

Independent advocacy with older people

A national conference hosted by the Older People's Advocacy Alliance (OPAAL) UK 25 July 2002

FOREWORD

Andrew Dunning, Chair, OPAAL

ndependent advocacy is needed so that older people can secure and exercise their rights and choices; ensure that their voices are heard when decisions are made concerning their care and quality of life; and to combat age discrimination and abuse.

This report captures the highlights and headlines of the Older People's Advocacy Alliance (OPAAL) UK conference on Independent advocacy with older people, held in London in July 2002. The event was convened at a time of unprecedented change in government policy, service provision, older people's participation and the advocacy movement.

Over 100 delegates discussed top-down and bottom-up developments, stimulated by a wide-ranging set of presentations and workshops led by government officials, academics and activists from the advocacy and pensioners' movements.

The key themes to emerge from this eclectic and essential mix of contributions were:

- Advocacy must remain independent and free from conflicts of interest in order to represent fully the rights and interests of older people.
- Older people must have access to advocacy as of right, particularly in the fields of health and social care.

- Older people must be involved in the management and running of advocacy schemes as well as using such representation and support when needed.
- Advocacy schemes must further develop their roles and expertise in working with older people with dementia and in the field of abuse and adult protection.
- Politicians, policy-makers and professionals must work in partnership with advocacy groups and older people to develop quality frameworks and standards.
- OPAAL must play a more strategic role in the promotion and development of independent advocacy with older people in the UK.

Founded in 1999, OPAAL is a unique alliance of advocacy schemes with organisations of and organisations for older people at national and local level. OPAAL is a registered charity whose objects are the promotion and development of independent advocacy with older people across the UK. Towards this end OPAAL has 'advocated for advocacy' with politicians, policymakers and professionals; produced a range of publications and training materials; contributed to a variety of conferences and advisory bodies; and provided services to its membership.

OPAAL is grateful to Help the Aged for its practical support in making this conference such a success. In particular Help the Aged provided help with the organisation of the event and bursaries for older people who might otherwise have been unable to attend. The nature of this assistance has been exemplary – collaboration without colonisation. Now there's another key message.

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Why independent advocacy with older people is so important

(presentation)

Helen Grew, Vice-President of the National Pensioners' Convention (NPC), told the conference that the pensioner movement and the advocacy movement must work together in an organised way: 'Pensioners certainly have the experience and OPAAL has the expertise. Together that would be a wonderful combination.'

Many older people are living alone, isolated and marginalised. The well-being of some older people in such circumstances may well rely on an advocate because it can be difficult for them to access the advice, information and services they need.

As the policies of the present government concentrate more and more on self-sufficiency in older age, advocacy will be needed in a variety of areas as well as health and social care. Welfare benefits, for example, are targeted and increasingly complicated to claim. Instead of having a decent basic state pension you have to jump through more and more hoops to apply for benefits. Inevitably some people drop through the net because of an inability to claim what is rightfully theirs.

Helen said one of the most important things about an effective advocacy service was that it should be independent. One-to-one relationships were important, as was loyalty. The service is not a job — it's a relationship between the person and the advocate. In some cases, ideally, it should be long-term.

Peer involvement, bringing shared attitudes and experience, could be helpful. Older people who might have advocated in different ways in the past might be more acceptable to their peers. Yet younger people would bring a fresh perspective. The main thing is, of course, to be a good advocate.

Helen said the voice of the older person should be heard loud and clear in informing the development and delivery of independent advocacy services.

Advocacy and the pensioners' movement

(workshops)

These workshops, led by Helen Grew and Alison Purshouse of the National Pensioners' Convention, examined the relationship between independent advocacy services and older people's groups and how this might be developed. Participants agreed that a great deal more work is still to be done to flesh out the nature and characteristics of the relationship between advocacy and the older people's movement.

The following themes emerged during the workshops:

Independence and the advocate In discussions of potential problems with relatives, there was great clarity within the group that an advocate is for an individual and must not succumb to pressures from relatives or contact them unless the individual expressly requests this. Abuse was identified as an extremely sensitive area in this regard.

Lack of information means it is difficult for older people to find out about advocacy and advocacy schemes in their area. It was also agreed that there needs to be a wider awareness of advocacy among service providers.

Gaps in provision Participants felt that many advocacy projects and pensioners' groups did not have the resources or skills to deal with people suffering from dementia. The work currently being undertaken by Dementia North and presented at this conference seems crucial in this respect, as do the opportunities to influence the development of the patient and public involvement agenda within the NHS reforms.

Fragmentation within the older people's movement and advocacy movement reduces their political influence as well as making it difficult for older people to identify suitable help. OPAAL and the NPC have helped to change this by forging alliances between these movements.

Exerting influence It was agreed that local older people's forums should:

- find ways of feeding their knowledge of the need for advocacy services back to politicians, policy-makers and professionals;
- contribute to ensuring that the problems of, for example, systems failure, which advocacy schemes reveal, are used in campaigning for improvements; and
- explore ways of establishing advocacy projects locally.

Role for the pensioners' movement? One of the great benefits of pensioner organisations becoming more involved in advocacy is that they are able to speak with considerable authority about the problems older people face and the shortcomings of the services they receive. The view was expressed that the NPC should perhaps play a significant role in collating information from advocacy services, which could then be used to influence policy-making by government.

The need for person-centred care

(presentation)

Professor Ian Philp, National Director of Older People's Services at the Department of Health, described his role as an 'advocate' for older people at a policy level in relation to their health and social care.

He said: 'The problem is that often service providers don't start from the viewpoint of older people or their carers when they plan care.'

Person-centred care is about someone being in the mind of the person using the service and acting from their point of view. It is about ensuring that everything that is done is based on the needs, the circumstances and the priorities of the older person and their family in the way care is planned.

Although there is no right to independent advocacy, eight current instruments could help:

- the Independent Complaints Advisory Service (ICAS);
- the duty for NHS organisations to involve patients and the public in planning services;
- the new inspectorate bodies in health care and social care, which have a duty to take into account the views of users of services:
- the new Patients' Advice Liaison Service (PALS);
- the Patients' Forums;
- local government scrutiny committees, best value reviews, and the Better Government for Older People networks;

- a new commission for patient and public involvement;
- the National Service Framework (NSF) for older people's services, which has at its heart patient-centred care.

He commented on the concern that quite often care providers go over the head of the older person to their family. 'However', he added 'many older people we consulted were firm in their view that their families must be involved in the decision-making process.'

The balance in the NSF is toward routinely involving family carers in decision-making about the older person's needs.

A recent literature review had shown that developments in three fields would make a big difference in the shift toward person-centred care:

- the provision of information to older people and their carers;
- the skills and competencies of staff; and
- centres of excellence to generate and disseminate good practice.

Standard 2 of the NSF requires that information be provided to older people and their carers; also, that older people should be involved in decision-making about their care; guided to available advocacy services, and involved in service planning and planning feedback.

However, the NSF is time-limited, with two years and eight months left to run from the date of the conference, so others will also have to progress these aims.

Ian Philp concluded: 'Your job in OPAAL is to continue to push the agenda nationally and locally so that services respond to what older people and their families say they really want, not just what service providers say they need.'

Advocacy, the new National Health Service and older people

(workshops)

Jonathan Ellis, Health Policy Officer at Help the Aged, presented an overview of the revised structure of decision-making in the National Health Service, following the NHS Reform and Health Care Professions Act 2002. He warned that the system was more complex, and that the relationships between the new structures had not yet been finalised, especially in relation to patient and public involvement systems.

Jonathan focused on the bodies within the new structure which will have particular importance for providing or commissioning advocacy — the line on the left-hand side of the diagram.

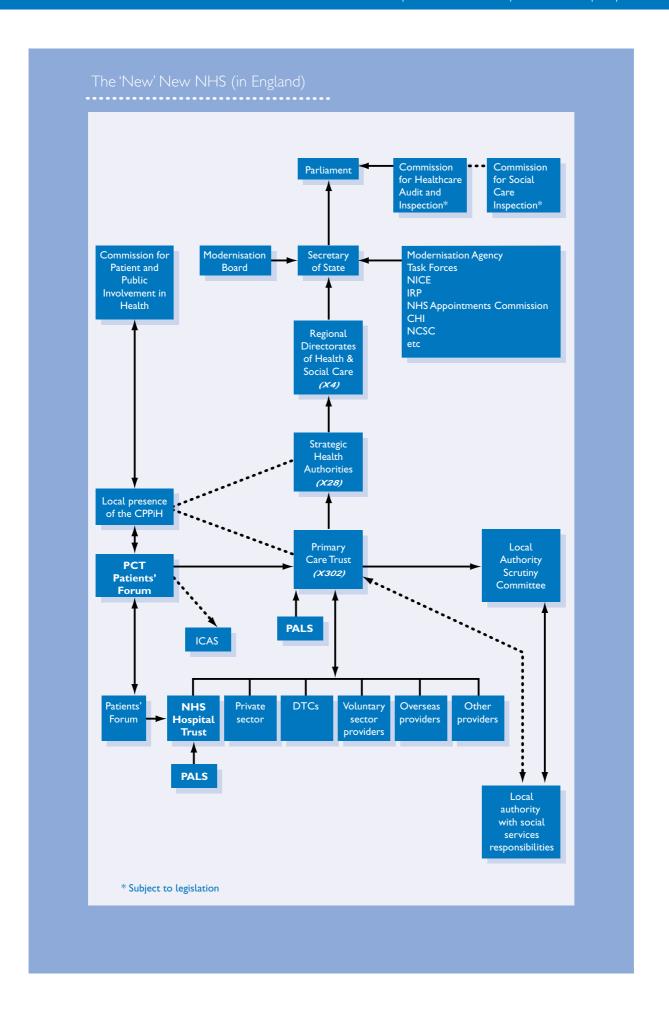
- 1 The Commission for Patient and Public Involvement in Health will from January 2003 be responsible for setting standards for Patients' Forums and providers of Independent Complaints Advocacy Services (ICAS). It will monitor and report on those services and have general responsibility for promoting patient and public involvement in the NHS.
- 2 All Health Trusts will have Patients' Forums, which will replace Community Health Councils. The most influential Forums will be those within the Primary Care Trusts (PCTs), because about 75 per cent of NHS spending will be made via the PCTs. They will commission local acute hospital services as well as primary care. The Forums will have the power to inspect all premises in which services paid for by the Trust are being performed, and this will include premises abroad if the Trust is paying for patients to be treated there.

- 3 The NHS now has a duty to ensure there are Independent Complaints Advocacy Services to support people making a complaint through the NHS complaints procedure, and this will be monitored by Patients' Forums. ICAS will not provide general or specialist advocacy. In most Trusts there will also be a Patients' Advice Liaison Service (PALS), with which Patients' Forums will also link. It will be important that PCTs do not equate these bodies with independent advocacy.
- 4 The next few months will be a formative time. At national level a Transitional Advisory Board (TAB) is advising the Department of Health on aspects of the implementation. It is keen to hear from people with advice to offer on topics such as how to ensure maximum broadbased involvement in Patients' Forums. The transitional board is also doing a lot of thinking about ICAS, and the difference between complaints, advocacy and other forms of representation.

The importance of Patients' Forums

Patients' Forums are expected to commence in early 2003, but although some areas are already setting up shadow Patients' Forums the Department of Health has not yet finalised its guidelines.

As Patients' Forums will have considerable power, their membership is crucial. There is no provision for elections, even though it is intended that the Forums should be responsive to local people. They will be appointed by the independent NHS Appointments Commission on the basis of guidelines which are yet to be determined. Each Forum will probably have about 15 members.



It is intended that members should represent a broad range of views, including those from normally excluded, hard-to-reach sectors and that members will serve for only two years so that the user perspective is regularly renewed.

Those appointed will be expected to act as conduits, making links with local community groups and voluntary organisations and finding ways to reach those who are not involved in any organisations. Such a role is time-consuming and requires back-up resources, so the TAB is thinking through these points in order to ensure that the best possible outcome is achieved. Suggestions are welcome.

These new practices are intended to continue evolving after implementation, but now is a particularly important time to feed in ideas nationally and to be making links locally.

There are problems with start-up funding not allowing long enough to develop a project, although delegates felt projects attached to a pensioners' group might have more success in obtaining funding for continued projects.

With the launch of PALS and ICAS there will be more funding for facilitators and co-ordinators of projects but delegates said there was never enough money to deal with the caseloads. Some projects reported great difficulty finding volunteers. This might be something on which OPAAL could circulate best practice guidance.

Some projects have obtained help with training by tapping into the training programmes of larger organisations: for example, one received help from a local not-for-profit residential and nursing care provider in training its advocates on dementia.

Further points from the discussion

- Some concern was expressed that, whatever the initial intentions, top-down appointments will tend towards appointments which do not seriously challenge.
- A plea was made for local authority and NHS complaints procedures to be made more alike. Issues can easily cross these overlapping sectors but service users who need to complain can find themselves falling between two stools or having to cope with two very different approaches.
- The importance of local advocacy projects making themselves known to PCTs was stressed and, if a project wishes to tender, it is essential to know what commissioning is taking place.
 One delegate described finding out at the last minute that the PCT was commissioning for its ICAS (a small number of pilot ICAS schemes are being established at the moment). Her project responded immediately, becoming the only local organisation apart from the CAB to do so.

Dementia care based on listening to people's needs

(presentation)

The Dementia Advocacy
Development Project is working
to identify specialist dementia
advocacy services in the UK,
review current practice, document
the experiences of advocacy
services, and produce and
disseminate good practice.

Caroline Cantley, Professor of Dementia Care at Northumbria University and Director of Dementia North, outlined some of the preliminary findings of the research and the key issues it identified.

Dementia care has been changing enormously, partly due to the increase in the numbers of people with dementia and partly to medical advances, including the arrival of new anti-dementia drugs which act as an incentive to early diagnosis. Until recently those with dementia were largely considered in a medical context. We need a new culture of dementia care based on a better understanding of people's needs.

Older people with dementia have a lot to say and we need to pay more attention to this.

The project recognises that people with dementia often have difficulty communicating their views and needs and in the past there was an assumption that they would be represented by family members.

'We realised we weren't hearing much about the effectiveness of dementia advocacy,' said Caroline.'There was a need to look at the different types of advocacy services being offered and to identify the key issues for service practice.' The project has four main components: service mapping, a national survey, case studies and spreading good practice.

A detailed survey of 35 organisations looked at the way they were funded, their management responsibilities and involvement and the types of advocacy offered. The vast majority of projects were in the voluntary sector, with a significant proportion of management committees involving carers and excarers. Most funding came from local and health authorities. The most frequent type of service was paid advocacy.

The next stage in the project is a series of case studies, chosen to reflect a range of advocacy services based in both rural and urban areas. These will be used to identify how many people are using services, which models are most useful, the different approaches used by advocates, and diverse attitudes to training and evaluation.

The final piece of work will be to develop and publish a good practice guide.

Advocacy and dementia

(workshop)

The workshop was led by Kay Steven, Research and Development Officer for the Dementia Advocacy Development Project.

Supporting people in finding their voice is widely recognised as an important aspect of dementia care. Advocacy services can help people with dementia to have their say about a wide range of matters affecting their lives, but service providers and commissioners are often unclear about how they should address the particular challenges encountered in advocacy work with people with dementia. Specialist dementia advocacy has developed unevenly across the country, often through locally based voluntary sector initiatives. Innovative practices have generally not been well documented and, as a result, lessons from their experiences have not been identified or widely disseminated.

Kay Steven invited workshop participants to contribute to the research project by testing out some of the emerging themes. These centre on:

- defining dementia advocacy;
- competence to consent;
- skills of the dementia advocate;
- ensuring equality of access;
- relationships with other agencies.

The workshop participants, through case studies and discussion, explored several key questions:

 They defined advocacy as 'speaking on behalf of someone', 'giving someone a voice', 'promoting independence', and 'enabling and empowering individuals to achieve the outcomes they desire'.

- The workshop recognised that advocates seeking to support people with dementia are often invited to participate at times of crisis or when people are facing difficult decisions regarding their future care. Advocates face a range of challenges: they need to spend time building up trust with the person with dementia and discussing the individual's wishes and potential options, ensure that that person wants an advocate, consider health and safety issues and maintain advocacy boundaries.
- Advocates need good communication skills, including an ability to negotiate and liaise with other professionals and knowledge of local services. They need to develop a flexible approach, be sensitive to the individual needs of the person with dementia and aware of cultural issues.
- Workshop participants felt it was important for the advocate to establish a consistent view regarding the wishes of the person with dementia. They suggested that advocates vary the time and length of visits; where appropriate, encourage service providers to avoid an 'all or nothing' approach; and be open to the individual taking decisions that involve some risk.

The workshop provided the research team with valuable insights, which will inform the dementia advocacy project. Further information about the work can be obtained from Kay Steven on 0191 215 6110 or kay.steven@unn.ac.uk

Advocacy – there to make a difference

(presentation)

'As advocates we can make a significant contribution – and a real difference,' said Glyn Jones, Vice Chair of the Practitioners' Alliance Against the Abuse of Vulnerable Adults (PAVA).

PAVA treats as a vulnerable adult a person over 18 'who is or may be in need of community care services by reason of mental or other disability, age or illness and who may be unable to protect him or herself against significant harm or exploitation'.

Problems relating to abuse

Glyn Jones highlighted some important points:

- abuse can be extremely difficult to recognise and often remains well hidden;
- it can take years to identify or prove that abuse has taken place;
- the victim may deny that abuse is happening to protect the abuser;
- many victims choose to stay in the abusive situation.

The Department of Health's 'No Secrets' initiative has been the main driver to ensure the safety of vulnerable adults. The Care Standards Act 2000 has imposed a duty on residential homeowners to report staff they take action against in cases of abuse and introduced a Protection of Vulnerable Adults list, against which staff can be checked.

Key roles for advocates in countering abuse

These include:

- establishing a relationship of trust with the abused person;
- acting as a sounding board;
- exploring issues of self-esteem, confidence, ability to make choices;
- assisting in communication;
- recognising the person's capacity to make informed choices;
- facilitating access to information about options.

How best to support an abused person

Effective advocacy in protecting vulnerable adults starts with statutory agencies recognising its value and engaging with advocacy groups. To support the abused person in dealing with professional agencies, advocates need:

- to be from an independent service;
- to respect confidentiality;
- to ensure professionals are appraised;
- to discuss the level of risk;
- to offer assistance at interviews.

There must be recognition that advocacy offers no quick fixes. We all have to ensure that advocates have the necessary skills, and understand the timescales involved. It is important that multi-agency management committees include advocate representatives and that advocacy is included in training programmes. The necessity of adequate funding must be recognised.

Advocacy, abuse and adult protection

(workshops)

These workshops, also led by Glyn Jones, stressed the obligation on professional bodies to promote and support advocacy and to avoid misusing advocates or misrepresenting their role.

A key theme was that the bulk of abuse remains hidden. One reason is that some victims choose to stay in their situation because they fear damaging family relationships. This could pose a considerable dilemma to advocates, although sometimes their mere presence could change the dynamics of an abusive relationship. Many older people said that simply having someone listen and believe them gave them immense support.

Problems facing older people

These include:

- professional failure to review medication, both in psychiatry and primary care;
- lack of resources to facilitate professional reviews;
- concentration of resources on the investigation of abuse, and neglect of its identification, prevention, or deterrence;
- difficulties of confidence, or of trust, in coming forward to report abuse;
- culture of secrecy in families, where a disclosure of abuse would be regarded as an act of bad faith;
- the power, and capacity for intimidation, available to abusers;
- acquisitive, or ambiguous, positions taken up by family members with regard to the inheritance of property;

- being given little credibility, especially when experiencing dementia;
- being judged competent to take informed decisions only when the outcome matches the expectations of others, professionals or relatives (for example, being considered competent to confer powers of attorney but not to express wishes and preferences).

Problems facing advocates

These include:

- confidentiality what to do when faced with a disclosure of abuse 'in confidence';
- difficulty for small organisations in sustaining adequate supervision procedures;
- difficulty of developing partnerships to encourage and sustain active mutual support among vulnerable advocacy service-users;
- the pressure to provide crisis advocacy, through short-term, case-led commissioning, and to provide services (like the 'appropriate adult' in child protection)
- being co-opted largely to legitimate a case-conference;
- becoming over-stretched in complex situations, where representative work and robust 'case management' were required simultaneously;
- seemingly deliberate misrepresentation: 'let's get the advocate in to make the final decision' at a divided case-conference;
- conflicts of interest within close working relationships when required to present complaints against individual members of staff.

Opportunities to raise standards and improve practice

- The potential for advocacy services to provide a continuous involvement (including regular visiting) with a ward or residential home.
- The scope for networking in complex case management so that advocates work as part of an alliance of independent services.
- Potential for older advocates and service-users of advocacy to develop a climate of greater confidence among their peers.

A review of information advice and advocacy services

(workshop only)

Andrew Dunning, chair of OPAAL, and deputy director of the Beth Johnson Foundation, is undertaking a review, commissioned by the Joseph Rowntree Foundation, of information, advocacy and advice for older people. The work will be finalised later in 2002.

The project aims to clarify:

- understanding of 'information', 'advice' and 'advocacy' and explore ways in which they overlap in practice, as well as the differences between them;
- what is known about older people's perspectives and how they define good services, with a view to developing guidelines to inform developments;
- good practice, and to examine different models of emerging thinking.

It is clear that clarity is needed about the way the terms 'advice', 'information' and 'advocacy' are used in order that older people know exactly what to ask for. However, it is also emerging that the process of getting information, advice and advocacy is not a linear one, for in practice older people see it more as a circular, inter-connected means of obtaining support. Older people view these services as key components of involvement, empowerment and inclusion in citizenship.

Points from the discussion

- Concern was raised about accessing hard-to-reach groups, especially older people in residential care and nursing homes, and individual older people who are not in contact with any support services.
- There were many examples of good practice and participants agreed that OPAAL should be a mechanism through which good practice could inform policy and be shared between organisations.
- The importance of advocacy being independent was raised, and the need to address areas of potential conflict if an organisation provides services as well as advocacy.
- So was the importance of confidentiality and the pressure some projects face when funders see them as a mechanism for consultation.
- The contract culture has pushed advocacy relationships into services.
 The Community Legal Services' Quality Marks are needed by advocacy services and yet advocacy does not fit easily.
 Delegates suggested that Community Legal Services should rethink their boundaries.
- Discussion took place on how recent government policy could have an adverse effect on older people by taking away their rights as citizens.
 An example was given of the crosscharging being brought in, in April 2003, when fines will be introduced for authorities and trusts who are seen to be responsible for delaying the discharge of a patient.
- As the need for more advocacy services increases, so does the urgency of the need to share good practice, clarify roles, responsibilities and accountability and ensure that advocacy services are independent.

- The group heard from PostWatch about its published report on post office reform and the proposals to develop post offices into providers of information about local services.
- Concerns were raised about the eventual closure of CHCs and the need for OPAAL to continue lobbying the Government to ensure the development of independent advocacy through the 'new' NHS.

Advocacy, accreditation and standards

(workshop)

This workshop, facilitated by Rick Henderson, Director of Advocacy Across London (AAL), discussed current initiatives on standards and accreditation for advocacy with older people and the role of advocacy organisations working with older people to inform policy, quality frameworks and practice.

AAL provides support and resources to advocacy schemes in all London boroughs. A range of local and national standards initiatives is being introduced, and new independent advocacy evaluation and quality assurance systems, such as CAPE (Citizen Advocacy Programme Evaluation), ANNETTE (Advocacy Newcastle Evaluation Tool) and the CAIT (Citizen Advocacy Information and Training) pack.

A number of networks are being set up at national and local level, with support from agencies such as CAIT, AAL and Advocacy 2000.

To make any progress on standards what will be needed are:

- more schemes
- better funding
- higher standards
- increased recognition
- greater public awareness
- increased user satisfaction
- better co-ordination.

The workshop discussed what was next for advocacy and concluded that there is no room for complacency. Effective action will need to focus on:

- the threats to advocacy principles and the danger of advocacy becoming 'just another brick in the wall';
- contrasting issues about what users want, what advocates want, and the agendas of other people in service and policy systems.

Independent advocacy with older people

OPAAL CHAIR'S ANNUAL REPORT

OPAAL held its AGM in association with the conference. This report is from OPAAL's chair, Andrew Dunning.

elcome to the third AGM of OPAAL. This year has seen OPAAL respond to a number of challenges and opportunities and the management committee has endeavoured to advance OPAAL and independent advocacy with older people with some notable success.

Organisation

This year OPAAL achieved registered charity status. We are working hard to ensure that the organisation is robust enough to meet the demands of the Charity Commission as well as the needs of our members as we develop and grow.

We have prepared to make applications to secure significant funding. We are anticipating the opening of the Community Fund Strategic Grants in September. We are also pursuing Section 64 funding as we feel that OPAAL's work is indeed vital, innovative, inclusive and of national significance.

The management committee has put in place sub-committee structures to devise and implement our work plan efficiently and effectively. The business subcommittee, chaired by John Miles, has focused on the effective working of the organisation, including management of finances; staffing systems; fundraising and publicity; and services to member organisations and their users. The development sub-committee has been chaired by Teresa Lefort and is intended to hold a more issue-based agenda focusing on the promotion of independent advocacy with older people, including the review and progress of our statement of intent; the principles of independent advocacy; training requirements for independent advocacy; and quality standards and evaluation.

I would like to extend my thanks to all those members of the management committee who have worked unstintingly to achieve the objects of OPAAL. Particular thanks are due to Chris Bratchie, a founder member of OPAAL, who is standing down at this AGM. Her grass-roots grasp of the issues and inspired commonsense will be missed. We will also greatly miss Mary Duncan, another founder member of OPAAL and advocacy angel with attitude in the North, who has had to stand down as Treasurer. The pressures of work in local projects are indeed mirrored in their participation in developing a national organisation. However, I am sure that those nominated to the management committee this year will provide us with a boost in what promises to be a bumper year in our growth.

Member services

This year, in responding to the feedback of our members, we have been able to produce the OPAAL newsletter more regularly and in an improved format. We hope that in the coming year more members will submit articles, comments and other material to their newsletter.

In the spring 2002 edition of the newsletter we sadly announced the tragic death of our website consultant David Arndt. As David was a sole trader, we had to undergo the process of 'reclaiming' our domain name and site, which is still accessible at www.opaal.org.uk.

I am pleased to say that we recently received a very generous offer to complete the work David started and to provide ongoing support. We hope that members will see the results of this very soon. In the meantime, we welcome your comments and suggestions on what you would like to see and do with the site.

Promoting the development of independent advocacy with older people

Alongside our AGM last year we held workshops on PALS and standards. This year we have put a great deal of effort into trying to influence developments in both. We were pleased to see the government recasting PALS, but we now need to rise to the potential opportunities and challenges presented by ICAS. Indeed, this coming year will require those of us who have been around independent advocacy with older people for a while to be even more vigilant and vociferous in promoting its principles and practice. Advocacy is clearly on the agenda, but as Richard Holloway suggested some time ago, power co-opts and absolute power co-opts absolutely. As advocacy becomes more mainstream we need to ensure that 'true' advocacy is not airbrushed out or relegated to the margins.

OPAAL has been represented at several national advocacy support organisations, including CAIT, UKAN, NAN and AAL, to share information and establish common concerns at a time of unprecedented change in the field. We have also supported the call for the right to independent advocacy for people with physical and sensory disabilities in line with people with mental health problems and learning disabilities. Older people of course cut across all of these groups, but in an area in which labels seem to matter, they remain largely invisible in the policy debates, legal requirements and practice guidance.

Some members of OPAAL, advocacy schemes and older people's organisations have provided an invaluable sounding board for a review of information, advice and advocacy that I was commissioned to undertake by the Joseph Rowntree Foundation. This report will help to inform the Joseph Rowntree Foundation Older People's Programme research agenda and support for practical projects. A review of the literature and subsequent meetings with key informants across the country has confirmed the need for clarity, conviction and quality in the development and delivery of advocacy. It is essential to supporting independence and involvement.

The OPAAL management committee has contributed to the realisation of the timely and much anticipated Independent Advocacy with Older People conference that is being held alongside this year's AGM. The event filled up shortly after it was announced and we have attracted an excellent line-up of speakers in support of our work. We are grateful to Help the Aged for providing us with support 'in kind' from its events team and bursaries to enable the participation of older people with an interest in advocacy who might not otherwise have been able to afford the costs of attendance. I would also like to thank the Beth Johnson Foundation for similarly providing in kind' support from Ellen Goodwin and myself. I hope that we can continue to develop such positive alliances with other organisations prepared to play a principled and productive part in the development of independent advocacy with older people.

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Independent advocacy with older people

ATTENDANCE

- Carl Alexandra Older People's Representative Healthy Living Network
- Jennifer Amner Consultant
 ASSET (Advice on Social Care,
 Support, Education and Training)
- Helen April Volunteer Advocate WASSR
- Lesley Archibald Advocate
 West Dorset Mental Health Forum
- Naureen Ashraf Age Concern Slough Advocacy
- Kevin Barlow *Director*Liverpool Citizen Advocacy
- Trevor Barnett Hospital Advocacy Project Worker Age Concern Slough Advocacy
- Gabriel Barry *Trustee*Westminster Advocacy Service
 for Senior Residents
- Paula Baxter Advocacy Worker Independent Advocacy (North Tyneside)
- Nikki Bell Advocacy Development Officer Age Concern
- Chris Bray Help the Aged
- Shane Brennan Deputy Chief Executive
 Age Concern Kingston Upon Thames
- Bonnie Brimstone *Conference Organiser* Help the Aged
- Tony Brindle Advocacy Manager Older Citizens' Advocacy York
- Pauline Buchanan Administrator Older Citizens' Advocacy York

- Alan Burnett *Policy Officer* Help the Aged
- Caroline Cantley Advocacy and Dementia National Research Project Dementia North, University of Northumbria
- Ronald Carter Committee Member Older Citizens' Advocacy York
- Beryl Clark Service User Manchester Older People's Network
- Helen Clarke *Director* Kingston Advocacy Group
- Easbail Clements Advocacy Co-ordinator Lewisham Independent Pensioner's Advocacy
- Lorraine Colnaghi Assistant Co-ordinator Advocacy Service Continuing Care Advocacy Service for Older People
- Aileen Costar Advocacy Worker Age Concern Oxfordshire
- Saskia Daggett Conference Administrator Help the Aged
- Alys Daines *Co-ordinator* Healthy Living Network
- Barbara Dearing Advisor for Long Term Care Age Concern Leicestershire and Rutland
- Mary Dervish Advocacy Manager Age Concern Harrow
- Pushpa Devi Bij Older People's Representative Healthy Living Network
- Mary Duncan *Project Manager* Manchester Alliance for Community Care
- Andrew Dunning *Chair* OPAAL

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- Shirley Fagan
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- Malcolm Felberg *CCHC Member*Croydon Community Health Council
- Terry Fisher Committee Member and Supervisor of Advocate Project Pensioners Rights Group, East Riding
- Amanda Fitch Advocacy Co-ordinator North Essex Advocacy Teams
- Elaine Fletcher Advocacy Development Worker Elders'Voice
- Bill Fowler Area Manager, Older People's Services Citizens Advocacy Lincolnshire Link
- Gloria Fowler Area Co-ordinator Norfolk Elders' Advocacy Alliance
- Colin Glover Advocacy Co-ordinator Age Concern Carlisle & District
- Eric Green Crisis Co-ordinator
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- Helen Grew Vice President National Pensioners' Convention
- Sadie Hall Deputy Sister, Community Hospital Wycombe PCT
- Fiona Hammond *Director*Liverpool Citizen Advocacy
- Jane Handscombe Advocacy Manager's Assistant Age Concern Buckinghamshire
- Brenda Hardy Warwickshire Older People's Forum
- Stephen Harris *Chief Executive*PostWatch
- Jill Hazelwood Advocacy Worker Age Concern Hertfordshire

- Mary Heaword *Director*The Gerontius Group
- Wendy Heley Advocacy Officer
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- Rick Henderson *Director*Advocacy Across London
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- Margaret Hill
- Lynne Horlacher Acting Chief Officer South Cumbria County Council
- Claire Horton Events Administrator Help the Aged
- Steve Howarth Regional Development Officer Help the Aged
- Isobel Hunter Volunteer/Trustee
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 for Senior Residents
- Nancy Ireland Assistant Chief Officer Lancaster and Morecambe Community Health Council
- Moyra Jean Advocacy Co-ordinator
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- Elcena Jeffers
 Black Disabled People's Organisation
- Glyn Jones *Vice Chair*Practitioner Alliance Against the

 Abuse of Vulnerable Adults (PAVA)
- Jennifer Jones Sector Manager Social Services
- Judy Josephs Social Work Student Westminster Advocacy Service for Senior Residents
- Jane Kendall *Advocacy Development Officer*Age Concern
- Nicky Kentell *Advocacy Development Officer* Advocacy Service Action Project
- Sandra Knowles *Advocacy Worker* Independent Advocacy (North Tyneside)

Irene Kohler *Director* WASSR

Linda Lawless *Project Co-ordinator* Elders' Choice Advocacy Project

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Jean Ware-Morphy Advocacy Worker Oxfordshire Advocacy Development Group

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Help the Aged

Working for a future where older people are highly valued, have lives that are richer and voices that are heard.