



# “Wheelchair access? That’s a lifestyle choice!”

Lessons from a Pilot Advocacy Service in South West England

MAY 2009

## About us

**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.

We have 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.

We work closely with central and local government, health trusts and others, advising on independent advocacy work with older people, and undertaking development projects and commissions.

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# Introduction

This report describes the emergence of a small pilot advocacy service for adults in the South West of England during 2008. The Older People's Advocacy Alliance (OPAAL) was invited to conduct an evaluation of the project, and during the course of that work it was felt that it would be useful to share some of the findings more widely – beyond the partner agencies and county boundaries.

The identity of individuals using the service has been protected by presenting information entirely anonymously. Each of the users whose comments on the service are reported gave consent to being quoted.

The facts contained in the report have been derived from a range of sources, most importantly service files held by the advocacy scheme themselves, but the opinions and ideas are largely those of the writer and OPAAL.

At the time of writing, decisions about longer term funding for the scheme had not been finalised. But if service performance were the only or predominant factor influencing the outcome, there would be little doubt about the continued existence and further development of a modest – but far from marginal – addition to the services available for citizens of the area which this scheme serves.

**Les Bright**  
**Exeter**  
**May 2009**

# Key lessons from the pilot advocacy service

## **For OPAAL:**

Think carefully about the scope for achieving goals at local level where no friends (real or imagined) exist. Build on contacts, pursue leads and embrace local organisations as leaders in their communities.

Produce an explanatory/descriptive leaflet for potential users – and for staff of agencies making referrals – outlining the roles an advocate can play.

## **For OPAAL and others:**

Identify and exploit opportunities to work with other organisations whose skills, knowledge or experience will add to existing internal resources.

## **For OPAAL and service providers:**

Work referred to an advocacy service may not always fit within a strictly defined vision of what an advocacy service does, but should be seen as appropriate and providing evidence of gaps in provision, which could form the basis of lobbying for wider change to policies and provisions as well as practical support to individuals.

## **For organisations working in partnership:**

Draft and sign an agreement outlining roles, functions and accountabilities at the outset, but don't be afraid to change arrangements in the light of experience. Ensure that appropriate and sufficient support is available to the person managing the service.

## **For service providers:**

Separating management from supervision and support can look fine on paper but may be tricky or problematic for supervisor, manager and managed – especially in a start-up phase.

Recognise and respond to the exceptional fragility of small teams. Hope for the best, plan for the worst and manage the consequences!

Working from home may be the right answer – in some situations – but care is needed to ensure that it does not 'turn into its opposite' and become the only, or dominant, rationale for how cases are managed or allocated.

**For service commissioners and providers:**

Searching for average times spent with users – without understanding the factors involved – adds little to our understanding of the work being undertaken, but could consume a disproportionate amount of time.

Transport availability, distances and density of traffic impact on efficiency and need to be factored into any targets given to services or individual staff.

**For service commissioners:**

Commissioning the service is only part of the story – ensuring that it is known about and used requires ongoing attention.

Loneliness and isolation are features of some older people's lives, and for some service users a 'little bit of help' will make a major difference to their well being.

**For service commissioners, providers, and older people:**

There is plenty of unmet need for people living alone or with others – in the community or in care homes.

**For older people:**

Organisations describe their work and priorities in terms that may lead you to think that you don't qualify for help, but it's worth persisting unless and until you are told that you don't qualify.

**For all:**

Leadership can be hit and miss – when it emerges, people should be nurtured and supported in order to prevent 'burn out'.

Volunteers are not a 'free' source of labour. They need as much training and support as paid colleagues if they are to be effective.

# Background

The pilot independent advocacy service on which this report is based began its operations in April 2008. It was established as a joint venture by a user led organisation focused on physical and sensory disability issues, and a voluntary organisation concerned with the needs of older people which serves much of the county. The local authority with social services responsibilities for the area provided funding for one year.

## Building momentum: combining national and local agendas

The service was intended to function as an action research project, and the local authority's decision to fund its pilot phase followed on from discussion and consultation around the need for advocacy services led by one of the project partners in the summer and autumn of 2007. That consultative process had culminated in a 'Stakeholder Day' in mid October 2007, and the subsequent establishment of a county-wide Advocacy Forum, whose members have been thinking through policies that will define and underpin the provision of high quality advocacy services to support a wide range of different needs.

Early in the life of the pilot project the Older People's Advocacy Alliance (OPAAL), which had become known in the area during the summer of 2007, was appointed to conduct an evaluation of the service, and was directed to deliver a report at the half way point in the financial year in order to inform the council's strategy and future commissioning intentions. This allowed very little time for patterns to emerge, referrals to take off, and for advocates to meet users and work through what needed to be done to resolve the problems being presented to them. However, the need for an informed but independent commentary on the project's work was considered to be central to presenting a credible bid for additional funding. So, with this important caveat, data was collected and analysed with a report being produced on time.

## Luck?

OPAAL is a small organisation with only one full time member of staff, and a number of associates who undertake project work on an 'as required' basis. It was entirely coincidental that OPAAL had a presence in the region through one of these associates (the writer of this paper) who had been commissioned to undertake a small project in the South West, as part of OPAAL's wider programme of promoting the need for and value of advocacy.

During the course of that work, which was slow to yield any opportunities for development, I stumbled across one of the partner organisations when it was conducting a piece of work funded by a 'Capacity Builders' grant, looking at the availability of and need for advocacy services in the county. This had arisen from



concerns expressed by government inspectors reviewing the council's provisions for people with physical disabilities. They had identified the absence of advocacy services to support people in expressing and fulfilling their choices, and the council had begun working on a response.

This 'providential stumbling' is perhaps the first lesson – at least for small national bodies like OPAAL, aspiring to do something 'on the ground' – that local connections count for a lot and make progress possible that could otherwise only be dreamed of, when making occasional trips into an area where there is no local network known to them, no support structure, no history and perhaps no friends either. Local needs are more likely to create the conditions under which support can be gained for the establishment of new projects, rather than the power of proselytising about the latest policy ideas emanating from the national policy agenda – unless, of course that national connection comes with dedicated project funds.

So, it seems that a happy coincidence or lucky timing had the effect of acting as a matchmaker where two organisations discovered they had interests in common and a shared set of values that led to them laying plans to work together. The fact that this fitted with an emerging priority for the county council – a potential funder of any development – suggested another layer of luck.

## Lesson 1

**(for OPAAL):** Think carefully about the scope for achieving goals at local level where no friends (real or imagined) exist. Build on contacts, pursue leads and embrace local organisations as leaders in their communities.



## Partnership parameters

Much is rightly made of partnership working, and in the run-up to what became the starting point for the pilot project, OPAAL and the local organisation worked as partners. Together they organised an event that set out to bring together a wide range of organisations and individuals to generate momentum and support for improvements in the availability of and access to advocacy services. In addition the two organisations also submitted a proposal for support from the Department of Health's scheme of grants for voluntary organisations. While this failed to progress – in a very competitive environment – the process of working on the ideas proved to be valuable in clarifying what was needed and how a future project might be arranged.

This initial planning phase was greatly assisted by the active engagement of a policy manager from the council who shared a vision for improvements to services. This was very welcome and also led to a small grant to meet the costs of putting on the meeting that later proved to be pivotal to developing ideas capable of securing funding – albeit on a short-term basis.

When it came to establishing the service the county council was looking for some form of partnership working, in the belief that this delivers more than the sum of the parts. While this may be true it is not without costs in terms of time spent developing the 'rules of partnership' and maybe an element of 'double reporting' for staff who feel the need to be accountable to all partners.

The local organisation had to consider possible partners. OPAAL was not in the running, as it had neither a local network nor any resources that it could offer up, other than the associate who happened to live in the region. And in any event, OPAAL does not set out to be a service provider, preferring to remain a catalyst for ideas and a supporter and promoter of others' activities.

In the preceding year, the user led local organisation had had some experience in providing advocacy services as the joint promoter of an Independent Mental Capacity Advocacy (IMCA) service, in partnership with a voluntary organisation concerned with the needs of older people. This existing relationship meant that conducting an extensive search for possible partners for the new pilot service became unnecessary. Partnership emerged from a tacit acknowledgement that the two organisations could build on work that they were already undertaking together.

### Lesson 2

**(for OPAAL and others):** Identify and exploit opportunities to work with other organisations whose skills, knowledge or experience will add to existing internal resources.

# Service start-up

The service specification stated that the partners should:

***“...provide high quality instructed advocacy for vulnerable people over the age of 18 with complex health, social care and accommodation support needs due to physical and/or sensory disability.”***

The service’s promotional brochure, distributed to a range of agencies, stated:

***“[The service] assists and empowers individuals with physical and sensory disabilities or older people experiencing general frailty to access services in order to lead full and independent lives.”***

This leaflet, with the strap line “Helping you to express what you want”, suggesting that it is aimed at users, goes on to describe the ways in which the service could help in terms that are particularly well suited to a lay audience.

## Management arrangements

The service was a joint venture between two established organisations, each with substantial track records of providing services.

Both partners were named on the contract as being equally accountable for service delivery. One partner received and managed the funds on behalf of both organisations and distributed finance in accordance with the agreed budget.

Initially the operations director for the voluntary organisation concerned with the needs of older people was accountable – professionally and managerially – for the service. This included ensuring that it was delivered in accordance with the contract and that team members were appropriately recruited, trained and supervised. The user led organisation acted as employer for the Lead Advocate and the team members responsible for delivering the service, and also provided an office base and practical support.

The resignation of the operations director led to some key changes. Consequently the chief officer of the user led organisation became more involved in operational management and it seemed that this, while not fitting with the original notion of shared operations and management between the two sponsoring agencies, was more effective than the arrangement it replaced.

The team appeared to want and need a more empathetic style, of the kind that might arise from the manager being closer to the issues faced by the team and any problems arising for them in managing their work, rather than a task orientated approach, checking that individual and team goals were being met. This may have been exacerbated by inter-organisational issues and cultures, or simply by one person’s perceptions of such factors.

## Lesson 3

**(for service providers):** Separating management from supervision and support can look fine on paper but may be tricky or problematic for supervisor, manager and managed – especially in a start-up phase.

### The challenge of partnership

One problem should not become the basis for developing an aversion to encouraging organisations to work together in partnership or to enter into other joint working arrangements. However, partners need to consider the management arrangements and potential risks, such as structural weaknesses, or unfortunate events of the kind that can occur at any time in any single organisation and the impact these can have on service delivery.

Commissioners should also consider whether partnership always delivers added value, or whether the costs or downsides cancel out any gains that accrue.

Tensions can and do arise because organisations have different ways of managing their affairs; or a lack of clarity among partners about their respective roles and functions; or elements of competitiveness between partner organisations. As mature and experienced organisations with experienced CEOs, the partners appeared to have recognised these possibilities by producing a partnership agreement to govern their relationships and functions, as they had done earlier with the IMCA service.

The unplanned changes to management did not prove to have a damaging effect on the service provided, although it placed more pressure on the chief officer of the user led organisation to fill some of the vacuum, and on the Lead Advocate to adjust to that situation, by taking responsibility for more day-to-day decisions without recourse to a second opinion from a senior manager. Given the size of the workload – supervising others and managing day-to-day, while also acting as an advocate – it did seem that, in common with many voluntary sector posts, the job called for an extraordinary person to fill it, and for them to have significant reserves of energy to keep going through a period of disruption.

Removing this layer of management can be seen as a positive demonstration of a flexible and responsive approach by the partners. But if that approach is followed it seems important to identify ways in which the person fulfilling the first line management role will be supported to avoid crumbling under the weight of expectations – and daily routines. ‘Under managing’ ought to be seen as comparable with under performing – in service delivery – and to be avoided,

but there may be a tendency to present it as a bonus – “we’re completely productive, and don’t ‘waste’ too much on management”

## Lesson 4

**(for organisations working in partnership):** Draft and sign an agreement outlining roles, functions and accountabilities at the outset, but don’t be afraid to change arrangements in the light of experience. Ensure that appropriate and sufficient support is available to the person managing the service.

## Staffing

The service consists of three staff. The Lead Advocate is a full time post while the other two members of staff are each employed for 20 hours per week. The Lead Advocate is based at the user led organisation’s offices, while two colleagues operate partly from home and partly from the office base.

Small staff teams can rapidly build a sense of cohesiveness and shared endeavour, though this may take longer when people work independently and from home. Time spent on team meetings and other shared activities is vital to this process, but may seem to be a bit of a luxury when staff are part time, and there is ‘real work’ waiting to be done.

Small teams may also be quite fragile and therefore vulnerable to small events which have bigger impacts on their overall functioning. This was borne out by two events relating to staffing. First, one of the start-up team went on maternity leave just 3 months into the life of the service. Her replacement was appointed and took up post before her departure, and therefore effective handover arrangements were put in place to ensure that this change did not adversely affect users of the service. Next, the other part time advocate was absent on compassionate leave for some weeks and returned to work only sporadically throughout the ensuing months. This uncertainty put considerable strain on the Lead Advocate who continued with all their own duties while also reviewing progress and keeping an eye open for any critical timescales – or the need for action – in relation to the absent colleague’s caseload.

Even if it is possible to find, pay for and deploy a temporary member of staff to fill in during an indeterminate period it may not be desirable in all circumstances. It is often the case that people have arrived at an advocacy service after trying a number of other sources of help or remedies without success; or following a disagreement about

the advice given, having rejected the help or advice being offered from those other sources. Having been allocated an advocate with whom the individual hopes to build a productive relationship, and then being required to transfer to another person because the first advocate has taken maternity leave may be acceptable – even if not desirable. If, however, the second person withdraws or becomes unavailable then the user may lose faith in the service – rapidly. The Lead Advocate was faced with a tricky balancing act as they attempted to make best use of limited resources while also complying with the specification’s requirement to provide a “high quality instructed advocacy service”. Consequently the **Lead Advocate** opted to keep an eye on **their** absent colleague’s workload rather than seeking additional staffing. This was almost certainly best for the users, but put considerable pressure on them.

## Lesson 5

**(for service providers):** Recognise and respond to the exceptional fragility of small teams. Hope for the best, plan for the worst and manage the consequences!

## Leadership

It is important to draw attention to the importance of leadership in the success – or failure – of any endeavour. The county council gave a lead by funding the pilot service in order that there could be a greater shared understanding of the need for advocacy to support some of the county’s citizens.

The partner organisations also offered leadership in campaigning for and then developing the service. But each of these elements would have counted for nothing if there had not been effective daily team leadership from the Lead Advocate – providing direction, inspiring and supporting team members and gaining the trust and respect of colleagues – and manager.

I was greatly impressed by the clarity of thought and purpose shown by the Lead Advocate, throughout the evaluation period and beyond, and with their readiness to reflect on difficulties in a constructive way.

## Lesson 6

**(for all):** Leadership can be hit and miss – when it emerges, people should be nurtured and supported in order to prevent ‘burn out’.

# Service delivery

## 'Averages'

Team members kept careful notes of the work undertaken, and on most (though not all) occasions, the time it took to do that work. But it has not been possible to come up with an 'average' time per case, or an average amount of time spent travelling to visit someone at home – a critical issue particularly in a rural county when totting up the use of advocates' time.

Although commissioners may see the need for some measurement of the time spent on each case, this will prove only to be indicative of the time spent on those cases, rather than being a reliable measure of how long it takes to advocate successfully for someone who needs an advocate. In a predominantly rural county a significant issue is the distance from office locations to people's homes.

### Lesson 7

**(for service commissioners and providers):** Searching for average times spent with users – without understanding the factors involved – adds little to our understanding of the work being undertaken, but could consume a disproportionate amount of time.

In some situations, it was helpful that two members of the team operated from home and this in part determined which cases were allocated to them – on the basis of ease of access with contingent savings on time and travel costs. So, with a team member living around 30 miles north west of the office location it made sense for them to pick up work in that part of the county, reducing the amount of time that would otherwise have been spent reaching a user's home. However, it should be noted that the distribution of cases did not helpfully follow that pattern. There was insufficient work close to the staff member's home, with one in four cases emanating from the area in which the office was located, and one in five from the south-eastern side of the county. The 'mismatch' between where staff live and the locations from which the largest number of cases are being referred is likely to continue to be a logistical challenge for the service.

## Lesson 8

**(for service providers):** Working from home may be the right answer – in some situations – but care is needed to ensure that it does not ‘turn into its opposite’ and become the only, or dominant rationale for how cases are managed or allocated.

### Distances

Conducting a home visit to an individual at their home in the most southerly district consumed in excess of one half day – and during the holiday season journey times can increase significantly. One home visit – travel to/from the interview, to say nothing of any subsequent recording and action – consumed almost 20% of the time available in a week for that full time member of staff (or 40% if the case had been allocated to one of the part time staff on the basis of specific knowledge or skills relevant to the user’s problems).

This is clearly a critical issue impacting on the efficiency of the service – if time and cost are the indicators of efficiency. Careful consideration had been given to ways of minimising travel time by allocating cases on the basis of geography. But adopting this approach may not provide the best fit of advocates’ knowledge, skills and experience to the user’s needs. Once again the Lead Advocate was faced with a balancing act that was managed well.

As time goes by and the strengths of the staff team become clearer, the matching process will become even more important, and may lead to geographical considerations featuring less than specialist knowledge or skills of team members. But there is a price for this – substantially higher travel costs arising from longer journeys being made by all or part of the team.

This is a standard feature of services planned for and delivered in rural areas (SCIE 2007, Allen et al 1994) although people working in cities and other urban areas may counter with the view that time spent in slow moving traffic can more than match the time spent travelling longer distances to appointments. Time is precious and costly; travel is time-consuming and also costly – for small organisations these considerations may become more important as they wrestle with demands to make best use of resources while also demonstrating shrewd use of limited finance and a small team.



## Lesson 9

**(for service commissioners and providers):** Transport availability, distances and density of traffic impact on efficiency and need to be factored into any targets given to services or individual staff.

### The advocate's role

The content of an advocate's work changes, depending on the nature of the presenting problem, any other issues that emerge as cases are explored, and the capacity and capability of individual users. These are some of the roles – or combinations over the lifetime of a case – that advocates took on during the project:

#### A range of roles for independent advocates

##### ***“Interpreter”***

Advocates play a vital role interpreting the situation facing the user, and then attempting to translate this into a form that can be understood and acted on by the person concerned.

##### ***“Navigator”***

People frequently need help to work out their way around the system. For some people, being given a map and some navigational equipment enables them to manage their journey for themselves, coming back to port only if they run into heavy seas.

##### ***“Communicator”***

Producing letters in response to a user's instructions is altogether more manageable as the advocate can apportion time and take action in a more orderly and controlled fashion. However, written communications do not necessarily evoke swift or meaningful responses and so time is then expended on chasing for answers or clarifications.

Given that the service was established with the needs of people with sensory impairments in mind, further dimensions of communication needs (either for signers or equipment to facilitate participation and understanding) may arise. Alongside this, being able to call on interpretation and translation services for people whose first language is not English can also present challenges.

***“Listener”***

People report difficulties getting their voice heard, sometimes because they have been talking to the wrong person or agency. Being an effective and empathetic listener is time consuming, especially in the early stages of establishing a meaningful relationship with the user.

***“Mediator”***

Taking action to get people talking to one another, where communications have broken down (thus exacerbating already difficult situations) is a common advocacy role.

***“Supporter”***

Where people are in conflict with agencies or are wishing to pursue a complaint, the advocate is seen by the user as a supporter, even when the advocate may be helping the user to rethink their options and the usefulness of continuing to tussle with one or more people with whom they are in conflict.

***“Befriender”***

There is some evidence to suggest that users – particularly those who are isolated – may view the advocate as a friend, putting unrealistic expectations on them for a closer or more demanding relationship than that being offered through the medium of a small service.

This list is not exhaustive and is only intended to highlight the range of possible roles, as well as the scope for confusion in the user’s mind about what the service will be able to do. Staff of agencies making referrals to the service may also share this confusion.

**Lesson 10**

**(for OPAAL):** Produce an explanatory/descriptive leaflet for potential users – and for staff of agencies making referrals – outlining the roles an advocate can play.

## Other key areas of activity

### Signposting

Within the roles outlined above there is a significant amount of activity that could be described as 'signposting'. This is vital to assist people to remain in control of their situation, and is also part of the process of building a relationship of trust by doing things the user considers to be useful.

Despite the existence of various sources of information people continue to be unaware of the range of services that they might be able to draw on for help, or are wary of making contact with a statutory service because they don't know where this might lead. Resolving such a big issue was beyond the remit of a small pilot advocacy project, but it does provide an opportunity to ask why the people helped by the pilot service had not made use of other long established and ostensibly better known services. (However, questions like this could be seen as of greater interest to the advocate or evaluator asking the question than to the user.)

There is substantial evidence that people considered to have 'lower level' needs are pointed away from contact with local authority services as a way of managing demand<sup>1</sup>. One possible consequence of people learning that this may happen to them is that they just don't bother to check out whether they might pass or fail an eligibility test for services (any more than they would voluntarily offer to undergo a test of their financial means). So it is likely that users may arrive at a voluntary organisation's service without having been subject to any service rationing techniques.

The Equality and Human Rights Commission<sup>2</sup>, outlining its thinking around the reform of social care, identifies the need for information and advice – and where necessary independent advocacy – to empower everyone requiring care and support. Pointing people towards sources of further information and giving them the confidence to ask for more fits very closely with this need, and contributes effectively to enabling people to be in control of their situation.

### Form filling and 'paperwork'

Many people have great difficulty in understanding and completing forms necessary to secure access to a wide range of services and benefits – and thus simply do not bother to pursue their legitimate entitlements. Coincidentally, at the time of evaluating the pilot's activities, the Local Government Association had something significant to say on this issue, underlining these emerging findings<sup>3</sup>.

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1 CSCI's annual state of social care report published in January 2008 identified people as being "lost to the system" as a result of rationing by discretion (professional), direction (policy) and diversion (signposting).

2 "From safety net to springboard: a new approach to care and support for all based on equality and human rights" (2009)

3 "Our lives, our choices" highlights the possibility that some people seeking help to meet their social care needs may be confronted by up to 700 questions, from 8 different bodies.

Completing forms, and providing help with other kinds of 'paperwork', was a feature of many contacts. While it may not be necessary or desirable to establish an advocacy service to assist people to complete lengthy (or any) forms, there is little doubt that this need should be attended to in some way. Locally, the council's Care Direct service can provide assistance for people seeking welfare benefits, but this is not the only area of service that produces forms that cause confusion and anxiety. Capturing such activity within the context of an advocacy service may enable people to express their concerns across a wider range of issues for which they need support than might otherwise be possible in a more limited service focused solely on completing forms.

Existing support, dedicated to completing baffling assessment and/or application forms produced by various agencies, is only part of the picture. There is evidence to suggest that some people – especially older people – habitually ignore written communications, believing that they will not understand the contents or be able to cope with the required response<sup>4</sup>. In some cases this leads to failure to pay household bills, and to even greater hardship as steps are taken to collect payment or withdraw services. Again, this situation may not constitute the conditions under which an advocate would be called on (until the situation had deteriorated to a point of imminent danger) but it clearly highlights an area of need for support to manage aspects of daily life – dealing with correspondence, agreeing what has to be done, and assisting with tasks that follow on that could include payment of bills, and accompanying someone to a bank or post office to enable them to transact their business with confidence.

## Lesson 11

**(for OPAAL and service providers):** Work referred to an advocacy service may not always fit within a strictly defined vision of what an advocacy service does, but should be seen as appropriate and providing evidence of gaps in provision, which could form the basis of lobbying for wider change to policies and provisions as well as practical support to individuals.

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<sup>4</sup> 'Managing personal affairs' is an area of concern expressed by many of those whose views were systematically sought in research commissioned by Joseph Rowntree Foundation aimed at establishing 'the support they need and the services they need'

# Referrals

## Types and sources of referral

The flow of people referred to the service began slowly and initially seemed to be based on internal or cross referral within the two partner organisations, rather than by people being passed on by staff of various statutory services. Of course this could have been a reflection that people had been inappropriately 'diverted' – to either one of the partner organisations – at an earlier stage, and that the emergence of the pilot offered an alternative and altogether more suitable response to their needs. Staff could see the new service as another remedy to someone's needs, and one that could commit focused time to resolve longstanding difficulties or relatively minor issues (and in some cases, collections of them). More positively, the reason why so much work was coming from these two sources could be attributed to the high esteem in which their respective constituencies hold them, or the effectiveness of their communications with people using services. **The fact that** one of the partners had been successful in attracting **Department of Health** funding as part of the 'User Led Organisations' demonstration programme adds some weight to this explanation.

But, given the volume of cases being dealt with by adult social care services across the county, either directly or through contracted services, and the levels of disappointment frequently expressed about the quality or flexibility of (for instance) various home care agencies, there was room for concern about the low level of referral from either health or social care staff. At the time of writing this report (as opposed to completing the evaluation 6 months previously) this had begun to change. But it is worth thinking about why it might have happened, especially as at a later stage, when money needs to be saved, it could be suggested that the advocates had not been dealing with 'high priority' cases.

The low level of referrals from adult social care services may not be unusual or worrying, but it is worth considering factors that may have caused this pattern:

### **Factors which can contribute to slow service take-up by statutory services**

- Poor communication within and between social care and health – so that many staff are unaware of the service and its ‘terms of business’;
- Individual workers may harbour quite natural anxieties about the scope for independent advocates to challenge their own practice – or that of a colleague, or their agency’s policies;
- “Wait and see”: staff may know about the service but want to be confident of its usefulness, reliability or the outcomes it can achieve;
- Lack of belief in the need for, or principle of, spending time, effort and money ‘undoing’ perfectly sound practice by colleagues;
- Lack of connectedness between policy, principles, commissioners’ decisions/expenditure and frontline workers’ experiences;
- A climate of uncertainty – such as that which seemed to pervade fieldwork teams at the time of the pilot’s launch due to reorganisation of services.

This range of possible reasons suggests that there may be no easy answer to raising the level of referrals from adult social care and health sources. However, there was a strong case to be made to each of these sources for making a determined effort to elicit more business from them. Adult social care and health services might contend that few people are referred on because people using services are largely happy, have their voices heard, can get decisions changed, express themselves freely and are listened to intently. If this were the case, the area would be a truly remarkable place!

However, such a claim would also need to acknowledge that there are others who, as a result of eligibility criteria, may have been denied a service and are then left to ‘sink or swim’. They are unlikely to have been supplied with the contact details of an advocate to act on their behalf to overturn a decision.

## A parallel situation in Cornwall

Even though the group of people served was different, it is worth noting that when a scandal around learning disability services in Cornwall emerged and was investigated by the Commission for Social Care Inspection (now the Care Quality Commission) and the Healthcare Commission, they discovered:

*“...staff [of health and care services] who were interviewed were largely unaware of the advocacy services that were available and some did not know what advocacy was.”*

This was particularly worrying because the relevant NHS trust had understood the need for advocates for vulnerable people in their care, and had funded local services, yet failed to inform staff of how to access the services (CSCI and Healthcare Commission 2006).

When I read the report of that investigation I argued that the difficulties identified would have strong echoes for staff working with older people whose ability to communicate may be restricted by hearing or sight impairment, or cognitive functioning – or a combination of them (NOP 2006). With those findings fresh in my mind I felt strongly that the commissioners should be encouraged to promote awareness of the service they were paying for within all relevant teams.

## Lesson 12

**(for service commissioners):** Commissioning the service is only part of the story – ensuring that it is known about and used requires ongoing attention.

## Housing and accommodation – and the importance of ‘home’

More than half of the cases referred to the service related to matters of housing and accommodation. Housing – and home – is a significant cause of anxiety, and made a disproportionately large impact on the work of the service.

It is telling that the service specification for the pilot service is couched in terms of accommodation support, while a significant number of cases have related to housing needs (including finding it, paying for it, arranging to swap it, or to find other accommodation more suited to changing circumstances). All of us, regardless of whether we have other social or health care needs, become anxious if there is some doubt about the security of our housing or problems in maintaining it.



Research<sup>5</sup> focused on older people's housing decisions makes clear that they want housing designed to help manage reduced mobility; that provides safety and security; and gives comfort and pleasure. They want space that is flexible enough to enable them to construct the diversity and fullness of their lives (Clough et al 2004). Many of those participating in the research identified the need for independent advisers with whom they could test out their worries and find solutions. Some even chose to give this role the label "housing advocate" or "barefoot adviser" – someone non-professional, who could empathise with the issues being faced by an individual. It was clear that advocates were playing this role for a number of people.

## Lesson 13

**(for older people):** Organisations describe their work and priorities in terms that may lead you to think that you don't qualify for help, but it's worth persisting unless and until you are told that by someone.

## Some case studies

It was striking how complex some apparently straightforward referrals (which might have led to people being considered 'low risk') actually were when an advocate had the time to explore the situation. Generally such discussions happened in users' homes where they were likely to be more at ease and ready to share their worries in greater detail than if they were going through a telephone assessment with a larger organisation such as the county council or the Department of Work and Pensions.

### Case A

This case is a very clear example of profound difficulties lurking behind something simpler. It relates to a situation that at first assessment seemed to be a simple need for information, signposting and perhaps a little support to begin a process that could be met with minimal time and effort expended, and then closed – with all parties satisfied. This person ostensibly needed assistance to identify opportunities to move to sheltered housing in another county.

*Continued*

<sup>5</sup> A collaborative project between Lancaster University's Department of Applied Social Science and the national charity Counsel and Care explored housing decisions in later life and drew on the views of over 1000 older people, including in-depth interviews conducted by other older people, questionnaires and detailed 'housing biographies' submitted in response to a call for evidence.

However, the story unfolded in such a way as to lead towards the need to ensure that the individual was safe and aware of the range of protective services that could be assembled to safeguard them. This was done in an appropriately low-key fashion, suited to the family situation and the user's wishes. This person is under lots of pressure but remains resolutely capable of making up their own mind about key issues, including declining to be referred to the vulnerable adults team serving the area. They are considered to be safe and their situation is known to local police.

### **Case B**

After a period of hospitalisation B needed to move to a care home, as they were no longer capable of living independently in their former home. Despite having adult children who are articulate and capable of representing their parent's needs, B's children were unaware of the options or of the statutory obligations on the council or its health partners. Even when armed with such information it may not always be easy for people to get a result that contributes positively to their sense of well being, because of the tensions between the county's policies and procedures, the statutory guidance available, the user's needs, the wishes of family members – and budgetary considerations.

In this instance the advocate was able to identify a way forward that ensured that all guidance was complied with and that the user's needs prevailed over the council's previously intransigent position. Although relatively few agencies were involved, the complexity of the situation and the implied challenge to the council's standard approach was time consuming and could have reached a quite different conclusion.

### **Case C**

C had returned to England from southern Africa and confronted a series of difficulties associated with their entitlement to various sources of income. A particular concern was the availability of local housing allowance to enable C to occupy their preferred accommodation, where they could confidently rely on the support of family members living close by to have a reasonable quality of life. C had experienced a number of recent traumatic before arriving in the UK after many years away in a different country and culture.

This case could have become complex and demanding in view of C's health status and unfamiliarity with the British welfare system. However the skilled intervention of a knowledgeable and sensitive advocate enabled things to move more rapidly to a very satisfactory conclusion. This was a relatively 'quick fix' that has delivered a good outcome for both the user and immediate family. The speed of action should not obscure the complexity of co-ordinating involvement with more than a dozen statutory, voluntary and commercial organisations.

### **Case D**

D has a range of health problems relating to physical and mental health, and lives alone. The knowledge – or interest – of D’s two principal health ‘supports’ suggests that we are still a long way from the holistic approach to meeting people’s needs envisaged in national and local policy (and highlighted during the time the evaluation was being conducted in a key report<sup>6</sup>). D is in need of funds to enable the purchase of equipment – initially a specialist mattress – that will help with comfort. Her GP, replying to a request from the service for assistance by way of a letter to accompany funding applications, acknowledged that if D could sleep better, their whole life might be improved.

The service has assisted D by identifying sources of charitable funding and then drafting applications to them. Having secured some success, D has identified a number of other needs with which they would like some help. While these are all legitimate needs and D’s personal situation falls within the remit of the pilot project’s services, the advocate needed to ensure that the user didn’t become overly reliant, or monopolise available time. There may be other agencies that can provide some of the support needed outside of the helpful role played by the advocate. This case involved research to establish eligibility criteria, and subsequent contact with 15 charitable trusts in addition to contact with the GP and a community psychiatric nurse.

### **Case E**

This resident – who died in August 2008 – had lived in a care home for the previous 11 years, and concerns about the quality of care received had led to a referral to the advocacy service by their niece.

During the course of supporting the relative in raising concerns about a succession of issues (including dehydration, changing of catheter, keeping records of fluid intake and ‘attitudes’ – an all-encompassing term for difficulties with the proprietor/manager) the advocate has observed and/or come up against difficulties with both the resident’s social worker and with the limitations that the Commission for Social Care Inspection<sup>7</sup> (CSCI) had put around its own role in responding to complaints about services. As a result of following CSCI’s advice – to take up the matter with the provider – the resident was threatened with eviction, and this led to their niece making arrangements to move them to another home. Sadly the resident’s death occurred only two weeks after moving to the new care home. The advocate continued to provide support to the relative, who is going ahead with the complaints already begun before the resident’s death.

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6 Age Concern England and the Mental Health Foundation ran a 3-year inquiry into mental health in later life; this is part of the continuing output from that work.

7 now the Care Quality Commission.

This case illustrates some of the likely unmet need to support people living in care homes that has been identified and acknowledged at the highest level and was the subject of recent legislation<sup>8</sup>.

## Lesson 14

**(for service commissioners, providers and older people):** There is plenty of unmet need for people living alone or with others – in the community or in care homes.

### What do case studies tell us?

These brief descriptions do not provide the full picture of either the specific cases highlighted or the progress made more generally. They are intended to be indicative of what can be achieved, and to demonstrate that even though staff of statutory services had made few referrals this should not be interpreted as an indication that users were not in considerable need. It may more accurately reflect the extent to which older people experience social exclusion that leads them to neither seek, nor be offered assistance to combat loneliness and gradual withdrawal from society.

As well as cases that illustrate the need for sustained intervention over a protracted period, the team has also been effective in closing cases with minimum fuss and maximum effect, passing people on to other agencies where they are better able to deal with the user's problem. A good example of this is where someone wanting to appeal a decision in relation to Disability Living Allowance was referred on to the Citizens Advice Bureau because they can provide a superior service, and they specialise in tribunal representation. In another instance someone was referred on to the Patient Advocacy and Liaison Service at the hospital because that service is better placed to pursue concerns around the quality of care being provided to an inpatient.

It is important to acknowledge the time and skill needed to reach these 'closures', and to recognise that those situations could be classified as 'effective' or 'successful' just as much as other cases where significantly more time is used up while extensive work is undertaken. They also provide indications of the range of unmet need that exists and should lead us to reflect on the extent to which people's well being can be adversely affected by the aggregate effect of a series of small, sometimes long-running, unresolved issues. For some people the only need is to

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<sup>8</sup> The Health and Social Care Act 2008 was amended to extend the rights of redress for self-funders, not previously able to utilise the complaints procedures available to publicly funded residents. The Office of Fair Trading 2005 market study also highlighted the need for advocacy to be made more widely available to older people living in care homes.

have someone to talk a concern through with and then, in line with conventional wisdom – a problem shared is a problem halved. The issue or anxiety that had consumed the person dissolves or fades away, albeit to be replaced (in some cases) by another, similar worry at a later stage.

## Lesson 15

**(for service commissioners):** Loneliness and isolation are features of some older people's lives, and for some service users a 'little bit of help' will make a major difference to their well being.

These situations demonstrate the need for an exploratory or assessment phase to establish what needs to be done, and whether the case will require high-level skills and substantial time input – immediately, or over a long period of time. The pilot service opted to do this as the best way of responding to people referred on to them, rather than applying a crude test of eligibility. Had they used an eligibility test, they may well not have given time and attention to the person whose safety was compromised by their living arrangements, or the resident who was ostensibly 'appropriately placed' – in line with the council's policies, though not in line with their needs or wishes, and the extant guidance from the Department of Health<sup>9</sup>. However, the approach adopted does put pressure on such a small service and may yet be modified in some way in the future.

Of course not all cases have been equally demanding. But try telling the person whose need is deemed to be 'low priority' that yet again they have drawn a blank when looking for help. The service is valuable because it mixes together concern for people who are highly dependent and 'tick all the boxes' as far as qualifying for help, with those who are more capable but need assistance and a bit of personal attention to work things out for the better. A lady whose debts have been rescheduled or written off and who discovered hitherto unknown and unclaimed benefits to which she is entitled, was able to purchase her very first washing machine. Consequently, her life has changed forever.

## 'Customer satisfaction'

Some users agreed to discuss their experiences of the service. Three users are cited here, one of whom features as one of the five case studies described earlier.

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<sup>9</sup> Recent evidence presented in Dalley and Mandelstam's report identifies problems in the accuracy of information available publicly to assist people to make informed choices about their care.

### **User A**

This person spoke warmly and enthusiastically about the attention they had received from staff (their initial advocate went on maternity leave and so the case was passed to another member of staff). User A has tinnitus and finds some situations very difficult to deal with, but had no problems in dealings with staff of the pilot service. The principal concerns for which User A was seeking support were related to their 'park home'; they had been referred to the service by one of the **service delivery partner organisations**, following a call from their daughter. *"I'd been so worried about things but now I feel in safe hands. I've got nothing valuable, but it's my home and I wouldn't want to lose it, so what they've been doing is long overdue – and I'm calmer now."*

### **User B**

User B was also very enthusiastic in their endorsement of the service and the way in which staff had dealt with the situation – both personally and by telephone. However, they reported some delay in managing the situation as a result of a change of advocate, and difficulties in getting an appointment with their GP to ask for a letter of support to accompany bids for funding that the advocate would be making on their behalf. *"I'm very grateful for the help I've had from this service. Help of this kind feels overdue, as I have spent a good deal of my time being a 'good neighbour' and friend. It's good that the boot is on the other foot now. If I get this new mattress my life will be so much better as the one I'm sleeping on isn't much good now and I wake up every morning with bruises."*

### **User C**

This service user was also very positive about the help received. *"...[the advocate] was really excellent. She came to the house – and that makes such a difference. I was altogether more at ease as a result. She went through lots of complicated forms, and then – the real bonus – she was able to use her skills as an OT [occupational therapist] to sort out another problem I was having"* Although in touch with lots of services, and also knowing their way around the system having been a family support worker before the onset of disability, none of the staff from these other agencies had been sufficiently interested or skilled to undertake the work necessary to enable User C to move from their present council accommodation to somewhere more suited to reduced mobility. User C noted that the service had become a little less proactive since the advocate originally allocated to them had gone on maternity leave. They assumed that this was due to the staff team being under more pressure with the loss of a member of staff. In this sense User C wasn't wrong, and their views were conveyed back to the Lead Advocate so that they could review the commitments made and progress achieved, and ensure that the User C is fully informed about the reasons for, and length of, any delays occurring. This is vital in order that the pilot service doesn't sink into some pre-ordained role – 'just like the others' – and appear to have lost interest in the user and their needs.

# Managing demand

Most services, regardless of their size, have to confront the tensions that arise around managing demand.

## Key questions about managing demand

- How can we encourage more people to use our services without becoming overwhelmed and then letting them down because we are unable to cope?
- How can we go on providing a service to ‘all comers’ – those who have managed to find out about us/been referred on – while also staying within the boundaries set down by those who are funding the service?
- How do we decide who needs help, and in what order?

In addressing these questions, the pilot service could have become indistinguishable from some of the established services about which people frequently complain, and perceived as always trying to manage the level of demand downwards by focusing on a smaller number of people whose needs are seen to be most pressing, or who are in some way more worthy of attention because they fit categories of agency-determined need.

Early attempts at developing a prioritisation tool arose from a concern to have a robust system in place that would stand up to examination by the service commissioners. But this approach seemed to be at variance with the position which those providing the service preferred, and could have had the effect of changing the character of a new service that set out to be responsive to people and their needs. Such a tool could very easily lead to responding to the most obvious presenting problem rather than any underlying issues. So, it made more sense to run an assessment model where the Lead Advocate and team attempted to make judgements based on listening to people’s descriptions of the problems, issues and concerns they had. This method tended to be more satisfactory as long as it extended to meeting people face-to-face to discuss their needs before determining the extent to which it would be possible to work with them, and the terms and duration of any such involvement. But hard realities – too many cases and too few staff to cover them – as well as the substantial distances involved – made this extremely difficult, very time-consuming and not always an option.

Nevertheless the team attempted to deal with these thorny questions, and searched for ways of managing the pressures without resorting to the crude terminology of *critical*, *substantial* and *moderate* – or, in everyday language “work with them,” “maybe work with them” and “tell them that we can’t help”.



These discussions highlighted how staff from other organisations had called on advocates to perform roles that were inappropriate, such as befriending isolated people.

As noted earlier, advocates can provide information to enable people to identify what they need to do, and the routes they can take to do so; or they can be an interpreter helping someone to deal with the language and processes of organisations; or act as a supporter to someone wanting to use the complaints processes open to them. This is not an exhaustive list but it illustrates the range and variety of pressures, and perhaps also the lack of precision around why an advocate has been asked to get involved. All or any of these roles may be further complicated by what has gone before: other agencies and individuals who may have worked with the person, the decisions taken, and the frustrations that may have provoked the need for an advocate.

The service is expected to work with people whose needs are allied to health, care or accommodation support needs – though the team chose to interpret the latter term as being about housing – and this provided a very broad canvas on which to work, rather than placing restrictions on who should be helped or what events must have occurred. The notion of well-being and preventive working is the centrepiece of much publicly available information on health and care services – so this approach seemed to fit very well.

# Innovation

In thinking about other ways to determine priorities without turning people away, and how to assess for either the quantity or content of 'unmet needs', the staff team at the pilot service developed a number of innovative approaches.

One approach which proved helpful in identifying some of the factors which influenced whether the service could provide a worthwhile response was a working model which the team referred to as the "3Ps". This considered factors in terms of the *Person*, the *Place* and the *Presenting* issues:

## An approach to identifying factors which influence a worthwhile service response: the "3 Ps"

### **Person:**

- Isolated: socially, geographically, behaviourally – any one or more of these dimensions
- Confused by: language, rules, culture, decisions – of agencies with which they have had dealings
- Personal style: aggressive, assertive, personable, demanding, difficult to communicate with

### **Place:**

- Home situation: safe, secure, permanent, temporary, shared – with a partner, friend, other family members, or with co-residents (care home)

### **Presenting problem:**

- Serious – threatening health or impacting widely
- Timing – imminence of any difficulties – time limits on taking/failing to take action; or
- Self determination – simply the importance to the person concerned – how much does it matter – a little or a lot, beyond the bounds of acceptability.

An alternative way to express this, which recognises similar facets of people's lives, was articulated as follows:

## Potential factors influencing worthwhile service response

**Vulnerability:** an individual's isolation, confusion, fragility of existence, fearfulness, inability to understand simple or complex matters – or any combination of these

**Urgency:** deadlines, opportunities, impact in the short, medium and longer term

**Situational:** environment – within and outside of the home, family and neighbourhood

Another list provides clues to the breadth of issues that people may present as being problematic, most of which are not labelled 'health', 'care' or 'accommodation support' but which impact on those parts of their lives.

### Dimensions of need

- Care – personal and social
- Health – physical and mental
- Well-being – not just a state of mind, but the factors that cause it
- Income – benefits and other financial matters
- Housing – worries about it: location, suitability or state of repair
- Mobility – as a means of independence within and outside of the home
- Communication – translation, interpretation
- Leisure – quality of life, relationships and networks
- Work – less significant for likely users?
- Education – access to vocational and/or academic opportunities
- Citizenship – inclusion, involvement and participation
- Spiritual and emotional – how we feel about self/world and values

This could be divided into factors in various ways.

However, the scope for making and amending lists seems endless and ultimately unproductive. The service needed to be clear about what it could do – the strengths and any known weaknesses, the limitations arising from time pressures, and the creation of dependencies that are likely to be a product of success. If someone uses the service and 'gets a (positive) result' then they are likely to identify more things on which the service can work its magic!

Being successful – and getting known for this – may lead to more demand being put on the service from all sides, perhaps destabilising it so that it becomes more erratic, less enthusiastic and nothing like as empowering for those who use it. Success could be yet another tension to be added to the others that need to be managed.

# Added value from volunteers?

One factor that promised to bring an element of 'added value' was the scope for using volunteers to play a part in the service. Early indications were that the user led organisation's network of district-based forums, spread across the county, would provide a number of people eager to play a part in supporting others to secure their rights and entitlements. A characteristic of some forum members is their determination to advocate on behalf of themselves and others, or around a theme, such as access to and availability of services to support independent living.

Early on there had been serious offers to get involved as volunteers from a small number of people – small, but still exceeding the size of the staff team! It was thought that numbers would grow further over the following months. In addition the second project partner also has a network of volunteers engaged in a variety of services and activities, which could also be called upon to provide additional support for the team's work in the future. However, additional resources are rarely 'free', and they open up a series of tasks which could bring yet more pressure on the Lead Advocate to organise and co-deliver a course of training aimed at giving volunteers necessary skills and knowledge. Any training provided needs to be sensitive to people's experience and commitment, but remain alive to any weaknesses in style and approach such as a predilection for 'doing' over 'enabling' and 'supporting'.

Volunteers need to be managed, supervised and supported and the Lead Advocate could increasingly find themselves absorbed in staff management. If volunteers are to be used this is unavoidable. But the quality of service provided should not be compromised in a drive to reach more people by deploying volunteers with fewer skills, less knowledge and no personal support.

Although one of the partners already had an established member of staff who leads on volunteer recruitment, training and support who could assist with some tasks, and the other partner organisation has spent time reviewing and revising its policies and procedures, the supervision of individual volunteers could not be 'contracted out' as volunteers will need advice and guidance on managing difficult and complex cases from someone familiar with the issues which arise when working as an advocate.

Further development of a service that seeks to involve and make use of the latent skills of volunteers is a significant piece of work, almost certainly beyond the scope of this small time limited pilot service. However, it provides evidence to support the role of an overarching organisation to provide 'common services', as envisaged within the emerging plans of the county-wide advocacy forum..

## Lesson 16

**(for all):** Volunteers are not a 'free' source of labour. They need as much training and support as paid colleagues if they are to be effective.

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*The title of this report is not intended to be cryptic. It is based on a direct quote from an exchange between an advocate and a member of staff of a housing association when discussing the situation facing a disabled tenant, and the difficulties the tenant was experiencing with wheelchair access to their home. The exchange took place during the evaluation on which this report is based. It highlights the prejudice and misunderstanding experienced by some advocacy service users, and indicates the valuable role that independent advocates can play in helping people to get their voices heard and action taken.*

**“Wheelchair access? That’s a Lifestyle Choice!”** is the report of lessons arising from the evaluation of a pilot advocacy service for people with physical and sensory disabilities, and older people experiencing general frailty, in South West England during 2008.

Combining findings from the project evaluation with reflections from the advocacy scheme’s staff and case examples, the report provides an in-depth insight into the emergence of an innovative independent advocacy scheme and the issues and factors which influenced its success.

*“Wheelchair access? That’s a Lifestyle Choice!”* will be of interest to policy makers, academics, commissioners, health and social care and related practitioners, voluntary organisations, and older people – as well to emerging or established advocacy schemes.

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