

'Choosing Health' Citizen Advice's response to the Department of Health

June 2004

Executive summary and key recommendations

Citizens Advice has contributions to make in response to questions 5, 7, 9, 10, and 12 of the consultation document. Our response addresses both policy issues, and service delivery issues, from the experience of the 2,000 Citizens Advice Bureaux outlets all over England and Wales dealing with nearly 6 million problems of which 500,000 are health related. 879 of these services are delivered in partnership with local healthcare providers and have been shown by research to provide tangible successful outcomes for patients. The CAB service is therefore well placed to comment on the need for preventative measures.

Advice and information provision

Question 7 – What actions can voluntary and community organisations take to improve healthby improving access to services?

Access to advice and information

We recommend that any plans drawn up with the aim of improving access to services should include provision for access to advice and information, not just about medical issues, but about the wider social issues which impact on the health of the individual and the family.

Research (see Appendix 2) has found that CAB services are more accessible in outreach venues such as health settings, and reach clients who would not otherwise seek help. Advice services in healthcare settings are an excellent way of bringing advice to those who find it difficult / impossible to reach services - people who are sick, disabled, elderly, with mental health problems and who have terminal illnesses and their carers. Advice projects can focus on the families and carers of people who are ill.

Question 9 – What can be done to help people in all social and ethnic groups cope with the stresses of life?

Citizens Advice Bureaux daily deal with people facing these transitions, and others like them. They are able to give detailed information, provide advice and in many cases advocacy to help people survive and learn from transitions and crises in their lives. Bureaux are community based, and many work with minority and socially excluded groups, and are aware of their needs.

The CAB Service would like to see more priority given to the provision of advice and information services in health planning. Having control of your life is often about having the right information and knowledge to make decisions.

- CAB advice reduces stress and improves well being. Poverty is the root cause of many illnesses - for example that this can often lead to patients developing conditions of stress, anxiety and depression, and that it can be the reason they

cannot follow medical advice to turn up their heating or modify their diet. It is impractical to suggest that doctors and other medical staff should become experts in welfare benefits, housing rights or debt counselling, but by working together healthcare professionals and CABx can develop strategies to address these problems.

- Patients who visit GP based advisers visit their doctors less often and need fewer prescriptions. For example a group of GPs in Buckingham reported about their CAB project for older people: 'With the help of CAB, our patients have not only benefited greatly financially as in many cases, but with peace of mind. This has resulted in a marked decrease in the number of GP consultations and home visits requested by our older patient population and in turn has increased the access and GP availability for other patients.'
- CAB advice can boost incomes. An evaluation has been done by Bangor University on the first two years of CAB 'Better Advice Better Health in Wales' Project. This provides a CAB service in one or more primary care settings in each local authority in Wales. The results of this show that in the period from October 2002 to September 2003 the project raised £3,448,672.70 in new benefits across Wales. It was also found that performance as assessed by these outcomes improved over the year.

Question 10 – Working together to support healthy choices

Citizens Advice believes access to timely and relevant advice and information, not just on clinical issues, but on wider social problems, has a big impact on peoples' ability to make better choices in life, including life-style. We would hope that more priority be given to linkages between health professionals and the advice sector, to offer services to individuals and organisations in health settings.

- CAB advice reduces poverty and health inequalities. Common themes arising from research have been the significant amount of additional benefits obtained for clients, perceived improvements in the health status of the people receiving the additional benefits, and that the people seen at the outreach sites have tended to be older than the clients who go to the main bureaux, and to be people who would be less likely to visit main bureaux. Research published by Liverpool University stated: 'Our research demonstrates for the first time that such a service has a measurable impact on the health of those whose income increases after receiving advice. The potential for such services for improving health deserves careful consideration by Primary Care Groups'.
- Advice services are welcomed and valued by health professionals. Research has also been carried out by Manchester University which shows that nurses and doctors in the practice where the CAB operated found the service helped them to address the social and economic needs of their population, which they had previously found difficult to do, and users expressed a high level of satisfaction with the service, with people who were anxious at initial visits particularly appreciating the adviser's approach.

Evidence and policy issues

There are key social policy issues which CAB evidence indicates need to be tackled if we are to overcome the barriers of disadvantage that prevent people from leading healthier lives. As providers of generalist advice, CABx are well placed to identify those policies and practices where change is most urgently needed.

Question 5 - The role of regulation in tackling mental health discrimination

CAB evidence indicates that improving awareness and regulation around tackling mental health discrimination is a key issue. Urgent action is needed by the government to:

- Broaden the definition of mental impairment in the Disability Discrimination Act to take account of the range of mental illness and to reflect the effect of mental disability on peoples' lives so as to help people with mental health problems challenge unacceptable discrimination.
- Require all statutory and voluntary agencies and public and private bodies that deal with the public should ensure relevant staff receive mental health awareness training which includes information about the difficulties this illness creates for people.

Question 7 – What actions can voluntary and community organisations take to improve healthby improving access to services?

CAB evidence indicates that improving access to health and health related services is a key issue. Urgent action is needed by the government to:

- Significantly improve communication and information, especially for people for whom English is not a first language. Otherwise there is a danger that the patient choice agenda will only exacerbate the existing health inequalities experienced by some people in black and minority ethnic groups.
- Ensure that people in rural areas are not disadvantaged because of the costs of travel to services. This particularly applies to accessing NHS dental services. The help with travel costs provided through the health benefits low-income scheme is often poorly promoted and difficult to use. It is also too narrow in scope as it provides help only with the costs of travel to hospital. The costs of travel to an NHS dentist, for example, cannot be claimed, despite Government recognition of the lack of NHS dental services in many parts of the country.

Question 9 – Helping people deal with the stresses of life

CAB evidence indicates that tackling financial exclusion in health care and prioritising rehabilitation are key issues. Urgent action is needed by the government to:

- Remove the cost barriers created by prescription charges. We believe that a fundamental review of prescription charges is needed, including an assessment of the case for abolition of charges. As a priority we have recommended that the pre-payment certificate should be included in the low-income scheme and its cost tapered so that it becomes affordable for people on low incomes.
- Adequately resource services such as community care, which underpin better health, so that they move from a crisis focused to a prevention focused approach. Despite the increase in social services funding in recent years, it is clear that in many cases the level of services provided remains quite inadequate to enable some of the most vulnerable people even to maintain, let alone improve, their health. The objectives outlined in the Wanless report will not be achieved unless community care services are resourced to achieve a similar step change so that they can move from a crisis to a preventative agenda, providing people with a level of certainty that their needs will be met within a timeframe which is swift and transparent.

Question 10 – Working together to support healthy choices

CAB evidence indicates that tackling fuel poverty and protecting mental health consumer choices are key issues. Urgent action is needed by the government to:

- Ensure health professionals are linked in to the delivery of the fuel poverty agenda. There is a need for health professionals to create a bridge between the patients they see, such as those with respiratory ailments, and access to grants and initiatives for relevant home improvements. It is the cause, rather than the effect of poor living conditions that will need to be addressed for the improvement of patient health to be achieved. A direct means of access to the practical help available through fuel poverty initiatives could contribute to both access and awareness.

Introduction

The CAB Service welcomes Wanless' second report, and particularly its focus on how to prevent ill health, what are the wider determinants of health and the cost-effectiveness of actions that can be taken to improve health and reduce inequalities. In particular we welcome that measures should be taken to address health inequalities, and the proposal for a new independent body to monitor the nation's health and for a health future beyond 'short term targets, short term projects with short term funding'.

The Citizens Advice service would like to see access to independent advice, information and advocacy as an integral part of the agenda for prevention, and for tackling health inequalities. Timely and appropriate advice has been shown to have a very positive impact on health outcomes.

About the CAB Service

The CAB Service provides information, advice, advocacy and help to individuals, and also looks at the evidence and experience gained from this to influence policy development.

CABx provide free, confidential, independent and impartial information and advice, and in the year 2002/3 the service was open to the public for over one million hours and dealt with 5,671,987 new problems from over 2,800 outlets in high street and outreach locations. This includes 879 regular outreach advice services delivered in partnership with local healthcare providers.

The service comprises:

- **Bureaux** – local and autonomous, managed by trustee boards. Both these and the bureaux' staff seek to reflect the local communities that they serve, and provide many outreaches and special sessions where people most need the service, including health settings.
- **Citizens Advice** – which provides the regional and national support services to bureaux and a public information service, and which uses the wealth of evidence provided by bureaux to influence the development of social policies. There is also a website, 'Adviceguide', at www.adviceguide.org.uk.

Advice and information provision - prescribing advice

This part of the report deals with issues around what the CAB service and other advice organisations can contribute to addressing the issues raised in the consultation, what the CAB service and its partner organisations are doing at present, and what we believe would make a key contribution in the future.

Question 7 – What actions can voluntary and community organisations take to improve healthby improving access to services?

Accessibility

CABx offer accessible services. As well as securing health benefits, advice services in healthcare settings are an excellent way of bringing advice to those who find it difficult / impossible to reach services - people who are sick, disabled, elderly, with mental health problems and who have terminal illnesses and their carers. Advice projects can focus on the families and carers of people who are ill.

Poverty and illness

Most health practitioners understand that the poverty of many of their patients is the root cause of many illnesses - for example that this can often lead to patients developing conditions of stress, anxiety and depression, and that it can be the reason they cannot follow medical advice to turn up their heating or modify their diet. It is impractical to suggest that doctors and other medical staff should become experts in welfare benefits, housing rights or debt counselling, but by working together healthcare professionals and CABx can develop strategies to address these problems.

Partnerships

Partnership schemes between CABx and health practitioners give them the additional resource of skilled, experienced CAB advisers on hand to tackle some of the social and economic problems directly associated with ill health. Patients get on the spot advice and assistance with benefits claims, employment rights, housing problems such as damp and overcrowding, debt management, and family and personal problems. CAB experience and expertise in these areas extend to advocacy and representation, for instance at tribunals.

CABx also work with GPs and other health professionals in other ways, providing help to obtain for clients good quality and appropriate medical evidence for benefits appeals, whilst at the same time minimising the administrative burden of this on doctors. For example the Stamford CAB has produced a booklet for doctors on providing such evidence.

Question 9 - What can be done to help people in all social and ethnic groups cope with the stresses of life?

The CAB service has an important contribution to make. CABx are well placed to address issues of health inequalities and poverty as very many clients are from the most disadvantaged sectors of communities and CABx provide very local services which are closely in touch with, and reflective of, the communities which they serve. Many people turn to the CAB at moments of crisis, or at turning points in their lives.

Advisers have considerable expertise and experience in maximising income and often find that people are not claiming benefits to which they are entitled. They also help

people to tackle their poor housing, to get adaptations for their homes and to access community care services.

The advice process allows for interconnected problems, such as job loss, relationship breakdown and debt, which may be factors contributing to depression and anxiety, to be dealt with effectively in one place.

When ill health strikes, whether it is suddenly, as a result of an accident, or gradually, due to a debilitating illness, it can bring all sorts of problems. Patients can be helped with putting their affairs in order, (advice on wills, powers of attorney), the special rules for disability living allowances, issues around compensation, finances for the person who has lost their partner, carers benefits, and community care issues, as well as general welfare benefits, and housing advice.

Appendix 1 sets out in more detail what the CAB Service can offer and why CABx are well placed to do this work.

Question 10 – Working together to support healthy choices

Whilst the Wanless report states that there is limited evidence on what works to reduce health inequalities, there is a growing bank of independent academic research evidence which shows that advice services in healthcare settings can have a very beneficial impact on peoples' health. See Appendix 2.

An evaluation has been done by Bangor University on the first two years of CAB 'Better Advice Better Health in Wales' Project. This provides a CAB service in one or more primary care settings in each local authority in Wales. The Welsh Assembly has now agreed mainstream funding for continuation from April 2004. Citizens Advice recommends the provision of such a service across the whole of England too.

The 22 bureaux in the Welsh initiative were assessed against three key outcomes, and the results of this show that in the period from October 2002 to September 2003 the project overall saw 6,445 clients, dealt with 10,732 new enquiries and raised £3,448,673 in new benefits across Wales. It was also found that performance as assessed by these outcomes improved over the year. By the fourth quarter, July to September 2003, the targets set for the whole of Wales had been exceeded, and very positive effects were detailed, both in terms of clients' satisfaction and the impact of this work on primary healthcare teams. A full report will be available on this very soon.

Developing advice services

The Choosing Health report describes three scenarios for the development of public health – the 'slow uptake', 'solid progress' and 'fully engaged' states, with the aim of reaching the 'fully engaged' scenario. It is useful to consider what the parallel development might be within the CAB service:

Current provision

The present 'slow uptake' situation is that there are services in over 2,800 high street and outreach locations where the public go within England, and CABx are working with a range of trusts, - primary care, acute and specialist. Services are provided in the following healthcare settings:

- 672 GPs' surgeries / health centre
- 30 Healthy Living Centres
- 80 general hospitals
- 72 psychiatric hospitals.
- 2 hospices
- Since September 2003 the CAB service has run Independent Complaints Advocacy Services, (ICASs.), in six local government regions, and the contract has recently been extended until February, 2005
- Partnerships funded by the New Opportunities Fund to provide support for either children or adults and their families where a family member is receiving palliative care

Some examples of the generalist, specialist, preventative and partnership working, are detailed at Appendix 3

However, these services are mostly not located wholly strategically across a health economy, having often grown up as a result of particular good individual contacts between a member of a bureau's staff and a health service clinician or manager, and their funding is often neither consistent nor mainstreamed.

The Birmingham CAB Health Unit is perhaps the most strategically developed CAB service in healthcare settings, but even so this falls short of a fully comprehensive service. This initiative provides advice in some 46 GP surgeries, advice workers based within social services community mental health teams, sessions in a local organisation for people with HIV, supported self advocacy in a medium secure forensic unit and a partnership with two other voluntary organisations to provide home visiting for people who would not otherwise have access to advice.

The 'solid state' scenario

This would be an expansion of the scope and range of these services, albeit in the above relatively piecemeal manner.

Our vision is for a 'fully engaged' scenario

We would like to see a 'Better Advice, Better Health in England' project', with advice services rolled out strategically to health economies across the whole of England - covering hospitals, GPs' surgeries, mental health and primary care settings and hospices.

In such a vision, CABx could provide services to patients, their relatives and staff, in outpatients and on wards, and with home visits where necessary. People would make

self-referrals to the service or be referred 'on prescription' by healthcare staff from all parts of the health and social care systems. These services would be able to be accessed quickly.

Learning from experience

Each part of these services would be feeding back information from the evidence and experience gained from individual clients to identify problems that could be addressed for everyone and to influence local, regional and national policies, and we would have strong partnerships with our health and healthcare, social care and voluntary organisation colleagues.

A range of methods of delivery

There would be a comprehensive e-mail advice service and the Citizens Advice national Adviceguide website, with information in a range of languages and a variety of information fact-sheets answering frequently asked questions. In addition advice could be linked to bedside telephones and televisions to be provided for hospital patients and with NHS Direct, and be providing widely, in healthcare and other settings, touch screen information kiosks with CAB advice and advice about health and healthcare matters, and there would be linking of different sites by video-conferencing.

Funding

The health services in England have so far taken the view that, given the competing clinical and other pressures on their funding, they cannot afford across the board to invest in an advice service such as ours, despite the benefits of this described above. It might be helpful for them to consider whether they can afford not to.

The current funding for advice services in healthcare settings tends to be on the basis of projects, whereas what is needed for successful projects is for funding for them to be mainstreamed. This often proves not to be possible, despite the projects being a success. Also advisers observe that money is often available for new projects but not for ongoing work despite the fact that clients need stability. These projects are competing for funding with peoples' clinical needs, which tend to be given the priority for mainstreamed funding. The successive closure of projects for lack of funds can generate a sense of betrayal amongst users for whom continuity of service and of personnel is an important issue.

Citizens Advice recommendation:

It is recommended that independent advice services in healthcare settings be rolled out strategically across health economies and embedded into their structures with mainstreamed funding, and for advice and information services to be developed in a strategic and complementary way to enable the CAB Service's contribution, and that of the voluntary sector to be at their most effective.

Evidence and Experience of our Work with Clients

This part of our response details some of the key social policy issues which CAB evidence indicates need to be tackled if we are to overcome the barriers of disadvantage preventing people from leading healthier lives. As providers of generalist advice, CABx are well placed to identify those policies and practices where change is most urgently needed.

Question 5 - The role of regulation

Tackling mental health discrimination

Discrimination is a major barrier facing people with mental health problems when they try to make choices which could improve their health. If we are to tackle discrimination, it is important that we have not only awareness training but that the Government leads through legislation, as this determines how the market responds. CAB clients who have experienced a mental health problem speak of low self-esteem and confidence because of the attitudes they meet when their condition is known. CAB advisers working in projects for people with mental health problems describe discriminatory behaviour and organisation processes whose outcomes are discriminatory. Concerted action is needed to tackle this discrimination to help create positive experiences in and outside work for people that can be building blocks that may help them to recover more quickly.

For example, people with mental health problems are excluded from insurance protection when member organisations of the Association of British Insurers translate guidelines on the Disability Discrimination Act into policies of not recognising mental health problems as grounds for payment, unless the illness is clinically well recognised. A loan protection plan typically says 'We will not pay benefit if ... your disability arises from stress, anxiety, or depression or any mental or nervous disorder, unless a specialist certifies that the condition prevents you from working.'

Citizens Advice Recommendation:

The definition of mental impairment in the Disability Discrimination Act should be broadened to take account of the range of mental illness and to reflect the effect of mental disability on peoples' lives so as to help people with mental health problems challenge unacceptable discrimination.

All statutory and voluntary agencies and public and private bodies that deal with the public should ensure relevant staff receive mental health awareness training which includes information about the difficulties this illness creates for people.

Question 7 – What actions can voluntary and community organisations take to improve healthby improving access to services?

Removing the cost barriers of prescription charges

A key principle of the NHS is that services are free at the point of delivery so that no one should be prevented for financial reasons from seeking the health care they need. This however does not apply to prescription charges. Although there is a range of exemptions, 80% of people aged between 18 and 60 have to pay prescription charges

As many as 750,000 people are failing to get their prescriptions dispensed because they cannot afford the charge. Problems can be compounded when patients requires a combination of drugs, each of which gives rise to a charge, or where for good clinical reasons, the medication is prescribed in small quantities over a lengthy period. The pre-payment certificate is intended to enable people with heavy prescription needs to cap their costs. However the lump sum cost of £33.40 for four months or £91.80 for a year, makes it of no help to people on low incomes facing affordability problems.

A CAB in Wales reported a very vulnerable client with serious mental health problems in receipt of long-term incapacity benefit. He was failing to take his prescribed medication because he could not afford the charge.

A CAB in Lincolnshire reported a client with terminal cancer who needs four prescriptions per week. She is struggling to manage her bills including mortgage costs, and the money worries were increasing the stress on her and her husband.

A CAB in Cornwall reported a client on long-term incapacity benefit who has one kidney which is not functioning normally. He requires 8 tablets a day and the cost of prescriptions is leaving him extremely poor.

In April 2004 the Department of Health introduced new regulations which extended exemption from charges to people with incomes up to £3.20 above income support levels. This is helpful, but it falls short of addressing the affordability problems that face many people with chronic health problems who are living long term on low incomes.

Citizens Advice recommendation:

Given the Government's recognition of the links between health and poverty, and commitment to tackle health inequalities, we believe that a fundamental review of prescription charges is needed, including an assessment of the case for abolition of charges. As a priority we have recommended that the pre-payment certificate should be included in the low-income scheme and its cost tapered so that it becomes affordable for people on low incomes.

Making services accessible for minority ethnic groups

CAB evidence indicates that too often the health service fails to meet the needs of people from minority ethnic groups, with the result that they experience additional difficulties in accessing services. In recent months, the CAB Service has been involved in the delivery of the Independent Complaints Advocacy Service in six health regions. Early evidence from this work is already showing an over representation of complaints from minority ethnic groups in some areas, when compared with census data.

It is well recognised that effective communication is central to the provision of good health services, yet CAB evidence indicates that a common problem is the absence of adequate provision for interpreting services.

A CAB in Essex reported a Portuguese client with very little English who had waited 9 months for an appointment with a hospital specialist. When she attended she was not seen but was simply given a further appointment in six months time, because the doctor said an interpreter was needed.

A CAB in Buckinghamshire reported a Pakistani woman whose husband had had to go into hospital the previous night as an emergency. She wanted the CAB to tell the school that her child would not be at school that day as he had spent all night at the hospital interpreting for her husband.

A CAB in Leicestershire reported an Asian client whose mother works full time and also struggles to care for her father who may have Alzheimer's Disease. The GP had referred her father to the hospital for a scan nine months earlier but nothing had happened since. Her mother does not speak English well and had had difficulty understanding what was said. She had therefore not enquired about the delay. When the daughter made enquires it emerged that the records had been lost in the system and no appointment had been made.

If patient choice is to become a reality then good communication and the provision of full information, in a manner which meets the needs of the patient, is clearly essential. Adequate translation facilities must be a first priority. Otherwise there is a danger that the patient choice agenda will only exacerbate the existing health inequalities experienced by some people in black and minority ethnic groups.

Citizens Advice recommendation:

Translation and interpretation facilities should be made available and promoted publicly in every locality.

Tackling transport and travel barriers

CABs in rural areas regularly report the problems clients face in accessing health services outside their local area. The cost of travel can be a major barrier. The help with travel costs provided through the health benefits low-income scheme is often poorly promoted and difficult to use. It is also too narrow in scope as it provides help

only with the costs of travel to hospital. The costs of travel to an NHS dentist, for example, cannot be claimed, despite Government recognition of the lack of NHS dental services in many parts of the country.

A client sought advice from a CAB in Cornwall when the hospital refused to refund fully his fares to a hospital appointment. He could not get to the appointment and return home by bus the same day so he used transport provided by a charity, which cost £26. Although he was entitled to a refund, the hospital would only reimburse £9.24 until the CAB intervened.

CAB in Wiltshire reported that a client on income support living in a remote rural area six miles from her GP's surgery had to have weekly blood tests. When these were performed at the hospital her travelling costs were refunded but not when her tests were done at the surgery.

Where there is no local access to services, people will be less likely to take up the services they need.

Alton CAB reports a growing need for drug support and rehabilitation services in the local area. There are no local services and clients have to travel to Basingstoke or Oxford to access services. The bureau comments that the inconvenience and cost of travelling such distances increases the likelihood that people will fail to complete the programme.

The crisis around access to NHS dentistry is perhaps the clearest demonstration of the way transport problems can prevent access to health services. CABs in many parts of the country are regularly dealing with clients who are distressed that they cannot access NHS dental services because of the cost and availability of public transport. Government efforts to address the crisis have focussed on making sure there is some provision for emergency treatment, albeit at a distance. No provision has been made for the increased burden and cost of access which these arrangements have placed on patients.

A CAB in Cornwall reported a disabled man in his late 50s living on benefits who found there was no NHS dentist in the area to which he had moved. He cannot afford private treatment but travelling to the nearest NHS dentist would mean a round trip of some 50/60 miles.

A CAB in Cumbria reported a lone parent in poor health and on income support who whose dentist informed her that he no longer treated NHS patients. She contacted NHS direct and was told there were only 2 dentists taking NHS patients in an area covering some 600 square miles.

Citizens Advice recommendation:

One way to help address this problem would be to extend the provisions for help with health costs provided through the health benefits (hospital travel costs) scheme, to include NHS dentistry, at least as a temporary measure until wider Government reforms are able to ensure a comprehensive NHS dentistry service.

Question 9 - Helping people deal with the stresses of life

Ending the shortage of rehabilitation and transition services

A regular feature of CAB evidence is the extent to which services which could result in improvements in health are rationed because of budgetary constraints, with services focused only on those with the most acute needs. This inevitably undermines the preventative agenda. For example CABx regularly report cases where a shortage of drug rehabilitation services mean that people are not able to access services when they are keen to do so:

A CAB in Wiltshire reported a woman in her late 20s with a longstanding heroin addiction. She is spending all her money on drugs, is in rent arrears in her bed and breakfast accommodation and fears she will be evicted. She has been told that no places are available in rehab and no funding is available for treatment in the community.

A CAB in Surrey reported a client with a long-term heroin addiction resulting in mental health problems that had attempted to seek help. He wanted to go into de-tox but instead he was only offered an outpatient appointment where he would receive methadone. When his mother telephoned on his behalf she was told that no further support is available because of lack of resources.

CAB evidence indicates that the need for a prevention agenda is particularly acute in relation to the provision of community care services. Good community care services are vital to enabling people to lead healthy and active lives. On the other hand when services are not provided, then it is likely that the end result will be increased pressure on often more costly health services. It is therefore essential that the wider reform agenda embraces both health and community care services.

Part of the problem is the way community care services are allocated with the use of eligibility criteria. The flip side of targeting scarce resources at people with the most critical or substantial needs is that the prevention agenda is overlooked. The most obvious manifestation of this is the extent to which, year on year, the number of people receiving community care services reduces, despite the fact that the number of hours of care delivered has risen. Since 1996, the number of people receiving services has fallen by 25% whilst within those households receiving services; the number of contact hours per household has increased by 60%. (DoH, Personal Social Services statistics)

CAB evidence graphically demonstrates the impact of this rationing on individuals, and how this prevents people “choosing health”.

A CAB in Hampshire reported a client in her 90s who is very unsteady on her feet and requires help with personal care in the mornings. She is still awaiting an initial contact from social services nearly three weeks after referral. Repeated enquiries from the bureau have elicited a number of excuses – staff shortages, annual leave and “only able to deal with emergencies”. The client is concerned that she will fall and become an emergency before help is provided.

A CAB in South Yorkshire reported a woman in her 80s with substantial care needs and restricted mobility, who lives alone. It takes her two hours to get up and dressed in the morning and she cannot use the bath or shower. She has no downstairs toilet so eats and drinks very little during the day to avoid the need to go upstairs to the toilet. Social Services could not say how long it would be before they could do an assessment.

A CAB in the West Midlands reported a frail Pakistani woman in her 80s living with her family, who was discharged after a hospital stay of several weeks, without a community care assessment. She cannot dress, wash, bathe, feed herself or drink unaided and is incontinent. Her case was categorized as non-urgent and she was told a visit could take 12 weeks.

Where the assessment involves the need for aids and adaptations, waiting times can be significantly longer.

A CAB in Cheshire reported a client in his 80s who was prone to falling as a result of a series of mini-strokes. He had recently been discharged from hospital and had since fallen in the bath and so had an urgent need for adaptations to provide a walk-in shower. The CAB made the necessary enquiries to establish that there was 14-month wait for an assessment and then an 8-month wait for installation. The bureau was told that social services classified bathing as a "non-essential" service.

A CAB in the West Midlands reported a client in her 90s with mobility problems and living alone. She has approached the occupational therapist for an assessment for a downstairs toilet but has been told the process will take two years. She was very angry, commenting that she was likely to be dead before it was installed.

From 2003/4, a new Best Value performance indicator has been introduced which sets clear time limits on the installation of aids and adaptations. Regrettably however this indicator is limited to smaller items where the cost is less than £1000. For more costly works, there are no targets on how quickly the work should be carried out.

Despite the increase in social services funding in recent years, it is clear that in many cases the level of services provided remains quite inadequate to enable to a preventative agenda, providing people with a level of certainty that their needs some of the most vulnerable people even to maintain, let alone improve, their health.

Citizens Advice recommendation:

The objectives outlined in the Wanless report will not be achieved unless community care services are resourced to achieve a similar step change so that they can move from a crisis will be met within a timeframe which is swift and transparent.

Question 10 – Working together to support healthy choices

Tackling Fuel Poverty

An initiative designed to tackle the prevention aspects of ill health is the UK Fuel Poverty Strategy, which aspires to eradicate fuel poverty by 2018 and to tackle this issue for vulnerable households by as soon as 2010. This links in with the Government's broader objective to reach, by 2010, its Decent Homes Target to ensure all council and housing association homes are warm and weatherproof, and to improve conditions for vulnerable households living in the private sector.

Damp homes in a poor state of repair will, by their nature, be expensive and difficult to heat and either cause or exacerbate health problems and it is the cause, rather than the effect of these living conditions that will need to be addressed for the improvement of patient health to be achieved. A direct means of access to the practical help available through fuel poverty initiatives could contribute to both access and awareness.

Citizens Advice recommendation:

For this aspiration to be realised there is a need for health professionals to create a bridge between the patients they see, such as those with respiratory ailments, and access to grants and initiatives for relevant home improvements.

Tackling the link between mental health and unemployment

Only 18 per cent, of people with mental health problems work. CAB evidence indicates that many want to work because they expect to feel better for doing so. Work has a significant and beneficial impact on their lives, giving the day structure, raising income, conferring confidence, self-esteem and a sense of social inclusion. Work contributes to people's social contacts, one of the most difficult areas to address when people become unwell and isolated at home. By increasing people's income, work can reduce the likelihood of debt and poor health associated with debt.

Employers are frequently accused of closing their doors on applicants who have or have had a mental illness and are criticised for their lack of understanding when people are in work and unwell. Advisers in CAB projects for people with mental health problems report that constant refusals for jobs deters further applications. People sometimes wonder if it is worth being honest about their history and condition, knowing that if they lie and the lie is discovered, they could lose their job. It is important to address people's lack of confidence and skills before they look for work, to provide guidelines on the support and training they can expect from employers and to provide more resources to develop a wider range of training options and supportive schemes for those considering a return to work.

Citizen Advice recommendation:

The Disability Discrimination Act should be broadened to help challenge unacceptable discrimination and the DTI should work with NIMHE to encourage employers to :

- separate the interviewing process from an applicant's disclosure of information about any medical conditions.
- publicise to job applicants that they have arrangements to accommodate people with mental health problems.
- make clear the help employees can anticipate through confidentiality, flexible working arrangements and reasonable adjustments.

Supporting people with mental health problems in work

Employers are criticised for their lack of understanding and management when people are in work and not well. They can misunderstand taking time off for treatment at hospital or sick leave, recurring absences, poor time-keeping, erratic behaviour and failure to attend meetings to resolve difficulties. This can lead to dismissal or people being encouraged to resign.

Recent research indicates mental health problems in the workplace are widespread and that most line managers are ill equipped to deal with them. Documents like the '*Line Managers' Resource*', need wide publicity if they are to help employers identify signs of distress and take early action to support employees. However, it is not clear how this document is being promoted and distributed, particularly to small employers.

Work itself is also a source of stress. Research shows about one in five workers were 'very stressed' by work; this potentially represents a major occupational health problem that need to be addressed.

There seems to be little point in encouraging people with mental health problems back into work unless the prejudices and discrimination of the workplace are effectively addressed. Otherwise, the stress of harassment and unsympathetic treatment will make their condition worse and lead to a breakdown of the work arrangement.

CAB advisers cite stigma, prejudice and discrimination from employers and colleague employees as the main reason for people with mental health problems leaving work and their main difficulty when trying to get work.

A CAB in Lincolnshire advised a man with a history of mental health problems who has ongoing psychiatric support. He obtained full time employment and was later asked to sign an employment contract saying that 'the employer may end the employment if.... (the employee) becomes of unsound mind or a patient under the Mental Health Act 1983'

Citizens Advice recommendation:

There should be wide publicity for employers about the nature of mental illness and the difficulties illness creates for people in the workplace. This should be accompanied by information about the way work can contribute to stress and illness. NIHME should work with the DTI to raise awareness about these issues and back this with support for employers to achieve changes in employer and employee workplace practices, such as :

- active promotion and distribution of documents such as *The Line Manager's Resource* with guidance on phasing people into work, flexible working, supervision and support for people when they are ill and for assisting their return to work giving employees with mental health problems the same right as parents to flexible working
- helping smaller employers to support people with mental health problems using subsidies and training grants.

Appendix 1 - Why CABx are well placed to do this work

Citizens Advice Bureaux have the national and local infrastructures of information, management, supervision and support, training, information and quality assurance, to provide high quality advice and information services in healthcare settings.

- CABs provide a very full service tailored to individuals' circumstances. Provision ranges from information and advice to advocacy on clients' behalf.
- The CAB service is confidential, free at the point of delivery, impartial and independent.
- The advice service is a generalist one, and can therefore address all aspects of a client's situation.
- It also has a range of specialist advisers and services available when required.

The bureaux are very local and managed by a local Trustee Board, and very much reflect the local communities which they serve.

Each bureau is supported by a national and regional infrastructure. These support services are funded by central government and bring added value to local funding agreements and the local funding means that the central funding is very cost effective.

- There is a growing body of academic research evidence that independent, timely and effective advice and help can improve peoples' health and well-being.
- The research shows that health professionals value advice services, which free up their time from social rather than clinical matters.
- CABx are used to reaching out to the 'hard to reach', providing services for people whose first language is not English and people with disabilities, who have sight or hearing impairments.
- The Citizens Advice service is a well-established organisation with a large network and a sound track record of work in this field.

Individuals have a high level of trust in the CAB service. MORI research has found that trust ratings are higher than other organisations, and research by the Finance Services Authority found that trust in CAB financial advice is higher than all other bodies that give financial advice.

An example of the benefits of early advice

Mrs. Smith becomes anxious and depressed due to her family's debt problems, caused when her husband had to give up work because of his health. She therefore needs to be treated with Prozac for some two to two and a half years. The stress of the situation causes Mr. and Mrs. Smith's relationship to deteriorate, and he leaves the family home. She claims income support and the Child Support Agency seeks maintenance from him for their two children. She is summonsed for mortgage arrears, loses the house and has to obtain accommodation in the private rented sector.

With advice at an early stage, to manage the debts, maximise income, liaise with creditors, and set up a sustainable budget it is possible the depression could have been minimised, and the relationship and housing saved.

The Cost to the Health Economy of no intervention: This represents a high cost to the Primary Care Trust's prescribing budget for her treatment with an antidepressant, and this would be likely to be necessary for some 2 years at least. There is also the cost of this in GP's time – a seven minute consultation each month, and costs such as the receptionist's time and of any missed appointments.

The Cost to the Community: This includes the cost of the income support, housing benefit and council tax benefit, plus the costs of processing these benefit claims, the local authority homelessness application, the Child Support Agency administration and the court time for the house repossession, the cost of the temporary accommodation, and the effect of their debts on local businesses.

The Cost to the Individuals: Above all there is the human cost to the family, in terms of relationship breakdowns, the effects on family life and schooling disruptions.

Appendix 2

Independent research on services provided by CABx in health and healthcare settings

- A - a summary of the key pieces of this research and their main findings
- B - a list of the independent research on CABs in healthcare settings and précis of what they cover
- C - some qualitative evidence – other peoples' views of the CAB Service.

A The Key Pieces of Research and Their Main Findings

The advice given in CAB outreach services has been the subject of lottery funded research projects in Birmingham, Wear Valley, Bournemouth and North Staffordshire. Common themes arising from this research have been the significant amount of additional benefits obtained for clients, perceived improvements in the health status of the people receiving the additional benefits, and that the people seen at the outreach sites have tended to be older than the clients who go to the main bureaux, and to be people who would be less likely to visit main bureaux.

Research published by Stephen Abbott and Lindsay Hobby, of the Health and Community Care Research Unit, (HACCRU), Liverpool University, in July 1999, was based on the Garston CAB Health Unit, in Liverpool, which offers advice to primary care patients. The evaluation study of this project says :

‘Although many felt that it is only common sense that increasing the incomes of people living in poverty will lead to health gain, evidence of a measurable impact on health is scarce. Our research demonstrates for the first time that such a service has a measurable impact on the health of those whose income increases after receiving advice. The potential for such services for improving health deserves careful consideration by (then) Primary Care Groups’.

Birmingham District Health Unit, Bournemouth CAB and High Peak CAB, in conjunction with Liverpool University, were awarded a further lottery grant for a more detailed study. This research was published in 2002.

Research has also been carried out by Manchester University, in conjunction with Sandwell CAB in the West Midlands, and its conclusions mirrored those in the Liverpool research. Taken with the results of the Abbott and Hobby 1999 study, the findings suggest both health improvement and economic benefit for people using CAB services in primary care. In addition nurses and doctors in the practice found the service helped them to address the social and economic needs of their population, which they had previously found difficult to do, and users expressed a high level of satisfaction with the service, with people who were anxious at initial visits particularly appreciating the adviser's approach.

The Health and Community Care Research Unit of the University of Liverpool has undertaken an independent evaluation of the work of the Citizens Advice Bureau within Arrowe Park Hospital. It analysed the holistic effects a CAB service can offer

and provided information about the benefits that are derived from having this type of service based in a large general hospital, which will help in the development of similar services in other hospitals.

Research undertaken by the University of Aberdeen evaluating two CAB outreach services in healthcare settings describes CAB work as having two major impacts in relation to health:

- Services help clients who are already within the healthcare system and suffering from sudden, chronic or terminal illness. Their worries about loss of income, debt, perhaps loss of their home, adds to their anxiety.
- Advice and advocacy given by CABx can reduce the overall burden of stress. This was unanimously agreed to be important to health by clients and health and social care professionals

Services were perceived to have direct impacts on health inequalities, such as access to financial benefits and housing, and less tangible, indirect impacts, such as self-esteem and a sense of well being and housing, and less tangible, indirect impacts, such as self-esteem and a sense of well-being.

For clinical work the Aberdeen research found that CAB services saved hospital social workers three hours time each per week.

B - A List of the Independent Research on CABs in Healthcare Settings and Précis of What They Cover.

'Welfare Advice in Primary Care' – gives a synopsis of the various pieces of research done in this area by voluntary services including CABs. January 2002. Peter Greasley, Research Fellow, School of Health Studies, and Neil Small, Professor of Community and Primary Care, University of Bradford, Unity Building, 5 Trinity Road, Bradford, BD5 0BB. Tel. 01274.236550

Prescribing Citizens Advice – An Evaluation of the Work of the CABs with Health and Social Services in Birmingham. Report Commissioned by Birmingham and District CABs. Ltd., Birmingham Social Services Dept., and South Birmingham Health Authority. Debbie Veitch. February 1995. Available from The Birmingham and District CAB Health Units, 12a High Street, Edington, Birmingham, B23 6RJ.

A study to establish the pattern of previous medical history of those clients referred to the CAB from either their GPs or other involved professionals, to investigate subjective health status before and after CAB intervention, and to link this to the cost of the Project in terms of overall cost, cost per person seen and cost per problem dealt with.

An Evaluation of the Health and Advice Project : Its Impact on the Health of Those Using the Service. Report No. 99/63. Stephen Abbott and Lindsay Hobby, Health and Community Care Research Unit, Liverpool University, Thompson Yates Building, Quadrangle, Brownlow Hill, Liverpool, L69 3GB. Telephone. 0151.7945287. July 1999.

A study of the Garston CAB's Health and Advice Project, which offers welfare benefits advice in a number of primary care settings. This study investigated the impact of the service on the health of those using it.

What Do You Advise, Doc? A Citizens Advice Bureau in Primary Care in the West Midlands. ISBN 0 902252 34 8. Manchester Monograph 40. Commissioned by Sandwell Health Authority. Judith Emanuel and Shanaz Begum, Faculty of Education, University of Manchester, Oxford Road, Manchester, M13 9PL. Telephone 0161.275.3532. E-mail : judith.emanuel@man.ac.uk. April 2000.

An evaluation of the work of a CAB adviser attached to a primary healthcare team in a small town in the West Midlands, whose population experienced high levels of economic deprivation and ill health. An exploratory study to develop a greater understanding of the processes and content of the CAB service and to consider the appropriateness of the hospital Anxiety and Depression Scale and Measure Yourself Medical Outcome Profile as outcome measures assessing the health impact on users of the service.

Arrowe Park Hospital Outreach : Project Evaluation Lindsay Hobby, Health and Community Care Research Unit, The University of Liverpool, Thompson Yates Building, Quadrangle, Brownlow Hill, Liverpool, L69 3GB. Telephone 0151.794.5473. November 2001.

An evaluation over a three month period of the work of Arrowe Park Hospital CAB Outreach Project, a service for patients, staff and visitors to the Arrowe Park Hospital.

Evaluation of Citizens Advice Bureaux in Primary Care. Department of Public Health, University of Manchester. Judith Emanuel May 1998.

An exploratory study to influence the design of an evaluation of CAB activity in one practice in Sandwell, through interviews with GPs and a locality commissioner of health services.

Citizens Advice Bureaux Services for People with Mental Health Problems. An investigation of seven CAB mental health projects. January 1998

A report of a research project carried out by the Mental Health Foundation and the National Association of Citizens Advice Bureaux. This is intended to illustrate examples of good practice in the provision of advice and information to people with mental health problems. It is not an evaluation of the individual CABs., but an investigation of the different models of service provision, taking a holistic approach to reflect the diversity of CAB mental health work.

CAB Outreach Services Evaluation : A report on the impact of Citizen's Advice Bureau Outreach Services at Aberdeen Royal Infirmary and Banff and Buchan on client health and professional workload. Department of Management Studies, Edward Wright Building, University of Aberdeen, Dunbar Street, Old Aberdeen, AB24 3QY. Jane Farmer and Lucy Kennedy. May 2001.

An independent evaluation of two Citizens Advice Bureaux outreach services provided to clients in Grampian commissioned by Citizens Advice Scotland. This study sought to examine impacts of CAB outreach services on client health and health and social care professional workload to help in addressing appropriate funding sources and levels.

Citizens Advice in General Practice. Jim Paris and David Player. British Medical Journal 5/6/93. Vol 306 pp 1518 – 1520. This examined the introduction of Citizens Advice Bureaux into general practice, looking at 150 prospective attenders referred by primary health care workers in 10 practices in Birmingham.

An Assessment of Health and Social Issues Affecting Clients of the Citizens Advice Bureau in North West Surrey. Alexandra Bright-Paul. November 1994. This assessment reports the general health of those suffering a variety of social problems in North West Surrey. It aims to discover any relationships between social factors and ill health, identify any relevant health and social issues specific to particular sections of the community and produce recommendations for services to alleviate these problems.

Citizens Advice Bureaux in General Practice. A pilot project evaluation. Kathleen Galvin, Ann Sharples and Dawn Jackson. Institute of Health and Community Studies, Bournemouth University, Royal London House, Christchurch Road, Bournemouth, Dorset, BH1 3LT. November 1996.

This pilot project is a descriptive study of CAB services in General Practice in Dorset. This attempts to evaluate the value of these services from the perspectives of users of the service, the CAB advisers and the referral agents. Data was gathered from questionnaires, individual interviews and focus group interviews.

Getting Positive Results. Camden Citizens Advice Bureaux Service HIV Project. Penny Waterhouse, Research, Management and Organisational Consultancy Services, 21 Yoakley Road, London, N16 0BH. Telephone 0208.800.7509. August 1997. A research report describing user needs, service satisfaction and advice outcomes.

Evaluation of the In-Surgery Citizens Advice Service for Patients of the Auckland Medical Group. Chris Bowran. October 1997.

To evaluate the impact of this in-surgery CAB advice service on the health of patients who have used it. It concluded that access to this service has subjectively benefited the physical and mental health of the patients using it. The service has reached a population who would not have used it if it were not available in the surgery.

Evaluation of 4 CAT Funded Citizens Advice Bureaux Units. Birmingham : Soundings Research. B Fleming and L Golding. 1997.

A study involving 21 General Practices in 4 areas of Birmingham, analysing routine data collected by the Citizens Advice Bureaux for periods ranging from 52 to 61 weeks between September 1995 – October 1996.

Mental Health Study. Newbury and District Citizens Advice Bureau. Prepared by Fiona Gren, Independent Trainer and Consultant, 88 Craven Road, Newbury, Berkshire, RG14 5NP. 1998.

The Newbury Citizens Advice Bureau was asked to establish a limited advice service for people with enduring mental illness, and at the same time to carry out research into whether such services could be of benefit to those who were trying to live independently in the community.

Advocacy From the Outside Inside : A Review of the Patients' Advocacy Service at Ashworth Hospital. ISBN 0 903593 18 1. Commissioned by the High Security Psychiatric Services Commissioning Board. Di Barnes with Alison Tate. Centre for Applied Social Studies, University of Durham, 15 Old Elvet, Durham, DH1 3HL. Telephone 0191.374.7237 E-mail : d.k.barnes@durham.ac.uk. December 2000
The Ashworth CAB Patient's Advocacy Service was the first mental health advocacy service to be established in a high security hospital in Britain. This review was undertaken in part to acknowledge it's achievement.

Citizen's Advice Bureau and family health : report of a pilot study. Richard Reading, Shirley Reynolds, John Appleby, Mary Mclean, Sarah Steel, Jackie Wheatley and Sarah Kember. Report 8, HPP Report Series. February 2000. School of Health Policy and Practice, Elizabeth Fry Building, University of East Anglia, Norwich, NR4 7TJ. Telephone. 01603.593309. E-mail : s.lindsey@uea.ac.uk
This is a trial of the effects of CAB services on maternal and child health. This was a pilot study to examine the feasibility and organisation of such a trial, to estimate sample sizes, to identify useful outcome measures of child and maternal health, and to measure the financial and social benefits accruing to families using CAB services.

C Some qualitative research - other peoples' views of our service

The views of a group of GPs in Buckingham, about their CAB project for older people :

'With the help of CAB, our patients have benefited greatly, not only financially as in many cases, but with piece of mind. This has resulted in a marked decrease in the number of GP consultations and home visits requested by our older patient population and in turn has increased the access and GP availability for other patients.The Project has helped us in achieving our aim and the wishes of our older patients, that they should remain independent in their own homes for as long as possible This results in less 'bed blocking' in the hospitals, as patients are able to return to their own home, as support is available to them covering all aspects of everyday living'.

What some of our clients in Camden say about us :

- 'I was on a downward spiral of depression, fatigue and fear. The adviser brought me hope and gave me dignity which poverty and debt had taken away'. *(A 51 year old woman who had had a stroke)*
- '...After my husband's death I wasn't getting enough allowances. The CAB helped me to get my full entitlement. I can't praise them enough'. *(An 81 year old woman)*
- 'I was in a deplorable physical and mental condition... you gave me financial and domestic security.' *(A 67 year old man with enduring mental health problems who was evicted from his home)*

Appendix 3

Examples of the CAB Service's generalist, specialist, preventative and partnership working

Generalist and specialist CAB services in a hospital :

Combined Hospitals CAB is based in a major inner city hospital, located in an area which has some of the worst health and poverty indicators in the country. It serves the hospital community, including patients, carers, staff, relatives and visitors. It operates a four days per week general bureau service located in the outpatient area of the hospital. It carries out casework, mainly in disability and sickness benefits and issuers relating to community care. There is also a full time ward visiting service, which takes the CAB Service to hospital in-patients and their carers and families. Due to these clients' ill health problems, the majority of them are facing major life changes and urgently need advice. It is also part of the Independent Complaints Advocacy Service for the North West Region

A specialist advice service is based at the Brain and Spinal Injury Charity, (BASIC), Centre. This is affiliated to the hospital, and is situated just outside the hospital grounds. The service combines BASIC's specialist understanding of neurological and spinal conditions with CAB advice skills, and clients appreciate an advice worker who has an understanding of their disability and it's effects. The worker undertakes a high amount of casework, as often other agencies do not understand their clients' disabilities.

Support and information to children and their families in palliative care settings – an example of our work from a London bureau :

A woman was born severely disabled and requires 24 hour per day care and monitoring. She was in hospital for a long time, but was then discharged to her home with a substantial care plan and support, involving hospital and social services staff. Her mother has severe learning difficulties and was receiving treatment from depression, and was unable to care for her and their other child by herself. Therefore her father ceased his full time employment to care for them. Their first language is Bengali and they do not speak much English.

Following giving up his work, he was claiming jobseekers' allowance, but subsequently his Job Centre arranged for him to attend an interview for a work placement and to get a job. However, due to his obvious care commitments he was not in a position to do this, He then faced the threat of losing his jobseekers' allowance and credits of national insurance contributions. This was their sole income, as he was not getting any invalid care allowance and his wife was not receiving any disability living allowance.

One of our palliative care partnership projects in London was able to correctly advise this family about their benefits situation and assist the father in advocating his case to the Job Centre, and their benefits position was resolved satisfactorily.

Partnership and preventative work :

'AskCAB' – www.askcab.co.uk/ website and related work with local schools, a partnership between the Wymondham Bureau, the Norwich Bureau and the Norwich Money Advice Service. This is a web based project to provide free and confidential advice for people in the age range of 13 - 25 living in Norfolk, and for professionals working with them. It has a Project Worker based with each of the three partner organisations, and each takes lead responsibility for one aspect of the project : 'Your Life' part of the site, providing general advice for children and young people on issues such as sex, drugs and housing problems, and also what help is available on a range of health issues.

There is also an e-mails answering service, and quizzes around health and related is '**Resource Center**' which provides teaching materials and resources for professionals working with children and young people about their rights and responsibilities and which can be used as part of the National Curriculum

'Your Money' which provides information on money for young people. Together the three project workers also visit schools to talk about teaching games with them.