OPAAL(UK)

THE OLDER PEOPLE'S ADVOCACY ALLIANCE

Help the Aged

Dignity on the Ward

Advocacy With Older People in Hospital

A Report written by

Andrew Dunning

With
Barbara Avila,
Mary Duncan
and John Miles
of the Older People's Advocacy Alliance
(OPAAL) UK

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CONNECT Advocacy Scheme

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LinkAge Advocacy Project, Manchester

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Introduction

"Independent advocacy can be invaluable in helping a patient to express his or her views if there are difficulties in communication. As the advocates are neither a relative or associated with the health facility, they can offer assistance without being influenced by conflicting interests".
'The Older Person: consent and care', British Medical Association/ Royal College of Nursing, 1995

"The experience of being a patient or service user is often a disempowering one in which other people hold the knowledge and power over your welfare. Older people are vulnerable to the erosion of autonomy and choice, to poor quality services and abuse... Independent local advocacy services are vital to support older people when key decisions and choices have to be made, and when things go wrong."
'Our Future Health: Older people's priorities for health and social care' Health and Older People Group (HOPe)/ Help the Aged, May 2000

Advocacy with older people is also increasingly being recognised by politicians, policy makers and providers of health and social care – as well as professional associations such at the British Medical Association and the Royal College of Nursing. In recent years advocacy with older people has developed rapidly in a variety of settings throughout the UK, including hospitals. This report aims to provide:

- A description of the setting up and running of advocacy schemes in hospital, considering both the benefits to patients and the lessons to be learned from existing schemes
- Policy, practice and research recommendations which would improve the scope and quality of advocacy in hospital

This report has been produced by the Older People's Advocacy Alliance (OPAAL) UK in partnership with the Help the Aged Dignity on the Ward campaign. OPAAL is an alliance of advocacy schemes, older peoples' groups and community organisations, committed to the development of independent advocacy of the highest quality in the interests of older people who need such support and representation.

The authors visited and interviewed management committee members, officers and volunteers – including older people – involved in the running of 14 advocacy schemes working within hospital settings. Participants set out the aims, structure and organisation of their schemes as well as sharing their experiences, challenges and aspirations. Further material was gathered from a variety of relevant publications, documents and other sources.

This report is intended for existing advocacy services, older people's forums and groups, voluntary organisations, Community Health Councils and patients' organisations, the NHS and related bodies, as well as politicians and policy makers. Whilst the advocacy schemes presented in this report are located in England, the information and issues raised will also be of relevance throughout the UK.

This report begins with a brief consideration of why older people might need advocacy in hospital and what is meant by advocacy in terms of definition, development, principles and roles. It then describes the setting up and running of advocacy schemes for older people in hospital, using case studies to illustrate a wide array of models, approaches and arrangements. It outlines the barriers, problems and pitfalls facing these advocacy schemes and the ways in which such difficulties might be overcome. Finally, it sets out recommendations for future development. A list of useful contacts and resources is also provided for those wishing to follow up beyond the parameters of this publication.

Why advocacy with older people in hospital?

Advocacy can be of great benefit to older people in hospital as a means of:

- Getting and using information .
- Being heard and making decisions
- Providing protection against abuse
- Challenging discrimination

Getting and using information

Information should be readily accessible, accurate, up to date and understandable. Older people in hospital need information relating to a number of matters, including treatment and care arrangements, policies and procedures or rights and entitlements.

Knowledge of such matters might simply bring about 'peace of mind' or, perhaps more crucially, it can help to make informed choices and decisions. It is an essential part of being able to take control in potentially life changing situations.

Information is power. An advocate can help to seek out and obtain relevant information, clarify and interpret the meaning of the information and support the older person in acting upon that information.

Being heard and making decisions

Older people may be faced with major decisions when they are in hospital. Such decisions could be concerned with medical treatment or intervention, discharge arrangements for returning home with a community care package or moving into long term residential or nursing home care.

Professionals and others can hold a lot of power and all too easily impose their own views. Their position might be seriously compromised by conflicts of interest, calling into question whose 'best interests' are being met and whether the preferences of the older person are paramount.
Advocacy can help to redress the balance of power. It can help to ensure that all relevant procedures are properly used, that all possible options are explored and that sufficient attention is given to individual circumstances. It can be a means of getting across the views of the older person and enabling their voice to be heard.

Providing protection against abuse

Older people may be subject to a variety of forms of abuse – physical, sexual, emotional and financial – in domestic or institutional settings. As well as the more 'heavy end' forms of abuse, older people can be affected adversely, if unintentionally, by institutional routines and regimes and by ill considered practice and procedures within the hospital setting.
Advocacy can play a part in the protection of older people who are vulnerable to or victims of abuse. It can be a means of preventing mistreatment as well as supporting those who have been mistreated.

In addition to providing protection against abuse, advocacy may provide protection against over-protection! Older people can sometimes find themselves being denied the right to take risks by professionals and carers who are in some way concerned about their welfare. They might require support in order to pursue a course of action others take for granted.

Challenging discrimination

Prevailing social attitudes, policies and services can create and perpetuate negative assumptions and stereotypes about older people. This is captured in relation to health and well-being by the all too often used phrase – 'what do you expect at your age?'

Older people are discriminated against at an individual and institutional level. This can mean that they are denied access to health care on the basis of chronological age rather than individual assessment, that they receive a: 'second-class' service and, perhaps most insidiously, that the expectations of older people themselves are lower.

Advocacy is a means of challenging assumptions and stereotypes as well as combating ageism and other forms of discrimination at an individual and institutional level.

Definition and development

Advocacy generally involves people making a case for themselves and advancing their own interests, or representing others and supporting them to secure and exercise their rights on an individual or collective basis. In the context of this report, advocacy refers to the activities of advocacy schemes and paid or volunteer advocates who provide independent representation and support for individual older people in the hospital setting. Advocates might be younger people or older peers. The advocacy relationship might be short term or longer term.

It should be acknowledged that there are a variety of forms of advocacy, such as self advocacy and group advocacy, all of which might interrelate with the one to one advocacy partnership and are indeed provided by several of the advocacy schemes mentioned in this report. In order to clarify the one to one focus further, this report also includes reference to the principles of advocacy and the roles of advocates.

There is nothing new about advocacy in hospital. Around 150 years ago John Perceval acted as a peer advocate and founded the Alleged Lunatics' Friends Society at Bethlam Hospital in London. However, the first advocacy schemes specifically concerned with the interests of older people in the UK were established by the Beth Johnson Foundation, Birmingham Citizen Advocacy and a handful of local Age Concern groups during the late 1980s. There now appears to be well over a hundred such schemes across the UK, including those providing advocacy for older people in hospitals.

The rights and representation of older people in health and social care settings has been promoted in government reforms concerning person centred care, choice and participation over the last decade or so. Advocacy is mentioned in a number of official charters, notes of guidance and quality standards documents. In 1995 the Department of Health commissioned the Centre for Policy on Ageing to produce 'Citizen Advocacy for Older People: a code of good practice'. At present, however, advocacy has no legal status in the UK and there is no requirement upon the relevant statutory authorities to support local advocacy schemes.

Advocacy schemes vary in their organisational origins, including those established by statutory providers, voluntary sector providers, existing advocacy schemes and groups of older people themselves. Some schemes have paid co-ordinators who recruit, train and support advocates, a few have paid advocates, whilst others are run on a completely voluntary basis. Some advocacy schemes have developed on a generic basis, others have focused their activities in various ways to cover specific groups, situations and settings. Most schemes struggle to survive due to a lack of funding.

The exact scale, scope and standards of advocacy with older people is difficult to state. This is because there has not been a comprehensive al1d up to date surveyor agreed measurement of quality across the UK. A number of advocacy schemes have commissioned research or undertaken an evaluation of their work, but there is little material published widely or readily available in the public domain. Gathering information of the bigger picture beyond the local level currently requires a knowledge of networks of advocacy schemes, older people's groups and community organisations.

It is hoped that the development of the Older People's Advocacy Alliance (OPAAL) UK, the impact of campaigns such as Dignity on the Ward and the influence Help the Aged and other key organisations both of and for older people, will help to ensure that advocacy with older people is recognised, resourced and robust.

Advocacy principles

The three key principles for advocacy with older people are independence, empowerment and inclusion. Here is an outline of what these guiding principles might mean in practice:

- **Independence**
  - Advocacy must be free from conflicts of interest. Older people in hospital can find themselves in the middle of the competing agendas of professionals, relatives and others.
  - At an organisational level, providers of direct services in the statutory, voluntary or private sector can find that there are a multitude of demands which make it difficult to truly represent the interests of the older person in hospital. The organisation might stand to lose a contract or credibility if it is seen to support the older person through a contentious issue.
  - Organisations might also have their own priorities and these might divert or detract from the efforts of the advocacy scheme which solely seeks to meet the needs of the older person. For example, when a health authority closes a long stay hospital it might put pressure on an advocacy scheme to concentrate its resources on that, rather than older people on acute care wards or difficulties on discharge.
  - Individual advocates also need to be free from conflicts of interest. Medical professionals, nurses and social workers might all possess and use advocacy skills. However, there might be a question as to how vigorously they can pursue the interests of the individual when they have the pressures of their own wider workload, colleagues, management and organisational priorities. There is also the issue of the perception of older people themselves, for whom the professional might be part of the problem rather than being viewed as an ally or representative. The older person might be afraid to be seen to 'bite the hand that (sometimes literally) feeds them' or of losing the service they already receive. They might also simply be concerned about 'bothering' seemingly busy staff.

- **Inclusion**
  - Advocacy should be inclusive in that it should be accessible to 'hard to reach' older people who might need it, including those who are disabled and with whom there are communication difficulties, as well as older people from black and minority ethnic groups. It is not just about working with older people with whom there will be an immediate reciprocal relationship or for whom the presenting problems are speedily resolved.
  - The running of advocacy schemes also needs to be highlighted here. Who are the managers of the advocacy scheme and who are the advocates? To what extent is the running of the advocacy scheme really inclusive? As well as being an important principle, there is a practical purpose to involving a diversity of people – the advocacy scheme will be able to tap into a huge resource of experience, networks and community of interest.

- **Empowerment**
  - Advocacy should be about the older person taking control, redressing the balance of power in relation to professionals and other influential parties, as well as exercising their rights and interests. The advocate should enable the older person to speak up for themselves wherever possible and act as a spokesperson who is loyal to the older person alone if needed. It should mean supporting, being alongside and speaking with rather than for the older person. In this respect it is important to make a distinction between advocacy and substitute decision making.

Advocacy roles

"The role of the Health Advocate is to inform, empower and interpret for patients to improve the appropriateness and accessibility of health services and to improve health outcomes". **City & Hackney Community Services NHS Trust**

"The advocate is there alongside the older person. They're in their shoes, so to speak, and standing up for their rights. The advocate takes

the time to check what the older person really wants and explains the options and things happening around them in a way that can be fully understood... Sometimes the advocate has to say things to the hospital staff that shouldn't have to be said". **Bridlington Advocacy Awareness Project**

Advocates can be said to undertake two main types of roles – instrumental and expressive. The instrumental role is more formal, practical and about 'doing'. The expressive role is more informal, emotional and about 'being'. Here are some of the elements of each of these roles.

- Instrumental (formal/practical/'doing')
  Representative
  Spokesperson
  Guardian/ Attorney/Appointee Information aide .
- Expressive (informal/emotional/'being')
  Confidante
  Companion
  Witness/'being there'
  Enabler

Of course, instrumental and expressive roles are often inter-related. The following case studies illustrate how advocates carry out these roles in practice.

Miss Aherne and Alice

Miss Aherne was admitted to hospital from a residential home following a series of falls. She had lived in the residential home for several years. She did not appear to have any visits from family members or friends. She was very frail due to arthritis and osteoporosis. She was also very withdrawn. During her hospital admission Miss Aherne had been assessed to be in need of nursing home care. It appeared that Miss Aherne had agreed to such a move. A placements officer quickly followed up and was at an advanced stage in securing a nursing home for her some considerable distance away. A member of the ward staff commented, 'We'll miss that one. You forget she's there most of the time... I wish we had more of them like that in here!' – a statement which indicated to Alice, an advocate on the wards, that Miss Aherne might need support.

Alice the advocate met with Miss Aherne and was able to ascertain that she was of Irish origin and had been in service for many years. Miss Aherne had lost contact with her relatives, but had sometimes received visits from long-standing friends when she lived in the residential home. She had also enjoyed the company of two other Irish residents, but both of them had died within the past 18 months. Miss Aherne informed A lice that she had been 'low' because of her recent losses and the uncertainty about what was going to happen to her next. She had been reluctant to tell staff what she would like to do herself because, 'They're such busy people... they're angels'. She disclosed to Alice that she did not particularly want to return to the residential home even if she could. However; she did want to remain in the area and to maintain her occasional contact with friends and acquaintances from the Irish community.

Alice requested a meeting with the placements officer and ward staff, in which Miss Aherne was able to voice her true feelings, views and preferences regarding this life changing decision. The placements officer revised her trawl of suitable nursing homes, concentrating on the more immediate locality. Miss Aherne was able to make a positive choice of nursing home, where she now feels happy. Alice still visits her regularly and is involved in any important meetings concerning Miss Aherne's care.

Mr Brown and Ben

Mr Brown had initially been hospitalised having suffered from a series of strokes. However; he had now been re-admitted following a breakdown in his care package within 24 hours of his discharge. Mr Brown had seemingly lost confidence and was sometimes more disorientated since this incident. Mrs Brown approached the advocacy service on behalf of her husband. She was worried about saying anything herself in case of losing community care services or of hospital staff assuming that she could not cope with her husband and wanting him to enter institutional care.

Ben, the advocate, established that the necessary services were not fully in place at the time of the discharge. A home care provider confirmed that the discharge had taken place two days before the service was expecting to commence. Ben spent time finding out what was 'normal' for Mr Brown and discovering ways of

communicating with him. He found that' Mr Brown was more lucid and capable of discussion and making decisions sometimes more than others. Ben used . personal information given by Mrs. Brown. Following guidance from the advocacy scheme co-ordinator; he also used material from the Stroke Association and a dementia services development centre to aid communication techniques. He established that Mr Brown wanted to go home again with support.

Ben then requested a review of Mr Brown's discharge plan. Mr and Mrs Brown received apologies from the providers for the previous breakdown of service and the impression they had given of questioning Mrs Brown's motivation and capacity to share the care of her husband at home. Fresh arrangements for a return home with additional support were confirmed. A new date for discharge was set – with all parties committed to better co-ordination and communication.

Mrs Clarke and Kulvinder

Mrs Clarke had a severe dementia and was frequently distressed and disorientated. She was in hospital after being found with hypothermia having wandered out at night wearing only her bedclothes. A visitor for another patient on the ward had been alarmed by an episode in which Mrs Clarke was apparently being 'force fed' by an agitated, rude and rushed member of the ward staff. The incident had left Mrs Clarke struggling to breathe, covered in breakfast and beside herself in tears.

The visitor later witnessed the same member of staff taking Mrs Clarke to the toilet in a rough manner. She immediately approached the hospital advocacy service. Kulvinder; the advocate, arrived on the ward two hours later to find that Mrs Clarke was still in the toilet. When Kulvinder approached a member of staff she was told that Mrs Clarke had been left in the toilet for the benefit of other patients as she was so disruptive. The member of staff also suggested that Kulvinder was wasting her time and interfering. Kulvinder attempted to communicate with Mrs Clarke but found it very difficult to do so. Although she was still upset, she appeared to have forgotten – or was unable to say what had happened to her.

Kulvinder had not established a relationship with Mrs Clarke, who was not capable of giving consent or complaining. However, she took up her case as it was apparent that she was being mistreated and that her human rights were being abused. Kulvinder called for the ward manager and reported the situation. She then told the manager and the member of staff that she would be making a formal complaint. She also informed the local Community Health Council so that they could formally take up Mrs Clarke's case and look into the treatment of other patients in a similar situation. Consequently, two members of staff were suspended and staff training and ward procedures were reviewed.

Origins and organisation

Advocacy schemes working with older people in hospitals are varied in their origins and organisation. In this section we will look at four different models, highlighting their key characteristics and giving examples of related schemes.

Service development by statutory sector organisation

Statutory sector organisations such as health authorities and social services departments have developed advocacy for older people on an 'in house' basis.

City & Hackney Community Services NHS Trust Advocacy Services

This service was formally established in September 1998 when City & Hackney Community Services NHS Trust was awarded the contract for health advocacy within the locality by East London and the City Health Authority (ELCHA). This entailed merging the existing providers in the locality who were active in advocacy, including the Health Authority's own service and the Multi-Ethnic Women's Health Project, which was set up in 1980 and managed by the Community Health Council. The current contract with the Health Authority will end on 31 August 2001 and be re-tendered. Commissioning responsibility will be transferred to the Primary Care Group. The Advocacy Services Manager reports through the line management structure of City <80 Hackney

Community Services NHS Trust. Commissioners also hold regular monitoring meetings with the Dust to review and comment on provision. A team . of paid health advocates work on a full time or sessional basis.

Service development by voluntary sector organisation

Large voluntary sector organisations which have traditionally sought both to provide direct services and to represent the interests of older people have also developed advocacy schemes**.**

Age Concern Mid Essex Hospitals Scheme

The Mid Essex Hospital Advocacy Service was set up by Age Concern Essex as a pilot project to provide advocacy for older people in five Mid Essex Hospitals – Broomfield, St John's, St Peter's, St Michael's and WI Courtauld. Age Concern Essex provides a range of other services, including advice and information, home support, counselling, aid call, holidays and insurance. The advocacy scheme is joint financed for a period of three years from 1997. It is run on a day to day basis by an advocacy service co-ordinator employed by Age Concern Essex. The co-ordinator recruits, trains and supports a team of volunteer advocates. The scheme was initially aimed at older people on hospital wards, but was extended to follow up after discharge in response to need.

Service development by an established advocacy scheme

Established advocacy schemes have sought to broaden or complement their existing work to include advocacy with older people:

Birmingham Citizen Advocacy

Birmingham Citizen Advocacy (BCA) was set up by Birmingham Association for Mental Health (Birmingham MIND) in 1987 as a pilot project to provide advocates for people with mental health problems being resettled from long stay hospitals to the community. Since that time, BCA has been run by an independent management committee comprised of lay people, professionals and representatives of interested groups such as the Community Health Council. It is a Limited Company by Guarantee and a registered charity. The project has largely received its funding from Birmingham City Council and the Health Authority. By the early 1990s the project recognised a need to develop advocacy with older people with mental health problems and dementia in addition to its work with younger adults. A second co-ordinator was employed to develop this work. The project has subsequently established specific advocacy work with Asian older people and people with hearing impairments as well as mental health problems in both hospital and community settings.

Community and peer action by local groups

Local pensioners' forums and community organisations have developed advocacy schemes in a grassroots response to protect the rights and interests of vulnerable older people.

Lewisham Pensioners' Forum, Pensioners Advocacy in Lewisham Scheme (PALS)

The Pensioners Advocacy in Lewisham Scheme (PALS) was founded by members of a well established pensioners' forum at the time of the European Year of Older People in 1993. The scheme is primarily for older people in hospital who have been assessed as needing residential or nursing home care and require the support of an advocate in choosing a home and monitoring their placement, though it has also been involved with residents when homes are closing and with other older people living in the community. The scheme initially secured a small grant from a charitable trust and is now set to sign a service level agreement with the local authority. Advocates are members of the Forum. They are supported by a part time trainer/mentor as well as the co-ordinator of the Forum. The trainer/mentor and the co-ordinator report to the management committee of the Forum. The Forum can connect individual concerns to a collective voice and also take up wider issues raised by the advocacy scheme with the relevant authorities.

These models have a number of potential strengths and opportunities as well as weaknesses and challenges.

Development by statutory sector organisation

Potential strengths and opportunities:

- Recognition of the value of advocacy on the part of the statutory body
- Message to all staff that the rights of older people are important
- Access to the resources and networks of the wider organisation
- Influence policy and decision making of the wider organisation from the 'inside'

Potential weaknesses and challenges:

- Conflicts of interest in maintaining the independence of the advocacy role
- Older people not taking up the service due to association with the service provider .
- Emphasis on consumer satisfaction, complaints and quality assurance rather than human rights
- Funds diverted away from independent, citizen-led advocacy initiatives

Development by voluntary sector organisation

Potential strengths and opportunities:

- Access to complementary services of the organisation eg counselling, welfare rights, advice and information services
- Access to influence through local and national structures and networks
- Public perception of organisation as a 'known quantity' traditionally concerned with the interests of older people
- Sharpens awareness of the responsibilities of organisation towards the rights of older people in all its activities

Potential weaknesses and challenges:

- Potential conflicts of interest between independent advocacy and direct service delivery. This is sometimes less apparent than the case of the statutory sector, but no less acute
- There might be a blurring of the roles of advocacy scheme personnel undertaking other services and activities within the organisation
- As with the statutory sector, older people not taking up the service due to association with service provision
- Also as with statutory service provider, funding might be diverted from bodies seeking to concentrate upon independent advocacy

Service development by established advocacy scheme

Potential strengths and opportunities:

- Maintaining independence from direct service provision
- Economies of scale, experience and expertise
- Intergenerational contact
- Status/acknowledgement/identification of advocacy as a distinctive means of support

Potential weaknesses and challenges:

- The needs of older people being subsumed under work with other groups
- Being overlooked as an obvious source of support for older people, due to identification with other groups
- Being used as a 'catch all' without adequate resources to meet the diversity of older people and the range of groups, settings and situations in which such support might be needed
- Diverting resources from smaller neighbourhood based initiatives

Community and peer action by local groups

Potential Strengths and Opportunities:

- Maintain independence from service providers .
- Symbolises citizens rights and community responses
- Peer approach for and by older people themselves

- Focus on rights and interests of older people alone
- Potential weaknesses and challenges:
- Lack of recognition
- Lack of resources – funding, access etc .
- Lack of intergenerational opportunity/choice
- Chronological age alone might not always accord with empathy, experience or expertise

Generic and specialist approaches

Some advocacy schemes have developed on a generic basis to cover a range of groups, situations and settings:

South Warwickshire Independent Advocacy Alliance
South Warwickshire Independent Advocacy Alliance has a management committee made up of ex-service users, independent individuals and representatives of voluntary organisations. As well as a scheme manager, there are four project workers and volunteer advocates. The alliance is generic in that it provides advocacy for younger adults with physical disabilities, learning disabilities and mental health problems as well as for older people. Advocacy is undertaken in both community and institutional settings, including hospitals.

Age Concern Somerset Advocacy Services
Age Concern Somerset Advocacy Service has a county-wide remit to provide advocacy for all older people across a range of situations and settings. The scheme is managed by Age Concern Somerset and is run by an advocacy services manager who recruits, trains and supports a large team of volunteer advocates. The scheme provides advocacy support for older people in their own homes, in residential care or nursing home care as well as in hospitals, on a variety of issues including health, social care and welfare rights.

Other advocacy schemes have focused or specialised their activities in relation to particular disabilities, specific situations or in other respects, as illustrated by the following examples:

Beth Johnson Foundation Advocacy and Dementia Project
In 1989 the Beth Johnson Foundation established one of the first advocacy schemes for older people in the UK The scheme was intended for 'frail' older people who were receiving or who wished to receive health or social services. Almost a decade later the Foundation determined to sharpen the focus of its advocacy work, launching the advocacy and dementia project. The project aims to develop a working model of advocacy with an emphasis on working with people with dementia and sharing these experiences with the widest possible audience. The project is exploring ways of direct communication and determining the nature and extent of the need for advocacy in order to make a positive impact on the lives of older people and people with dementia. The project is being externally evaluated by the Dementia Services Development Centre at Stirling University.

Age Concern Manchester Older Peoples' Advocacy Service (OPAS) Hospital Discharge Advocacy Scheme
The Older People's Advocacy Service (OPAS) is financed by Manchester Health Authority, run by Age Concern Manchester and based in a hospital in the south of the city. Project development and staff support is led by a steering group made up of older people with representation from Age Concern Manchester, Manchester Social Services, Manchester Health Authority and Manchester Alliance for Community Care. OPAS members were concerned that hospitals were under constant pressure to increase their 'throughputs' and 'unblock' beds, that care management for older people was often compromised and that older people themselves could experience a loss of power and independence during their time on the ward. South Manchester NHS Trust agreed to fund a pilot project in which an independent advocate would specifically support older people at the discharge planning stage.

Generic advocacy schemes such as the South Warwickshire Independent Advocacy Alliance and the Age Concern Somerset Advocacy Service can help to ensure that there is in effect a 'one stop shop' for the rights and representation of citizens in a whole host of circumstances. They might also serve to avoid the replication of service categories through which older people and other groups can fall.

However, there are also benefits in the more focused or specialised approaches adopted by other advocacy schemes in concentrating resources and expertise on the most 'hard to reach' groups and hard to resolve situations. This is exemplified in the work of the Beth Johnson Foundation and Age Concern Manchester Older People's Advocacy Service above. Other examples of such focused work include the MIND in Brighton and Hove Advocacy with people with Dementia Project and the POWhER New Connections Mental Health Advocacy Service in Hertfordshire.

Hospital based and community based advocacy schemes

Advocacy schemes working with older people in hospital may be based in the hospital itself or in the community. Each location has its particular advantages and disadvantages. These considerations are clearly articulated by the contributions of the following advocacy schemes:

Hospital based work – The ASIST Advocacy Scheme, Staffordshire

ASIST is a generic advocacy group working throughout Staffordshire. It runs eight 'one to one' advocacy projects in a variety of settings, half of which are open to any person with a disability whilst the other half are targeted at specific groups. Depending on the service, ASIST provides a mixture of volunteer and professional advocates as well as both long term and short term relationships. Three projects are hospital based – one otters a service to the long term residents of a hospital due for closure; the other two based on acute hospital wards.

A hospital based service otters the immediacy that is afforded by being on-site and thereby gives such schemes a slightly different flavour. This offers advocacy many advantages such as speed of response and the ease of getting to people. It also otters ease by which people can get to the advocate. Being able to address issues quickly, on the spot, can mean that problems can be resolved before they worsen.

However, such constant availability can put extra strains on the hospital based advocacy service. The advocate must be even more aware of not colluding with providers or even giving the impression of doing so. This can be particularly difficult when working with the same staff over a long period of time. Maintaining a professional distance whilst being friendly is all-important. Additionally, the service must ensure that it is not seen as just another part of the 'system'. The independence of the advocacy relationship is at the core of the service.

Community based work – The Link-Age Advocacy Project, Manchester Link-Age

Advocacy Project was founded by North Manchester Pensioners' Association, before becoming an independent organisation in 1995. The project is . managed by a committee of seven older people who employ a full time development worker. The project currently receives joint funding from health and social services. It is based at Crumpsall Methodist Church in Manchester and provides advocacy for anyone over the age of 55 years in any setting.

"We would like to see more people being involved in hospitals but based in the community. The community base allows the advocate to build up local experience and knowledge about services and resources. The relationships made in the community are invaluable when people are discharged from hospital.

We have worked most effectively as a team with hospital personnel, for example, joint working on discharge assessments with the discharge co-ordinator, placements officer, community care manager and the LinkAge advocate. The main obstacle to further development is that we lack personnel. We are community based, therefore relationships with the hospital have to be maintained and built upon – which takes time. A quarter of our referrals came from the hospital; if we had more staff this could be increased dramatically".

Funding issues

Advocacy schemes for older people in hospital are funded in a variety of ways. The main sources of funding are:

- Commissioning and joint financing by health authorities and local authorities

- Grant giving by local and national voluntary organisations, trusts and other charitable bodies

However, advocacy schemes generally face acute problems in obtaining funding which is both adequate and appropriate. This position may reduce the availability and quality of advocacy as well as diminishing the status of advocacy and the rights and representation of older people themselves.

Whilst the roots of some independent advocacy schemes (such as the Beth Johnson Foundation, Birmingham Citizen Advocacy and South Warwickshire Independent Advocacy Alliance) can be traced back over a decade, most have a somewhat limited lifespan. A number of the schemes mentioned in this report exist on a shoestring or face extreme uncertainty about their future funding.

The CONNECT advocacy scheme ran for four years during the mid 1990s, but members of its former management committee agreed to its inclusion here in order to illustrate the problems that independent advocacy schemes can have in securing recognition and resources.

CONNECT advocacy project provided an advocacy service for older people on four long stay wards in a hospital in the London Borough of Hackney. It arose in anticipation of the closure of the hospital and the movement of patients into nursing home care where they might need ongoing advocacy support in their care planning. The scheme was run by a small independent management committee comprised of representatives from the voluntary sector and the Community Health Council with input from the head of nursing services. Funding was short term and tenuous from the outset, including a small grant from the King's Fund for one year, some joint finance slippage, funding from the health authority for six months and a little more from the Community Trust.

The closure of the scheme within four years can be largely attributed to the lack of requirement upon or commitment by the relevant statutory authorities to support independent advocacy, the lack of management continuity and loss of allies with awareness about independent advocacy within the statutory authorities, as well as concerns about budgets within the statutory authorities and similar pressures upon voluntary sector partners. More recently the local Community Services NHS Trust has been funded by the health authority to provide advocacy services for older people in health settings within the borough.

The 'hidden history' of advocacy schemes is largely a consequence of a lack of resources to raise their profile, share information and maintain networks. New schemes have to spend valuable time reinventing wheels, perennially pursuing funds and developing survival strategies rather than flourishing and fighting for the voices of older people to be heard.

When funding is available there can be serious challenges to the independence of advocacy on offer and uncomfortable compromises for the aims and activities of advocacy schemes. For those schemes seeking funding from statutory sector sources, the 'contract culture' and split between commissioning and provision has not dispelled difficulties at a local level. The following questions and comments highlight the issues raised:

- Which advocacy schemes are being funded?

In some areas funding has tended go to large statutory and voluntary sector providers rather than independent advocacy initiatives by local schemes and grassroots groups.

> *'We lost out to established interests. It is hard to inject some independence into proceedings. Commissioners and providers can conveniently fail to recognise the conflicts of interest of keeping advocacy 'in house'.*
> **Advocacy Scheme Management Committee Member**

- What are advocacy schemes being funded to do?

The priorities of commissioners might not be those identified by independent advocacy schemes or expressed by older people themselves.

'In effect, the advocate was being expected to clear out the older people 'blocking beds' rather than ensure that the views of the older person were properly taken into account before being discharged from hospital'.
Advocacy Scheme Steering Group Member

- How are advocacy schemes being monitored and measured by funders?

The commissioning process might not accommodate independent advocacy in the same way as it provides for the provision of direct services.

'Commissioners need to appreciate that commissioning advocacy is not the same as commissioning day care. We also had to argue against 'spot purchasing'. The set targets, the figures, the outcomes are all thrown out.'
Advocacy Scheme Co-ordinator

Some contributors point out that advocacy for older people in hospital or any other setting does not receive any significant funding from central government sources. This position contrasts with other agendas and mechanisms. Victim support schemes, for example, have coordinating staff and independent management committees locally and receive funding from the Home Office nationally.

Similarly, the rights and representation of vulnerable children are recognised and resourced through the independent guardian ad litem system, yet there is no equivalent when the views and interests of a vulnerable older person should be held paramount with regard to determining future care and living arrangements.

There is no guaranteed recipe for success in obtaining funding. However, contributors from some of the advocacy schemes in this report suggest that the following strategies might be fruitful for those seeking to maintain their independence as well as their existence in the current climate:

- Obtain a 'mix' of funding from a variety of sources in the statutory and charity sectors. Examples include advocacy schemes which have received funding from the National Lottery Board and Comic Relief as well as signing up to service level agreements with their local Council and health authority. Some advocacy schemes have pooled the funding from various sources to cover all of their work, others have used specific funding for discrete pieces of work.

- Influence the commissioning process by working with commissioners in devising and drafting more appropriate agreements including the essential principles, aims, organisation, outcomes and measures of the work of the advocacy scheme. This might be undertaken in partnership with other advocacy schemes in your area.

- Be alert to new opportunities for funding, especially in a rapidly changing policy environment in which there have been a number of new health and social care initiatives. Some advocacy schemes are already looking at the potential for some recognition and resourcing from primary care groups and primary care trusts as well as within the implementation of the National Service Framework for Older People.

Staffing arrangements

Some schemes have paid advocates, a few are run on a completely voluntary basis, while others employ co-ordinators who recruit, train and support volunteer advocates. Here we look at some of the positive features as well as the problems of the staffing arrangements of advocacy schemes:

Paid advocacy

Advantages:

- Paid advocates might ensure that work is carried out with 'hard to reach' older people, particularly where there are difficulties with communication
- Paid advocates might be perceived to hold a higher status by professionals, carers and some older people themselves

Disadvantages:

- Paid advocacy might be seen to herald 'over-professionalisation' within a movement more associated with citizen rights and representation.
- Advocacy schemes which only employ advocates might have less capacity and offer less choice to older people than advocacy schemes working with a number and diversity of volunteer advocates.

Volunteer advocacy

Advantages: .

- Volunteer advocates are there because they want to be, not because they are paid to be, and can be strongly loyal. They symbolise a spirit of citizenship and reciprocity rather than a client/expert or user/provider relationship
- Volunteer advocates are greater in number and might offer greater choice and diversity for the older person in need of such support

Disadvantages:

- Volunteer advocates might be seen to lack status in the eyes of some professionals, carers and older people themselves
- Volunteer advocates can be hard to recruit, particularly for older people with whom it is difficult to communicate and in the most distressing situations

Paid co-ordinator/volunteer advocates

Advocacy schemes staffed by paid coordinating staff and volunteers can help to bridge the relative strengths and weaknesses of paid or voluntary advocacy. In practice, many of such schemes also offer volunteer advocates some out of pocket expenses so as not to exclude people on low incomes.

In contributing to this report, advocacy schemes starting from the grassroots emphasised the importance and desirability of having a co-ordinator in post in order to support the volunteers and take the scheme forward.

The Bridlington Advocacy Awareness Project

The Bridlington Advocacy Awareness Project in East Yorkshire is seeking to raise the profile of advocacy and lay the foundations for a new advocacy scheme in the locality:

> *'We are particularly pushing for advocacy for older people in hospital. I get very concerned and sometimes even horrified by what I see is going on. I speak up, but I can't always be on hand for everyone who needs it. We need funding for a co-ordinator who can get in there with a team of advocates.'*
> **Advocacy Steering Group Member**

Significant variations and differences in staffing arrangements are apparent across advocacy schemes of all kinds. One advocacy service is run by a senior manager and employs a large team of fixed term and sessional health advocates, whilst all of the work of another scheme is carried out by a single paid health advocate. The co-ordinator of one scheme supports the work of 130 volunteer advocates, while another supports the work of a dozen. One scheme employs up to four full-time project workers; another can only pay their project worker for two hours per week.

This situation would seem to raise a number of issues relating to:

- The levels of funding and areas of priority given to advocacy with older people
- The capacity of advocacy schemes to recruit, train and support their advocates
- The availability and accessibility of advocacy in different localities – even where a scheme exists
- The quality and intensity of the advocacy relationship with the older person requiring such support
- Which advocacy schemes are being funded?

Training and awareness raising

Many advocacy schemes working with older people in hospital stress the importance of training for advocates:

'Advocates, be they paid or volunteers, must be well trained to cope with the demands they encounter.'
Advocacy co-ordinator

'Training is needed to make sure that advocates understand and are happy with the role. It is part of the selection process, both for the advocate and the scheme – the last thing an older person requiring representation in hospital needs is a bad advocate who creates even more barriers to being heard.'
Older volunteer/peer advocate

There is no nationally recognised qualification, accreditation or training in advocacy for advocates. The training of advocates varies tremendously between schemes. In most areas training is undertaken by advocacy schemes themselves on an 'in house' basis, while in some parts of the country local colleges have devised advocacy courses.

The content of training for advocates varies from a brief orientation to advocacy and the scheme itself, to detailed training programmes which last for a number of weeks.

Common elements of training include:

Values

- advocacy principles
- person-centred approaches
- anti-discriminatory practice

Knowledge

- the nature of advocacy,the advocacy scheme and the advocacy role
- legal, policy and procedural issues
- local services and resources

Skills

- assertiveness
- negotiation
- listening and communication

Some advocacy schemes train advocates on an individual basis, others train advocates as a group. Outside contributors such as medical staff, nurses, social workers and solicitors may also be involved in delivering elements of the training.

Several schemes pointed out that training should be ongoing rather than a one off event. Advocates need to be provided with supervision and support by the scheme. They need opportunities to share and reflect on what they are doing and how they are doing it.

However, advocacy schemes for older people in hospitals are not only occupied with the training of advocates. A potentially major barrier facing advocacy schemes – even those with the most highly trained, competent and committed advocates – is that of the attitudes and knowledge of hospital staff. Given their lack of legal status, advocates remain at the behest of professionals in many instances. Therefore, a number of schemes emphasised the need to work with hospital staff to raise their awareness about why advocacy is needed, what it is and how it relates to their role:

'Advocacy schemes must ensure that everyone understands the role of the advocates – so they (the hospital staff) do not feel either threatened or, conversely, have ideas that the advocate will solve all of their problems'.
Advocacy Scheme Steering Group Member

'Relationships between the hospital staff and the advocacy scheme used to be difficult, requiring much work behind the scenes to prepare the ground. Giving talks to all the staff has made our job a lot easier. Hospitals are still run on a hierarchical system, so the consultants need to be

involved. If you are accepted at the top, the rest will be much easier. We have now become part of the hospital training programme.'
Advocacy Project Manager

Of course, training in itself is only part of the solution towards creating an environment in which advocacy can operate effectively. In the absence of legislation or statutory requirement, another essential element is to ensure that there are strong policies, procedures and protocols in place.

Policies, procedures and protocols

The need for clear policies, procedures and protocols regarding the advocacy role within a hospital setting is highlighted by the following experiences:

'It was extremely difficult to get onto the wards at all when we started. Then, despite repeated visits to talk to staff about what we did, they still didn't refer anything to us. There was also poor communications and a lack of information about older people who did become known to us.'
Advocacy Scheme Co-ordinator

'The scheme has not functioned well when called in at the last minute to supposedly 'advocate' but basically support a decision already made.'
Advocacy Project Worker

'Confusion reigned amongst health and associated professionals over the roles of the hospital discharge co-ordinator and the advocate. Both can be involved appropriately with the same patient at the same time, in their different ways. But, there has been a wrongful assumption that these roles are interchangeable and that the service provided by both is fundamentally to prevent any delay in discharge.'
Advocacy Scheme Steering Group Member

The main areas seen by advocacy schemes themselves to require explicit arrangements and agreements include:

- The referral system of the advocacy scheme
- Access to the ward and to patients who might need advocacy
- Access to patient information
- Access to key assessment, care planning, review, discharge and decision making meetings
- Access to complaints procedures

The position and presence of the advocacy scheme should also be made explicit within relevant multi-agency documents – ideally, with the schemes themselves involved in the preliminary planning and drafting stages. This point is echoed in the recent Department of Health publication, No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse. The guidance includes advocacy services amongst those responsible and relevant agencies needed to form an 'interagency administrative framework'. The report also makes direct reference to the role of advocates:

'In some cases, it will be necessary to appoint an independent advocate to represent the interests of those subject to abuse. In such cases, all agencies should set out how the services of advocates can be accessed, and the role they should take.'
'No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults' Section 6.32 Department of Health March 2000

A number of advocacy schemes also stress the importance of clarifying roles and relationships with other organisations and groups providing support of various kinds for older people in hospital. These vary around the country, but include 'ward friend' schemes, 'patient supporter' services and 'home from hospital' initiatives. Community Health Councils also provide a crucial source of representation for

patients on a statutory basis, but do not have advocates in every locality.

Clarity is needed in terms of core principles and practice. When the aims and activities of the respective bodies are established, then there is a basis for determining the roles and relationships each can play without duplicating effort or diminishing the value of the distinctive contribution they can make to the patient. Such arrangements might include: Patient supporters providing the basis for the development of a new advocacy scheme.

The advocacy scheme working closely with the local Community Health Council in taking up individual complaints and organisational issues

Ward friends referring an older person to an advocacy scheme when a situation requires not only befriending, but a focus on rights and independent representation

Concluding comments

This report has provided a snapshot of the work of advocacy schemes for older people in hospital. It has highlighted the benefits to patients and the lessons learned from existing schemes, with all of their various organisational origins, approaches and arrangements.

Advocacy is necessarily a highly principled activity which can make a positive difference to the lives and circumstances of otherwise vulnerable older people in hospital. Yet advocacy with older people generally lacks the recognition and resourcing it requires in order to flourish. Perhaps as a consequence of this position, it also lacks co-ordination and its own commonly agreed set of standards and quality frameworks.

The Health and Older People (HOPe) Group provide a poignant and powerful message on the importance of advocacy:

'Independent advocacy is essential to promote older people's autonomy, to enable them to access appropriate services and to protect their interests and well-being. Advocacy is needed at home, when people need extra support; in care homes; in hospital; and at any time of crisis or major change. A comprehensive, properly funded, independent network of advocacy organisations is needed which is able to cater for older people in all these circumstances.'

'Our Future Health: Older people's priorities for health and social care' Health and Older People Group (HOPe)/Help the Aged, May 2000

Recommendations

The following recommendations are based upon the contributions that advocacy schemes working with older people in hospital have made towards this report, and also the knowledge and experience of members of the Older People's Advocacy Alliance (OPAAL) UK. These recommendations are primarily intended to improve the scope and quality of advocacy for older people in hospital, but necessarily reflect a wider gaze:

1. Government should introduce legislation for the right to independent advocacy and legal status for advocates

2. Government should promote the role of independent advocacy with older people in hospitals and other health settings within the introduction and implementation of the National Service Framework for Older People

3. Government should support the work of a national development body for advocacy with older people, comprised of advocacy schemes, older people's organisations and other relevant representative and professional groups

4. Commissioners, providers, Community Health Councils, advocacy schemes, older people's organisations and other relevant groups should work in partnership to devise a strategic approach to the development of advocacy for older people in hospitals and other settings within their locality

5. Commissioners should be required to support the development of independent advocacy schemes for older people in hospital at a local level

6. Providers should be required to work in cooperation with advocacy schemes in establishing policies, protocols and procedures for advocacy to work effectively with older people in hospital at a local level

7. Advocacy schemes and older people's organisations should lead on the development of nationally recognised quality standards and evaluation tools for advocacy for older people in hospital

8. Advocacy schemes and older people's organisations should lead on the development of nationally recognised training for advocates for older people in hospital

9. Advocacy schemes working with older people and older people's organisations should develop networks with bodies concerned with the rights and representation of other groups, including younger disabled people and black and minority ethnic communities

10. Further research should be undertaken into the scale, status and scope of advocacy throughout the UK, not only to develop our understanding of advocacy at a conceptual level, but to improve the efficacy of advocacy and contribute to specific practice issues such as capacity, consent and communication

Useful contacts and resources

The Older People's Advocacy Alliance (OPAAL) UK
c/o Parkfield House
Princes Road
Hartshill
STOKE ON TRENT
ST47JL
Tel: 01782 844036

OPAAL is an alliance of advocacy schemes, older people's organisations and community groups which aims to promote and develop high quality independent advocacy with older people throughout the UK. OPAAL can put you in touch with all of the advocacy schemes for older people in hospital included in this report – along with a range of other advocacy schemes and related organisations, older people's forums and organisations, voluntary agencies and community groups and professional associations with an interest in advocacy. OPAAL also produces a regular newsletter of its activities and related issues.

Help the Aged
207-221 Pentonville Road
LONDON
N1 9UZ
Tel: 020 7278 1114
SeniorLine: 0808 800 6565
Help the Aged provides practical support to help older people live independent lives, particularly those who are frail, isolated or poor. The Charity provides services for older people in the UK and campaigns on their behalf. It also supports – through both grants and expertise – other organisations which help older people.

The Dignity on the Ward Campaign aims to improve the quality of care that older people receive in hospital, and to combat ageism in the NHS.

For more information on the Dignity on the Ward Campaign or any other part of the Charity's work, please write to us at the address above.

Age Concern England
Astral House
1268 London Road
LONDON
SW16 4ER
Tel: 020 8679 8000

Facilitates an established network of coordinators working in Age Concern and other advocacy schemes. Has developed a range of advocacy resources.

Beth Johnson Foundation
Parkfield House
Princes Road
Hartshill
STOKE ON TRENT
ST4 7JL
Tel: 01782 844036

Charitable Trust for research and development of innovative projects aimed at improving the quality of life of older people. Publications include advocacy with older people.

Better Government for Older People
207-221 Pentonville Road
LONDON
N1 9UZ
Tel: 020 7843 1582

A Cabinet Office led national action research programme aimed at improving public services for older people. Engagement and advocacy are key themes of its work. There is a national network and an Older People's Advisory Group, including a sub groups on interest health and social care, active ageing and consultation and involvement.

Centre for Policy on Ageing
19-23 Ironmonger Row
LONDON
EC1 V 3QP
Tel: 020 7253 1787
Independent policy research institute, library and information service and publishing house on ageing and old age. Long track record of research on advocacy with older people. Various publications include advocacy with older people.

Dementia Services Development Centres are now established at several Universities, including Bradford, Bristol and Stirling.

Joseph Rowntree Foundation
The Homestead
40 Water End
YORK
YO30 6WP
Tel: 01904 629241

Independent charitable organisation which carries out and funds programmes of research and innovative development projects in health and social care related fields. Recent work has included advocacy, advice and information as well as the involvement of older people.

The King's Fund
11-13 Cavendish Square
LONDON
W1M OAN
Tel: 020 7307 2400

Independent charitable organisation which carries out research and development work into health and social care policy and practice as well as grant-giving to individuals and organisations.

National Pensioners' Convention
19 – 23 Ironmonger Row
LONDON
EC1V 3QP
Tel: 020 7553 6510

Umbrella organisation of the UK pensioners' movement. Campaigning and lobbying body with regular newsletter, pamphlets and briefings on pensions, rights and the quality of life issues. Also the office of the National Senior Citizens' Forum Network.

Relatives and Residents Association
5 Tavistock Place
LONDON
WC1H 9SN
Tel: 020 7916 6055

The Relatives and Residents Association is a national charity working in the interests of residents in Residential Care, Nursing Homes and Long Stay Hospitals and their relatives and friends. An information and advice service is available on 020 7916 6055.

Notes

Notes

A stay in hospital can be upsetting and distressing at the best of times. While many people have the support of family, friends or carers throughout their stay in hospital, a significant number of people have nobody to offer them support. They may be on their own, or loved ones may be a long way away. For these people in particular, and for older people in general, the benefits of advocacy in hospital can be far reaching.

There are a wide variety of different schemes up and down the country offering 'advocacy' to older people in hospital. Many of these schemes are very small.

As an important part of the Dignity on the Ward campaign, Help the Aged was delighted to commission this report from the Older People's Advocacy Alliance to explore some of the issues and challenges facing advocacy schemes. We hope that this report will serve as a valuable resource to advocates, NHS managers and older people's groups across the country.

Help the Aged

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