BUILDING BRIDGES FOR HEALTH

Exploring the potential of advocacy in London

Baljinder Heer

putting
health
first

Building Bridges for Health

EXPLORING THE POTENTIAL OF ADVOCACY IN LONDON

BALJINDER HEER

This working paper makes the basic case for supporting and developing advocacy. It explores the advocacy sector in London and the Government's growing interest through a literature review, document analysis, and explorative questionnaire to advocacy providers, in-depth interviews with key stakeholders, and focus groups with a range of community leaders. It also draws sector and policy views together and makes recommendations about the way forward. The paper is part of Putting Health First, a programme of work set up by the King's Fund to explore the idea of a health system that gives priority to promoting health and reducing inequalities, as well as delivering health care services.

Contents

About the author

Baljinder Heer is a researcher in Health Policy at the King's Fund. Her current work focuses on inequalities in London, health advocacy, and nutrition and health. She has held various academic posts and has worked extensively with South Asian communities in east London, researching determinants of poor obstetric outcome and investigating community-based health promotion initiatives.

Acknowledgements

Summary

Advocacy plays an important role in supporting and empowering disadvantaged individuals to access the information and services they need to improve their own health and well-being. In the United Kingdom advocacy has developed rapidly over the past 20 years, but little has been known about what the advocacy sector 'looks like', how many advocacy organisations there are, how they work and the challenges and opportunities they face.

The King's Fund set out to explore these issues through original research, including an extensive literature review, in-depth interviews with people working in the advocacy sector, and analysis of government policy.

Our research shows that there are many organisations in London that provide advocacy, and are committed to ensuring that the voices of individuals, groups and communities are heard and their views acted upon.

However, we also found that advocacy and government policy have developed in an ad hoc manner and that the advocacy sector now faces a number of fundamental dilemmas that, if not addressed, may threaten its continued progress.

The King's Fund has a long-standing interest in promoting the health of disadvantaged communities. Advocacy can play a part in that by helping individuals and communities to exercise their rights and access the services and knowledge they need, and by empowering them to voice their own needs and implement their own solutions.

The King's Fund has a long history of supporting and funding the advocacy sector, both by helping to develop advocacy networks and by making grants to individual projects. This support has contributed to the growth of advocacy, particularly in London.

Putting Health First

This working paper is part of Putting Health First, a programme of work set up by the King's Fund to explore the idea of a health system that gives priority to promoting health and reducing inequalities, as well as delivering health care services.

Disadvantaged individuals and groups need effective ways of linking into such a system, to ensure they received the best possible health maintenance and care. We believe that one way of doing this might be to create a stronger cohort of community-based advocates to help disadvantaged and socially excluded groups gain access to the knowledge and means to secure good health.

This is not a role that many advocates in the United Kingdom have adopted, and not one that all would want to embrace. Nevertheless, we believe it is worth exploring.

Methods

Our research included an extensive literature review, document analysis, an exploratory questionnaire to advocacy providers, in-depth interviews with key stakeholders, and focus groups with a range of community leaders.

We conducted 32 semi-structured interviews with people responsible for advocacy policy, leaders of advocacy networks, managers and/or workers in advocacy projects, and academics who have carried out research in advocacy.

We analysed a number of pieces of government legislation giving more prominent or new roles to advocates, including the Race Relations Amendment Act 2000,[1] the Special Educational Needs and Disability Act 2001,[2] Valuing People: A new strategy for learning disability for the 21st century (2001),[3] the Health and Social Care Act 2001,[4] the Adoption and Children Act 2002,[5] the Draft Mental Health Bill 2004[6] and the Draft Code of Practice for the Mental Capacity Bill 2004.[7] We also looked at advocacy in other countries, particularly Scotland and Canada.

The advocacy sector

The concept of advocacy first arose in the United States in the 1960s. It is hard to pinpoint exactly when it arrived in the United Kingdom, but it has been present in the health and social care field for over 20 years.

This research established that there are between 450 and 500 projects providing advocacy in London alone, either as the only thing they do or as a component of their work. The majority work with specific client groups and provision is patchy; some areas have high levels of provision, while others have little or none.

Most of the respondents to our questionnaire said the reason for setting up their projects was identified need, reinforcing the fact that advocacy has developed in a sporadic way. Most projects operate with insecure sources of funding and long waiting lists.

Government policy

Since Labour came to power in 1997, there has been an increasing interest in advocacy among government departments. However, they have different conceptions of the role of advocacy, how it should be funded and developed and who should provide it. Some pieces of legislation establish services that many within the advocacy sector would regard as crisis support or dispute resolution rather than advocacy.

Key issues

Defining advocacy

Advocacy groups, government departments, and service commissioners and providers all seem unsure about what advocates are and what they do – while the public generally has no understanding of 'advocacy' at all. There is also considerable confusion over where the boundaries of advocacy do and should lie.

Our recommendations

We believe it would be useful to develop a consensus on a working definition of advocacy, to facilitate working relationships between advocacy organisations and build wider understanding.

We also think that advocacy should include a range of activities:

- helping to protect and support individuals who are particularly vulnerable because of illness or lack of capacity to make informed decisions
- representing individuals' views to service providers and others, and helping them resolve issues about their health and health care
- providing information and advice about preventing illness and improving health, and about health services
- empowering individuals/groups to define their own needs, make their voices heard, and gain access to the knowledge, support and services they require.

Developing advocacy

The ad hoc manner in which advocacy has developed has resulted in patchy provision. Government policy on advocacy has also been piecemeal and disjointed, with some disadvantaged groups being given a right to advocacy and others being ignored.

Our recommendations

We believe that a strategic approach is required. At a national level, government departments should ensure that their various policies on advocacy are consistent and coherent. This could be achieved by having one piece of legislation that covers all forms of advocacy and gives a right to independent advocacy for all vulnerable groups. A similar approach has been taken in Scotland.

At a local level, advocacy plans should be drawn up by local authorities and primary care trusts, in consultation with advocacy organisations and other stakeholders, to ensure equity of access, appropriate specialisation and adequate funding. This model is used in the Government's White Paper, Valuing People, which focuses on improving the lives of people with learning disabilities, and in Scotland, where the Advocacy Safeguards Agency – an independent body funded by the Scottish Executive – supports and monitors the development of local plans.

Awareness and identity

The research found that many advocacy providers feel they are working in an environment where there is little knowledge of who they are or what they do. In England, advocacy also lacks a national identity and presence, which reduces its capacity to influence government policy.

Our recommendations

There are many regional and specialist networks that aim to play an influencing role and to provide opportunities for shared training, information exchange and regular policy and practice updates. We believe these should be encouraged and supported.

However, as advocacy rises up the national political agenda, we also believe there is a case for developing a stronger collective identity and a shared voice through a single body or alliance for the whole sector. A recently formed organisation, The Advocacy Federation (TAF), plans to develop in this way.

Funding

Most advocacy projects are unstable because of inadequate and unreliable funding. One route to stability is to win long-term funding through contracts and service-level agreements with statutory organisations. There is a danger that this may compromise advocacy's independence from statutory services. However, independence is a mixed blessing; this research suggests that the more separate and independent advocates are, the more likely they are to come up against institutional barriers.

Our recommendations

We believe that central government needs to make more money available to local statutory bodies and that they should be partly responsible for funding advocacy in their areas. Clear service-level agreements can help minimise the problems associated with independence.

Training and development

Service commissioners want a trained workforce, and many advocates would like to be on a career path. Many different courses now exist, but they can be inaccessible because of location, time or cost, and there are debates about the quality and appropriateness of their content.

Our recommendations

We believe advocacy should be placed on the NHS 'skills escalator' – a structure by which NHS staff can acquire new skills and invest in professional development – as a mechanism for moving from unpaid voluntary work to paid employment. We also believe there should be formal courses available to encourage career advancement.

Standards

There are currently no shared national standards or guidelines for advocacy providers, except those that are client specific and are developed by the networks or those that accompany specific government interventions. We recognise that some in the advocacy sector feel standards will formalise and professionalise advocacy, stifling the energy and spontaneity of grass roots volunteerism.

Our recommendations

We believe that standards are needed to protect individuals, make advocates accountable for their actions and provide some consistency between providers. They should also grant legitimacy and credibility to organisations – something that funders are often looking for. We believe these should be provided by an independent organisation or alliance representing the advocacy sector and should cover organisational issues, such as maintaining independence.

Evaluation

Many advocacy organisations lack the capacity and resources to self-evaluate or measure their progress against standards.

Our recommendations

We believe advocacy projects need more support to carry out evaluations. Alternatively, an independent organisation could be responsible for carrying them out. In Scotland, it is recommended that all advocacy projects be evaluated every three years and most evaluations are conducted by the Advocacy Safeguards Agency.

Conclusion

We believe this is a critical time for health advocacy. The advocacy sector has developed rapidly over the past 20 years. Government departments are showing an increasing interest in it, and the Government's agendas on choice, public participation and public health are likely to present new opportunities but also present new challenges.

Our questionnaires and interviews show that recent government attention, while welcomed, has already prompted many within the advocacy sector to take a long hard look at their work, and where the sector is heading on such key issues as funding, independence, professionalism and accountability.

We believe that the sector now needs to develop a more strategic approach, along with a stronger national identity and voice for the sector itself. We recognise that the proposals set out in this working paper will not appeal to all. Nevertheless, we believe the time is right for a debate, and we hope this working paper will contribute to it.

Introduction

Advocacy at its simplest means supporting and empowering disadvantaged individuals so that their views and concerns are heard in order to secure enhanced rights and entitlements. It covers virtually every aspect of human life and operates in many ways.

The advocacy sector in the United Kingdom has developed rapidly over the past 20 years, but until now little has been known about how many advocacy organisations there are, how they work and what they do.

This working paper shows that there are as many as 500 advocacy organisations in London alone, and that they play an important role in ensuring that people's voices are heard and their views acted upon. However, it also shows that advocacy has developed in a non-strategic manner. There is no agreement on how advocacy should be defined or delivered, and the sector is facing a number of fundamental dilemmas that, if not addressed, may pose a threat to its continued progress.

There are good reasons for raising these issues now. In recent years, the Government has paid more attention to advocacy, with a number of White Papers and initiatives creating more prominent or new roles for advocates.

Yet the King's Fund analysis shows that the Government has also failed to take a consistent approach. Different models of advocacy and different approaches to such key issues as funding, regulation and professionalism have been applied – some of which are difficult, or even threatening, for many within the advocacy sector.

Meanwhile, the second Wanless report, *Securing Good Health for the Whole Population*,[8] has reignited interest in public health, with its description of a 'fully engaged scenario' in which individuals are committed to safeguarding their own health, and the Government is committed to enabling them to do so.

The King's Fund believes that we need to create a health system in the United Kingdom that gives priority to keeping people healthy and reducing inequalities, as well as delivering health services.

We believe that advocates have an important contribution to make in such a system, by helping to empower individuals, particularly those who are disadvantaged, to access the information and support they need to improve their own health and well-being.

The Government's 'choice' agenda in health care and its focus on patient and public involvement in health services also suggests a new need for advocacy, to ensure that everyone

can benefit from enhanced choice and take up the new opportunities for participation that are on offer.

All these developments present further opportunities and challenges for the advocacy sector; to meet them the sector needs to develop in a more strategic way. This working paper explores these issues. It starts by setting out the background to our research and making the case for supporting and developing advocacy. It then explores the advocacy sector in London and the Government's growing interest. Finally, it draws sector and policy views together and makes recommendations about the way forward.

We realise this is not uncontested ground. Other groups may question our views and recommendations. Nevertheless, we believe that at this crucial point for advocacy it is time for a debate: we hope this working paper will contribute to that.

1 The King's Fund and advocacy

The King's Fund works to promote the health of disadvantaged communities. This is not just a matter of improving health services or improving access to them: it requires action to tackle the underlying social, economic and environmental factors that affect individuals' chances of living long and healthy lives.

Advocacy has a role to play in helping disadvantaged individuals, groups and communities to exercise their rights, access services, voice their own needs and obtain the information and support they need to implement their own solutions. As a result, we also have a long history of supporting and funding the advocacy sector. Over the years, our support has included:

- A major grants programme for health advocacy for black and minority ethnic communities in London. This grew out of a review of provision and is a five–six-year commitment, with funds of £1 million (*see* box right).

- Funding to support Advocacy Across London (now called Action for Advocacy, A4A) and a current development grant of £120,000 to support their policy and communication work. A4A is a support and resource agency for independent advocacy services in Greater London. In the past three years they have developed a reputation as one of the United Kingdom's leading authorities on the development of effective advocacy services for vulnerable and disempowered people.

- Substantial investment in development grants for individual advocacy projects, and in mental health and homelessness projects and programmes that have included elements of advocacy.

The support we have provided has contributed to the growth and development of advocacy, particularly in London, and given an insight into both the success of the movement and some of the dilemmas it now faces. We are therefore well placed to act as a 'critical friend' to the sector.

Putting Health First

This working paper is part of Putting Health First, a programme of work set up by the King's Fund to explore a health system that gives priority to promoting health and reducing inequalities, as well as delivering health care services.

Disadvantaged individuals and groups need effective ways of linking into such a system, to ensure they receive the best possible health maintenance and care. One way of doing this

HEALTH ADVOCACY FOR BLACK AND MINORITY ETHNIC LONDONERS

In 1999, in partnership with the NHS Executive London, the King's Fund commissioned a review of the provision of health advocacy services for minority ethnic communities in London. Subsequently, it set aside a grant of £1 million to promote and support their development, with the aim of making an impact both locally and at a strategic level. This work has the following strands:

A pan-London network
The Council of Ethnic Minority Voluntary Organisations (CEMVO) was commissioned to:
- establish and run a network to promote the growth and strategic development of health advocacy services
- share good practice
- raise awareness among mainstream health and social care services
- campaign for better policies and more resources, working collaboratively with member organisations, individuals and advocacy agencies.

Qualifications
The East London Advocacy Consortium (ELAC), Making Training Work, the University of East London and the Urban Learning Foundation were commissioned to develop and deliver a new course for health advocates at higher education level, along with access courses, and pre-course and on-course support. Bursaries were offered as part of the initiative. The course has been running since September 2001, with students of various ages and ethnic groups. The King's Fund has commissioned an external evaluation, which will be published in due course.

Quality standards
An advocacy standards framework for black and minority ethnic communities was developed and published in March 2002.[9] The framework is a tool that offers a set of standards for health and social care advocacy and a process for implementing standards. It can be used by service users or clients, advocacy providers, commissioners and funders. The framework is currently being tested in two organisations – the North West London Strategic Health Authority and Croydon Primary Care Trust.

Contact: Mercy Jeyasingham, Programme Manager, Grants Department, King's Fund

---

would be to develop a stronger cohort of community-based advocates to help disadvantaged and socially excluded groups secure access to the knowledge and means to secure good health.

This is not a role that many advocates in the United Kingdom have adopted and it is not one that many within the advocacy sector would recognise or accept. Nevertheless, we believe it is worth exploring, and it is discussed throughout this paper as one of the many opportunities and challenges that advocacy now faces.

Research aims and methods

The advocacy sector has been developing rapidly. However, little is known about what this sector 'looks like', that is, how it works, what it achieves and what opportunities and challenges it faces. We set out to explore these issues, focusing on the following questions:

■ What is the state of advocacy provision in London – how many advocacy organisations are there, what do they do and how do they operate?

■ What does the policy framework look like and how is it affecting providers?

■ What are the opportunities for and barriers to developing advocacy further?

We based the research on qualitative methodology. We included an extensive literature review, document analysis, an explorative questionnaire to advocacy providers, in-depth interviews with key stakeholders, and focus groups with a range of community leaders.

We sent the exploratory questionnaire to all known advocacy providers in London with the aim of identifying the current state of advocacy provision. We sought general data that would provide a 'snapshot' of the spread of provision, and were not aiming to obtain comprehensive data on every scheme in London. We also used the questionnaire as a tool to explore some of the key thinking about health advocacy, which we would then discuss in more detail in the interviews.

We sent a total of 470 questionnaires; we received 78 responses (73 fully completed), a response rate of 17 per cent. Our results are comparable with two other surveys carried out in the same year with the same spread of organisations,[10, 11] which achieved 5 per cent and 20 per cent response rates, and are concordant with other mapping exercises in recent years.[12, 13]

We then conducted 32 semi-structured interviews with people responsible for developing advocacy policy, leaders of advocacy networks, managers and/or workers in advocacy projects, and academics who have carried out research in advocacy.

All the people we approached were willing to be interviewed and were keen to express their personal views and to discuss issues in detail, particularly as anonymity had been assured. The views we heard were remarkably consistent across the range of interviewees.

The interviews also confirmed what we had learnt during the scoping study and in the focus groups, and had extracted from the literature review. The key points are discussed in Section 2, pp 16–25, with quotations to support the assertions made. The majority of the quotations are from the interviews, although some are taken from other strands of the research.

In total, 133 people participated in this research, which began in May 2003 and ended in July 2004.

What is health advocacy?

There is no single accepted definition of advocacy, although the majority of London advocacy organisations (and others elsewhere) have adopted the definition coined by A4A:

> *Advocacy is taking action to help people say what they want, secure their rights, represent their interest and obtain the services they need. Advocates… work in partnership with the people they support and take their side. Advocacy promotes social inclusion and social justice.*
> *Advocacy Charter*,[14] Advocacy Across London

The concept of health advocacy is even more contested. By 'health advocacy' we mean an independent, community-based service that not only includes support for individuals to get their views heard but also – and crucially – empowers individuals and communities to identify their own needs and implement their own solutions. We do not confine health advocacy to health services; indeed, we believe that all advocacy is health advocacy as the aim is always to achieve improved well-being, which has a close link with health.

The health advocate's role

The health advocate's role has developed in two main settings: health and social care services, and the community (although there is some overlap between them).

In health and social care settings, advocates help individuals to navigate and understand the health care and social services systems and mediate between the two. They may accompany users to meetings, help them obtain information about their rights, medication or discharge plans, or provide support on other issues, such as obtaining culturally appropriate food. They can help users voice fears and complaints, and act as cultural interpreters, educating providers about the health beliefs and practices of particular communities.

In community settings, health advocacy is more geared towards addressing the underlying causes of ill health and preventing illness. Advocates may help an individual to make a benefit claim, to find work, education or leisure opportunities, to access information on how to prevent illness, or to secure appropriate community services. Advocates also act as information brokers in communities, providing health information and guidance in culturally appropriate ways and securing more productive relationships with service providers.

The core principles of advocacy

There is also no single set of principles or standards that the advocacy sector as a whole agrees on. However, there are four main values that are generally accepted as being the core principles of advocacy.[15] These are:

- **Independence** Advocates represent disadvantaged individuals and groups. An important debate is the extent to which they need to remain financially and structurally independent of organisations involved in commissioning and providing services.

- **Empowerment** Advocacy is about sharing knowledge and passing on skills, not simply befriending, advising or acting on an individual's behalf. Many in the advocacy sector believe the ultimate aim of all forms of advocacy is self-advocacy, in which individuals can argue their own case and access rights themselves.

- **Accessibility** Advocacy should be available to all who need it and free of charge to the user.

- **Confidentiality** Effective advocacy involves intensive information exchange and high levels of trust. Explicit agreements on confidentiality, strictly observed, are therefore essential.

Models of advocacy

Even though there is widespread agreement on the principles of advocacy, many different models exist.[15, 16] These include:

- **Self-advocacy** This encourages people to speak up for themselves. It is often organised and driven by disabled people or service users, offering mutual support and confidence-building, and challenging stereotypes and discrimination.

- **Group advocacy** A group of people with similar experiences meet together to put forward shared views. Local user groups, support groups and patient councils are all examples of group advocacy, as are larger national groups, such as MIND and Help the Aged, which campaign about issues raised by their membership.

- **Peer advocacy** This is support from those with experience of using the same services, usually mental health services. Peer advocates can draw on their own experiences to understand and empathise with the person they are working with, which makes it easier to have an equal relationship between the advocate and user.

- **Formal, professional or paid advocacy** Many voluntary organisations develop advocacy services in which some, or all, of the advocates are trained and paid to work with anyone who wants to use their service (although many of the advocates are also users or survivors). This kind of advocacy is usually focused on short-term or 'crisis' work, rather than providing long-term support.

- **Citizen advocacy** This matches people with partners from their local community, to provide help in specific situations, develop long-term, supportive relationships or help vulnerable people take a fuller part in the life of the community. Most citizen advocacy schemes have paid co-ordinators, who train and support unpaid volunteer partners.

- **Legal advocacy** This involves people with specialist knowledge and training, such as lawyers and advice workers, representing people in formal settings, such as courts, tribunals or complaints processes. A legal advocate will often give advice and express an opinion about the best course of action.

- **Bilingual advocacy** This is not only about translation, but also relaying cultural, religious and social messages about clients to health professionals and vice versa. Bilingual advocacy means all advocacy in which the client and the professional use different languages, including British Sign Language.

However, there have been moves within the advocacy sector to reclassify advocacy, using just three service models:

- **paid or formal advocacy** – is essentially short-term case work, often provided by a paid worker
- **citizen advocacy** – is long-term, supportive and provided by volunteers
- **collective or group advocacy** – is a group of people with similar experiences supporting each other and campaigning for change.

The case for health advocacy

The concept of advocacy arose out of the civil rights movement in the United States in the 1960s. It recognises that many people in society feel disempowered and voiceless, and aims to give them respect, dignity and control over their own lives.

Some people have to rely on powerful service systems for help with all aspects of their life – housing, occupation, income, mobility, decision-making. Individuals who rely on these services often have limited personal power and resources to argue their case. This is especially true if they are very young or very old, have reduced mental capacity or do not use English as their first language.

In addition, there are well-documented inequalities in the availability and quality of services and care available to some groups of people.[17] There are, for example, historic and persistent differences in the health services available in relatively affluent and in relatively disadvantaged areas.[18] The volume and cost of drugs, operations and other health expenditures tend to be higher in more affluent areas than in poorer areas, even though health needs are greater in the latter. There are similar negative correlations between expenditure on people in professional and unskilled populations.[19]

There is substantial evidence that advocacy can be an effective mechanism for promoting access to services and so helps to promote the health of those in need (*see* box pp 14–15).

We believe this role is likely to become more important as the Government develops its 'choice' and patient involvement agendas. Patients will have more information and options open to them, but we must ensure that this benefits everybody, not just those who have the time, resources and education to make effective use of the system.

Improving the health of the population is also becoming a central goal for the Government and the National Health Service. The Government has introduced a range of policies aimed at improving health – from tackling child poverty and social exclusion to addressing the causes of obesity.

However, inequalities in health between different socio-economic and ethnic groups have continued to grow.[20] Measures aimed at improving health tend to have a greater impact on those who are better off than on those who are worse off. Groups and individuals who are most vulnerable to physical and mental ill health find it hardest – for a range of reasons – to respond to messages about safeguarding their own health.[21]

We believe that health advocates could play an important role in building bridges between disadvantaged citizens and the knowledge, support and services they need to prevent illness and improve their health.

It may be asked why we should focus on advocacy rather than on improving the ability of health services to respond to the needs of disadvantaged members of the community, or on other responses. Doctors, nurses and other clinical professionals do speak up for the people they serve, but advocates have a number of significant advantages. First, it is clear that their primary loyalty and accountability is to the people on whose behalf they advocate, as they have no organisational or professional conflicts of interest.

Second, as members of the communities they serve, advocates are familiar with their ethnic, cultural, social, environmental and historical experiences. They may therefore be more effective in promoting preventive behaviours and disseminating health information than health care providers, who often do not share the same experiences or understanding of health as those they serve.

Third, the Whitehall studies[22] conducted by Sir Michael Marmot show that perceived control is strongly related to how individuals measure their own health and actual health outcomes. Advocacy aims to empower individuals and give them more control of their own lives, which should not only increase health but also mitigate some of the effects of material deprivation.[23] It can also play an extremely important role in combating social isolation and exclusion by facilitating the development of social networks and contributing to social capital.[24]

Despite these powerful arguments, advocacy is poorly understood and generally remains undervalued and under-resourced.

THE EVIDENCE BASE

Substantial evidence now points to advocacy as an effective mechanism for promoting the health of those in most need, helping individuals to manage chronic conditions, helping them to access services, and improving the responsiveness and quality of those services. We have not conducted an exhaustive literature review, but some examples are given below.

Improving health
A five-year study in Hackney, London, showed that providing women from minority ethnic groups with the support of an advocate during their pregnancy had a significant effect statistically on maternal and infant health.[25] The retrospective study involved almost 4,000 mothers and three different control groups. It showed a dramatic difference in rates of caesarean section, induction and antenatal length of stay between the test and control groups, and improvements in birth weight. The researchers speculate this may be because the women felt more confident to voice concerns, ask questions and provide information about themselves when they had the support of an advocate.

A three-year controlled trial in Liverpool found that providing health advocacy for homeless people in primary care resulted in significant improvements in their health-related Quality of Life (QoL).[26]

Research from the United States and Canada suggests that advocates who also carry out health promotion activities, such as providing information and advice about specific health issues, have increased the detection of breast and cervical cancer through: higher rates of screening uptake; improved childhood immunisation rates; lower rates of infant mortality and low birthweight; and improved hypertension control, diet and nutrition, and smoking cessation rates.[27-30]

Access to statutory services

A two-year prison link-worker scheme, set up in the south-east of England for people with mental health needs who come into contact with the criminal justice system, was extremely successful at increasing registrations with general practitioners (GPs) (from 64 to 99 per cent), arranging mental health assessments and referring clients to drug and alcohol agencies.[31] It was also able to help with housing and other needs. The study went on to conclude that this type of assertive outreach had a positive impact on the health and well-being of these vulnerable people.

A three-year project to provide advocacy for an Armenian population in London was able to identify many isolated and vulnerable people with unaddressed health needs, including depression, anxiety and arthritis. The project supported them using appropriate services and helped them to become more integrated into the community.[32]

Improving the quality of care

The Hackney study (*see* p 14) also improved communication between patients and clinicians. As a result, clinical practices were modified and standards of clinical care and outcomes were significantly improved – as were levels of satisfaction for patients and staff.[25] Enhanced communication can also lead to prompter use of medical services, better appointment-keeping and increased compliance with treatment and prescribed medication.[33]

Reducing the burden on services

The Liverpool study (*see* p 14) also found that homeless adults who were registered with a GP by a health advocate during outreach visits to hostels made significantly less use of health centre resources and were prescribed less medication than homeless adults in two control groups.[34] The additional costs of providing health advocacy were, indeed, offset by a reduction in demand for health-centre-based care, so 'the intervention was cost neutral'.

Ro *et al* carried out an extensive review[35] of the cost-effectiveness of several US advocacy-based health promotion programmes and concluded that they not only reduce costs, but also save lives. For example, one large-scale evaluation found that those clients served by the programme used health services by a considerable $2,700 less per year per client than the control group. They then projected a $50,000 per year saving for each community health worker employed. Another US programme evaluation found that Kentucky's health care system saved $935,000 over one year, largely because the community health workers were successful in keeping clients well and, as a result, out of nursing homes and hospital emergency departments. All the studies reviewed report improved health outcomes to varying degrees for those clients in programmes compared with the control groups.

2 Lessons from the research

Advocacy is an international concept. In the United States, Australia, New Zealand and Canada, the predominant model is group advocacy and centres much more around political lobbying and campaigning activity on behalf of disadvantaged communities or groups.

Citizen and paid advocacy programmes often incorporate a stronger health promotion function than those in the United Kingdom, and frequently use different terminology such as community health advisors and lay health workers.[33, 36]

It is difficult to pinpoint exactly when advocacy arrived in the United Kingdom but it has been prevalent in the health and social care field for over 20 years.[15, 16] As in many other countries, the advocacy sector has developed upwards from the grass roots, forming loose networks that have been sporadic and local in focus. Many different models have emerged, with no single one predominating.

Advocacy providers in London

The data collected during this research indicates that between 450 and 500 projects provide advocacy in London, either as their sole function or as a component of their work. Few provide generic advocacy services; instead, nearly all work with specific client groups.

The majority of advocacy providers identified were registered charities and the rest were either voluntary organisations or statutory bodies. Advocacy for mental health and older people was more likely to be provided by large, national organisations – the two key stakeholders in these fields were MIND and Age Concern – while all the providers of bilingual advocacy and advocacy for black and minority ethnic groups and refugee communities were small, local organisations.

Figure 1 (*see* right) shows the diversity of the work done by respondents to the mapping questionnaire.

Most respondents to the questionnaire said the reason for setting up their project was an identified need, reinforcing the fact that advocacy has developed in a sporadic way.

> *We've never sat down in this borough and had a conversation about what kind of advocacy services we need and how many – they just appear when someone in the community sees that there's a desperate need for it. But things are changing. Government policies are ensuring that at least some kinds of advocacy are available in each locality.*
> Learning Disability Advocacy project manager

1 CATEGORIES IDENTIFIED BY ADVOCACY PROVIDERS IN LONDON

Housing 3%
Carers 1%
HIV 3%
General 3%
Mental health 19%
Physical disability and sensory impairment 8%
Black and minority ethnic and refugee 19%
Older people 10%
Independent Advocacy and Complaints Service 1%
Patient Advice and Liaison Service 10%
Learning disability 11%
Children and young people 12%

Source: King's Fund 2004
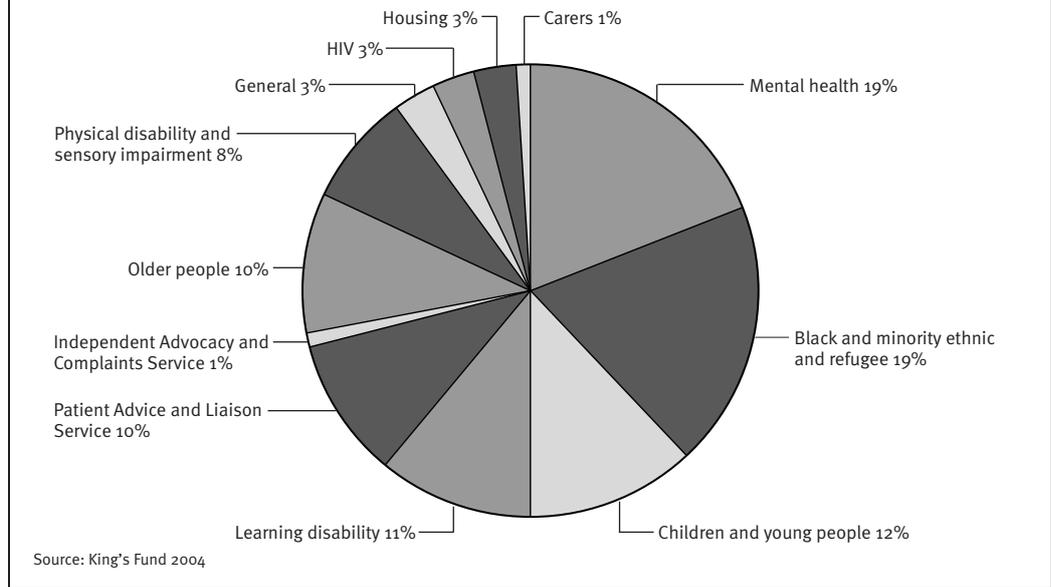
Defining advocacy

As a result of this ad hoc and piecemeal development, there is no clear consensus on the definition of advocacy.

> *We need some conceptual clarity about what we're talking about. Advocacy captures so many diverse activities and is provided in a myriad of ways. It is hard to embody this diversity in one catch-all term, which is what most people are used to.*
> Academic

To add to the confusion, a great deal of work that we would consider to be advocacy is not labelled as such. People who are identified as 'link workers', 'community health workers' and 'bilingual interpreters' may all have an advocacy role.

> *I've been providing advocacy for years as part of my role as a community HIV worker, but I've only recently realised that that's what it's called. But I've met other people who are called 'advocates' who say I don't fit in with their gang because I provide other services as well, such as health advice. I say I am an advocate.*
> HIV project manager

Meanwhile, some services may be described as advocacy by policy-makers and providers that are not regarded as advocacy by many within the advocacy sector.

For example, the Government created patient advice and liaison services (PALS) in 2002 for the National Health Service (NHS). Some of the PALS involved in this research did not regard their work as advocacy while others did; one said the service they provided 'was advocacy with a small "a"'.

> *Our original title included advocacy in it. This then changed to advice as it wasn't considered appropriate [by the advocacy sector] for the NHS to be providing advocacy, but if you speak*

to the different PALS some will say they do and some will say they don't provide it. I think we all provide it. You can't advise and support patients through problem resolution without sometimes providing advocacy, and quite often there just isn't time to get an independent advocate.
London PALS manager

The role of advocacy

There is general agreement within the sector about the fundamental principles of advocacy, but disagreement over where its boundaries lie. Many of those interviewed believed advocacy is only, and should be only, about safeguarding the rights of citizens and supporting them to make their views heard.

Others believed that giving advice and raising awareness of health issues can be an important feature of advocacy work. For example, health advocates at Newham General Hospital are actively involved in health promotion programmes and events, and others are involved in similar programmes.

We provide advocacy services in Tower Hamlets and work quite closely with the local GP surgeries. They refer patients on to us who are not taking up cervical smear tests. We then get in touch with them and explain the procedure to them and the importance of it. Many women just don't understand what it is.
Black and Minority Ethnic Health Advocacy project manager

Models of advocacy

Our research suggests that there can be tensions and conflict between different sections of the advocacy sector with disagreements about what is 'true' or 'good' advocacy.

There are real differences between our movements and we should recognise and respect these differences. But we don't. We allow them to divide us. If we spend all of our energy and time arguing among ourselves we will never achieve anything. We must present a united front that encompasses all models and groups.
Advocacy Resource Agency manager

Some interviewees believed that only 'users' or 'peers' are able to provide real empathy and understanding and that professional advocates may not able to do this, because they may not have a similar background or have experienced similar problems to the client.

Some interviewees also argued that advocacy should be about long-term supportive 'friendships' and not about short-term crisis intervention, saying that, historically, advocacy has been centred around the client not the problem, and that it takes time to build trust and develop a relationship between client and advocate. Others, however, could see a role for short-term work.

All these forms of advocacy are important and complementary. There is no 'best' or 'purest' form of advocacy. Strong collective advocacy organisations are an essential part of a healthy democratic society and make a unique contribution to changing law and policy. Independent professional advocacy is an essential part of a fair system; it levels up the scales for people who are disadvantaged and vulnerable. Citizen advocacy is an essential part of a healthy

community; it introduces people who would otherwise not meet and it strengthens the social fabric by reconnecting people who are disconnected.
Scottish Executive[37]

However, our research shows these debates may gradually be coming to an end as various organisations and individuals try to bring the sector together. For example, the newly formed Advocacy Federation aims to provide representation to all types of advocacy organisations in England. Action for Advocacy (A4A) currently does this in London and is exploring the idea of playing this role at a national level.

Changing systems

The insights and knowledge that advocates gain through their work make them potentially powerful catalysts for change. The information gained could be used to challenge and reform systems, policies and practices in health and social care settings. However, very few organisations feel they have the skills or resources to do this.

> *We see the same issues coming up again and again. But what can we do? Even if we could do something, would they [the service providers] be willing to listen or change?*
> Black and Minority Ethnic Advocacy project manager

Larger organisations, such as MIND and Age Concern, which provide both individual and collective advocacy, do campaign for change on behalf of their client groups. However, some people within the advocacy sector believe this makes the organisations political and therefore no longer independent.

> *If you're campaigning for change at a policy level and providing advocacy at an individual level you may just get confused about whose views you're representing. It can be so easy for a client to become a pawn in a political game. We should keep the two separate.*
> Mental Health Advocacy project manager

The new NHS complaint handling and advocacy services, PALS and the Independent Complaints and Advocacy Services (ICAS) are also intended both to advise individuals and provide an early warning of problems for trusts to help them to improve their systems. Some within the advocacy sector are uneasy about this joint role. It remains to be seen how they will work in practice.

Awareness

The research found that many advocacy providers feel they are working in an environment where there is little knowledge of who they are or what they do. Very often, members of the general public have never even heard of 'advocacy' and health and social care professionals may not have done so either. If they have, they usually have a poor understanding of the role. For example, many health and social care professionals are unable to distinguish between bilingual advocacy and interpreting.

> *The biggest barrier we face as a movement is that we are up against ignorance of who we are and what we do. That includes the ordinary man on the street but more importantly the supposedly educated doctors, clinicians and NHS managers.*
> Advocacy Resource Agency manager

A few advocates do have positive relationships with health professionals, particularly senior managers, and feel that NHS acute and primary care trusts (PCTs), local authorities and other statutory bodies are becoming more aware of the importance of advocacy.

> *They [professionals] used to see us as a pain in the neck; that we are here to cause problems for them. But things are gradually changing. Some of them now want to work with us rather than against us.*
> Learning Disability Advocacy project manager

However, many in the advocacy sector feel there is a need for frontline staff to have training in this issue and feel this should not be left to individual advocacy organisations.

> *We will often go in to the [mental health] wards and talk with the nurses about advocacy and hold training sessions. This works really well. We really get them on board and build excellent working relationships. But then we go back some weeks later and there's a whole new set of nurses and we have to start all over again. Plus we don't have the resources to do this. No one funds this work.*
> Mental Health Advocacy project manager

Many advocacy organisations have tried to gain media interest, particularly at a local level, to raise awareness of their work. However, they met with little success. Respondents usually put this down to the people they worked with not being 'attractive' enough.

> *We held a summer fair where we invited all our advocates and all our clients and their families and the local GPs and residents. We tried to get the local paper interested. They were at first, but as soon as we said that our work is with children with learning disabilities and severe physical disabilities they lost interest. They more or less said, 'They don't photograph well.'*
> Learning Disability Advocacy project manager

However, there have been some success stories. For example, one day-time television soap opera based around a general practitioner (GP) surgery had involved a learning disability advocate in one of its story lines.[38] This was seen as extremely positive and people were keen to see this repeated.

Outreach

Advocacy organisations would like to do more outreach work. Many felt that their services were 'reactive' in nature – responding to requests and referrals, although many also try to be 'proactive' by ensuring advocates make themselves and their services known to service users and staff.

> *We would like to go out there and find the really isolated vulnerable people that need our help but we're too busy just dealing with all our referrals.*
> Older People Advocacy project manager

Very few organisations can go out to reach the people in most need of advocacy – those who don't access services at all despite having greatest need of them. Our interviewees said the main barrier to doing this was lack of resources.

There are still significant gaps in advocacy provision. Perhaps the largest gap concerns 'hidden' groups that don't fit with the major client group categories, such as homeless people, people with a substance abuse problem, those leaving prison and other marginalised individuals. But we don't have the money to do this work.
Advocacy Resource Agency manager

Many projects said that in order to work successfully with the most excluded people, they needed to adopt a flexible approach based on voluntary involvement and responsiveness to the needs of individuals. However, there was sometimes a tension with the expectations of some funders, who were concerned about single issues and quick, quantifiable results.

The PCT and other funders are just concerned with value for money. They want to see nice quick results. Sometimes it can take a long time to develop a relationship with somebody. If somebody has a severe communication impairment it can take a while to develop a system of communicating. These people don't always fit in nice, neat boxes where you can give them ten-minute appointments once a week.
Advocate working with severely disabled children

Funding and capacity

There is a severe shortage of funding for advocacy; projects are often limping from one insecure source of finance to another.

Funding is only ever available on a short-term basis – two or three years. By the time you get the project up and running and marketed so people know you exist, the money runs out. If you don't secure other funds you have to stop the project. What a waste of time and resources. It is so frustrating.
Advocacy Resource Agency manager

Currently, the advocacy sector does not have the capacity to deal with the high demand for its services and most providers have large waiting lists. This is partly because of funding problems and partly because of a severe shortage of advocates.

We have to turn people away. We just can't deal with the demand for our services. We're working to full capacity already and have a long waiting list. We do try to deal with all urgent cases, though.
Mental health advocate

This problem is likely to be further exacerbated as new legislation gives more legal rights to advocacy for some client groups.

Advocacy organisations are already running at full capacity. The new Draft Mental Health Bill and other policies are giving even more people a legal right to it, without providing adequate extra funding. How are we going to cope?
Advocacy Resource Agency manager

Our research suggests that the main sources of finance for London advocacy providers are local authorities, primary care trusts and charitable foundations, such as the King's Fund and the

Community Fund. Receiving funding from the statutory sector makes many in the advocacy sector uneasy; they feel it can compromise their independence.

> *Advocates often find themselves in the unenviable position of 'biting the hand that feeds them', for example, when advocating for users whose services have been cut or reduced by the funding authority.*
> Advocacy Resource Agency manager

Training

Most advocacy providers do not require any specific qualifications or training from their advocates. Instead they assess the skills, competence and suitability of potential advocates through an informal interview.

> *We need our advocates to have empathy, understanding and a strong affinity for the communities they support. Confidence and assertiveness are important too, but formal training is not.*
> Learning Disability Advocacy project manager

New recruits generally receive advocacy induction training, which is largely provided in-house. However, many organisations lack the capacity to deliver regular induction training to all new advocates and the content differs according to the organisation delivering it.[39] The lack of accredited training and career structure were seen as significant barriers to recruiting and retaining advocates.

> *One of the largest problems facing advocacy is recruitment of volunteers, and then keeping them. There is usually a high drop-out rate. There need to be incentives such as a career structure to attract people to advocacy.*
> Older people, learning disability and disability advocacy manager

A pan-London Training Task Force was set up in 2001, led by A4A – then known as Advocacy Across London – to explore the issues around affordable and appropriate training. The task force has identified a core content for induction programmes that will complement current training initiatives and address gaps. This will be developed and delivered flexibly in partnership with London advocacy organisations.

A4A is also working on a comprehensive induction manual, featuring good practice, training materials and teaching methods, to support the induction programme. A4A's website provides more details and a list of advocacy-related training in London, including its own.

Accredited training in advocacy is also becoming more widespread. The Open College Network and some universities – including East London and Essex – provide courses that mix academic learning with practical knowledge and experience and lead to a recognised qualification.

> *There was a general awareness that developing different levels of advocacy training, including a university level of training, would not only provide a way of meeting some of the skills shortages within the advocacy movement, it would also be a way of providing career development opportunities.*
> Advocacy course leader

Quality standards

There is no widely accepted standards framework or good practice guidance for providing, monitoring and evaluating advocacy in the UK, although frameworks have been developed by different groups. Some of the better known ones include the United Kingdom Advocacy Network's (UKAN) code of practice for mental health advocacy,[40] the King's Fund black and minority ethnic health advocacy standards framework,[9] Advocacy 2000's *Principles and Standards*[41] and the *Advocacy Charter* by Advocacy Across London.[14]

Government advocacy initiatives have often been accompanied by standards[42, 43] and this has made the advocacy sector fearful that standards may be developed without their involvement and then imposed upon them.

> We have not been approached. Our knowledge and experience is not valued. They are busy developing these standards up there in their ivory tower without involving the advocacy sector.
> Mental Health Advocacy project manager

Some interviewees argued that there is no need for standards – that these would only formalise or professionalise advocacy, inhibiting the spontaneity and energy of volunteerism.

> What makes advocacy work is that advocates are everyday, ordinary people. Our clients can identify with us and we can identify with them. If we start trying to formalise advocacy into a profession with all the bureaucracy that comes with it, we'll end up being part of the problem as well. We are not supposed to be the system.
> Advocacy Resource Agency manager

Others argued that standards are needed to protect individuals, to make advocates accountable for their actions and to provide some consistency among providers.

> Most advocacy projects are good but we are worryingly unaccountable. Often, people use the criteria of friendliness, not effectiveness.
> Advocacy Resource Agency manager

Overall, this research suggests that the predominant view is that standards are now very important and will lead to a professional service, without leading to negative professionalisation. However, reaching a consensus on what these standards should look like is proving to be very difficult. We return to this issue in our recommendations on pp 34–39.

Measuring outcomes

Many advocacy organisations feel pressure to prove their worth. Often funders and commissioners want to see evidence of effectiveness and efficiency. But organisations lack the capacity to self-evaluate or the resources to fund external evaluation.

> Everyone talks about evaluation these days. It seems to be the latest buzz word. But how are we supposed to find the time and money to do one. And to what standards are we being evaluated against?
> Black and Minority Ethnic Advocacy project manager

In addition, the process of evaluating advocacy can be riddled with difficulties.

How do we measure upholding human rights, giving a voice to people, the involvement of people in decision-making, the journey travelled? Who wants to know?
Planet Advocacy[44]

The future of advocacy

There is considerable debate about the future role and development of advocacy. Our questionnaires and interviews demonstrate that, while the Government's recent attention to advocacy is very much welcomed, it has prompted the sector to take a long, hard look at itself and where it is heading.

We as advocates need to put our house in order. We need to be taking the lead in developing and driving the agenda forward for advocacy. Not the Government or anybody else. We have not come this far to just pass the controls over to somebody else now.
Advocacy Resource Agency manager

The Department of Health is showing commitment to advocacy. That should be celebrated. They have taken a valuable first step, but there is still a long way to go.
Learning Disability Advocacy project manager

Some individuals within the advocacy sector fear the nature of advocacy is being changed by the Government's intervention. They believe the focus of many initiatives is on task-driven and time-limited crisis intervention or complaint handling, when they would like to see more advocacy centred around personal outcomes and supporting people before problems develop.

Advocacy is not about problem-solving and complaint handling. It's much more than that. It's about supporting vulnerable people in everyday life to get the things they need. Things that many of us take for granted.
Children's Advocacy project manager

NETWORKS

Many advocacy organisations feel isolated – unaware of the work that others are doing in their areas or what is happening nationally. In recent years, several regional and client-specific networks have been developed to help overcome this, to promote advocacy and to provide training and quality frameworks. Some of the most active ones include:

■ **Action for Advocacy (A4A)**, formerly Advocacy Across London, is a support and resource agency for independent advocacy services in Greater London and is partly funded by the King's Fund. Its aims include 'advocating for advocacy at a strategic level, as well as providing the advocacy sector with essential support and information services'. It runs a website and the magazine *Planet Advocacy*.44 Over the next three years it plans to develop training and capacity-building initiatives.

■ **Association of Mental Health Advocates** aims to provide a coherent structure for advocates (not advocacy organisations) working with people who use mental health services. It will take an educational role, lobby the Government and work to achieve greater credibility for mental health advocates.

■ **Citizen Advocacy Information and Training (CAIT)** is the national resource agency for citizen advocacy. It provides regular workshops and courses for advocates, staff, volunteers and managers of advocacy projects on a wide range of subjects, from basic introductions to citizen advocacy to specialised areas of law. It also provides support for advocacy providers, a database of projects and on-site evaluations. In April 2005, CAIT will be replaced by a new organisation, the Advocacy Resource Exchange (ARX), which will provide resources for the broader independent advocacy sector.

■ **Heath Advocacy Network**, formerly Health Advocacy Network for Black and Minority Ethnic Organisations in London, is now open to non-advocacy organisations and was set up by the Council for Ethnic Minority Voluntary Organisations (CEMVO) in partnership with the King's Fund to meet the health advocacy needs of London's minority ethnic communities. It has commissioned accredited health advocacy training, which is currently being evaluated.

■ **Older People's Advocacy Alliance (OPAAL)** is an alliance of advocacy schemes, older people's groups and community organisations. Its aims include the promotion and development of independent advocacy for older people in the United Kingdom, the establishment of standards and quality frameworks, and being acknowledged as the lead agency for independent advocacy for older people in the United Kingdom.

■ **United Kingdom Advocacy Network (UKAN)** is a network of UK advocacy groups run by the service users. It provides information and support for local groups and campaigns for improvements to mental health services. It also supports patients' councils and user forums.

Contact details for these organisations can be found in the Appendix on pp 40–44.

3 The policy environment

Since Labour came to power in 1997, there has been an increasing interest in advocacy across government departments, and a number of White Papers and Bills have sought to establish advocacy for different groups.

Some key pieces of legislation include the Race Relations Amendment Act 2000,[1] the Special Educational Needs and Disability Act 2001,[2] Valuing People: A new strategy for learning disability for the 21st century (2001),[3] the Health and Social Care Act 2001,[4] the Adoption and Children Act 2002,[5] the Draft Mental Health Bill 2004[6] and the Mental Capacity Bill: Draft Code of Practice 2004.[7]

- **The Race Relations Amendment Act 2000**[1] gave important new duties to public bodies to eliminate unlawful discrimination and promote equality of opportunity. National Health Service (NHS) trusts and primary care trusts (PCTs) use bilingual advocacy and black and minority ethnic advocacy as a way of doing this.

- **The Special Educational Needs and Disability Act 2001**[2] outlined a stronger right for children with special educational needs to be educated at a mainstream school and placed new duties on local educational authorities to arrange for parents and children with special educational needs to be given advice and information through Parent Partnership Services (PPS). Many of these provide advocacy, although they may not use this term to describe their work. Most are a partnership between a voluntary organisation and the local authority, and use paid and volunteer workers.

- **Valuing People**[3] sets out major changes to improve the lives of people with learning disabilities. It is based on four principles – rights, independence, choice and inclusion – and stresses that people with learning disabilities should be able to access advocacy support, with a focus on self-advocacy and citizen advocacy.

- **The Health and Social Care Act 2001**[4] legislated for the formation of the Commission for Public and Patient Involvement in Health (set up in January 2003, but due to be merged with the Health Commission), Patient Advice and Liaison Services (PALS) and the Independent Complaints and Advocacy Service (ICAS, which started in September 2003). All NHS trusts and PCTs must have PALS and the staff are employed by, and accountable to, the trust. ICAS is independent of the NHS and not based in hospitals or surgeries. ICAS is provided on a regional basis by Citizens Advice Bureaux, the Carers' Federation, POhWER and South East Advocacy Projects (SEAP) (*see* the appendix on pp 40–44 for contact details for each organisation). The Department of Health manages these contracts.

- **The Adoption and Children Act 2002**[5] gave a new duty to local authorities to make arrangements to provide advocacy to children and young people under 21 making a complaint under the Children Act 1989. The legislation was accompanied by national standards covering planning, commissioning and providing advocacy, which must be independent.

- **The Draft Mental Health Bill 2004**[6] proposes that all patients subject to compulsory mental health orders should have independent advocacy available to them and proposes a new definition and model of service focusing on professional advocacy. An earlier Draft Act[45] was accompanied by core standards for commissioning, managing, staffing, providing and monitoring advocacy.[43]

- **The Mental Capacity Bill 2004**[46] is about enabling decisions to be made on behalf of people who lack the capacity to do so – including people with dementia, learning disabilities, mental health problems, autism and severe head injuries. The Bill does not feature advocacy at all but the Mental Capacity Bill: Draft Code of Practice 2004[7] mentions advocacy on several occasions.

Choosing Health (2004),[47] the Government's White Paper on public health, outlines plans to enable people to make healthy choices. In its consultations, the Department of Health considered the role advocates could play in ensuring that people in disadvantaged communities and groups were able to gain access to the information, advice and support they needed to make healthy choices.[48] The White Paper promotes the idea of NHS accredited 'health trainers', which closely mirrors the model of the generic community health advocate described on p 11.

Embedded within local communities, these 'health trainers' will be developed by the NHS to deliver personalised health advice on what individuals can do to maintain or improve their health – such as stopping smoking, doing more exercise, healthy eating, practicing safer sex, dealing with stress or tackling social isolation. They will be focused initially on disadvantaged communities. Health advocates working with specific groups should be able to link their clients up with 'health trainers' where appropriate.

Despite this growing interest in advocacy, however, government departments have different ideas of what advocacy is, what it is useful for, where it should be located and how it should be funded and developed.

Our interviews with stakeholders in the advocacy sector indicated that most welcomed the new interest in advocacy, but had concerns about the names and models used for some of these services. Indeed, some within the advocacy sector would not recognise much of the activity as advocacy at all.

Defining advocacy

All of the documents described above set out clear roles for advocacy, but they may or may not use the term, thus contributing further to confusion over what advocacy is. The Draft Mental Health Bill and the Valuing People White Paper state clearly what is meant by the term 'advocate' and describe a distinct role.

The Valuing People White Paper proposes the use of well-established models of advocacy – citizen and self-advocacy – and promotes the use and development of existing schemes.

The Draft Mental Health Act 2002[45] and a consultation document published in conjunction with it introduced a new model of advocacy called 'independent specialist advocacy', to be provided by trained advocates with specialist knowledge of mental health.

The term has been dropped in the 2004 Draft Bill, in favour of 'independent Mental Health Act advocacy' (IMHAA). This uses the same model as the earlier Bill, but the name has been changed because it was considered that 'specialist' was confusing and that the new model should be clearly associated with mental health.[49]

The Special Educational Needs and Disability Act gives duties to parent partnership services (PPS) and independent parental supporters (IPS) that include advocacy without using the term to describe their work. The term 'advocacy' does not appear in any literature relating to the service either but all of the PPSs involved in our research confirmed that they do provide advocacy services.

The status of services set out in other government documents has been subject to considerable debate. The Patient Advice and Liaison Services (PALS) created by the Health and Social Care Act 2001 to replace community health councils were originally to be called Patient Advocacy and Liaison Services. The name was changed after the advocacy sector welcomed this interest in advocacy, but expressed outrage that it would be provided by the statutory sector. It was felt that if the NHS was providing advocacy for patients using the NHS, then the core advocacy value of independence would be compromised.

PALS were redefined as a service that provides information or advice rather than advocacy. The core functions of PALS include providing on-the-spot help in every NHS and primary care trust, with the 'power to negotiate immediate solutions or speedy resolutions of problems'.[50] PALS also act as a 'gateway' to appropriate independent advocacy support from local and national sources, including the Independent Complaints Advocacy Services (ICAS) also set up by the Health and Social Care Act 2001.

However, only one of the PALS involved in this research said their work was not advocacy. Seven others completed our questionnaire and considered their work to be advocacy – albeit one said they provided 'advocacy with a small "a"'. Some PALS managers are also patient advocacy managers, responsible for the provision of bilingual advocacy. It is therefore inevitable that there will be some overlap of the two roles.

The Draft Mental Incapacity Bill 2003[51] made no provision for advocacy. The Joint Committee on the Draft Bill[52] appointed to scrutinise it recognised the need for independent advocacy for vulnerable people who may lack the capacity to make their views or decisions known; but the recent Mental Capacity Bill 2004 still makes no provision for advocacy. Instead, it creates roles for attorneys, deputies and independent consultees who may carry out advocacy activities.

> *The Government agrees that independent advocacy has a role to play in supporting those who may lack capacity. The Bill itself provides new ways of supporting those who may lack capacity by allowing for the possibility of attorneys and deputies.*
> The Government Response to the Scrutiny Committee's Report (February 2004)[53]

All these new services and models of advocacy will sit with already existing services. In particular, the new independent Mental Health Act advocates will work alongside traditional mental health advocacy, which many within the advocacy sector believe will confuse service users.

> *Policy-makers are being too prescriptive over the models of advocacy they recommend. This is leading to more and more definitions and service models. This is in contrast to the*

advocacy movement, which is working to reduce the number of definitions we have. We would like to see just the term 'advocacy' used.
Mental health advocate

The role of advocacy

The focus of advocacy also varies in the different papers listed in this section. The Adoption and Children Act is concerned with complaints, and, even then, the right to an advocate is confined to children and young people making a complaint under the Children Act 1989. The right does not apply to a parent or other adult who wants to complain on behalf of a child.

The Health and Social Care Act also gives PALS a complaints focus, in that one of its core functions is to 'negotiate immediate solutions or speedy resolutions of problems' and to help monitor problems within trusts. Many of our interviewees felt ICAS are also geared towards complaints, as their advocates only become involved once the PALS are no longer able to deal with the NHS user's problem, and would like the word advocacy removed from the name.

Advocacy organisations are also concerned that, given their limited resources, local authorities and NHS trusts will prioritise statutory advocacy services to the detriment of general advocacy.

The Draft Mental Health Act sets out a new model for advocacy, but it gives a right to this service only to those detained in hospital under compulsory orders. It will not be available to all users of mental health services. Many of our interviewees felt that all service users could benefit from a legal right to an advocate.

The Scottish Mental Health (Care and Treatment) Act 2003[54] gives every person with a mental disorder a right of access to independent advocacy and puts duties on health boards and local authorities to ensure that independent advocacy services are available. Furthermore, the Act is not prescriptive about the model(s) of advocacy that should be provided.

The Valuing People White Paper also stresses that all people with learning disabilities should be able to access advocacy support in order to enable their greater inclusion and independence. The advocacy sector sees this as a positive move. However, Valuing People focuses on self-advocacy and citizen advocacy, and many within the advocacy movement feel that other models, such as formal and group advocacy, could also have been included. The Valuing People team at the Department of Health says the emphasis on these models merely reflects who was involved in the consultations at the time of writing the White Paper.

With the exception of Valuing People, therefore, all the government policies listed in this section place advocacy within services, with the focus mainly on crisis or complaint management.

The potential for advocacy in the community to support individuals in accessing and negotiating services is ignored. The potential for advocacy to empower people to become more active in community life, to raise health literacy and improve health is also neglected.

Independence

The Adoption and Children Act puts a strong emphasis on independence. Advocacy must be independent and will often be commissioned from the independent sector. Where it is provided by the local authority, services must be separate from the line management of operational

services. Children can choose their own advocate and local authorities must support them by providing information and paying expenses. All of this was welcomed by the advocacy sector.

Patient Advocacy and Liaison Services for the NHS were renamed Patient Advice and Liaison Services because the advocacy sector felt strongly that if the NHS was providing advocacy for patients using the NHS, the core value of independence would be compromised.

ICAS have been set up to provide independent advocacy. The advocacy sector is divided about the ICAS model. Some believe it is an excellent example of embedding advocacy in the statutory sector and a good mechanism for integrating community and NHS advocacy. Others see it as being too embedded in the NHS and would like to see the name changed to something that distances it from independent advocacy services.

The advocacy service outlined in the Draft Mental Health Bill will be provided by existing advocacy organisations, as long as these have undergone accredited training. This should maintain an independent service and may provide opportunities for integrating community and NHS-based advocacy. For example, service users may have the support of an independent Mental Health Act advocate (IMHAA) when issues arise around their treatment or medication in hospital, and continue to use that advocate, although in a different capacity, for support with housing or benefit issues when leaving hospital. This is obviously dependent on the capacity of IMHAA services.

Independence is a key principle of advocacy, and there is real concern that it is being compromised in some of the services being established as a result of the papers and policies outlined above. There is also a broader concern that advocacy is being too tightly linked to specific services and client groups, instead of being available to all who need it.

Funding and capacity

Some of the initiatives come with major funding and development programmes; some rely on existing funding and partnership with voluntary groups. Most of the organisations that provide PPS are partnerships between a voluntary organisation and a local authority, with the bulk of the work funded through the local education authority and some through Sure Start.

Valuing People was introduced with an implementation support fund of £1.3 million per year for three years to support and develop citizen- and self-advocacy projects across the country. The plan is to establish a National Citizen Advocacy Network for Learning Disability with the aim of working 'towards at least one citizen-advocacy group in each local authority area'.

Each local authority also has to say how much money they spend on advocacy for this group. A toolkit for developing local advocacy plans has been put together for Learning Disability Partnership Boards (the local authority-led inter-agency groups responsible for implementation at a local level) and is being piloted.[55]

This programme is similar to the system found in Scotland. Both the Scottish and Valuing People models have three-year local advocacy plans, teams responsible for implementing them and a responsibility to declare advocacy funding on locally based statutory bodies.

Many of those involved in this research feel that having a commitment from local statutory bodies in term of funding and developing advocacy projects is needed for the whole advocacy

sector and not just segments of it. They believe this would lead to a more strategic approach to advocacy provision while retaining the local focus required to meet local community needs.

Training

The only piece of existing legislation that discusses training for advocates is the Draft Mental Health Act. This may be a reflection of existing practice in the the advocacy sector, which tends to require no minimum training.

Work carried out by Durham University on Mental Health Act advocacy points to the need for a recognised training programme for all IMHA advocates.[43] The report's authors believe this would ensure a minimum level of skills, knowledge and competence, giving service users, relatives and friends, staff and commissioners confidence in the advocacy service, as well as improving consistency of the service. However, the design and content of such a course has not yet been decided on.

Some of the London PALS expect or would like their officers to have a certificate in advocacy or other relevant qualification, which is surprising as their remit does not formally cover advocacy. Other London PALS send their officers on training courses specific to PALS which have been developed by local PALS networks. PPS networks work in a similar way by developing training courses at a regional level for their officers.

The introduction of accredited training raises the issue of the professionalisation of advocacy; concerns about this have been raised by many in the advocacy sector. These concerns include fear that training will discriminate unfairly against service users who may not have the confidence to complete a course that is too academic in style and content, and the difficulty of balancing the need for regulated and accountable advocacy against the need for flexible services delivered by lay people that clients can relate to.

Quality standards

There is no consistency in the government papers listed above on setting minimum standards for advocacy services. PALS,[51] children's advocacy,[42, 56] PPS[57] and IMHAA[43] are accompanied by a set of core standards, which centre around who should be able to act as an advocate, how the service should be provided and for whom, and addressing issues such as independence, confidentiality and accessibility. The Valuing People White Paper leaves it to local partnership boards to assess the quality of the advocacy they commission. No core standards for ICAS have been developed as yet.

Our research shows that the advocacy sector is divided about whether these standards should be welcomed or not. The majority of those working in it believe that they are a helpful start that could result in a more consistent service, but believe more work is needed in developing them.

The policy picture

The Government's increasing recognition of the importance of advocacy is much welcomed by advocacy providers and campaigners because it suggests a greater commitment to supporting and protecting vulnerable people. However, these developments have not been strategic or coordinated, and it could be argued that the Government has missed an excellent opportunity for bringing together different sections of the advocacy sector.

The papers discussed earlier refer to different models of advocacy with little explanation for the reasons behind the different choices made. There is also little consistency on key issues such as independence, funding and standards. Furthermore, many argue that the legislation does not go far enough in terms of protecting all vulnerable people and that there is too strong a focus on services and crisis intervention rather than on prevention.

Learning from other countries

Many of our interviewees, including policy-makers and advocacy organisations, believe there is a great deal we can learn from other countries where different approaches have been taken to developing advocacy. In particular, Canada and Scotland have both taken approaches that may offer some useful pointers for developing advocacy policy in other parts of the United Kingdom (*see* below).

Canada's approach to advocacy

Canada introduced a single piece of legislation focused on advocacy in 1992. The Ontario Advocacy Act[58] was passed as the centrepiece of a legislative package and its aims were clear and unambiguous: it gave rights to advocacy for vulnerable people. On introducing the Act into the legislative assembly, it was stated:

> *Society is judged in part on the basis of how it treats its most vulnerable citizens. Historically, many vulnerable adults have been silenced and deprived of the opportunity to exercise their fundamental rights. Such rights include the right to make choices; the right to participate in shaping one's own future and the future of the community, and above all, the right to speak out for change. The Advocacy Act is the centrepiece of a legislative package to address this injustice.*
> Hon. Ms Ziemba, Legislative Assembly of Ontario[59]

The Act was wide in the scope of premises and services that it covered: an advocate was given rights of entry into both private and public dwellings, and covered all statutory services, including health, education, police and detention facilities.

It was managed by an Advocacy Commission, which consisted of a chair and 12 other members. The commission was to 'provide advocacy services to help vulnerable persons to bring about systemic changes at the governmental, legal, social, economic and institutional levels' (Advocacy Act 1992:6,8).

But only four years later, in 1996,[60] the Conservative Harris Government repealed the Act in sweeping financial cuts and legislative changes. Although its abolition attracted some staunch opposition, the new Bill was pushed through within three weeks, with only limited debate.

Scotland's approach to advocacy

In Scotland, there is a statutory requirement to provide advocacy for anybody who needs it.[61] This statutory requirement relates to generic 'advocacy' not 'mental health advocacy', 'complaints advocacy' or 'bilingual advocacy', and is therefore a more holistic approach than that taken in England.

Each NHS board and local authority must have a joint three-year advocacy plan that crosses all health and social care groups, developed by advocacy planning and implementation teams. These are monitored and supported by the Advocacy Safeguards Agency (ASA), which also

advises on policy and evaluates providers. Advocacy providers also have the support of the Scottish Independent Advocacy Alliance (SIAA). These bodies are funded by the Scottish Executive. They work closely together and although there is some overlap in their duties, their main functions are described below.

The ASA has four roles:[62]
- It carries out research on matters relating to independent advocacy and its impact on the lives of people in Scotland.
- It develops policy and good practice.
- It helps health and local authority commissioners to develop independent advocacy.
- It evaluates advocacy providers to make sure that the principles, practice and outcomes of their work are meeting the needs of people who use them. In doing so, it identifies issues and suggests solutions to difficulties that may be affecting their work.

The SIAA, a registered charity, is a membership organisation for advocacy groups and other organisations with a commitment to providing independent advocacy. The SIAA also has a number of roles:
- It provides a strong national voice for advocacy organisations, promoting their worth to planners and decision-makers.
- It consults with the advocacy movement on developments in policy, legislation and practice.
- It raises awareness of advocacy by providing training about its role, impact and value.
- It provides capacity-building for advocates.
- In partnership with the ASA, the SIAA researches and identifies gaps in independent advocacy, supports existing organisations and encourages the development of new ones.

The Scottish model is not perfect. Many people disagree over the division of roles between the two bodies described above, with some arguing that evaluation and monitoring should lie with the advocacy network, the SIAA, and not with the ASA. Others feel the ASA needs more powers. For example, although it evaluates projects and assesses whether they meet set standards, it is unable to close down poor projects.

Even so, we believe there are distinct advantages to the Scottish model. There is one, clear definition of advocacy, encompassing the three main models, and advocacy is available for all, not just specific client groups. A coherent and strategic approach has been taken to providing and developing advocacy, while there is also one clear, national voice raising awareness and campaigning for it. We and many others believe a similar model would improve advocacy provision in England.

> *We recommend that the Government consider setting up an agency, similar to the Advocacy Safeguards Agency in Scotland, with the aim of promoting standards for good quality independent advocacy.... We believe that these measures would serve to raise awareness of the importance of advocacy while facilitating, so far as available resources allow, the development of a range of advocacy services, including self-advocacy, citizen advocacy and professional advocacy.*
> Joint Committee on the Draft Mental Incapacity Bill First Report (paragraph 304)[52]

4 Recommendations

Health advocacy is at a critical stage. It has developed rapidly and is doing valuable work, is increasingly attracting government interest and could face significant new opportunities in the mental health and public health Bills now being drafted.

However, neither the sector's growth nor the Government's interest has developed in a consistent, strategic way, and the sector as a whole faces many challenges. As Rick Henderson from Action for Advocacy (A4A) has pointed out, advocates who once saw themselves on the radical fringe, identifying with disenfranchised clients, are now 'struggling to work out where they fit in'.

Advocacy services must respond positively to opportunities for change and progress if they are to survive, develop and meet the needs of vulnerable people. This section considers the action we believe is needed to take advocacy forward.

Defining advocacy

Voluntary organisations, government departments, and service commissioners and providers all seem unsure about what advocates are and what they do – while the general public has relatively little understanding of 'advocacy' at all.

We believe it would be useful to develop a consensus on a working definition of advocacy in order to facilitate working relationships between advocacy organisations and to build wider understanding.

We also think that health advocacy should include a range of activities:

- helping to protect and support individuals who are particularly vulnerable because of illness or lack of capacity to make informed decisions
- empowering individuals/groups to define their own needs, make their voices heard, and gain access to the knowledge, support and services they require
- representing individuals' views to service providers and others, and helping them to resolve issues about their health and health care
- providing information and advice about preventing illness and improving health, and about health services
- reporting issues raised by individuals/groups to those providing and commissioning services, to help improve quality and relevance.

A strategic approach

The ad hoc and sporadic manner in which advocacy has developed has resulted in patchy provision, with many projects working in isolation and without adequate support. Government policy on advocacy has been piecemeal and disjointed, with some disadvantaged groups being given a right to advocacy while others have been ignored.

We believe that a clearer strategic approach is required, and that this will be particularly important with new opportunities for advocacy emerging as a result of the Government's choice and public health agendas.

At a national level, government departments should ensure that their various policies on advocacy are consistent and coherent. This could be achieved by having one piece of legislation that covers all forms of advocacy and gives a right to independent advocacy for all vulnerable groups. The models used in Scotland and Canada are good examples and should be explored in more depth.

At a local level, our review of advocacy organisations in London shows there can be tension between some sections of the advocacy sector, and that projects are sometimes run in parallel, duplicating funding and human resources.

We believe there should be planning to ensure equity of access, appropriate specialisation and adequate funding. This should be clearly set out in local advocacy plans, similar to those in Scotland and the Valuing People White Paper.[3] Ideally, the process of strategic planning should be shared by local authorities and primary care trusts (PCTs), in consultation with advocacy organisations and other local stakeholders.

Annual monitoring and mapping of advocacy organisations, in the way the Advocacy Safeguards Agency (ASA) does in Scotland, would also highlight any duplication of advocacy provision in each locality and could lead to greater collaboration.

The role of advocacy

Nearly all advocacy services in London are client-specific and government policy documents appear to endorse the specialist approach.

There are benefits to what is generally known as 'client-specific' advocacy, and there is a need for advocates with specialist knowledge of, for example, mental health law or of cultural issues associated with specific ethnic groups.

However, the multiplicity of services may confuse potential clients and exclude groups that do not fit into any one category, but who may need advocacy because they are socially excluded or have little control of their lives. They may also reinforce stereotypical images of specific client groups, suggesting they are homogeneous and distinct from the general population when they are neither.

In addition, when advocates are channelled into specialist services, it is unlikely that there will be enough in any one geographical area to cater for all potential clients. There may also be wasteful overlap and duplication of effort.

We recognise that advocacy provision was often established to meet a perceived need, and that the providers passionately believe in the work they do and in the approach they take. Nevertheless, we believe that generic advocacy organisations, providing generic and specialist advocates, might help to alleviate some of the problems outlined above.

Integrating service-based and community-based advocacy

Government policy focuses on service-based advocacy rather than on providing it in communities. The gap is especially noticeable in the Draft Mental Health Act,[45] where advocacy is available only for those subject to compulsory mental health orders and not for those in the community with mental ill health.

Advocacy services generally lack the skills to integrate service-based and community-based work. Again, this is a particular problem in mental health. Clients may face homelessness when they are discharged from acute mental health services, and still need help with housing, benefits and employment. We believe this is another reason to develop organisations that provide both kinds of advocacy.

It is envisaged that the new independent Mental Health Act advocates will be based within community advocacy organisations, and the advocates providing Independent Complaints and Advocacy Services (ICAS) will also come from community-based organisations. These may be good models to work on.

Awareness and identity

In England, advocacy lacks a national identity and presence. This reduces its capacity to influence government policy.

There are currently many regional and specialist networks that aim to play an influencing role and to provide opportunities for shared training, information exchange, and regular policy and practice updates. We believe these should be encouraged and supported.

However, as advocacy rises up the national political agenda, we also believe there is a case for developing a stronger collective identity and a shared voice for advocacy providers through a single body or alliance, representing the whole sector.

A recently formed organisation, The Advocacy Federation (TAF), plans to develop in this way, with the aim of 'providing a unified, coherent and influential voice to the advocacy movement'. We believe this is a positive move forward.

Funding

Most advocacy projects are unstable because of inadequate and unreliable funding, which they currently receive from a variety of sources.

One route to stability is to win long-term funding through contracts and service-level agreements with statutory organisations. There is a danger that this may compromise, in perception if not in reality, advocacy's independence from statutory services.

However, independence is a mixed blessing. This research suggests that the more separate and independent advocates are, the more likely they are to encounter resistance from services and to come up against institutional barriers.

In addition, the advocacy sector usually welcomes each new piece of legislation that gives people rights to advocacy services. Yet the majority of projects will need more resources and continuing support to provide what has been promised.

We believe central government needs to make more money available to local statutory bodies and that they should take greater responsibility for funding advocacy in their areas. This would help to ensure local focus is retained and that local needs are appropriately met. Clear service-level agreements can help minimise the problems associated with independence.

Advocacy organisations funded by other means, for example, by charities, should exist alongside those funded by the statutory sector.

Training and development

Service commissioners want a trained workforce and many advocates would like to be on a career path. Many different courses now exist, but they can be inaccessible because of location, time or cost, and there are debates about their content.

We recognise that there is no consensus about whether or how training and professional recognition should shape or influence the advocacy sector. However, it is generally agreed that opportunities for continuing education, skills development and qualification should be available to those who want them.

With that in mind, we believe advocacy should be placed on the NHS 'skills escalator' – a structure by which National Health Service (NHS) staff can acquire new skills and invest in professional development – as a mechanism for moving from unpaid voluntary work to paid employment. We also believe there should be formal courses available to encourage career advancement.

Standards

There are currently no shared national standards or guidelines for advocacy providers, except those that are client specific, developed by advocacy networks or that accompany specific government interventions. We recognise that some in the advocacy sector feel that standards

will formalise and professionalise advocacy, stifling the energy and spontaneity of grass roots volunteerism.

However, we believe that standards are needed to protect individuals, to make advocates accountable for their actions and to provide some consistency between providers. They should also grant legitimacy and credibility to organisations – something that funders are often looking for.

We believe that these standards should be provided by an independent organisation or alliance representing the advocacy sector and should cover organisational issues, such as maintaining independence.

It will be a challenge to make sure that, if standards are introduced, they can be kept under review and amended as necessary, so that they remain flexible and responsive. It will also be a challenge to work out how performance can be measured against them.

Measuring outcomes

Evaluating advocates' impact and effectiveness can be beneficial to the further development of the sector. However, many advocacy organisations lack the capacity to self-evaluate or the resources to fund external evaluation.

We believe those involved in advocacy projects need training and other forms of support if they are to carry out effective evaluations. Alternatively, an independent organisation, one like Scotland's Advocacy Safeguards Agency (ASA), could be responsible for carrying them out. In Scotland it is recommended that all advocacy projects be evaluated every three years and most evaluations are conducted by the ASA.

Conclusion

Health advocacy has developed rapidly in the UK, in response to the perceived needs of some of the most disadvantaged individuals and groups in society. However, this research has shown that, at present, the sector is a mixture of local, regional and national schemes.

There is no agreed definition of what advocacy is or does, and many models exist – sometimes in competition with each other. Schemes are often funded on a short-term basis and many find it hard to survive, as they are unco-ordinated and unregulated, relying largely on untrained and unpaid volunteers.

The Government has shown an increasing interest in advocacy, but it has also failed to take a co-ordinated approach. This has contributed to confusion and concern about what advocacy is, where it should be provided, and who it should be available to.

At the same time, there are huge strengths inherent in the advocacy sector. Advocates are committed, energetic, self-motivated and passionate about their work, and there is evidence that they make a real difference to the lives and health of disadvantaged individuals, groups

and communities. The recent developments in government policy are gradually shifting advocacy out of the margins, enabling it to become a real force for change. These trends can only continue: the Government's choice, participation and public health agendas all suggest a new need for advocacy, to make sure the benefits are available to all and to provide new opportunities for the advocacy sector.

However, we believe that a more strategic approach to the development of advocacy is now needed for it to fulfil its potential. First, a clearer working definition of advocacy is needed, which not only encompasses its independence and its role in empowering individuals, but also recognises its potential for improving health and well-being, and promoting active citizenship in its widest sense.

Second, there need to be more generic advocacy services: advocacy needs to be available to all who need it and be supported by government commitment and funding, preferably within a national policy framework. There is also a need for local planning and co-ordination.

Third, we believe that the advocacy sector needs to develop a strong identity and voice for itself, which will put it in a better position to influence policy and delivery at all levels. This could be achieved by the development of a national advocacy alliance representing the whole advocacy sector.

This is a crucial time for advocacy. Its further development is already the subject of lively debate within the movement itself. We recognise that the views set out in this working paper will not be welcomed by all. Nevertheless, we hope that they will contribute to the debate.

Appendix: Useful contacts

Advocacy resource agencies/networks

The Advocacy Alliance
The Advocacy Alliance is a coalition between national charities and the advocacy and user involvement sector. It was formerly known as the Independent Advocacy Campaign. The aim of the alliance is to improve access to advocacy for people who are not heard without the help of someone else – essentially, people with significant communication difficulties. The alliance does this through research, campaigning and the promotion of good practice in advocacy.

Angie Lee-Foster
Director of Advice and Advocacy
The National Autistic Society
393 City Road
London EC1V 1NG
Tel: 020 7903 3763
Email: aleefoster@nas.org.uk
Web: www.nas.org.uk/alliance

Action for Advocacy: A4A (formerly **Advocacy Across London)**
Originally Advocacy Across London, Action for Advocacy promotes advocacy at a strategic level and provides London's advocacy sector with essential support and information.

PO Box 31856
Lorrimore Square
London SE17 3XR
Tel: 020 7820 7868
Email: info@actionforadvocacy.org.uk
Web: www.actionforadvocacy.org.uk

Advocacy Safeguards Agency (ASA)
ASA's purpose is to make sure that good-quality independent advocacy is available to anyone in Scotland who needs it.

1–2 St Andrew Square
Edinburgh EH2 2BD
Tel: 0131 524 9380
Email: ASAinfo@advocacysafeguards.org
Web: www.advocacysafeguards.org

Association of Mental Health Advocates (AMHA)

AMHA's aim is to empower mental health advocates to work effectively with people who use mental health services to get their voices heard in the way they wish to be heard.

PO Box 31856
Lorrimore Square
London SE17 3XR
Tel: 020 7631 5251/ 020 7820 7868
Email: info@amha-online.org.uk
Web: www.amha-online.org.uk

British Institute for Learning Disability (BILD)

BILD administers the Department of Health Valuing People advocacy funding programme in England and Wales, and provides training and support to funded groups.

Campion House
Green Street
Kidderminster OY10 1JL
Tel: 01562 723 010
Email: enquiries@bild.org.uk
Web: www.bild.org.uk

Citizen Advocacy, Information and Training (CAIT)

CAIT is the national resource agency for citizenship advocacy. It provides training for advocates, staff, volunteers and managers of advocacy projects on a wide range of subjects. It also provides support for advocacy providers, a database of projects and on-site evaluations. In April 2005, CAIT will be replaced by the Advocacy Resource Exchange (ARX), which will provide resources for the broader independent advocacy sector.

Unit 162 Lee Valley Technopark
Ashley Road
London N17 9LN
Tel: 020 8880 4545
Email: cait@citizenadvocacy.org.uk
Web: www.citizenadvocacy.org.uk

Health Advocacy Network

The Health Advocacy Network was set up by the Council for Ethnic Minority Voluntary Organisations (CEMVO) in partnership with the King's Fund. Its core objectives are to: facilitate better access to health services; assist in the strategic growth and development of health advocacy services; and promote recognition and value of health advocacy.

Boardman House
64 Broadway
Stratford
London E15 1NG
Tel: 020 8432 0000
Email: enquiries@emf-cemvo.co.uk
Web: http://ethnicminorityfund.org.uk/html/HealthAdv.asp

National Advocacy Network (NAN)

NAN aims to: establish, facilitate and maintain a national network which supports all forms of advocacy; maintain a national database of advocacy projects; be a central source of information; promote and develop all forms of advocacy; and promote good-quality practice.

20 Beevor Street
Lincoln LN6 7DJ
Tel: 01522 511114
Email: nannews@yahoo.co.uk
Web: http://nanadvocacy.members.beet.net

National People First (Self-Advocacy)

National People First is an organisation run by and for people with learning difficulties. It campaigns for the rights of people with learning difficulties and gives support, advice and training to self-advocacy groups nationally.

3rd Floor
299 Kentish Town Road
London NW5 2TJ
Tel: 020 7485 6660
Email: general@peoplefirstltd.com
Web: www.peoplefirstltd.com

National Youth Advocacy Service (NYAS)

NYAS is a national children's charity which offers advice, information, support and representation to any child or young person who wants to have their wishes and feelings taken into account when decisions are made about them.

NYAS House Child Contact Centre
c/o 99–105 Argyle Street
Birkenhead
Wirral
Merseyside CH41 6AD
Tel: 0151 649 8700
Email: contactcentre@nyas.net
Web: www.nyas.net/

Older People's Advocacy Alliance (OPAAL)

OPAAL seeks to give a strategic lead in the development of independent advocacy for older people. It aims to contribute to the development of standards, to improve access, to develop better practice, involve older people and develop links with black and minority ethnic communities.

Parkfield House
64 Princes Road
Hartshill
Stoke-on-Trent ST4 7JL
Tel: 01782 844 036
Email: jacky@opaal.org.uk
Web: www.opaal.org.uk

Prevention of Professional Abuse Network (POPAN)

POPAN works with people who have been abused by health or social care workers. It runs a helpline for anyone concerned about this kind of abuse and a support and advocacy service for abuse survivors.

52–53 Russell Square
London WC1B 4HP
Tel: 020 7631 5251
Email: info@popan.org.uk
Web: www.popan.org.uk/index.htm

Scottish Independent Advocacy Alliance (SIAA)

SIAA provides information, advice and support to local advocacy organisations, undertakes training on advocacy and related issues, and ensures the 'voice' of the advocacy movement is heard at national level.

138–140 Slateford Road
Edinburgh EH14 1LR
Tel: 0131 455 8183
Email: enquiry@siaa.org.uk
Web: www.siaa.org.uk

United Kingdom Advocacy Network (UKAN)

UKAN provides advice, assistance and network contacts for any new mental health group. It promotes user participation and independent advocacy in any mental health setting.

Volserve House
14–18 West Bar Green
Sheffield S1 2DA
Tel/Fax/Minicom: 0114 272 8171
Email: liz@u-kan.co.uk
Web: www.u-kan.co.uk

Independent Complaints and Advocacy Services (ICAS) providers

The Carers Federation
1 Beech Avenue
Sherwood Rise
Nottingham NG7 7LY
Tel: 0115 985 8485
Email: info@carersfederation.co.uk
Web: www.carersfederation.co.uk/index.html

Helpline
East Midlands Tel: 0845 650 0088

Citizens Advice Bureaux
Citizens Advice ICAS Central Team
5th Floor
Norfolk House
Smallbrook Queensway
Birmingham B5 4LJ
Tel: 0121 634 1670
Email: icascentralteam@citizensadvice.org.uk
Web: www.citizensadvice.org.uk

Helplines
London Tel: 0845 120 3784
North East Tel: 0845 120 3732
North West Tel: 0845 120 3735
South West Tel: 0845 120 3782
West Midlands Tel: 0845 120 3748
Yorkshire and Humberside Tel: 0845 120 3734

POhWER
ICAS Project Director
Unit 14/15
33 Nobel Square
Burnt Mills Industrial Estate
Basildon
Essex SS13 1LT
Tel: 01268 727284/Minicom: 01268 722505
Email: pohwer@pohwericas.net
Web: www.pohwer.net/

Helplines
Cambridgeshire, Norfolk and Suffolk Tel: 0845 456 1084
Essex Tel: 0845 456 1083
Hertfordshire and Bedfordshire Tel: 0845 456 1082

South East Advocacy Projects (SEAP)
South East ICAS
18 Wellington Square
Hastings
East Sussex TN34 1PB

Helpline
South East Tel: 0845 600 8616

References

1. Home Office (2000). *The Race Relations Amendment Act 2000*. London: HMSO.

2. Department for Education and Employment (2001). *The Special Educational Needs and Disability Act 2001*. London: HMSO.

3. Department of Health (2001). *Valuing People: A new strategy for learning disability for the 21st century*. 2001. London: HMSO.

4. Department of Health (2001). *The Health and Social Care Act 2001*. London: HMSO.

5. Department of Health (2002). *The Adoption and Children Act 2002*. London: HMSO.

6. Department of Health (2004). *The Draft Mental Health Bill 2004*. London: HMSO.

7. Department for Constitutional Affairs (2004). *The Mental Capacity Bill: Draft Code of Practice*. London: HMSO.

8. Derek Wanless (2004). *Securing Good Health for the Whole Population: Final report*. London: HMSO.

9. Kapasi R, Silvera M, SILKAP Consultants, Office for Public Management, King's Fund (2002). *A Standards Framework for Delivering Effective Health and Social Care Advocacy for Black and Minority Ethnic Londoners*. London: SILKAP Consultants.

10. Citizen Advocacy Information and Training (2004). *New Advocacy Journal Survey*. London: CAIT.

11. Lewington W, Clipson C (2003). *Advocating for Equality*. London: Independent Advocacy Campaign.

12. Platzer H, Foley R (2002). *Mental Health Advocacy in London: A mapping report prepared for the Advocacy Advisory Group of the London Development Centre for Mental Health*. London: London Development Centre for Mental Health.

13. Silvera M, Kapasi R, King's Fund, SILKAP Consultants (2000). *Health Advocacy for Minority Ethnic Londoners: Putting services on the map*. London: King's Fund.

14. Advocacy Across London (2002). *Advocacy Charter*. London: Advocacy Across London.

15. Atkinson, D (2004). *Advocacy, a Review*. Brighton: Pavilion Publishing for Joseph Rowntree Foundation.

16. Henderson R, Pochin M (2001). *A Right Result? Advocacy, justice and empowerment*. Bristol: Policy Press.

17. Dixon A, Le Grand J, Henderson J, Murray R, Poteliakhoff E (2003). *Is the NHS Equitable? A review of the evidence*. LSE health and social care discussion paper number 11. London: London School of Economics and Political Science.

18. Acheson D (1998). *Independent Inquiry into Inequalities in Health Report*. London: The Stationery Office.

19. Black D, Morris J, Smith C, Townsend P (1980). *Inequalities in Health: Report of a working group*. London: DHSS.

20. Department of Health (2003). *Tackling Health Inequalities: A programme for action*. London: HMSO.

21. Benzeval M, Judge K, Whitehead M (1995). *Tackling Inequalities In Health: An agenda for action*. London: King's Fund.

22. Bosma H, Marmot MG, Hemingway H, Nicholson AG, Brunner E, Stansfeld A (1997). 'Low job control and risk of coronary heart disease in Whitehall II (prospective cohort) study'. *British Medical Journal* 1997;314:558–65.

23. Bobak M, Pikhart H, Hertzman C, Rose R, Marmot M (1998). 'Socioeconomic factors, perceived control and self-reported health in Russia. A cross-sectional survey'. *Social Science and Medicine* 1998;47:269–79.

24. Swann C, Morgan A (2002). *Social Capital for Health: Insights from qualitative research*. London: Health Development Agency.

25. Parsons L, Day S (1992). 'Improving obstetric outcomes in ethnic minorities: an evaluation of health advocacy in Hackney'. *Journal of Public Health Medicine* 1992;14(2):183–91.

26. Graham-Jones S, Reilly S, Gaulton E (2004). 'Tackling the needs of the homeless: a controlled trial of health advocacy'. *Health and Social Care in the Community* 2004;12:221–32.

27. Witmer A, Seifer SD, Finocchio L, Leslie J, O'Neill EH (1995). 'Community health workers: integral members of the health care workforce'. *American Journal of Public Health* 1995;85:1055–8.

28. Lacey L, Tukes S, Manfredi C, Warnecke RB (1991). 'Use of lay health educators for smoking cessation in a hard-to-reach urban community'. *Journal of Community Health* 1991;16:269–82.

29. Zhu K, Hunter S, Bernard LJ, Payne-Wilks K, Roland CL, Elam LC *et al* (2002). 'An intervention study on screening for breast cancer among single African-American women aged 65 and older'. *Preventive Medicine* 2002;34:536–45.

30. Black ME, Yamada J, Mann V (2002). 'A systematic literature review of the effectiveness of community-based strategies to increase cervical cancer screening'. *Canadian Journal of Public Health* 2002;93:386–93.

31. O'Shea N, Moran I, Bergin S, Revolving Doors Agency (2003). *Snakes and Ladders: Mental health and criminal justice: findings from the Revolving Doors Agency link workers schemes*. London: Revolving Doors Agency.

32. Ohanian M, Kalemkaryan E (2000). *Final Report on Armenian Health Advocacy and Outreach Project: 1997–2000*. London: Centre for Armenian Information and Advice.

33. University of Arizona and Annie E. Casey Foundation (1998). *The National Community Health Advisor Study: Weaving the future*. Tucson, Arizona: University of Arizona Press.

34. Reilly S, Graham-Jones S, Gaulton E, Davidson E (2004). 'Can a health advocate for homeless families reduce workload for the primary healthcare team? A controlled trial'. *Health and Social Care in the Community* 2004;12(1):63–74.

35. Ro MJ, Treadwell HM, Northridge M (2003). *Community Health Workers and Community Voices: Promoting good health*. Atlanta: Morehouse School of Medicine.

36. National Center for Chronic Disease Prevention and Health Promotion (2002). *Community health workers/promotores de salud: critical connections in communities*. Atlanta: Centers for Disease Control and Prevention.

37. Scottish Executive, Health Department (2002). *Independent Advocacy: A guide for commissioners: supplement*. Edinburgh: Scottish Executive.

38. BBC1 (2003). *Doctors*.

39. Mellanby K (2002). *Advocacy Training in London: Exploring opportunities and need*. London: Advocacy Across London.

40. UKAN (1997). *Advocacy – A Code of Practice*. London: NHS Executive Mental Health Task Force User Group.

41. Advocacy 2000 (2002). *Principles and Standards in Independent Advocacy Organisations and Groups*. Edinburgh: Advocacy 2000.

42. Department of Health (2002). *National Standards for the Provision of Children's Advocacy Services*. London: Department of Health.

43. Barnes D, Brandon T, Webb T (2002). *Independent Specialist Advocacy in England and Wales: Recommendations for good practice*. Durham: University of Durham.

44. Laidlaw L (2004). *Who Wants to Know? Planet Advocacy (8)*, 14–15. London: Action for Advocacy.

45. Department of Health (2002). *The Draft Mental Health Act 2002*. London: HMSO.

46. Department for Constitutional Affairs (2004). *The Mental Capacity Bill 2004*. London: HMSO.

47. Department of Health (2004). *Choosing Health: Making healthy choices easier*. London: HMSO.

48. Fiona Adshead, Deputy Chief Medical Officer, Department of Health, personal communication.

49. Di Barnes, Research Fellow, Centre for Public Mental Health, University of Durham, personal communication.

50. Department of Health (2002). *Supporting the Implementation of Patient Advice and Liaison Services: A resource pack*. London: HMSO.

51. Department of Health (2003). *Draft Mental Incapacity Bill 2003*. London: HMSO.

52. Joint Committee on the Draft Mental Incapacity Bill (2003). *Joint Committee on the Draft Mental Incapacity Bill First Report*. London: HMSO.

53. Department for Constitutional Affairs (2004). *The Government Response to the Scrutiny Committee's Report on the Draft Mental Incapacity Bill*. London: HMSO.

54. Scottish Executive (2003). *Mental Health (Care and Treatment) (Scotland) Act 2003*. Edinburgh: HMSO.

55. Department of Health, Valuing People Support Team (2004). *Local Planning for Advocacy: A toolkit for learning disability partnership boards*. London: HMSO.

56. Department of Health (2004). *Regulations and Guidance on Providing Effective Advocacy Services for Children and Young People Making a Complaint under the Children Act 1989*. London: Department of Health.

57. Department for Education and Skills (2001). *Special Educational Needs Code of Practice*. DfES/581/2001. London: Department for Education and Skills.

58. Ministry of Citizenship (1992). *Advocacy Act, 1992*. Statutes of Ontario, chapter 26. Toronto: Queen's Printer for Ontario.

59. Birmingham D (2001). 'Bill 26, the Savings and Restructuring Act, Ontario' in *Advocacy: A rights issue*. Dublin: Forum of People with Disabilities.

60. Bezanson K, Valentine F (1998). *Speaking Out Project: Periodic Report #2. Act in Haste ... The Style, Scope and Speed of Change in Ontario*. 1998. Ottawa, Canada: Caledon Institute of Social Policy.

61. Scottish Executive (2004). *Advocacy Safeguards Agency*. Edinburgh: Scottish Executive.

62. Advocacy Safeguards Agency (2004). *A Map of Independent Advocacy across Scotland*. Edinburgh: Advocacy Safeguards Agency.