

“Making it personal”

**An OPAAL project aiming to develop advocacy to support
older people using personal budgets**

***“It ain’t what you do – it’s the
way that you do it!”***

Report on the work of

“Advocacy for Independence”

a service provided by the

Independent Living Association (ILA) – West Sussex

About us

1. Organisation

OPAAL UK is the Older People's Advocacy Alliance, the only national strategic organisation throughout the UK promoting independent advocacy with older people. We consider ourselves to be unique, with a member base that focuses on independent advocacy services for older people across the UK.

There are around 200 members: this figure represents advocacy schemes, national organisations with an interest in advocacy such as Help the Aged and Age Concern England, and a small number of individuals, mostly academics and older activists. It undertakes projects and accepts commissions such as the invitation to evaluate the project whose work is described on the following pages.

2. Author

Les Bright, the author of this report is an OPAAL associate and an independent consultant. He has held a range of practitioner and manager posts in the public and voluntary sectors at local and national level since the mid 70s. He is the author of another recent OPAAL report "*Wheelchair access? That's a lifestyle choice...*" as well as a number of other practice-focused publications focused on the care of older people, is a regular contributor to the care sector press, and acts as a Professional Adviser to the Relatives and Residents Association.

3. Locality

West Sussex

"Advocacy services are well established and used imaginatively."
Commission for Social Care Inspection
Annual Performance Assessment of Social Care Services for Adults,
November 2008

4. Service

Advocacy for Independence

"Unfortunately we can no longer provide a service for older people as we have not been provided with funding for over 65s and we believe that there is no budget available to provide specific support for them in this area."
Independent Living Association's Advocacy for Independence Manager
September 2009

Acknowledgements

I am indebted to the staff, volunteers and users of the *Advocacy for Independence* team at the ILA for their help throughout this work.

The service manager, Nicky Kentell has been exceedingly helpful and always ready to share her knowledge. Her colleague Alison Stemp, who is the service co-ordinator, has also always been willing to respond to any requests for information or contacts. A number of their colleagues at the Independent Living Association – West Sussex, the parent organisation, which promotes independent living and provides a range of services, including acting as advisors to people setting out on the Direct Payments route, also assisted by either completing a questionnaire, going through a telephone interview or meeting with me.

The advocates, the large majority of whom are volunteers, gave time on top of their existing commitments. They assisted for no other reward than that they might be helping me to better understand the way they go about their work, and the particular challenges they face in managing the pressures of such demanding work. I am very grateful to them for their help. This tremendously self-effacing group of people, who clearly make such a big difference to the lives of people whose voices might not otherwise be heard, are clearly a great asset to the organisation.

A number of staff of the county's adult services department also made time to describe their perceptions of the service and its value to clients with whom they have worked.

I spent a significant amount of time talking to people who had used the service, to explore their experiences and gather their views on its effectiveness. They were very accommodating, and honest in giving feedback on their advocate and the situation which had led them to make use of the service. As is so often the case, lay people demonstrate remarkable levels of insight that professional colleagues sometimes lack.

Thank you all.

Les Bright
Exeter, Devon
November 2009

Executive Summary

Advocacy for Independence (Afi) is an established service that could serve as a model of good practice for organisations considering further developing their activities to include acting for people managing an Individual Budget (IB).

The service is well thought of by people who have used it and their families, as well as staff of other agencies. It was for those reasons that OPAAL decided to look more closely at the Afi's operations.

- Volunteers are a reliable source of independent advocacy for people with a wide variety of presenting problems provided that they are:
 1. Recruited through a careful selection process;
 2. Given a thorough induction to the work they will be undertaking;
 3. Provided with regular supervision;
 4. Can obtain support and advice when needed;
 5. Are offered access to top-up training; and
 6. Are provided with feedback on how they are doing.

- People stay in voluntary jobs for reasons similar to their paid counterparts, when:
 1. Their needs are understood and responded to – either in terms of training, support or opportunities to reflect on their performance and any challenges the work provides;
 2. Their achievements are recognised;
 3. They are enabled to exercise control over their hours of work – especially flexibility in when they work; and
 4. They are not overloaded with work.

- Organisations wishing to use volunteers in this way need to invest paid staff time in co-ordinating the work of the advocates to:
 1. Ensure that they are performing well and have ways of offloading concerns;
 2. Match advocates with people needing assistance;
 3. Assure users of the service - those referring, and the 'end users' - that the service is well managed, reliable, and operates within agreed policies and procedures.

- Getting a service known - and then used - can often be problematic, consuming lots of time and energy, but in this case good practice ensured that was less worrying:
 1. Being located alongside of, but separate from other services that may be of help to potential users is a good way of being noticed;
 2. Ensuring that agencies involved in care and support activities are aware of the service should lead to referrals; but
 3. There is nothing quite like satisfied users to promote a service.

- Being part of a bigger organisation that provides other services for the target group is useful, although:
 1. It is important to make clear the boundaries between any contracted services and an advocacy service so that the advocates' independence is not seen to be in any way compromised by this closeness or integration; but in this instance
 2. The ethos of a user led organisation that is a very convincing way of demonstrating independence than any amount of carefully drafted statements of intent.

- The style of communications an organisation adopts conveys much about its culture and can be powerful in attracting and retaining attention and support:
 1. Brief and simple forms conveying key information are more likely to be read and understood than longer complex versions;
 2. Concise forms outlining the role and function of the service and the person who will be providing it can go a long way towards reining in inappropriate demands; and
 3. Don't avoid being brief or sticking to simple sentences for fear of patronising readers - they will tell you soon enough if the material 'talks down' to them.

The mood music may have changed from the 'needs led assessment' and 'seamless service' which the last major set of community care changes heralded in the early 90s, but for organisations assisting people to get their voices heard in an era of 'personalisation' the song remains the same - "*it ain't what you do, it's the way that you do it!*"

Preamble

The Older People's Advocacy Alliance UK (OPAAL) is the only national strategic organisation throughout the UK promoting advocacy with older people.

It has around 200 members, predominantly organisations engaged in advocacy but also some academics and activists. It works closely with central and local government advising on independent advocacy and undertaking development projects aimed at demonstrating the value and values of independent advocacy. As a registered charity it is governed in accordance with the requirements of relevant legislation and makes policy through a board of trustees elected by the membership.

Introduction

The Department of Health awarded OPAAL a grant for a project entitled "Making it Personal" which aims to demonstrate the value of independent advocacy in supporting older people to make use of personal budgets.

OPAAL recognises that some good practice already exists, and the purpose of this paper is to collect together evidence of the work of one established service in such a way as to demonstrate its effectiveness and the steps others might take to emulate it. We have explored and drawn on the accumulated evidence arising from the work of "*Advocacy for Independence*" (Afl), a service operating under the umbrella of the Independent Living Association – West Sussex.

This paper describes the way that Afl works and illustrates it by reference to case studies, interviews and documentation.

Background

The direction of current and likely future welfare policy is towards greater personal control of decisions about care, access to the funds to procure services, and opportunities to specify the uses to which such funds will be put. This direction is unlikely to change - even with a change of government - as all the main parties recognise and support the notion of choice and control. They also recognise - to varying degrees - the impact this has on public sector organisations in their role as commissioners, purchasers or providers of services, and on citizens as users of services, or as people with care needs that should be met by services, facilities, staff and budgets.

Personal budgets are seen as critical to the successful development of this ethos and to enabling people to exploit the possibilities for their personal benefit, by way of improved outcomes and a greater sense of being in control of their lives. It is clear that some actual and potential beneficiaries are deeply cynical about the reasons that central and local government have embraced the concept so warmly, suggesting that the process is too closely associated with managing reduced and

reducing budgets. Despite such doubts people have nevertheless gone ahead with using the provisions of this policy to improve the quality of their lives and that of their family carers. Advocacy services have a critical role to play in ensuring that people have their say, and their voices are heard.

Approach

While it might have been possible to collect and collate plenty of useful information as a desktop exercise that approach was not adopted in this instance. The intention was to collect, reflect and analyse information gained through qualitative research and in-depth discussions with a cross section of interested parties.

Although more time and energy was consumed in making site visits to talk face-to-face with staff and volunteers and also to visit users of the service in their homes this has undoubtedly contributed significantly to the quality of the material gathered, and has enabled a richer more detailed understanding of those elements of good practice that need to be conveyed to organisations and individuals considering developing similar services to support people in their own localities.

Methods

Collecting information, experiences and opinions took place in a variety of ways.

- Face-to-face discussions with individual users of the service, in their own homes;
- Meeting with a group of 20 volunteer advocates;
- Face-to-face meetings with the service manager and service co-ordinator;
- E-mail exchanges with volunteers, followed up by completing a questionnaire;
- E-mail and telephone exchanges with Direct Payments advisors employed by the ILA;
- Sending an e-mail questionnaire to a number of other Direct Payments advisors;
- E-mail and telephone contacts with field social workers employed by the county council;
- Face-to-face meetings with selected other current – and one former – member of the staff of the adult services department;
- Review of Afl documentation
- Review of ILA and West Sussex County Council websites;
- Review of national policy guidance and allied research.

The work began with a scoping meeting early in September 09, and the fieldwork was concluded at the beginning of November 09. Telephone and face-to-face interviews were conducted using topic guides that set out to uncover peoples' views on a range of issues associated with the

organisation and performance of the service and their different perspectives, based on a variety of relationships:

- Users of the service,
- Volunteer advocates providing the service,
- Social workers and care managers who had engaged advocates or been required to engage with them; and
- Staff of the ILA and the county council.

Key Features

In looking at the way in which the service operates and why it is deemed to be successful there are a series of issues that need to be considered and commented on; the first of these is the advocates themselves – who are they, how are they recruited, inducted, trained, managed, supervised and supported?

Individuals reasons for volunteering may vary in some details but it is clear that there are clusters of motivating factors that should be considered and understood, to ensure that any systems and processes that are established match and respond to those needs and interests.

Volunteers as advocates

Some people - professionals and lay people - dismiss the idea of delivering services by using volunteers as being driven only by a wish to save money, at the same time compromising the quality and reliability of any service provided. Such views are not new and are not only applicable to the performance of complex roles such as that of an advocate. Healthy disagreement has been at the heart of the debate about the role of volunteers as replacements for paid staff, as supplements to the work of hard-pressed staff, or complementing the contributions made by them. It is unlikely, and probably not desirable to expect to arrive at a fixed position on whether volunteers are a 'good thing' that will suit all those who have an interest in the debate.

It is also suggested that the pool of people who could be called upon to volunteer is small, diminishing and hard to reach. Recruiting people is difficult; and then selecting out those who are suited to the tasks, and offering them training, in order to deliver a good service, is time consuming - and needs to be repeated regularly because of the turnover rate associated with undertaking difficult tasks.

The range of skills necessary to function effectively, and the body of knowledge required in order to be helpful is broad and deep. Again this is seen as a major obstruction to the involvement and effective performance of volunteers. But the experience of Afl seems to suggest that these problems are over-stated and, where they do exist, are not insurmountable.

The service is available, and seems to be valued by users and respected by staff of other agencies because there is a substantial

body of volunteers who have been recruited, inducted, trained and supported to deliver a reliable service. This is only possible because staff are employed whose primary focus is on selecting and supporting volunteers. Without such staff volunteer effort would be minimised, perhaps leading to situations in line with the pessimistic outlook on volunteer involvement.

A. Finding volunteers

1. Recruitment

Job descriptions and person specifications

Local media

Many of the advocates learned of the existence of the service at the same time as learning that the service was looking for people to volunteer. The 'call for volunteers' was obviously well written as it succeeded in presenting the role and tasks in a way that looked attractive to generalist readers in a generalist publication – the specialism of the paper was in communicating with its local population, with a diverse range of interests drawn to buying the paper because it kept them in touch with local news and events.

Local newspapers are perhaps less affected than their bigger more powerful national counterparts by the switch to digital media and online versions of the printed word. Free newspapers are often widely distributed within an area ensuring a high level of penetration of the target audience – local people. Such publications are often searching for stories and welcome well-written short articles/adverts for a service.

A job description and person specification is as important for a voluntary job as it is for a paid post. It ensures that both parties start with a position a shared understanding of the job to be done, and the arrangements in place for managing the work.

2. Selection

Application form

Individual interview

Group discussions

Although being an effective advocate can sometimes be a very tough task those volunteers to whom I spoke enjoyed the challenges this presented. That they had to complete an application form and go through a selection process did not appear to have been a barrier to any of them, indeed it constituted yet another welcome dimension to the challenge of being an advocate, in that they needed to present themselves as effectively as if they had been applying for paid work, and to expect to be asked tough questions about themselves during the process.

People welcome the need to go through a selection process, providing them with a sense of having been taken seriously, and ensuring that they too took this unpaid work as seriously as a paid job.

3. Training

Induction

Continuing 'education'

There was universal praise for a rigorous and demanding induction programme spread over three days covering knowledge, skills and attitudes as well as introducing the policies and procedures of Afl.

This 'baseline' is regularly 'topped up' by further sessions either in response to matters arising from the advocates themselves or topics which staff identify either due to changes in the wider environment or in response to perceived difficulties experienced by advocates. Such sessions generally occurred as part of the routine business of bringing people together so that their highly individualised practice could be seen as part of something bigger – or, put more simply, so that advocates could share the trials, tribulations and triumphs of doing the job with others engaged in similar activities.

Setting up ways of bringing people together for training and peer support is vital to the process of building the team and facilitates the development of relationships between people who might not otherwise meet.

4. Supervision

Regular

One-to-one

Recorded

Professionally qualified staff of statutory and voluntary agencies engaged in work similar to that undertaken by these volunteers are generally required to attend and participate in regular supervision sessions with their manager. Such sessions are intended to act as a source of support to talk through difficulties and to assist in achieving satisfactory outcomes. A valuable element of this approach is to offer personal support to enable the supervisee to manage pressures that could affect their performance or well-being.

The service co-ordinator provides regular supervision sessions for all advocates. The agreement between Afl and the volunteers makes it clear that this is not an optional extra or 'frill', but is an integral part of doing the job effectively. Volunteers commented favourably on the usefulness of these regular individual meetings. The co-ordinator keeps detailed notes of the sessions so as to be able to track any issues or problems and to take steps to reduce or eliminate recurrence in the future, and also to identify any training needs arising.

One-to-one sessions at which a volunteer is able to talk about progress – or a lack of it – and any problems s/he has encountered is a key part of assuring service quality.

5. Support

Availability

Accessibility

Experience shows that while formal structures and meetings - individual supervision or 'get togethers' with other volunteers - are important this should be augmented by ensuring that support is available between times. All volunteers have a range of contact details – mobiles/direct line/e-mail addresses - for the manager and co-ordinator and are encouraged to use them to ask questions and bounce ideas around. In addition other staff of the ILA are also available to answer queries of a technical nature.

Advocates are often dealing with complex issues and need to feel well supported. This can be done in many ways but it seems especially relevant to establish ways for people to get quick answers to issues that arise, alongside of planned/timetabled sessions and systems.

6. Reliability

Partnership

Commitment

Reinforcement

Peer support

One of the principal concerns expressed by those who have doubts about services provided by volunteers is that of reliability. This extends from "will they turn up?" – "will they stay?" – "will they be equal to the tasks?" to, "will the quality of service be compromised?"

While there can be no cast iron guarantees that volunteers (or paid staff) will know everything they need to know, or never go sick there is some evidence that the way in which the service is organised has led to an exceptionally high level of commitment by those who have been through the selection process and have gone on to take up the role of advocate.

Training and continuing support reinforces the importance of the advocate to the person with whom they are matched, and after that introduction the advocates need little reminding of the need to avoid making unrealistic commitments or to make promises to resolve difficult situations rapidly – or at all.

Volunteers are no more or less likely than paid staff to break commitments and become an unreliable source of help – but that doesn't happen without investing time and resources – that's staff time and training - to provide them with the support they need and deserve.

7. 'Added value'

Relevant life experience

Past professional skills

Maturity

The group of volunteers who have been recruited bring a wide variety of life experiences; many of them have retired from paid work and have experience in a number of industries and public services, as well as also having raised children, and in some cases also provided care for elderly parents.

This rich mix of life experience, professional qualifications, employment related skills, and knowledge derived from leisure interests and pursuits provide an appropriately qualified workforce.

When recruiting volunteers it may be worth highlighting this 'added value', over and above any other requirements – apart from minimum time commitment and a willingness to go through basic training.

8. Skills

Inter personal

Diplomacy

Resilience

One of the attractions that some volunteers describe as contributing to their decision to volunteer is the prospect of gaining new skills to add to those they have already. The manager and co-ordinator make skilful use of this broad repertoire of skills, recognising that many people have well developed communication skills and may have a role to play as trainers within the group.

Volunteers often bring many skills additional to those required to undertake their role, but may subsequently use them to the benefit of their colleagues.

9. Knowledge

Awareness

The range of topics that an advocate is likely to cover during the course of acting for someone who is engaging with welfare services is very broad. While some of the necessary material can be provided in the induction and in subsequent supervision sessions many of the

advocates described a process of searching on the internet to identify sources of information or the up to date position on fast moving issues.

It is important to provide volunteer advocates with a framework of knowledge, and sources of specialist that can expand over time in response to emerging needs, rather than being weighed down with substantial amounts of information that they may never have cause to use.

Access to the internet was not one of the criteria used to select people to act as advocates, and so for those who don't have a home computer or an internet service at home it may be useful to set up an account and to provide such training as is necessary to build personal confidence in this sphere.

10. Personal qualities

Selflessness

Altruism

Empathy

Warmth

'Nothing to prove'

Who said altruism was dead? Many of the volunteers talked of wanting to give something - unspecified - back. They had seen or learned of people who were less capable of making themselves heard or getting noticed and they wanted to apply their time to doing something to help. In some cases they had experienced the welfare system as a result of support for an ageing parent or other family member, providing them with valuable insights and the capacity to empathise.

They entered into the business of becoming an advocate with an open mind and a readiness to learn, and because, in many cases, this commitment was at the end of their working life they had 'nothing to prove' and so were willing learners.

In framing a call for volunteers it may be worth thinking about how to appeal to this impulse to volunteer – the gift of time – that appears to be driving many of the established group along.

B. Holding on to volunteers

1. Recognising motivation

The wish to do something that has the effect of 'giving something back', perhaps at the end of a long working career in which such motives may have been a long way from their employer's goals to which they were required to subscribe, was frequently cited as a key motivation. For others using their knowledge, skills or experience was seen as a way of remaining 'intellectually agile' – a variation on the

theme of 'use or lose it' as more than one, not especially old volunteer explained!

2. Making realistic commitments

Many of those who volunteered seemed to be leading busy lives, giving credence to the old saying, "if you want something doing, ask a busy person".

But this capacity to gather up yet more tasks in order to keep busy needs to be managed so that an advocate does not become overwhelmed and then under performs or withdraws as a consequence.

3. Offering flexibility

The role lends itself to being organised by the individual to fit their own needs, except when fixing to attend meetings with employees of various agencies, when the advocate needs to fit around those time constraints or demands.

Many advocates commented on this freedom as particularly useful in enabling them to do what needed to be done at times that suited their other commitments, while not compromising the commitment to work on behalf of their client.

Flexibility is a strong selling point to potential volunteers who may not wish to be tied to a commitment that demands a specific time or day each week.

4. Demonstrating their value

Without exception each of the users interviewed during the course of this work identified the advocate as playing a critical role in moving things on. They were warm in their praise for someone whom they recognised as doing worthwhile work for no monetary reward and seemed to relish the opportunity to give feedback that 'compensated' advocates for their time.

Users are encouraged to complete a form describing their experience of using the service and this has the effect of formalising the positive comments that may have been offered at regular intervals throughout the period of the 'contract' between them.

If positive comments are captured in a formal way they can be used for a number of purposes – to lift morale, if that's needed, to promote the service, and to demonstrate users' views to actual or potential sources of funding for the service.

5. Exit questionnaires

Turnover is low but this is not allowed to breed complacency and so each leaver is asked to complete an exit questionnaire, providing the opportunity to convey difficult messages about shortcomings in the service – its policies, procedures or personnel.

‘Leavers’ who have valued the support they have received are an excellent source of confirmation of good practice. And those who identify shortcomings are providing assistance to avoid a repeat performance.

C. Matching advocates with users

1. Role of Afl’s co-ordinator

It is self evident that without investing in a full time member of staff whose focus is explicitly on supporting and enabling volunteers the ‘return’ from investing in recruiting, training and deploying advocates would be significantly limited. The advocates obviously value the post and the post holder (it’s a bit of both!) and feel that they have someone on whom they call for help and guidance should they need it – at any point in the process.

The co-ordinator is well placed to make decisions on the ‘fit’ between people in need of an advocate, and the volunteers available, because she has been involved in each advocate’s journey from showing interest in undertaking the role through to carrying out various assignments. She is also the receiver of requests to allocate an advocate and speaks with the individual for whom the request has been made about their needs.

2. User’s preferences

People express preferences and the coordinator tries to ensure that these are understood and responded to. On one occasion it was put to her that a potential user must have a female advocate, but no woman was available at the time who fitted the bill in other ways. The coordinator met the user, talked through what her specific needs were, and why a female had been specified and then made the decision to offer the opportunity of linking up with a male advocate whose personal profile fitted well with the issues to be addressed, his personal qualities and the client’s concerns.

This matching went outside of what had been expected and what might have been judged unacceptable, but proved to be a great success. This of course is neither luck nor magic, but is the product of knowledge and skill – knowledge of what each advocate could offer and how they go about offering themselves to users; and skill in talking an initially wary user through a discussion about her preferences to arrive at a suitably respectful compromise with which the user was ultimately extremely satisfied.

3. Geography

Any organisation working across a geographically dispersed area is confronted with the tension between matching people on the basis of knowledge, skills, interest and past experiences while at the same time balancing the amount of time and money spent travelling. This is especially pronounced in areas where there are many smaller settlements as well as a few larger – though not especially large – urban areas.

Time spent in a car may vary from month to month, or more accurately season to season in an area with a coastline attracting extra visitors throughout the summer months when the roads are busier and journeys slower. While some people are happy to travel, and indeed specifically request engagements away from their immediate home area as a way of minimising the possibility of overlapping with other parts of their lives – perhaps causing role confusion, others prefer to stay within relatively close proximity to their home, enabling them to manage the use of their time most effectively without the complications or frustrations of travel.

4. Availability

One of the attractions of being an advocate, as expressed by a number of the volunteers, was that it was possible to manage time so as to fit commitments in at short notice – as may be the case when trying to manage appointments or contact with staff from a number of agencies – providing a degree of personal autonomy and flexibility which is not always possible or permitted when performing other roles, for example as part of a rota of staff.

The 'call' for volunteers suggested that people should be willing to make a commitment of 2 hours per week, but most of those who shared their opinions during the course of collecting this information suggested that it was a gross understatement of just how much time it was possible to spend when engaged as an advocate. However, this was never described in a negative fashion suggesting that it was not especially onerous or unwelcome – specifically because people felt in control of the time they were using. Research could be undertaken at times to suit the advocate, rather than during office hours, and tasks could be 'batched up' to suit the time available or the volunteer's other routines.

This facility for organising time to suit the needs of the assignment at the same time as fitting in with other aspects of everyday life is worth highlighting to maximise the possibility drawing in busy people who may wish to give time but don't wish to be subject to a regular time.

5. Experience and orientation

Volunteer advocates are as likely as their paid counterparts to have different interests, and aversions to some kinds of problems and

issues. Some assignments call for capacity or confidence in handling financial matters while others may be about managing conflict within or between family or formal carers.

In allocating people to cases it was clear that such sensitivities were understood and acknowledged so as to avoid feelings of discomfort or even personal lack of confidence or competence – not a feeling that one would like to associate with voluntary work.

The matching process needs to be holistic, taking account of people, places and preferences, while also making best use of the voluntary impulse to 'do good'.

Reaching people in need

Established...and respected

This service is reaching a relatively broad group of people, representative both of the breadth of people using care services and their locations within and outside the county's major population centres. This is not by accident but rather as a consequence of careful planning, effective networking, user satisfaction and the overall confidence in the quality of the service this breeds among potential and actual referrers.

There are presently around 40 advocates actively engaged in providing the service and most of them have at least one 'live' case on which they are working towards a resolution. There have been times when people in need of an advocate have had to join a waiting list. In some cases this may arise from the need to match a specific need, or the set of problems and issues to be addressed with the skills of a particular individual advocate, but it is also indicative of the reputation of the service and the readiness of staff of other agencies to make referrals.

Some care staff described feeling anxious that the intervention of an advocate should not become the basis for unpicking perfectly good decisions, albeit that the point arrived at did not necessarily meet with their client's approval or fulfil all their expectations. But they went on to praise the 'professionalism' of the volunteers – even if their advocacy had had the effect of overturning previous decisions, with which they (the paid worker) had been associated.

Interestingly, some social workers viewed the involvement of an advocate as being a way of getting a better deal for their client than they might have been able to secure, as they – independent advocates - were able to operate outside of the constraints of line management and departmental policies, staying focused on the needs of the person, and their wishes on how those needs might best be met, rather than having to comply with budgetary 'difficulties'.

It may not always be comfortable as the professional behind decisions and outcomes that may be presented as imperfect or inappropriate, but

those whom I spoke to did not express animosity towards either the individual advocates who were speaking up on behalf of clients, or the concept of independent support to enable people to get their voices heard more effectively. Indeed many welcomed this independent challenge to do better, and because they trusted the organisation of which the advocacy service is a part they were reassured that the service would be properly provided and of high quality. They did however report that often their clients were confused as to why yet another person needed to get involved, to ensure that they got what their social worker had recommended for them in the first place.

Satisfied customers are probably the single most important source of publicity any kind of service - commercial or charitable - can rely on to generate more users. Successive customer satisfaction surveys and the routine collection of user opinions at the conclusion of the previously agreed tasks suggest that Afl is highly respected.

Co-location helps

Afl is a service of the ILA, an organisation that supports disabled people, which employs staff who provide a variety of services to support people in leading as full and independent a life as is possible or desirable to the individual concerned.

The ILA has a contract with the county council to provide advice and support to people taking up the option of Direct Payments. The advisers working on this contract play a key role in guiding people through a system that can be very daunting for anyone unfamiliar with the world of welfare, local government and professional language and acronyms. The role they play is highly valued by users but stops short of acting as an advocate for people using the service. These advisers advise – they do not act on behalf of people who use their services to secure ‘a better deal’, rather they equip people with sufficient information to make informed choices, or to understand the limitations of the budget allocated for their needs. The limits may be about the amount of money or the agreed uses to which it can be put. They do however explain the existence and aims of Afl and are unsurprisingly, a significant source of referrals to it.

The boundaries between Afl and the DP advisers became clear in discussion with both parties. They may even have been clearer (to this writer) had they not been located within the same organisation – and in some cases in the same office, but any minor confusion arising was more than compensated for because it is clear that the traffic between two parts of the organisation makes for a smoother transition, with potential users having greater clarity about what they might expect from an advocate.

Being independent

It's not where you are – it's what you do...

The service is located within, and operates as a part of the Independent Living Association - West Sussex. This arrangement is of significant benefit to the advocates who made many mentions of the wisdom and helpfulness of various staff, especially the DP advisors who explained the intricacies of the care system to them.

The ILA provides other support services to enable people to control their budgets effectively and efficiently, including a payroll/personnel service, which users mentioned as being especially helpful in removing worries about recruiting and employing their own staff.

The payroll service is funded by the charges made to users, but the service provided by DP advisors assisting users to develop their individual support plans, and providing them with assistance to steer their way through the intricacies of the social care system is the subject of a service contract between the county council and the ILA.

This is an important contract providing users with access to a service that presents them with vital information to organise and manage their lives. It is important to separate the advocacy service from this contractual activity so that neither area of work is compromised. DP advisors recognise that sometimes users are unhappy with the budget allocated, the restrictions put on its use or attempts to claw back unspent funds and welcome the opportunity to refer people on to an independent source of support, so that they can pursue their concern without confusing users or those whose decisions they wish to challenge.

During the time that this work was being carried out it was interesting to note the way in which users responded to an online discussion in the Members' Forum (of the ILA website), initiated by a 'new' user who was not entirely convinced about the motivation of the council in offering him DP, nor in the value of engaging the services of an advocate provided by the ILA. He argued that Afl appeared to be close to the council because it was part of an organisation providing services on the council's behalf, and therefore unlikely to challenge its authority.

Although the Forum is perhaps not as widely used as the association might wish for it was interesting nevertheless to note that other members were quick to reassure him - in some cases providing evidence drawn from their personal experiences - of the absolute independence of the advocacy service. The strength of response from just a few people whom he could judge as being as sceptical or cynical as himself - by reference to their postings on other discussion strands - had the effect of putting his mind at rest, and his subsequent use of an advocate confirmed him in this judgement. This provided evidence, if it were needed, that the views of one's peers are often more powerful than any amount of well-argued papers.

Policies and procedures

Much of this paper has focused on the people delivering the service. This is not unreasonable as they are very evidently one of the great assets of the service. But their individual and collective performance is regulated by the policies and procedures that Afl has developed to ensure that the organisation functions effectively, and keeps all records necessary in order to be accountable to users and commissioners of the service.

Some of the people seeking help have just one specific need with which they need some help, but others may have a number of issues that they want to have resolved. Afl's policy is that there should be no more than three issues receiving attention during an advocacy 'episode'. The issues to be addressed are agreed at the outset when the co-ordinator takes and accepts the referral. In some instances advocates may identify other issues and concerns that could benefit from attention or the user highlights other matters, but both parties have been instructed not to tackle additional work without first completing the task or tasks set at the beginning and not without reporting back to Afl to ensure that the topic fits with wider policies, such as not taking on advising about issues that should be dealt with by another specialist agency. This is partly to protect advocates from becoming over run or enveloped by a host of issues that prevent them from thinking and acting clearly on behalf of their client, but it is also intended to act as a barrier to someone acquiring their own semi-permanent personal supporter, and becoming dependent on that person. It is also aimed at maintaining the integrity and distinctiveness of an advocacy service rather than becoming another source of advice and information.

Producing a simple description of the aims of an advocacy service and the role of an advocate goes a long way to ensuring that all parties are clear about expectations and obligations.

The co-ordinator discusses the issue or issues that brought the user into contact with the service and then having agreed the priority (or only) tasks drafts a brief agreement which states the 'advocacy issue' and also has space to identify goals, actions and dates. This is a key document, but there are others - not so many as to create the need for shortcuts to avoid excess paperwork - but enough to ensure that records are kept which the advocate can use to track progress, highlight actions taken or outstanding and use to progress chase either agencies or individual staff members in relation to their role or responsibilities for the person they are advocating for.

Probably the single most impressive thing about each of the forms and other paperwork produced by Afl was the brevity and simplicity. Even if a form is only for internal use it is written with a view to being read and

understood by a layperson, with no prior knowledge of the language of the world of care and support.

Documentation is vital, but need be neither long nor complicated to be useful. The words used should be free of jargon and acronyms.

Some users' experiences

1. Mr Thames

- *Referred by an ILA DP advisor*

Mr Thames lives alone and receives assistance with various daily activities, after a series of health problems that have left him struggling to look after himself. A DP Advisor had referred him to Afl after visiting to discuss setting up an individual budget (IB). He had been assessed as needing to contribute £30.30 per week towards the cost of his care, but was having great difficulty understanding what an IB was and didn't think it was what he wanted.

- *Social worker needed to be better informed*

His social worker had drawn up a Support Plan but he wasn't happy with it and didn't think it reflected his needs. The advocate's first contact with Mr T was in the company of his social worker who confessed to not having enough knowledge of IBs and wanted to listen to a fuller explanation of how the money could be used. The advocate also used this time to enable Mr T to describe his current situation, and to outline the range of help he drew on informally as well as formally, in order to lead a life that suited him. It became clear that he had several informal carers as well as someone he paid from his benefits to help him once a week with his personal care and some domestic chores. Alongside of this he also received help from the council's homecare team, although there was only person whom he felt comfortable enough to permit her to assist with his personal care.

- *Exploring the real cost of living*

The advocate's next task was to review Mr T's disability related expenditure. When this was completed it led the council to revise their view on how much he should contribute to his care, reducing it to £8.70 per week. This enabled him to move on to consider how he might use his IB. Initially he agreed to use an agency, in line with his social worker's wish, but then after thinking through the options he decided that he would prefer to employ the person with whom he was already familiar. This didn't please the social worker who had wanted him to choose from a restricted list of agencies, of her choosing with which she would subsequently be able to check that he was using for purposes consistent with her view of what her client needed. The advocate explained to the social worker that Mr T did not feel comfortable entrusting his personal care to just anyone and that he wanted to carry on using someone with whom he had developed trust and understanding. His social worker had difficulty in accepting that Mr T should have such a degree of choice but reluctantly agreed.

- *Explaining, clarifying and supporting*

Afl's advocate played a vital role by explaining more fully than anyone else had managed to do, the options open to him and had assisted him to take stock of his present and projected future spending patterns so that a more accurate assessment of his personal liability was made, in

turn giving him greater confidence that an IB was a route that he could make use of. She was a support in meetings that had previously been unequal, unsatisfactory and inaccurate. At the end of the process Mr T had developed a new Support Plan that has enabled him to take charge of his situation. The last words are his, *“I don’t know what I would have done without her – she’s the only one who seemed to speak my language, and she made sure that they knew what I wanted.”*

2. Mrs Severn

- *Social work manager recognises need*

Mrs Severn was referred to Afl by a social services manager who was concerned that there had been a lot of delays in getting her care package set up.

- *Understanding and responding to choice*

When the advocate got involved it became apparent that the principal reason why this 90-year-old lady’s package was taking so long was because she was very particular about what mattered to her. She considered a clean home to be important and she wasn’t going to compromise on that as an essential element of meeting her needs, any more than she would accept inadequate, inappropriate or insensitive help with her personal care. The advocate met with Mrs S and her daughter, who while being helpful and involved, did not live locally and so could not fill in the gaps that had emerged. Together the three of them identified the elements of a plan that would ensure the safety of a physically frail and visually impaired lady, at the same time as also recognising that her well being would be affected by a failure to address things that were important to her. Such tasks if left undone might lead her to put herself at risk by attempting to complete them.

- *Interpreting, mediating and compromising too*

Through carefully noting Mrs S’s needs and preferences, and then ensuring that these were conveyed back to the manager in language that fitted with how that organisation sees its priorities, it was possible to sign off a Support Plan that was responsive to the user’s needs. There was an element of compromise on both sides as Mrs S and her daughter agreed pay some of the cost - having previously being assessed as not needing to make a contribution - because the cost of meeting all her wishes exceeded the allocated funding. This was a small price to pay for assuming full control and having all the support she believed she needed, *“...life is now worth living again...”*. She now employs personal assistants who are happy to provide her with the standards of care and cleanliness that she considers to be so important.

3. Mr Nene

- *Disappointed and sceptical*

Mr Nene lives with his wife and one of his three daughters in a small village. Since having a stroke a few years ago and then returning to the family home he had received help from a home care agency arranged by the council. He passed retirement age a few years ago. Sometimes the services haven't been all that he might have hoped for in terms of flexibility around timing and the tasks to be undertaken and he has found himself frustrated at his inability to change things to suit his needs and wishes. It was after a series of "blunders" and yet another change of social worker that he was encouraged to explore the use of Direct Payments to manage his care needs. He was somewhat cynical about the underlying reasons for this being suggested to him, and some of his experiences since then have strengthened those feelings.

- *Getting to grips with the system*

He subsequently made contact with the advocacy service as he felt that his social worker was neither knowledgeable about the use of DP nor especially sensitive to his situation and needed more of a challenge than he could provide alone. Mr N is capable of representing himself but has some difficulties in doing so as a result of the continuing effects of his stroke and also feels handicapped by being unable to get out without assistance. In beginning the process of working towards agreeing a budget for his care needs his social worker has asked him to reconsider his current attendance at a specialist day centre for people with an acquired brain injury on two days a week, as it is "too expensive". She suggested that he should visit two alternative centres. While he was unhappy at the prospect of giving up the specialist place he attends, and has gained so much from, he was open-minded enough to be prepared to put himself out to visit the alternatives. It seems that because he passed retirement age a few years ago he is to be slotted into a day centre for older people. *"It wasn't difficult to see why both the places would be a lot cheaper, and this has made it all so much clearer why I must challenge her at this stage. If I don't I'll be left with a small budget, and day care completely unsuited to my needs and preferences. This has confirmed my worst fears."*

- *Valuing the service – more to come*

Mr N has been grateful for the support he has received from his advocate and expects to be making a lot of use of him over the coming period.

Discussion

The mood music may have changed from the 'needs led assessment' and 'seamless service' which the last major set of community care changes heralded in the early 90s, but for organisations assisting people to get their voices heard in an era of 'personalisation' the song remains the same - "*it ain't what you do, it's the way that you do it!*"

Helping people to take control of budgets, articulating what they want the money for, asserting their right to be heard and their wishes acted on may lead some of us to feel unequal to the task. We may think that we need to be equipped with calculators and mathematical formulae, and a grasp of the opaque systems for arriving at the precise sum of money to be allocated, but it is very clear that some enduring truths come into play before the accountants have their way.

Being clear about the focus of an advocacy service, and communicating that to users and referring organisations from the outset is more likely to lead to satisfaction for all concerned than to allow expectations to develop that cannot be met.

Where Afl seems to have been particularly effective is in building a team of committed people who seem to be unperturbed by the possibility that they will be up against more powerful agencies and more knowledgeable staff. The story of individual successes and of some users experiences suggests that staff of these bigger agencies do not have a monopoly on knowledge. But even if - or when - they do, being non-judgemental, having good listening skills and being committed to empowering people to seek out and secure their rights and entitlements is at least an even match for them.

End note

It was disappointing to discover that Afl is no longer able to provide a service to older people in the county. This is a consequence of budgetary pressures and the belief that there are sufficient sources of information and advice available to meet most needs. It is not a comment on the work of the service as council officers who contributed to this report were each very positive in their comments.

However, older people or their families continued to contact Afl for help because it's work is known about, respected and trusted. This has now diminished as it has become clear that advocacy - as distinct from information and advice - is no longer available. It is reasonable to suggest that there are still plenty of people who could benefit from the help that an independent advocate can provide and the difference they can make.

The Care Quality Commission undertook an inspection of West Sussex County Council Adult Social Care services in the autumn of 2009. The inspection focused on “safeguarding” and “increased choice and control for older people”, and was published on 5th January 2010.

The inspectors noted that:

“Advocacy services did not have a high profile and were not routinely used to support people in their decision-making or through the assessment processes. The Independent Mental Capacity Advocates (IMCA) service was used to provide advocacy support for older people who did not have the mental capacity to make their own decisions. Outside of this specific remit there were no other advocacy services available to support older people through assessment and support planning processes. This was a significant gap that needed to be addressed.”

The report recommends that:

“The council should ensure that...all older people who use services should have access to advocacy.”

In discussing the work of Afl with the council’s strategic manager for commissioning and policy development, ahead of the CQC inspection findings being in the public domain, it became clear that considerable thought is being given as to how best they can respond to CQC’s recommendations. Although budgetary constraints make finding new resources difficult it was suggested that the critical issue is to make use of existing resources – financial, organisational and personnel – to ensure that older people have the widest range of support available to enable them to exercise choice and control.

This is an optimistic – and hopefully realistic – note on which to end.

APPENDIX

Advocacy for Independence documentation

1. Explanatory/promotional brochure
Introduces the organisation, describes advocacy and the ways in can help, and identifies the groups of people eligible for the service
2. Promotional poster “Do you need an advocate?”
Abbreviated version of above leaflet, designed for notice boards
3. Promotional poster “Could you be a volunteer advocate?”
Similarly abbreviated version of what an advocate does, designed for notice boards
4. Response letter – following enquiry from potential advocate
Letter outlining the process leading up to becoming an advocate – selection process and training
5. Explanation: What is advocacy?
Brief description of advocacy and Afl
6. Person Specification and Job Description for volunteer advocates
List of knowledge, skills and attributes and major tasks of advocates
7. FAQ – on becoming a volunteer advocate
Answers to issues that may influence whether enquirers apply to become advocates
8. Volunteer application form
9. Policy statement on the recruitment of ex-offenders
Explanation of the context for seeking information relating to criminal record
10. Applicant’s declaration in relation to criminal offences (pre CRB check)
11. Agreement – between Afl and user
Outline of issue, goals and planned actions
12. Client Log sheet
Log of contacts, actions and any relevant notes
13. Client details
Name, address and contact points with space for other information
14. Client record sheet (visits, telephone calls, letters)
Record of activity undertaken for management/supervisory purposes
15. Consent form (authority to act)

Letter authorising Afl to act on behalf of the client

16. Calling card

Providing client with advocate's name and Afl contact points

17. Service agreement

Outline of the purposes and limits of advocacy and of Afl's expectations clients using the service

18. Letter to client, accompanying end of agreement questionnaire

19. End of agreement questionnaire

Form seeking views on service/advocate performance and/or satisfaction

20. Exit form – for volunteer advocates

Form seeking views on why the advocate has decided to cease volunteering