support may have percolated through to those who did not. Results of such studies are, therefore, not wholly conclusive.
- Each linkworker scheme has distinctive characteristics, and comparisons between workers and across communities is difficult.

However, even in the face of conflicting evidence, there appear to be enough positive indicators to pursue further the use of linkworkers in a range of tasks, which may include:

- giving information about screening services in appropriate languages and formats
- encouraging uptake of services
- helping professionals make services more user-friendly and acceptable to ethnic minority communities.

In so far as all schemes aimed to improve understanding of appropriate health care, all had elements of health education and health promotion. However, in this section, we examine the aspects of schemes that particularly emphasised these activities.

Although a review of ethnographic literature was outside the remit of this paper, it is possible that such studies would yield further indications of potential linkworker roles in promoting better health. For example, a recent study of health beliefs and folk models of diabetes in British Bangladeshis (Greenhalgh et al 1998), while pointing out that Bangladeshi culture is neither static nor seamless, identified some widely held beliefs and behaviours that were relevant to successful diabetes management. A linkworker who can understand the beliefs and knowledge of the community, and can take into account such issues as body concepts, attitudes to exercise, views on the origins of diabetes etc., is likely to help the multi-disciplinary team offer effective disease management and health promotion that is both effective and acceptable.

Baylav notes that some services, e.g. dental and optician services, are poorly taken up by some minority ethnic groups. She argues that primary health care advocates not only inform their clients about existing services, but also about the benefits to be gained from regular eye tests, for example, to promote good general health. She also notes that substantial sections of minority ethnic communities are not included in health promotion programmes designed and carried out in general practice. However, there is a high incidence of particular conditions within certain communities, e.g. diabetes among the Afro-Caribbean and Asian communities, thalassaemia in Turkish and Greek Cypriots. Health advocates can help involve minority ethnic communities in health promotion programmes (Baylav 1994).

A thesis on dental health advocacy in the Turkish/Kurdish community in East London (Khan 1997) showed that many people were unaware of the dental services that were available. Over 30 percent were not registered with a dentist and attendance rates at dentists were low in both adults and children. 50 percent of the community also reported communication difficulties with dentists. Khan concludes that more health education materials in Turkish and Kurdish would be useful, and that there should be an increase in the number of health advocates to take part in dental health educational activities.

Box 6 The impact of linkworkers in a maternity service

A randomised control trial involving 50 Pakistani women, resident in Birmingham who had booked for delivery at Marston Green Maternity Hospital, allocated half the women to receive three to five linkworker visits during the ante-natal period and half the women not to receive linkworker visits. The researcher examined the impact of a "social intervention" by linkworkers in the pregnancies of Pakistani women who had already had one low birthweight delivery, by comparing data about them with data about a control group who did not have assistance from linkworkers. The linkworker's role was to give information/education on "health needs, facilities, services and routine screening procedures available to all pregnant women". In addition, linkworkers advised, counselled, befriended and supported the women assigned to them throughout their pregnancies.

This study demonstrated that linkworkers promoted better health in both Pakistani mothers and their babies in a number of ways. One significant finding was that the mean birthweight of babies born to mothers who had received linkworker visits was 226.12 gms heavier than the babies born to the control group who did not have a linkworker.

Cases with linkworker support:

- had less medical problems during pregnancy
- were happier during pregnancy
- had better levels of social/medical support
- had shorter labours
- required lower levels of analgesia during labour
- had babies of greater birthweight
- had less babies with feeding problems
- had more post-natal (and internal examinations) carried out at the six week post-natal check up
- had significantly more information on normal pregnancy, routine procedures and their importance, health needs of the mother and baby during pregnancy etc.

(Dance 1987)

Linkworker effectiveness

There is mixed evidence on the effectiveness of the linkworker's role in health education. When the Leicestershire experience as one of the AMBC districts was evaluated (Mason 1990) it was found that linkworkers provided a much-needed interpreting service, but were less successful in their attempts to impart health education knowledge to Asian women. An increase in health education knowledge mainly occurred in women who already had a good understanding of English.

In another rare example of a randomised control trial, the effects of linkworker intervention on the uptake of breast screening was studied. (Hoare 1996; Hoare et al 1994). It was found that linkworker support made no difference to the uptake of breast

screening by Asian women, though a number of administrative issues (e.g. confusion over Asian naming systems, inaccurate screening registers, literacy issues) were probable barriers to uptake. Hoare states that these findings do not undermine the role of the linkworker, but suggests that their efforts should be directed in other ways.

A more optimistic view of the impact of linkworkers is taken by researchers who sought to determine the factors that deter ethnic minority women from attending their GP for cervical cytology screening (Naish et al 1994). They found that some of the reported attitudinal barriers to screening (such as fear of cancer) were not deterrents to uptake of screening among non-English speakers in East London. The most important barriers were administrative and language issues, as well as inadequate surgery premises and concerns among the women about sterility. It was possible to work with bilingual health advocates to consult with community groups in their own languages through focus group discussions. This form of user consultation could generate broader understanding of the barriers to health promotion and screening activities in minority ethnic populations.

Box 7 London Initiative Zone Schemes

Several schemes included a health promotion component, among other explicit objectives related to the shift of services from secondary to primary care. They included a Turkish advocacy project in Hackney, a Bengali and Sylheti project in Tower Hamlets and a TB outreach service, also in Tower Hamlets.

Objectives of TB outreach service in Tower Hamlets

- Providing a health care advocate for Bengali speaking people with TB
- Developing outreach work via linkworkers
- Providing an information service
- Visiting people at home to support family and friends during treatment
- Providing further health education material

(Hall 1995)

Another example of the role of health advocates, as they were called in Newham, (Harding and Pandya 1995) also demonstrated an extended role for the workers, who

worked closely within a structured health visiting team in one locality for a 6 month period. In some cases the advocates worked alongside the health visitor, as an interpreter, advocate and adviser. In other cases, the advocate carried out visits alone.

However, it was agreed that independent visits by advocates should not be first visits, and must be preceded by joint discussion with a health visitor. After independent visits, issues were reported back to health visitors who followed them up, if required.

Box 8 Independent visits by health advocates in Newham

Independent visits were carried out in the following circumstances:

- support for children already attending child development centre
- follow up of weaning/equipment sterilisation advice
- continuing support, e.g. in bereavement
- to establish GP registration
- to take messages, letters etc. e.g. on housing, or benefits

In addition, "immunisation defaulters" were contacted by telephone by advocates.

(Harding and Pandya 1995)

Linkworkers in disease management

There is also evidence that linkworkers can play a full and successful part in primary care in health promotion and disease management. Khanchandani and Gillam (1998) describe the evaluation of the role of a linkworker in undertaking health promotion and managing patients with diabetes and asthma in an inner city practice with a multi ethnic population. The linkworker could successfully carry out many of the nurses' tasks, including blood sugar monitoring and blood pressure measurements, and several indices of improved care for both diabetics and asthmatics were noted. As a result, it was concluded that a linkworker can be successfully trained to do traditional nursing tasks. In some respects, these linkworkers carried out a quasi-nursing role and their tasks resembled those that a health care assistant might perform under supervision.

However, we should note that this is a very particular role for a primary care-based linkworker, and distinctively different from most other British usages of the term, as the linkworker in this instance is carrying out some traditional medical and/or nursing tasks on her own, rather than simply linking in the patient to the skills of others. This work has relevance to debates about skill mix and the need to actively recruit more staff from ethnic minorities, rather than to the more specific question of how bilingual workers can facilitate access to and use of health services. Many medico-legal and managerial issues need to be resolved if these wider, clinical roles are to be developed.

It will be important to examine whether linkworkers who are directly involved in screening or disease management or in other aspects of direct patient care can also fulfil other, longer established tasks such as interpreting, promoting better access to other services, advocacy etc. If they are able to combine these roles in primary care, they may prove to be a very cost effective and acceptable resource. If they become so integrated into mainstream health screening and health care delivery that they are unable to find time to (or wish to) pursue other aspects of the linkworker's role, they may still be of value to the primary health care team, but may leave a vacuum for ethnic minority communities who will have a linkworker in name, but not in terms of some of the functions that have been associated with that title in the recent past.

Another more troubling aspect of this development is that it could conceivably perpetuate unequal opportunities for black and minority ethnic health care workers, who may be channelled into enhanced so-called linkworker roles, while being denied equal access to health care careers with more status, pay and opportunity for career development. If however, the enhanced linkworker role came to be seen as an access route into health care professions where ethnic minorities (especially women from ethnic minorities) have been traditionally under-represented, then new opportunities would be opened up.

There are some indications of trained linkworkers aspiring to other paramedical and nursing careers, for example in Birmingham. This is encouraging at an individual level and for the NHS as a whole. However the ethnic profile of the health care assistant workforce in hospital settings now, and the ethnic profile of enrolled nurses in the past, should give pause for thought. A good idea could backfire on ethnic minority staff, unless they are supported and encouraged within a properly managed framework of equal opportunities.

Making health care systems accessible

One of the roles that linkworkers can perform is to facilitate access to primary care. This may be done by work with individuals, by education, encouragement and exhortation, and above all, by demonstrating that primary care will be responsive to the needs of patients when they use it. Thus, linkworkers can be ambassadors for primary care.

The project manager of Small Heath (Birmingham) GP commissioning group saw the linkworker's role as assisting "two-way signposting" to enable actual and potential users to access services, as well as informing commissioners and providers of what is appropriate. He also pointed out that individuals and communities may have different types of need in relation to increasing the accessibility of health services.

The bilingual development worker in Leeds (who favours the term "development worker") had a clear vision of the multiple roles of development workers in primary care. Among them was explaining to people what is available, and talking to religious elders who may have considerable influence in sections of the community.

1.4. Roles and professional boundaries

KEY POINTS

- **It is common for there to be tension about roles and professional boundaries, with some suspicion from health care professionals.**
- **These tensions are best avoided by careful negotiation in establishing projects.**
- **Tensions about professional roles and boundaries tend to resolve over time and are alleviated by the inclusion of linkworkers in the wider team.**

One of the recurrent themes in the brief history of linkworking is the sometimes tense relationship between linkworkers and their colleagues. Such problems appear to be characteristic of the early stages of projects, particularly where the understanding of the precise nature of the linkworker's task is not wholly shared or understood within a wider staff group.

> ***There were times when staff seemed to prefer to use the cleaner to interpret rather than call one of the linkworkers. To the staff they [health advocates] were interpreters who should tell the patient what they, the staff, wished the patient to know. But instead, the workers queried why a woman had no food all day, or asked for women doctors etc.***
> **(Winkler 1985/1988)**

Winkler also notes the frustration arising from the constant turnover of junior medical staff and the consequent requirement to ensure they understand linkerworkers' roles.

Another commentator notes:

> ***Most organisations find it extremely difficult to accept new roles and this type of initiative is bound to encounter concern and unease from other health workers about encroachment into professional territory; it is also likely to expose undercurrents of racism and therefore needs to be handled sensitively.***
>
> ***Concerns about encroaching on professional territory need to be allayed. Preparation is likely to involve a carefully planned promotion and education programme, an early opportunity for other staff to meet and discuss the scheme with the new workers as well as training for staff who will be working closely with the bilingual workers.***
> **(Baxter et al 1996)**

There are also indications of difficulties met by interpreters based in GP surgeries, including role conflict, where the worker has to carry out more than one role in the same situation, and role incompatibility, where clients and professionals each expect the worker to be "on their side" (Reynolds 1993).

Some lessons are apparent from advocacy for mental health service users. A study of Tameside Advocacy Service (Copperman and Morrison 1995) argues that it is crucial to acknowledge that there will be difficulties that need to be addressed. To avoid scapegoating and share responsibility for change, this needs to be managed through the group, rather than on an individual basis. The authors also commend the study of how a particular organisation works, and the targeting of key individuals, in seeking support and dealing with potential conflicts. In another mental health service the anxieties of workers at the start of the project, and resistance to advocates improved over time (Jones 1997).

The AMBC also had to contend with issues around professional boundaries, and there were early difficulties in all sites (Rocheron et al 1989). Once again, health professionals perceived linkworkers as interpreters, while linkworkers themselves experienced a dual role, partly responsible to health professionals, and partly responsible to patients, where they required a "broad role definition".

In Newham the role of health advocates in health visiting teams was examined. Health visitors respected the health advocates' contribution, and a structured approach to changing roles appears to have borne fruit (Harding and Pandya 1995).

Initial difficulties around linkworker roles were also noted in primary care settings (Khanchandani and Gillam 1998), but solutions to initial problems were found by several means, including fully involving the linkworker in practice meetings and by clarifying the roles of the linkworker, as well as other members of the Primary Health Care Team in terms of specific tasks.

Some related issues are explored further in the section on Management, Supervision and Accountability.

1.5. Why linkworker projects were established

KEY POINTS

- **Linkworker schemes were established for many reasons, including as a response to language and communication difficulties and to promote advocacy and outreach.**
- **Some schemes were established to meet assessed needs and to respond to issues raised by research, whereas others were more loosely based on perceived needs.**
- **Some schemes were established opportunistically, in response to a funding opportunity, or as a result of local pressure.**

Linkworker schemes were established in response to a variety of stimuli, and often as a result of a loosely defined awareness of unmet need. Some of the triggers for establishing projects are discussed below.

A response to language and communication issues

The establishment of linkworker posts and projects, and the reasons for their inception, has varied. The Asian Mother and Baby Project (AMBC) (Bahl 1987) was a project sponsored by the (then) DHSS and the Save the Children Fund. It focused on the care of Asian mothers and babies before, during and after birth. The campaign grew out of the Stop Rickets Campaign, which had highlighted problems encountered by Asian families in making full use of maternity services. For example, in Leicestershire, one of the 10 districts included in the AMBC, approximately 50 percent of Asian women were unable to communicate in English and were therefore unable to make full use of available services (Mason 1990).

Some recent schemes, such as the outreach advocacy service for Somali people in Cardiff (Dobson 1996) also cite communication and language issues, alongside cultural and physical isolation which make it difficult for that community to access services.

Promoting advocacy and outreach

The MEWHP had some of the same impetus, i.e. language and communication difficulties, but advocacy (which had also formed part of the AMBC remit) took a prominent role from the earliest days (Winkler 1985/1988). The MEWHP was influenced by community projects from the developing world and from patient advocacy projects in the USA. (Baxter et al 1996). Linkworkers in Haringey were also set up to interpret in ante-natal and maternity services, but their role included acting as intermediaries, supporters of the women and helping the women to obtain information (Abdi et al - undated , after 1993)

A scheme proposed by the (then) Brent and Harrow Family Practitioner Committee to appoint an outreach worker to work with the African/Afro-Caribbean communities had the dual purpose of encouraging access to primary care, and also identifying the needs and problems perceived by these communities in gaining access to primary health care services (Attlee 1990). However, the linkworker concept has never been associated with the English speaking ethnic minorities.

> ***While a GP may be encouraged to employ a linkworker/advocate for his non-English speaking patients it is impractical to expect any GP to employ a linkworker solely to overcome cultural barriers.***
> **(Attlee 1990)**

Are schemes established in response to need?

In a very broad sense, all projects were established in response to a perceived need. However, the extent of needs assessment that pre-dated the establishment of any given project varied. The Chorlton Locality Linkworker Scheme in South Manchester grew out of a needs assessment project in the locality (Ford 1993).

Many linkworker schemes in the past have been funded through FHSAs, and have been set up through the initiative of a manager in the FHSA, who has acted as a champion for the concept of linkworking, advocacy or bilingual development work. The bilingual development project in Leeds is a useful illustration of how one scheme developed. This project was based on research by the FHSA, funded by a bid through Yorkshire Region to the Department of Health for quality monies. (Stafford 1992b). The project manager took up post with the FHSA in 1994 and was managed by the Director of Consumer Affairs in the FHSA. However, when the FHSA merged with the District Health Authority to become Leeds Health Authority, like all Health Authorities, its focus became more clearly the commissioning of services, rather than service development. The Health Authority now commissions the bilingual development service, from mainstream funding for an initial three year period, and the service operates from the Acute Trust under the management of Trust staff.

As it happened, the same person who had been influential in developing the project in Leeds FHSA was also in post in the Health Authority and was active in ensuring that careful arrangements were set up for specifying quality indicators, and for having a clear view of what was needed in Service Level Agreements. While effective commissioning, in theory, should ensure that the service continues to thrive, it remains to be seen whether this will work well in practice.

While some projects were initially inspired by research evidence on ethnic minority needs, elsewhere scant information and poor record keeping undermined the ability to deliver a needs-based service (Hayes 1989; Hicks and Hayes 1991). In 1993, a study of the effectiveness of three linkworker and advocacy schemes in empowering minority ethnic users of maternity services was conducted (Warrier and Goodman 1996). Many strengths were noted in the linkworker and advocacy schemes that were studied, but it was also noted that all three services failed respond adequately to current needs or systematically to address them.

Hicks and Hayes demonstrated from a survey of a sample of 30 health districts that there was a worrying mismatch between client need and service planning, largely because information about supply and demand was not collated. At the time of their study, they judged that many "at risk" groups were still denied linkworker services.

In contrast, some of the early schemes developed in relation to a very specific need. (Baylav 1994). For example, the establishment of a linkworker post in a primary care setting by the (then) City and East London Family Practitioners Committee reflected the urgent needs of a GP to communicate with the Bengali Sylheti-speaking population who were in homeless families' bed and breakfast accommodation around a particular surgery. This service expanded to improve access to primary care services for diverse refugee and immigrant populations.

A report to the Department of Health (Marr 1993) noted that bilingual services first developed in the early 1980s, but most had developed within the 5 years prior to his research.

> ***....the development of the majority of services were highly dependent on two main facts: pressure from the local communities (this being particularly so in areas with large minority ethnic communities) and the particular interest and commitment of individual managers.***
> **(Marr 1993)**

It is also clear from interviews that the establishment of linkworker posts and projects, while being loosely based on a body of knowledge about differential access to health care for different ethnic groups, is sometimes kick-started by a specific funding opportunity.

Whatever the apparent reason for establishing a scheme, there are often different expectations of what it can offer. Each professional and client group perceives the worker's role as performing what they need most. For example, GPs value the interpreting function, receptionists hope that the workers will enable clients to keep appointments, while the clients expect a variety of tasks to be performed (Baylav 1994).

1.6. Funding

KEY POINTS

- **Information on costs and sources of funding is patchy and comparable, national data were not found in this study.**
- **Funding for linkworkers has usually been short-term and this has been a serious restricting factor.**
- **Charities have played a significant role in funding linkworkers and other schemes for black and minority ethnic communities**
- **Linkworkers are usually on low A&C salary grades; this has consequences on their status.**

In this section, we examine information on funding, looking at both sources of funding for linkworking, and at the scanty comparative information that is available on costings. There appears to be no national information on the costs of linkworking. One study is currently in progress in East London to look at the costs and consequences of bilingual health advocacy/interpretation services.

Linkworkers have not become embedded in the mainstream of NHS funding. Over many years, charitable funders have played a significant part in supporting community-based Black and minority ethnic projects, with the King's Fund and the City Parochial Foundation supporting health advocacy, while the Nuffield Trust funded the Interpreting Project for many years, which did some limited work in the health field. Many projects have found it difficult to move into the mainstream after charitable support.

Overwhelmingly, funding has been opportunistic, short term and ad hoc.

> ***Lack of permanent funding has important implications for the role of bilingual workers. Short term funding is a serious restricting factor and has serious implications for their employment and career development and, perhaps most importantly, for the communities they serve. When services are abandoned after a period of short term funding, this can have a serious impact upon the community's access to health and related services.***
>
> ***Many community organisations argue, with considerable justification, that health and health care needs of Black and minority ethnic communities will continue to be seen as marginal while reliant on short-term funding.***
> **(Baxter et al 1996)**

Various funding sources are referred to in the literature. In Haringey (Abdi et al-undated, after 1993), the original linkworkers scheme in 1984 was run by the Community Health Council (CHC) and sponsored by the Manpower Services Commission, who funded it until 1987, when the Health Authority took over the funding and employed its own linkworkers. This later moved to a situation where the Health Authority funded a service which was run by the local NHS Trust.

The AMBC was financed initially through central funds provided by the Department of Health and Social Security (DHSS) to meet the costs of campaign staff and the employment of 80 linkworkers for two years. The costs of accommodation at Save the Children Fund were met by DHSS grants. The second year of schemes tended to be dominated by discussions on the future (Rocheron et al 1989). In Brent, for example, financial and administrative pressures contributed to the decision not to extend the AMBC linkworker scheme beyond the initial two years.

The MEWHP (Winkler 1985/1988) was initially funded by Inner City Partnership money, which in 1987 began to taper into mainstream funding. The MEWHP is unusual in that the CHC has been the budget holder for the project, although the future of the project was being reviewed when this paper was in preparation.

In Chorlton (Ford 1993) the initial bid for funding one linkworker and a sum for training was met by Joint Finance.

FHSAs (formerly FPCs) were also sources of initial funding, as in East London (Baylav 1994), Brent and Harrow (Attlee 1990) and Leeds (Mir 1996; Stafford 1992; Stafford 1996).The Leeds bilingual development project later benefited from a successful Single Regeneration Bid, to fund two part-time maternity health workers. Funding will come on stream for those workers from April 1999. The demise of FHSAs and the changing role of Health Authorities leaves considerable doubt as to future funding and development across the country.

Some schemes which include workers with a linkworker/advocacy brief started up as funds became available through geographically-specific schemes such as the London Initiative Zone (LIZ), which arose out of the concerns of the Report of the Inquiry into London's Health Service, Medical Education and Research (Tomlinson 1992). Studies of advocacy services in East London conducted by London Guildhall University (Hall 1995 - draft/unpublished) show that in 1993/4 £98,965 was budgeted for service specific advocacy in Newham and Tower Hamlets (£144,400 in 1994-5). In addition, in 1993/4 £182,565 was budgeted for "broadly based advocacy" for ethnic communities in East London (£428,200 in 1994-5).The question of funding after LIZ posed quandaries for Health Authorities.

Indeed, for many years there has been concern about the vulnerability of funding for linkworkers. As long ago as 1989, a multi-disciplinary group was recommended to consider the needs of ethnic minority communities:

> ***The group should act as a monitoring device to assess the effects of cutbacks in health budgets, particularly in relation to services which affect ethnic minority patients.***
> **(Hayes 1989)**

Pay scales

It is surprisingly difficult to glean from the published literature the precise costs of particular schemes, though the papers of FHSAs and Health Authorities yield specific information on local schemes. Most schemes that have employed linkworkers have done so on low salaries for individual workers. It has not been possible to identify the total national expenditure on linkworker schemes.

Most bilingual workers are employed on Whitley Council A&C grades, but there is great disparity in the grading. Some workers are paid on A&C grade 5-6, while others are on A&C grade 2-4. (Baxter et al 1996). The low salary levels have several consequences. Firstly, and most obviously, it is a matter of personal disadvantage to the post-holders themselves, which is compounded by the lack of career structures

with opportunities for progression up a salary scale (Warrier and Goodman 1996). Secondly, in a status conscious and hierarchical body like the NHS, linkworkers on A&C grades are likely to find that their low salaries are reflected in the low esteem that their posts may have in the eyes of colleagues, particularly clinical colleagues. The salary issue may well also be relevant to the anxieties of other health workers, such as midwives in the early days of the MEWHP (Cornwell and Gordon 1984) where initially some midwives feared that the new health workers would devalue their own jobs.

A Trust manager with a nursing background felt that language skills were consistently undervalued in the NHS, and this was reflected in their pay and status.

> ***A linkworker might speak several languages - Urdu, Bengali and Pushtu - and people take that for granted. But if I told you that I could speak French, German and Spanish fluently, you would say "What are you doing working here?"***

Finally, in areas with large ethnic minority populations and high indices of deprivation, the range and number of linkworker, advocacy and interpretation schemes can still amount to a very large sum of money, notwithstanding the low remuneration to individual workers. For example, East London and the City Health Authority noted a total spend in 1996-7 of £2,937,880 (against which they were seeking to identify savings of £200,000). (ELCHA 1997/8).

1.7. Recruitment, training, support and development

KEY POINTS

- **Recruitment policies, training, support and development are inter-linked.**
- **Many schemes have tried to recruit linkworkers with relevant knowledge of communities, and their training has been designed to reinforce and supplement existing knowledge.**
- **Many people consider that linkworkers are insufficiently trained.**
- **There are some attempts to make training more systematic, and to link it in with accredited courses and access to higher education.**

The issue of recruitment of linkworkers cannot be wholly separated from their training and qualifications, or from their ongoing need for support and development in their roles.

In selecting staff for the long established Multi-Ethnic Women's Health Project that was developed by City and Hackney Community Health Council the emphasis was on commitment and knowledge of the relevant communities, and on finding workers who shared as many characteristics as possible with the women with whom they would work. (Winkler 1985/1988) Consequently, the training of MEWHP workers was seen as emphasising workers' existing knowledge and commitment, supplementing it on demand and helping them to develop new skills, as appropriate. Thus, in the early days of the MEWHP, a regular half day per week was allocated to enable support and skills development, and in addition, there were occasional sessions on clinical care from District Health Authority community medicine staff. Another account of the MEWHP (Cornwell and Gordon 1984) noted an emphasis in training on reinforcing, not replacing, workers' experiential knowledge.

As various schemes developed, training apparently became less ad hoc, though the emphasis on practical skills and placements was retained, alongside more formal study. A six month full-time advocacy course at St. Bartholomew's Hospital Medical College which combined placements in GP practices with study on a variety of topics, e.g. how the NHS works, interpreting skills, equal opportunities and patients' rights, is described (Glassman 1991).

In some of the early schemes, such as the AMBC, which began in 1984, short periods of training and ongoing professional support and development were intrinsic to the scheme (Bahl 1987; Rocheron et al 1989).

Box 9 The initial four-week training for AMBC linkworkers

- the role and function of linkworkers
- understanding of the NHS and the professionals working in it
- basic knowledge of the different stages of pregnancy and the development of related bilingual fluency
- understanding and acceptance of different religions and cultures
- communication skills based on three-way interviews between pregnant women, health professionals and linkworkers
- development of self confidence and of the ability to act as an advocate for the Asian patient in the face of racial discrimination or inappropriate health services
- linkworkers' code of conduct (e.g. confidentiality etc.)

Tribe reflects on recruitment and selection issues (Tribe 1994). Her observations of bicultural workers are in the context of the Medical Foundation for the Care of Victims of Torture, and she notes the need for a rigorous process of selection, including language as well as personal and political motivation. She also refers to a support and supervision group, dealing with inter-disciplinary conflicts, boundaries, trust, core tasks, lack of professional identity and the emotional content of interviews.

However, within the NHS there has been a constant rumble of concern about lack of training for linkworkers. Hicks and Hayes (1991) report:

Linkworkers receive little or no training for their job

These authors note that the lack of training feeds into a perception by many hospital personnel of linkworking as a low status occupation, for which they have little regard.

The British literature also offers a little information on international comparators (Podro 1994) in a report of a seminar which compares the British, French and Belgian experience of "intercultural mediation". The report looks at specific examples of UK advocates, Belgian bemiddelaars (mediators) and French femmes relais (linkworkers) and mediatrices (mediators).

While the respective roles, contexts and their development are not precisely the same, it is interesting to note the different approaches to training and different examples of training courses which are described. Belgian mediators had three months full time

training, followed by a pattern of one day at college, three days in placements and one day supervision per week. At the end of three years, they sat an examination for a Diploma. In France, workers had an intensive four month course, including placements, visits and supervision. The British example that was described was an independent 18 week course of one day per week, with placements, run by the London Interpreting Project. This particular course was assessed for credits on four levels, up to a level stated to be equivalent to GCE A-level.[3]

There are some encouraging recent examples of serious attempts to take an overview of the needs of linkworkers for training and for career development, but these are rare. In one recent innovative scheme there has been collaboration between a Trust, the West Midlands Regional Office of the NHS Executive, University of Central England and a college. Linkworkers in Southern Birmingham NHS Trust attend a college-based course, which runs for ten hours per week for two years. The West Midlands Regional Office of the NHS Executive has contributed half the costs of linkworkers' time and paid their college course fees. The contribution from the NHS Executive has been £33,712 for replacement costs for 2 years and £8,500 for college fees and evaluation. This has come from their nursing budget and is seen as a way of encouraging people from Black and minority ethnic communities to enter nursing and allied professions.

Southern Birmingham Community Health NHS Trust and the University of Central England hope to develop the linkworkers' training into a module that would give them access into higher education.

[3] However, this course is not followed by all bicultural workers, linkworkers or equivalents in the UK.

Box 10 Southern Birmingham Community NHS Trust's vision of possible career development for linkworkers

Interpreter bank
↓
Interpreter permanent employment
↓
Linkworker
↓
Access course funded by West Midlands NHS Executive Regional Office, curriculum organised by East Birmingham College with links to University of Central England.
↓
Direct entry to nursing/paramedical training

(Source: Elizabeth Brasnett Operational Resource Manager, Southern Birmingham Community NHS Trust)

Unfortunately, schemes have re-invented the wheel for training, and the lack of a widely accepted, accredited national course is striking. What is also noteworthy is the double bind in which linkworkers sometimes seem to become ensnared. Either they may be perceived by professional colleagues as under-trained lay people, who lack professional status and respect. Or they run the risk of being seen as trained to a level where their acquired learning may distance them from their communities of origin.

A number of commentators, (Baxter et al 1996) note that it is not only linkworkers/advocates who need training, but also other health service staff. They identify the following three points:

Box 11 Recommended training needs of health service staff in relation to the provision of bilingual services within the NHS

1. *Health professionals should be invited to take part in the training as to how to work effectively with bilingual health advocates. Workshops should be organised where bilingual workers and health professionals learn about and develop the skills which a three-way consultation requires.*
2. *Develop racism awareness training programmes for all staff with an input from bilingual workers.*
3. *Ensure that health professionals working with patients whose first language is not English should assess their language needs and seek appropriate help.*

(Baxter et al 1996)

There is apparently no published material on the costs and benefits of such training for NHS staff.

1.8. Management, Supervision and Accountability

KEY POINTS

- **Opinion is divided on whether the management of linkworkers is best delivered from within the NHS or by an independent body.**
- **Each approach has pros and cons, but there are ways to develop hybrid forms of management which build on the advantages of each model.**
- **The involvement of local communities in management of linkworker schemes is desirable.**

There are two clear strands to the thinking behind the management arrangements for linkworkers. One school of thought places linkworkers firmly in NHS management structures, while another argues vehemently for the need for linkworkers to be managed by a body outside the NHS, in order to maintain and demonstrate their independence. Some people contend that the arguments are irrelevant if schemes are established carefully, and terms of reference are agreed at the outset.

Some schemes have mutated from outside the mainstream of the NHS to inside it. For example, the linkworker scheme in Haringey, was initially run by the CHC[4], but was later managed within the Directorate of Child and Adult Community Health within the local NHS Community Trust.

The MEWHP in Hackney has been distinctive in so far as it has a long history of independent management. The CHC Secretary (now known as Chief Officer) was responsible for day to day management and was the budget holder. Community and NHS interests were brought together in a steering group made up of community representatives and health service staff, which met six-weekly. The final say rested with the management group, which consisted of a CHC representative, a representative from the Commission for Racial Equality (CRE) and the General Manager of the (then) District Health Authority. (Winkler 1985/1988). Winkler describes the MEWHP as a "Community Supportive Scheme" (see box 12).

[4] It should be noted that while the CHC is a statutory body, which is part of the NHS, it is in many respects different from other statutory NHS bodies because of its orientation towards the concerns of users, and its status as an independent body.

Box 12 Factors common to community supportive schemes as follows:

1. *Narrow social distance between the community and project workers.*
2. *Responsibility to the community not to the organisation.*
3. *Ideology must be one of sharing knowledge.*
4. *Selection of workers for their commitment not formal knowledge.*
5. *Flexible training programmes that can adapt to local situations.*
6. *Ability to offer something more than advice.*

(Winkler 1985/1988)

MEWHP workers insisted that they were health workers, though not working for the hospital. This caused problems for the hospital staff who did not know where to fit them into the hospital hierarchy. The autonomy that the project's workers had suited them, but hospital staff and nursing officers would have liked more control over them (Cornwell and Gordon 1984).

Cornwell and Gordon also noted:

> ***The relationship within the health service .... has to be close enough for them to be able to do their work effectively, without being so close that they become absorbed into the service.***

Cornwell and Gordon note that the feeling within the MEWHP and the conference on which they reported was that an advocacy service run from within the health service is almost a contradiction in terms, and would, very rapidly, become an interpreting service.

In the AMBC, supervision and management differed in each site. In Brent, there was early involvement of the community (in contrast to Wandsworth and Dewsbury, where there was no effective representation of community groups or other local organisations) although the pressure to deal with issues of racism was perceived as so threatening that a more cautious approach to community involvement was later adopted. Rocheron et al note that the failure of active participation from community representatives stemmed from a lack of clear guidance and advice from the Campaign Team. The schemes were firmly in the hands of the nursing establishments. (Rocheron et al 1989).

Considering the large volume of literature on linkworking, there is relatively little written about the fine detail of management of schemes. Such material as exists is of great interest as a window on the inter-relatedness of theories of management and the nature and objectives of the particular schemes. It appears that the more a scheme is embedded in the NHS hierarchy, the better it is accepted by health care professionals, but the more restricted its brief. Conversely, the more a scheme is independent and accountable to the community, the less it is accepted (at least at first) but the broader its remit. Clearly, these management issues become intertwined with debates about effectiveness and purpose. However, one of the underlying problems may be a failure in many schemes to agree on explicit criteria against which the management model could be evaluated.

1.9. Administrative and organisational issues

KEY POINTS
- **There is room for improvement in administration and organisational issues in linkworker schemes.**
- **Most services offer a nine-to-five service, which usually falls short of meeting need.**

There is a limited amount in the literature about administrative and organisational issues, as distinct from managerial issues. One source of information is the evaluation of the Newham Healthcare Health Advocacy Service (Minns et al 1993). This evaluation noted the need for a more efficient system for ensuring availability of advocates. It noted that advocates spend too much time without clients, or waiting with clients. The need for an efficient computerised booking system and record keeping was noted.

Box 13 Summary of issues needing to be addressed in Newham

Improved notification of patients' language needs
- standard referral forms needed
- workshops for GPs
- self declaration of language
- letters of appointments to include details in Newham's commonest languages
- better publicity and marketing of the advocacy service
- identification of language needs at registration

Efficiency of referring patients to advocacy service
- need computerised system, identifying language needs, name of assigned advocate
- need daily list of advocates on duty
- record of need for advocacy support at future appointments
- follow up bookings
- crisis bookings

Availability of advocates
- Ideally need extended hours
- need for a flexi-sytem
- Need to log demand
- Need to consider extending service to men, and patients with advocacy needs despite no specific language difficulties

Increase the diversity of languages available
- need for flexibility - a small sessional budget could be earmarked

A number of recommendations were made about the future organisation of the advocacy service, reflecting managerial and organisational points indicated above.

(Minns et al 1993)

Others also emphasise that services for patients and clients should deploy bilingual workers in a way that maintains continuity of care for individual patients and families, and advances the organisation's equal opportunities policies. (Baxter et. al. 1996). They also support the establishment of a 24 hour call system, better publicity at clinics, health centres, surgeries and within minority ethnic communities, as well as a direct route of access to bilingual workers for potential clients.

The inadequacy of a nine-to-five Monday-Friday service is also noted in linkworker and advocacy schemes in maternity services, where there were inadequate staffing levels in the study sites to meet demand (Warrier and Goodman 1996). Warrier and Goodman also set out clearly a number of recommendations for purchasers and providers of linkworker and advocacy services, which emphasise the need for core standards, a needs-based service, regular review, better recording of language needs and client held records, among many other specific recommendations.

1.10. Evaluation of schemes

KEY POINTS

- **There are many difficulties in evaluating linkworking.**
- **The short-term nature of projects and lack of funds for evaluation are particular difficulties.**

While some published material is available on evaluation of schemes, it is still the case that most evaluations are specific to particular schemes or projects, rather than more generalised evaluations of linkworking as a whole. There are a number of factors that may make broad and comparative evaluations difficult, and these are listed in the box below:

Box 14 Difficulties in the evaluation of linkworker schemes

- Inconsistent terminology for job titles
- Lack of consensus on what a successful outcome would be
- Difficult to design research on the consequences of not having linkworker schemes
- Time limited projects often cease before their full effects are felt
- Time limited funding tends to lead to "talking up" benefits of particular schemes in order to secure further funding
- Inconsistent expectations and criteria for success from different stakeholders
- Inconsistent expectations of research methodology (doctors tend to favour quantitative research, whereas qualitative research may be equally/more appropriate)
- Insufficient understanding of those benefits to community from linkworking that may not be reflected in (short term) health outcome measures
- Ethical and political problems of offering service to part of a community as a means of comparing the effects of linkworker intervention with non-intervention.
- Problems of devising methodologies that evaluate interventions to part of a community, when in reality, benefits may "leak" into control group.
- Lack of funding for systematic evaluation

However, the need for effective evaluation that draws on both qualitative and quantitative methodologies, and reflects community priorities as well as clinical and managerial priorities is very urgent, if good practice is to be shared in a way that enables scarce resources to be applied most effectively.

PART 2

LOOKING TO THE FUTURE

KEY POINTS

- **There are particular aspects of primary care where linkworkers can make a valuable contribution, including at new patient health checks; at health promotion, screening, immunisation and advice sessions; disease management; women's health and mental health.**
- **A strategic approach to the development of linkworking in primary care is needed, with Health Authorities leading this partnership through Health Improvement Programmes.**
- **Primary Care Groups are likely to vary in their capacity to commission linkworking.**
- **There is a continuing need for development funding, but short term funding is not a suitable way forward.**
- **Hybrid models of management are possible.**

In this section the question of how linkworking might develop in a strategic way in the future is examined. First, the ways in which linkworkers can make the most valuable contribution in primary care is outlined. Second, some of the issues of how and where linkworking in primary care might fit into the new NHS are explored.

2.1. Making the most of linkworkers in primary care

While linkworking may be useful in primary care, there is insufficient funding for linkworkers to offer a comprehensive service across all the areas where it could make a difference, and for all communities, in the foreseeable future. In order to realise current governmental commitments to reducing health inequalities and social exclusion, it is important to ensure that everyone can access primary care and that language services and other aspects of linkworking are developed systematically in accordance with local needs.

In this section, we discuss the particular aspects of primary care where linkworkers can add value to an interaction between a primary care practitioner and a patient.

New patient health checks

When a patient - or, more usually a whole family - register with a GP, there is an opportunity to do far more than deal with any immediate medical problems. There may also be opportunities for health education, offering screening procedures, ensuring that ongoing medical problems are being properly managed and informing the family about what the practice can offer. The first meeting with a doctor and/or practice nurse is very important in setting the tone for future relationships with the practice. A successful introductory session involving the patient, primary care practitioners and a linkworker can save time later by avoiding the need for some future consultations.

Linkworkers can add value to all these aspects of the initial health check, and sessions can be organised for particular days when the services of appropriate linkworkers will be available. Whole families can be seen on a single day, making it economical and practical to use the linkworker's time.

Health promotion, screening, immunisation and advice sessions

Linkworkers can be very valuable in making health promotion services more accessible, acceptable and comprehensive to the communities with which they work. This is particularly so if the linkworker's task includes an outreach component, working at the level of the community, and not only with individuals, when health issues that are of particular importance to a specific community can receive attention. Even those GPs who may be less than enthusiastic about broader aspects of the linkworker's role may be keen on measures that may help them to meet their targets for cytology and immunisation.

Disease management

In similar ways, linkworkers can be effective in raising the standards of care and improving access for people with diabetes, asthma, hypertension and other long term conditions. As we have seen, there are several ways in which linkworkers might

function in disease management settings, including any permutation of the following (see box 15).

Box 15 How linkworkers might contribute to disease management in primary care

- Interpreting
- Education (of patient and professional)
- Supporting/reassuring patients
- Cultural mediation
- Lay health worker/health care assistant, undertaking routine tasks
- Outreach to communities and opinion formers
- Community development - linking into wider health promoting activities in the community

Women's health issues

The concentration of linkworkers' time on women derives from its origins with minority ethnic women patients and their health care professionals during pregnancy and birth. In primary care, linkworkers can usefully be involved with women's health issues, as they can offer a service to women which benefits a whole family, and may impact on child health too.

Mental health

Mental health problems have negative connotations in many cultures. In some communities, they are particularly difficult to acknowledge, and the presence of mental illness in one family member may be prejudicial to others. In general practice across all communities, it is estimated that mental health problems constitute 40 percent of all symptoms reported to GPs, and that 26 percent of the population consult their GP annually with a mental health problem (Wing et al 1995).

Since ideas about the aetiology of mental illness are often very culturally specific, the services of a linkworker can be invaluable in enabling people to share their concerns and to access appropriate help. Linkworkers can also be useful where there are indications of mental health-related issues that may not be identified as such by the patient. Linkworkers can be a valuable asset in the GP's surgery and also an important bridge to colleagues in Community Mental Health Teams, and to other relevant colleagues such as health visitors.

2.2. The development of linkworkers in primary care - whose responsibility for the future?

A strategic framework

There are many lessons to be learned from linkworking, from the workers, their managers, and the communities served by linkworking. Continuing organisational changes in the NHS, resulting in a greater emphasis on both primary care-led commissioning and on more service delivery within primary care settings make it imperative to derive the greatest possible value from these lessons. Changes in political priorities, including a renewed emphasis on the links between deprivation and health and a greater commitment to partnership working in the NHS also present major opportunities to build on past lessons.

Linkworking should no longer be seen in isolation and it is no longer adequate to develop services opportunistically in response to a one-off funding opportunity. The development of linkworker schemes should take place within the context of a needs-based strategic framework which encourages the development of services that are accessible, acceptable and appropriate for ethnic minorities.

Health Authorities and Health Improvement Programmes

Health Authorities should take the lead on the strategic development of services for ethnic minority communities. In their lead role on Health Improvement Programmes, they should also involve the Primary Care Groups, local authorities and the wider community in partnership activities that promote better health and better health services for ethnic minorities. In some areas, there may be also be scope for joint work with local authorities in Health Action Zones (HAZs).

An unresolved question is the extent to which Health Authorities should continue to be responsible for directly commissioning linkworker schemes, particularly given the

cost pressures within which they work. Health Authorities are sometimes uneasy about the appropriateness of existing linkworker provision, partly because of unease about how schemes had been initiated, and whether they are properly rooted in local needs. However, new configurations in primary care might well support the commissioning of linkworking as part of a population approach, particularly for more anticipatory services, e.g. health promotion, disease management.

Health Authorities may be sensitive to the wider needs of their local population, but that is not to say that they will feel that it is appropriate to fund linkworkers. However, there is a clear need to explore alternative ways of ensuring that existing valuable services are not lost, and that further services can be developed in primary care to support minority ethnic patients in getting better primary care. There are now real opportunities to develop partnerships with local authorities, to ensure that services which may be essential for a holistic approach to the needs of ethnic minority patients are not lost because of the inability of Health Authorities to assume financial responsibility for what is required. Health Improvement Programmes may enable co-ordinated efforts to support and develop schemes that transcend agency boundaries.

Primary Care Groups

The demise of Family Health Services Authorities (FHSAs) and the incorporation of their functions into new Health Authorities (HAs) has had a significant impact. It remains to be seen how primary care development and primary care services for ethnic minorities will be affected by the advent of Primary Care Groups (PCGs) and the changing role of Health Authorities.

The capacity and capabilities of PCGs to commission and/or employ linkworkers will vary across the country, reflecting the previous extent of the experience of local GPs in commissioning services and the nature of the populations which they serve. This will be reflected in the pace at which PCGs develop from groups that advise the Health Authority into free-standing bodies, responsible for commissioning and for delivering primary care services as Primary Care Trusts.

It is likely that for many years to come, the development of linkworkers and other services for ethnic minorities will have to come about through partnership and collaboration, between different parts of the NHS, and beyond. Neither PCGs nor Health Authorities will be able to address the issue alone.

Viability

The question of how large a commissioning body is necessary to commission linkworkers is a difficult one, and the answer is likely to vary according to the nature of the population covered by the PCG. In some cases, a population of 100,000 (the likely size of PCGs) may justify employment of a range of linkworkers, though this model will not offer a solution for improving access to primary care for smaller ethnic minorities or for areas of great cultural and linguistic diversity. However, if PCGs develop specialisms in particular aspects of primary care, that may open the way for use of linkworkers for particular clinics, for example, for diabetes, asthma or anti-coagulant therapy.

The diverse nature of London's population may point to the need for a London-wide approach to organising linkworkers/advocates. While some people see the formation of the new Greater London Authority (GLA) as an opportunity to be explored, there is no indication that the GLA sees itself in this way. However, the new London Region of the NHS Executive may well be able to play a part in ensuring that services are appropriate for all the diverse communities in its new boundaries, which will be co-terminous with the GLA.

It is likely that no single model will be applicable to the whole country, and that a multi-layered organisational model will be necessary, with some areas requiring some levels of service, while others required and could support more levels. Further evidence is necessary as a basis for development, but it is possible that services might develop as outlined in Box 16.

Box 16 Developing bi-lingual services in primary care - an incremental model

- practice based linkworkers - for practices with large numbers of minority ethnic patients who share linguistic and cultural similarities
- shared access to linkworkers within a PCG - for sessional work in identified priority areas
- whole city services - possibly jointly commissioned by health and local authorities, extending to social care and health issues.
- access to telephone interpreting as a safety-net and for small linguistic minorities.

Funding for the future

Funding will continue to be a key question, and the concerns of those who fear that a national formula for funding Primary Care Groups might result in little or nothing being available for commissioning linkworkers in primary care have not yet been addressed. The need for development funds to be made available for suitable services to meet the needs of minority ethnic patients is likely to remain for some time. It would be a great improvement on the past if future allocations recognised that linkworkers should be seen as part of the mainstream of services for those sections of the population that require them. If that recognition was given, the short termism and endless bidding for particular funds that has blighted the provision of linkworking and other services for ethnic minorities could be consigned to history.

2.3. Integration or independence - a continuing dilemma

A crucial question that arises from the larger question of who is to be responsible for arranging and funding services concerns the specific managerial and supervisory arrangements that are put in place. In particular, the issue of where schemes are located on a spectrum of accountability to the NHS and/or to the local community remains important.

Box 17 Independence and integration - a spectrum

A number of issues may be indicative of where a scheme fits into this spectrum.
For example:

Motivated by staff (paternalistic)	←→	Motivated by community concern (self help)
Accountable to NHS staff	←→	Accountable to community
Managed by NHS staff	←→	Managed by person outside NHS hierarchy
Emphasis on interpreting	←→	Emphasis on advocacy
Aims to educate patients and increase compliance	←→	Aims to empower clients to challenge treatment and care

Those who see themselves as potential funders of projects tend to favour a high degree of control over the management of projects. However, if linkworkers are to work effectively in primary care, models of management must be explored that promote:

- mutually respectful working relationships
- access to appropriate training, support and professional development
- links with and accountability to the communities being served
- safeguards that enable linkworkers to work for the needs of their clients in an independent manner

It may be that neither a purely NHS-driven model nor a purely independent community-led model can best deliver a service to meet all these criteria. If services are to become part of the mainstream, and not reliant on small pockets of time-limited finance, there is little doubt that NHS commissioning bodies, whether Health Authorities or PCGs, will want to ensure that effective management arrangements are in place to deliver the service they specify.

If commissioning is effective and Service Level Agreements are carefully negotiated, the NHS should receive an effective and value-for-money service, while respecting the benefits of independence and community involvement in management. This approach points to the need for sensitive hybrid models of management that combine features from diverse linkworking projects to date, and includes the community in their governance. However, unless linkworking schemes are embedded in a strategic framework, no model of management or accountability will guarantee their independence, their integrity, or indeed, their survival.

Box 18 Management of linkworker schemes

All schemes should have the following:

- Community involvement in management
- Involvement of senior NHS staff in management
- Ready access to managers
- Clear statements of purpose for scheme
- Explicit service level agreements
- A broad approach to performance management, including user-defined outcomes and qualitative evaluation
- Long term financial strategy to underpin service

PART 3

LINKWORKERS IN PRIMARY CARE - A CHECKLIST FOR COMMISSIONERS AND PROVIDERS OF PRIMARY CARE

This checklist is designed to remind commissioners and providers of primary care of questions that may be relevant to them in establishing and supporting linkworkers in primary care. There will be further points that need to be added in the light of local experience as primary care develops. Few schemes have, or are likely to have addressed all questions in a wholly satisfactory way. However, working towards comprehensive answers to the questions raised in the checklist should enable schemes to be more effective and sustainable and should provide a framework for increasing quality in linkworker schemes as well as better training and support for linkworkers themselves.

Strategic framework

- Is there an agreed strategy for improving ethnic minority health and access to health services?
- How does the linkworker scheme contribute to the development of a local strategy for improving ethnic minority health and access to health services?
- Who is involved in developing a local health strategy for improving ethnic minority health and access to health services?
- Are there robust links between the NHS, local authorities, voluntary organisations and the wider community in developing a local strategy?

Assessing need

Has there been an assessment of the local need for linkworkers that :

- Uses demographic information about the local population?
- Uses projections on future population changes?
- Uses morbidity and mortality data?
- Uses current information on language needs?
- Reflects discussions with the local communities on need?

- Involves all types of primary health care staff (not only GPs)?
- Reaches out to engage small minority communities, and those who may be less well represented by effective community organisations?
- Includes discussions with the appropriate Local Authorities?
- Includes an audit of existing relevant, local services?
- Is there a mechanism for recording unmet need that falls outside the scope of existing services for ethnic minorities?

Defining the linkworker's tasks

- Has there been explicit discussion to clarify the role/s of linkworkers, and to define the nature and scope of what they will do, and what they will not do?
- Have professional and lay interests been taken into account in defining tasks and priorities?

Management and supervision of linkworkers

- How will linkworkers be line managed and to whom will they be accountable?
- If joint funded, are there clear management arrangements that are acceptable to all funders?
- Has the line manager sufficient time in which to manage postholders, bearing in mind the likelihood of front-loading of management time at the outset of new schemes?
- What means of appraisal will be used to assess linkworkers' performance, and how will the appraiser develop competencies to carry out this appraisal?
- Are there clear Service Level Agreements in place between commissioners and providers?
- Is there a means by which linkworkers can access professional advice from someone other than a line manager, if required?
- Has there been discussion/decisions on whether/how to involve local communities in management arrangements?

Funding

- Has there been a clear estimate of the overall costs of starting up and maintaining linkworking?
- Is the cost of linkworkers (including management and administration) to be met through mainstream funding?
- What is the duration of the funding commitment?
- Has full use been made of available external funding sources?
- If funding is time-limited, what arrangements are in place to secure future funding?
- If long term funds are unlikely to be available, has a full assessment been made of the case for and against establishing short-term schemes?

Monitoring and evaluation

- What performance measures and indicators of outcome have been agreed?
- Is there agreement on what would constitute a successful outcome of linkworker involvement?
- Does the process of agreeing and reviewing performance measures and outcomes include professional and lay interests?
- What monitoring arrangements are in place to ensure an appropriate level and quality of service?
- How can the community be involved in monitoring and evaluating services?

Recruitment and selection of postholders

- Is there a clear job description for the post/s?
- Is there a clear person specification that relates to the job description?
- Does the person specification pay proper regard to valuing applicants' life experiences, voluntary and community activity and evidence of understanding of the needs of the communities to be served?
- Has there been consultation with local communities on the relevance of the job description and person specification?

- Who will be involved in the selection of postholders? Will there be community/lay involvement in selection, and if so, how?

- Where will posts be advertised and publicised in order to maximise access by relevant communities?

Training

- What arrangements have been made for induction training?

- What arrangements are in place for in-service training?

- Are there effective links with local colleges etc. to ensure their input to curriculum development and delivery of training programmes?

- Have there been discussions with professionals, community workers, community organisations and patients on content of training courses?

- Does the training programme for linkworkers include:
  - Communication and language skills?
  - Understanding how the NHS works?
  - Input on local policies?
  - Understanding of other relevant services (e.g. social services)?
  - Cultural and religious issues?
  - Assertiveness and confidence-building?
  - Input on relevant health/medical issues?
  - Needs assessment?
  - Community development?
  - Negotiating skills?
  - Information on anti-discrimination legislation?

- How will training be financed?

- Have local communities been invited to contribute to training courses?

- Have arrangements been made to ensure that all colleagues (including doctors of all levels of seniority) have access to training to enable them to understand the roles of linkworkers and to work effectively with them?

- Is anti-discrimination training and equal opportunities training mandatory and available for all staff?

Administration and support

Have arrangements been made for:

- desks and office space?
- health and safety provision?
- access to telephones, bleeps etc.?
- clerical/secretarial assistance?
- name badges?
- advising switchboard and local information services of start date, availability of workers?
- out of hours cover?
- cover for sickness, holidays and study leave?

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Appendix 1

The literature review: about the search strategy

A search was undertaken, using the following databases: King's Fund Library Database, DHdata, Helmis, Assia, Sociological Abstracts, HealthSTAR, Medline (1983 to January 1998 only) and CINAHL. In addition to the more obvious words "linkworker" and "advocate", which were known to be in common use in the NHS as terms for bilingual workers, a further selection of words was identified by reading the following article, which had noted over 30 terms in use in the USA for lay health workers: Eng E and Young R. *Lay health advisors as community change agents.* Family and Community Health 1992 15(1): 24-40. The Eng and Young article had come to our notice through a draft paper by Dr R. Khanchandani and Dr S. Gillam, entitled *The ethnic minority linkworker - a key member of the primary health care team?* Having consulted these sources, the databases were then searched using their respective thesaurus terms combined with the free-text descriptions of linkworkers as suggested by Eng and Young.

The free text terms were used in their truncated form (with the suffixing of the dollar sign) in order to maximise retrieval of relevant references. These terms were used in all eight databases, and were as follows:

advocate$1
linkworker$
lay health$ worker$
lay health$ advisor$
canvasser$
community health$ advisor$
Community health$ aide$
Community health$ opinion leader$
community health$ representative$

community health$ worker$
community health$ helper$
community helper$
health education aide$
health facilitator$
health promoter$
health visitor$
health liaison$
outreach
home visitor$
indigenous health aide$
paraprofesional$
informal helper$
lay community health worker$
lay volunteer$
natural caregiver$
natural healer$
natural helper$
natural neighbour$
natural neighbor$
nonprofessional$
non-professional$
resource mother$
voluntary health educator$

The subject term "advocacy" was also added to this list for each database searched. In the cases of HealthSTAR, Medline and CINAHL, the word "advocacy" was searched on as a heading word wherever it appears as any component of any thesaurus word or phrase.

Subject terms specific to each database were then searched on and combined with the above free-text terms and the subject "advocacy" in order to find a smaller and more relevant set of references. The King's Fund database was searched using the subject term of "black and ethnic minorities". DHdata, Helmis, Assia and Sociological Abstracts were all searched using the truncated terms "ethnic$", "black$", "asian$", "indian$", "pakistani$", "bangladeshi$", "chines$", "carribean$" and "african$". HealthSTAR, Medline and CINAHL were all searched using the exploded thesaurus terms from MeSH and CINAHL of "ethnic groups" and "racial stocks". The results from these three databases were limited to reference on humans only and those written in the English language.

In the end, 296 potentially relevant references were downloaded from the database. In practice, some proved to be of no relevance, some duplicated very similar material and some articles or books were unavailable. Other material was found through personal recommendation and by references within sources identified above. 51 references were looked at in detail.

Appendix 2

Interview schedule for linkworker project[5]

1. Do you see a place for linkworkers in primary care? If so, what?

Check possible roles:

translation/interpretation
cultural mediation
advocacy
health education/health promotion
lay health worker/aide
other

2. What would a commissioner of primary care need to know before commissioning linkworkers?

3. What are your views on

a) managerial issues

b) accountability

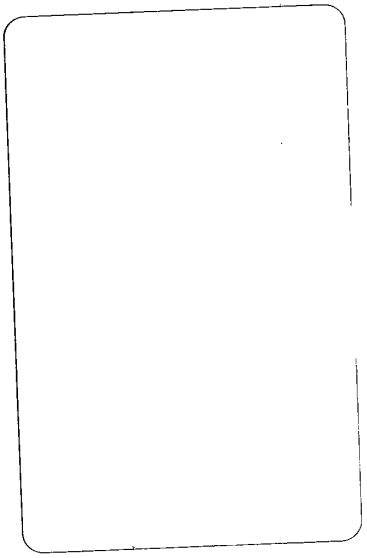
c) funding and costs

d) training

4. What lessons are there from previous linkworker schemes?

5. Any suggestions for further contacts?

[5] This schedule of questions was used as a basis for discussion, but its use varied according to the interests and experiences of the interviewee. Group discussions were structured more loosely, but covered similar issues.



ISBN 1-85717-224-8

King's Fund Primary Care series