

Older People's Advocacy Alliance (OPAAL) UK

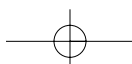
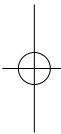
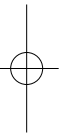
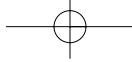
A voice that wasn't speaking

Older People Using Advocacy and
Shaping its Development

A report written by Mel Wright,
as part of the OPAAL user engagement initiative

Edited for publication by Andrew Dunning

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Foreword

OPAAL is proud to present this report, the first exploration of its kind in the UK. It gives an illuminating account of advocacy's importance for those who rely on it, with older participants' reflections on the feasibility of users organising for themselves in future. Our thanks are due to Mel Wright, our consultant, for his patience and insight, the valuable documentation he has prepared, and the challenges he and his interviewees have set. I'm grateful to Jackie Robinson for supervising the initiative as part of our Section 64 funded regional programme, and to the Department of Health for funding it.

John Miles, Chair, Older Peoples Advocacy Alliance (OPAAL) UK

Acknowledgements

All older people who were consulted during this project were referred by advocacy services, or by OPAAL. I would like to express my thanks to them for their contributions and the very stimulating and interesting discussions about their experiences of advocacy.

I would also like to acknowledge and thank the following organisations and individuals for their generous help and support for this project: Advocacy In Barnet – Renie Bowen & Karen Lewis; Bromley Advocacy Alliance – Linda Lawless; Age Concern Camden Advocacy Service – David Brooker & Betty Weale; Advocacy for Older People In Greenwich – Maria Day & Sam Everson; Nubian Life – Jazz Browne; Age Concern Harrow Advocacy Service – Zenda Green; Age Concern Hillingdon Advocacy Service – Margaret Fay; Kingston Advocacy Group – Susan Brooks; Age Concern Richmond Upon Thames Advocacy Service – Linda Nelhams & Carole Bult; Cambridge House Advocacy Service – Selma Omerkic; WASSR (Westminster Advocacy Service for Senior Residents) – Irene Kohler & Eleanor Gibson; Lewisham Independent Pensioners Advocacy – Easbail Clements; SAGE (Senior Action Group Edinburgh) – Ann Paget & service user; Maureen Anderson and the Independent Advocacy (North Tyneside) Women Together Group; Elcena Jeffers, Teresa Lefort, Zelda Curtis & Stan Davison. Finally, to the OPAAL team, Jackie Robinson and John Miles, who commissioned my original report to the management committee. Lastly I'm grateful for the expertise and experience of editor, Andrew Dunning.

Mel Wright, London, June 2006

Introduction

This report presents a summary of the main findings of a consultation with older people who have had contact with and/or received advocacy services. The consultation was undertaken on behalf of the Older Peoples Advocacy Alliance (OPAAL) UK as part of a project with the following aims:

1. To contribute to an evidence base for the effectiveness and impact of advocacy which can be reported to stakeholders, including policy-makers, commissioners and funders.
2. To engage older people with an interest in the development of advocacy services.
3. To explore the potential for a network of older people who have used advocacy services.

More specifically, the consultation focused on the following key considerations:

Experience and impact of advocacy on older people:

- a) whether or not they have used advocacy services
- b) if they have used advocacy services, what motivated them to do so
- c) whether they found the advocacy assistance helpful to their situation at the time
- d) whether advocacy met their expectations, and what these had been
- e) whether they felt supported throughout the process
- f) whether they would change anything about the advocacy process

Interest in seeing advocacy develop:

- g) what their interest is, or has been, in advocacy
- h) what they would see as the benefits to themselves, and to others, of older users involvement with independent advocacy
- i) whether they would be prepared to communicate with other older advocacy users, or meet others at a facilitated meeting
- j) whether their would be obstacles to their participation, and how these might be overcome

The findings presented in this report are intended to be of interest to older people, advocacy organisations, policy makers, commissioners and funders, as well as to inform the future work of OPAAL.

Consultation Process and Participants

The consultation was carried out from October 2005 to March 2006 and consisted of one-to-one interviews and focus group discussions. A semi structured questionnaire approach was used, with questions based upon the key considerations regarding the experience, impact and development of advocacy with older people outlined in the introduction of this report.

There were three main phases of the consultation process:

1. At the beginning of the project meetings were arranged with some key people involved in advocacy and this assisted in 'checking out' the OPAAL project plan and approach. These discussions proved to be extremely helpful in preparing for the interviews and have added to the feedback by older people about the value of advocacy.
2. One to one interviews and discussions with older people who had used advocacy services, regarding their experience of advocacy and their interest in the future development of advocacy.
3. A final focus group meeting of older people convened to discuss their interest in the future development of advocacy and the potential of an advocacy users network.

A total of 35 older people were engaged within the consultation process. They were drawn from Greater London, North Tyneside and Edinburgh. The profile of the participants was as follows:

Age: Late 50's to 80+ years of age.
Gender: Females: 18. Males: 17.
Ethnicity: UK White x 22, African x 1, African Caribbean x 8, Asian x 1, Sri Lankan x 1, Irish x 2
Disability: Participants included people who had physical disabilities and some who were wheelchair users.

Representatives of the following advocacy organisations also participated in interviews and discussions:

Advocacy in Barnet; Bromley Advocacy Alliance; Age Concern Camden Advocacy Service; Advocacy for Older People in Greenwich; Nubian Life; Age Concern Harrow Advocacy Service; Age Concern Hillingdon Advocacy Service; Kingston Advocacy Group; Age Concern Richmond-upon-Thames Advocacy Service; Cambridge House Advocacy Service; Westminster Advocacy Service for Senior Residents; Lewisham Independent Pensioners Advocacy; Senior Action Group Edinburgh (SAGE) Women Together Group Independent Advocacy North Tyneside.

What is Advocacy? The awareness and understanding of older people

Advocacy can be an unfamiliar and elusive term, meaning different things to different people. OPAAL defines advocacy as being:

“A one-to-one partnership between a trained, independent advocate and an older person who needs support in order to secure or exercise their rights, choices and interests.”

Furthermore, OPAAL highlights the three key principles of advocacy as being independence, inclusion and empowerment

It is important to understand what is meant by advocacy if people are to know what is available and what to expect from such services. As part of this consultation, older people were asked about the term “advocacy” and what it had meant to them at the initial stage of contact with an advocacy service. A number of participants reported that they had limited knowledge about or expectations of advocacy at the start of their involvement.

“I never really heard about it until a year ago when I got a leaflet.

“I hadn’t heard of it. I heard about from CAB. Advocacy helped me greatly.”

“I had given up hope so I had no expectations.”

“Advocacy was new to us. We did not know what to expect. We were surprised that they did so much.”

The term “advocacy” was regarded as being problematic, confusing or even off-putting for some older people. It was sometimes associated with the legal system, mediation or more general kinds of help and support.

“It’s a term that could frighten some old people. It’s a hard word.”

“The term don’t mean a thing to me. Help and support would be better.”

“It makes you think of legal aid and help.”

“It’s speaking for somebody – but it’s not immediately obvious.”

“Some people’s perception of the advocacy service is advice, befriending, or it’s misunderstood about helping with tasks. For example we go on a hospital ward and they expect you to take their washing away!”

Older People Using and Shaping the Development of Advocacy

Other older people who were consulted had developed an understanding of advocacy that was influenced by the style of advocacy they received or indeed undertook for themselves or their peers. Some advocacy services provide a short term task-orientated approach, others adopt a more befriending style and longer term approach. A number of advocacy services also support older people in representing themselves.

“Acting on your behalf.”

“It means, like a lawyer acting in your defence!”

“Advocacy helps to provide solutions...It’s taking control of your life. You don’t feel like you are on your own. Knowledge, which is a key to life, gives confidence especially through advocacy.”

Support if needed but not necessarily speaking for the person. There is a need for confidence building. An advocacy group helps to build up self-confidence and self-advocacy. Women who are not used to having their voices heard. You suddenly hear a voice that wasn’t speaking.

Having benefited from advocacy, a number of older people consulted were concerned that it should become more widely available and that there should be an attempt to raise awareness among their peers.

“I think it’s a shame that more older people don’t know about advocacy – what it is and that they can have the help.”

“It is important that people who have a need have access to advocacy... The difficulty is getting people to seek advocacy. They may wait too long to come and then it’s a crisis. More funds are needed to publicise, help raise awareness, supporting people, getting people to speak for themselves.”

Why is Advocacy Needed by Older People?

Older people involved in the consultation were asked about what had motivated them to use advocacy and why they had needed the service in the first place. This question generated a wide range of responses which broadly related to the need for protection from abuse; combating discrimination; obtaining and changing services; securing and exercising rights; as well as being involved in decision making and being heard.

The following examples highlight the variety and degrees of complexity and concern of cases presented by participants:

"There were problems with the sheltered scheme warden – the way that it was run was too draconian. The advocacy service helped by speaking to them."

"I was being fobbed off by doctors. No one was doing anything about it. I needed help. I was in tears, a terrible state."

I was being hounded by Council Tax – it had got out of hand. They (advocacy service) were very helpful, sorted it all out."

"They have been a great help to me. I'm learning a lot about what's going on and keeping abreast with things. They made a real difference – when I complained about a service they helped me."

"I needed help with my bathroom and shower – the Town Hall Social Services made me feel very small. Advocacy has greatly helped."

"They (advocacy service) helped us get temporary accommodation. And also the Council questioned my residency status. They helped sort that out. The advocate softened the blow from several quarters."

"One of the things was home care –they were useless. They asked me questions but didn't do the work. They were not working with me. It's important that I do things for myself. If you don't use it, you lose it! I have a nice carer now – very helpful and I'm very pleased."

Other examples included:

- Challenging builders to put right poor work
- Putting finances in order and obtaining legal help to make a Will
- Securing the correct welfare benefits and entitlements
- Helping to find a way around organisations and accessing services
- Dealing with agencies and arrangements after a fire gutted a home
- Preventing a patient from unnecessary and unhelpful moves in hospital
- Promoting the voices of people in specific settings eg residential care
- Creating a safer physical environment eg pavements and street lighting

Older People Using and Shaping the Development of Advocacy

A motivating factor for older people needing advocacy was that of the independence of the service they sought. One participant living in a residential care home said that she used advocacy services to talk through self advocacy action that she was taking. She valued checking out what she was doing and affirming her position with someone who was independent. Other contributors emphasising independence included the following:

"I needed help to get an NHS operation for cataracts – I thought about going private but it was £3000. I needed help so badly. I also wanted someone independent from outside to talk to about a will. Talking is important – I don't know what I would have done without them. I felt very depressed – suicidal.

"It (advocacy service) should be totally independent. The advocate was a friend at my elbow. The advocate steadied my ship against their (housing, health and social services) Armada."

What Works?

Part I: The Process of Advocacy with Older People

During the consultation, older people were asked whether they felt supported through the advocacy process and whether they would change anything about it. Their responses highlighted that the process of advocacy was just as important as the outcome.

At one stage he (the advocate) stopped the meeting in concern for my well-being. He was a prop – a stabilising influence. It helped with a feeling of not being isolated. Listening without criticising. Looking at any issue with an open mind. Advocacy enables a person to choose a path with relevant information. It is not always possible to reach the goal that they (the older people) have decided or to get what you want. However, the process is important. We like to be in control of our lives but may feel complete lack of it. The (advocacy group) strengthens and encourages people to retain self-control, knowing that it is not going to be detrimental for them. People can talk and feel comfortable. Sometimes people are afraid to speak up. There can be an erosion of individuality and status. De-humanising. We should be in control but not controlled.”

“Most people appear to find the advocacy service helpful. Some people would like the outcomes to be achieved more quickly, but this is not possible...Building up trust with the advocate is essential. People are asked and consulted about their needs. Sometimes the need is unrealistic and the outcome of meeting the need may be less than when they started out. The advocacy process itself is often as important to the person. The fact that people have been listened to and that an advocate can help pull things together is something that people often feel good about the service.”

“It may not always get people what they think that they want – but the feeling of being helped is important.”

Advocacy involves two main sets of roles – instrumental and expressive. Instrumental roles are more formal and are about “doing” eg being a spokesperson or representative. Expressive roles are more informal and are about “being” eg a confidante, witness or enabler. Older people involved in the consultation commented on the significance of both sets of roles in the support they received from the advocacy service.

“The advocate took a history of my situation. She supported and sat in with me during hospital appointments. The doctors can talk over you and her being there initially got the doctor’s back up, he thought they were PALS! (Patients Advice & Liaison Service) she explained and asked questions (of the doctor) – they relaxed. We wrote things down and took it to the meetings. I couldn’t have survived without it! They took more notice. I’d highly recommend it”

“The advocate visited me at home. This was very important to see me in my home situation. She made calls whilst she was with me and I then knew what was happening and that things were being sorted out.”

Older People Using and Shaping the Development of Advocacy

“Yes, I felt supported very much so, largely due to help from advocacy staff. All worries and concerns, they have helped at the time of bereavement. I was upset, not thinking straight and advocacy was there to help.”

“That old saying’s right – a problem shared is a problem halved.”

“Yes it was very helpful – still is. More from the visit and talking through things rather than having things done for me.”

“One-to-one is important when you are unable to do the things – it helps as a back up – they may write letters for you and the company helps.”

“You don’t want to think that your life is at an end. The advocate has helped me greatly – you can relate really well to them.”

“Yes, it has helped me. Advocacy is very important. Different departments can get you feeling lost. They take care of you.”

“The advocates try and build a picture of the person that they are working with – sometimes reassuring them over their options.”

One focus group identified the kinds of attributes and skills they valued in an advocate, as follows:

- *Listening,*
- *Understanding, knowledge,*
- *Treat you as a person not as a thing!*
- *Not be frightened to speak up for you,*
- *Sympathetic, caring,*
- *Have time to listen,*
- *Patience,*
- *Honesty,*
- *Identify the problem and sort it out,*
- *Trust*

Other contributors stated the significance of empathy; an understanding of people; an ability to see the person’s point of view; being able to work in partnership; being able to maintain confidentiality; being objective; having a critical eye; being properly trained – and having a passion for advocacy.

Some older people involved in the consultation used the term “friend” to describe their relationship with an advocate. However, most participants highlighted the need to distinguish the expressive role of the advocate from that of befriending. It was said that the older person had in their advocate a “companion” to support them through their advocacy journey, but that they should both be clear about the limits of role and relationship. Participants suggested the advocacy service could signpost the older person towards befriending or other forms of support if needed – a “Yellow Pages” approach.

Only one person identified a problem with the advocacy they had received, and that had been swiftly addressed by the service concerned. Also, in some cases, advocacy services had not been able to offer immediate assistance due to limited resources such as a lack of available advocates.

What Works?

Part II: The Outcomes of Advocacy with Older People

Throughout the consultation the overwhelming response from participants was that the advocacy process was valued and had exceeded expectations. Advocacy services were seen to have responded sensitively, skilfully and imaginatively across a wide range of needs. This was frequently translated into positive outcomes for older people themselves.

"I have had good results. I know there are limitations to what they can do but they exceeded my thoughts."

"I wasn't expecting much success – I'd almost given up but they helped much more than I had reckoned."

"Not half! When you know a person and trust them, you know it's going to get done – and it was!"

Two main sets of outcomes were identified by older people involved in the consultation. Firstly, there were outcomes relating to material or tangible gains. These included access to services, improved financial circumstances and skills development. Secondly, there were outcomes bound up in feelings and emotions. These were articulated in responses regarding self worth, esteem and confidence.

In terms of the material and tangible sets of outcomes, one participant said that he had needed advocacy when his step children, without telling him, took out an Enduring Power of Attorney on his wife who lived in residential care. The advocate supported him in mounting a successful challenge to the situation. Another participant told of how an advocate had supported him by chasing up relevant agencies to provide adaptations and improve physical accessibility so that he could get in and out of his home. Further examples are as follows:

"I was helped with other things too – attendance allowance, social care support, Council Tax, taxi card, information and practical help (and a handy person scheme.)"

"The advocate has been wonderful...helping with a dentist, going out. She got a wheelchair for me."

"Yes. Advocacy has been very helpful. Everything was a shambles. The advocate sat on the burnt out stairs in our property and began to work out what help we needed and got it (securing temporary accommodation and dealing with insurance companies and other services)."

"I had contact from an elders home support scheme who called to see how things are and they suggested advocacy. I refused it first of all as it had been going on so long and I didn't want to have to repeat saying what the problems were to somebody else. But then I thought, 'what a fool I was'. So I relented. I was told that the advocacy manager can go anywhere in the council – she can get action. They were right!"

Older People Using and Shaping the Development of Advocacy

"I was being hounded and summonsed for Council Tax. Advocacy was very helpful – in the end I received an apology from the Council Tax people. The advocate – I felt so comfortable with her. She seemed ordinary but she did this great job."

Successful outcomes relating to feelings and emotional wellbeing were also seen as being significant and were reported by a number of older people during the consultation, as captured in the following quotations:

"It was a big relief. When I agreed to have their support everything went right."

"My mind is clearer now that I have talked things through. I was getting very frustrated. I look forward..."

"Yes. They made me feel very confident. They are trustworthy, they give up to date information and practical help. I felt very relieved."

"I got a lot of my self confidence back. I now attend medical appointments on my own and I take in written questions to ask the health professionals. I don't take any nonsense now!"

"They have made me feel that they are safeguarding me. It saved my life! Everything is perfect."

"They've given me confidence to get on the phone. I have also passed information about the service to others."

"They encourage, help to find a solution. They make you confident."

"It helps you get up psychologically – a boost."

The Development of Advocacy with Older People – A Users Network?

Many rich and engaging contributions were made during the consultation, confirming the view that service users' active involvement is of great value in shaping and sharing in the future of advocacy. Moreover, there appears to be a real interest and potential for taking forward OPAAL's proposal of an older people's advocacy service user network.

Participants made a number of useful comments in relation to the purpose of such a network as well as its membership, structure and support.

The network was seen to have three possible sets of aims:

- Raising awareness and promoting advocacy more widely
- Sharing experiences and providing mutual support
- Contributing to the development of advocacy

Some participants suggested that the network might take the form of existing bodies and initiatives. These included the Association of Greater London Older Women and the Women Together Group in North Shields, which give the opportunity to share ideas and experience collectively. Participants also indicated that they might wish to meet as they had done in the process of the OPAAL consultation itself and focus on identifying gaps and best practice – shaping the national as well as local development of advocacy with older people.

The group briefly discussed these ideas and approaches. A focus on a specific project area might be a good way forward. As an example, residential and nursing care homes. A network should have realistic outcomes, be local to different areas, should perhaps first of all include as a pilot, a rural, town and city setting in order to consider the different types of organisation required in setting up a network and issues that arise.

In terms of membership, some participants questioned whether a “users network” should include both users and advocates. Others suggested ways in which a network could be made more inclusive. Older people who were unable to attend meetings could be linked by telephone, letters, e-mail and home visits to enable them to contribute their ideas and have an active part in service development. A “buddy” system was also proposed, linking up older people with experience of using advocacy services to those currently receiving a service.

Clearly, these initial ideas and discussions need to be considered and further work undertaken with service users and advocacy schemes on what type of network model would be appropriate for OPAAL to adopt, devising aims and objectives together with a development plan for its implementation.

“Some good may come of it, if it is focused on specific areas and outcomes.”

“In groups and organisations there are people who are ‘pushers’ who help move things along and those that may be quieter and ‘cautious’ who help in a different way – a mix of both types of people in a group is important.”

“Everyone needs to help spread the word!”

Summary and Conclusion

The key considerations of the consultation were the experience and impact of advocacy on older people and the engagement of older people in future development, including the potential for the creation of an advocacy service user network of older people.

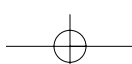
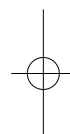
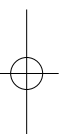
The main findings to emerge from the consultation as highlighted in this report can be summarised as follows:

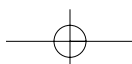
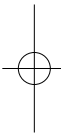
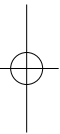
1. Older people were unfamiliar with term advocacy at the outset and remarked on its problematic and contested nature. Most had subsequently seen advocacy in terms of style or approach they received, which the advocate provided. They then became keen to encourage the promotion and development of advocacy more widely.
2. The motivation or need for advocacy was broadly related to protection from abuse; combating discrimination; obtaining and changing services; securing and exercising rights – as well as being involved in decision making and being heard. Participants presented a range of experiences of varying degrees of complexity and concern.
3. Participants generally felt supported by and emphasised the significance of the advocacy process. They valued both the instrumental and the expressive roles of advocates and highlighted the skills and attributes required.
4. Participants identified two sets of successful outcomes – those relating to tangible or material gains eg obtaining a service and those bound up in feelings of greater confidence and self esteem and of being better equipped to deal with life situations themselves.
5. The consultation confirmed the view that service users' active involvement is of great value in shaping and sharing in the future of advocacy. There was real interest in and potential for taking forward OPAAL's proposal of an older people's advocacy service user network.
6. Further work is now required to develop the aims, membership, organisational structure and support requirements of participants as well as the type of network model to be taken forward – by OPAAL, advocacy services and older people themselves.

Notes



Notes





“ An advocacy group helps to build up self-confidence and self-advocacy. Women who are not used to having their voices heard. You suddenly hear a voice that wasn't speaking. ”

Zelda Curtis and Stan Davidson in conversation with Mel Wright, November 2005.

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