

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

Lessons from a Pilot Advocacy Service in South West England

EXECUTIVE SUMMARY, MAY 2009

The title of this report refers to an exchange between an advocate and a housing service manager about the needs of a disabled tenant. 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.

## Introduction

In September 2008, Les Bright, an associate consultant for the Older People’s Advocacy Alliance (OPAAL) completed an evaluation of a pilot advocacy service in the South West region for adults with physical and sensory disabilities, and older people experiencing general frailty.

Following the evaluation, project partners felt it could be useful to share some of its findings more widely.

## Project background

The pilot advocacy service was established in April 2008 as a one-year project. The service specification stated that delivery 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”*.

## Building momentum: combining national and local agendas

In the year running up to the launch of the new service, OPAAL worked with a range of advocacy providers (including one of the partner organisations which now runs the service) to generate support across the region for increased provision of advocacy.



OPAAL is the national strategic organisation which promotes independent advocacy with older people. For them, their work in the region demonstrated the importance of local needs in providing momentum for services, rather than ideas from the national policy agenda which do not come with dedicated project funds. For the partner organisation, it was clear that the relationship with OPAAL was fruitful, but that OPAAL’s limited resources, their remit as a catalyst for others’ activities, and their lack of a local network, would prevent the two organisations from working together as service providers.

However, when it came to commissioning the new service, the local authority was seeking a partnership for service delivery. The local (user led) organisation which had been working with OPAAL prepared a successful joint bid for funding with a regionally-based voluntary organisation concerned with the needs of older people. For confidentiality, these delivery partners for the commissioned service are termed organisation A and organisation B.

**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.

**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.

## Management arrangements

Initially, organisation A's operations director was given professional and managerial accountability for service delivery – but during the life of the pilot this individual resigned, and organisation B's chief officer became more involved in operations and management. This did not reflect contractual arrangements for equal accountability between partners, but was considered effective. The team seemed to need an empathetic management style from someone close to issues on the ground, rather than a task- and goal-oriented approach.

**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 unplanned changes to management meant that the pilot service's Lead Advocate became more involved in day-to-day decisions, without recourse to a line manager. This could be seen as a flexible response by project partners – but it relied on significant energy and commitment from the person in the front line role.

**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 pilot service is staffed by a full-time Lead Advocate and two part-time staff – one of whom went on maternity leave three months into the life of the service, while the other was on compassionate leave for

some weeks and returned to work only sporadically. The Lead Advocate opted to oversee their absent colleague's caseload, rather than seek temporary staff. This was almost certainly best for service users, but again, put considerable pressure on the Lead Advocate.

**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

Leadership emerged in a number of ways, including the local authority's decision to fund the service, and the work of partner organisations in campaigning for and developing it. But this would have come to nothing without the effective daily team leadership provided by the Lead Advocate.

**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'.

## 'Averages'

Team members kept careful notes of work undertaken, and most time spent, but it was not possible to arrive at an 'average' time per case. Commissioners may see a need for averages but (especially given travel times for rural services) these may not be a reliable measure of successful advocacy.

**Lesson 7 (for service commissioners and providers):** Searching for average times spent with – without understanding the factors involved – adds little to our understanding of the work being undertaken, but could consume a disproportionate amount of time.

Some cases were allocated based on distance from the staff member's home. But since one in four cases emanated from the area in which the office was located, this was not always possible and did not prove efficient.

**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

Travel times are critical for small, rural services when time and cost are used as indicators of efficiency. But as the advocacy team delivering the pilot service develops specialist skills, allocation based on distance is likely to become less effective than matching user needs to staff strengths.

**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

A variety of roles for advocates emerged during provision of the service, including: *interpreter, navigator, communicator, listener, mediator, supporter and befriender*.

**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 for advocates included 'signposting' users to information and services to help them remain in control of their situation, and form-filling and paperwork to help them manage their lives and secure entitlements.

**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.

## Referrals

Referrals from health and social care staff were slow to develop. Underlying factors could include poor communication, low awareness, uncertainty about reliability or usefulness of the new service, and caution about the potential for advocacy to 'unpick' sound practice by colleagues.

**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.

The service specification is couched in terms of accommodation support – but a significant number of cases actually related to housing.

**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 you don't qualify.

## Case studies

Case studies from the pilot service demonstrate the complexity (and severity) of issues that can emerge from apparently straightforward referrals, including safeguarding from abuse, helping users to navigate contested pathways into care, and dealing with threat of eviction from care homes. They also show that timely, effective advocacy can reduce complexity by coordinating the involvement of numerous agencies around urgent needs which have a potentially simple, swift resolution.

**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.

Some case studies show high levels of social exclusion, loneliness and withdrawal from society, and demonstrate that small numbers of referrals from statutory services should not be seen as an indication that users are not in considerable need. They also show that advocacy can play an important role in helping people to overcome isolation, while addressing small, long-running, unresolved issues which have a disproportionate impact on their lives.

**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.

The pilot service opted for an exploratory 'needs assessment' for new referrals which identified requirements for high level skills and substantial (short or long term) time input, rather than applying a crude eligibility test. This helped to identify, and allocate time to, 'high needs' cases while simultaneously addressing smaller (but life-changing) issues and bringing cases to successful closure. Service users reported feelings of safety, calmness, ease and satisfaction.



## Managing demand

The staff team at the pilot service resisted pressure to manage demand downwards by focusing on a small number of people with needs perceived as pressing, or those who met agency-determined categories. In attempting to develop a prioritisation tool, staff quickly recognised that this could easily result in responding to the most obvious presenting problem rather than addressing underlying issues. It made more sense to listen to people's description of problems and concerns face to face (although the hard realities of caseloads made it unrealistic to always rely on this approach).

The team searched for ways to manage demand without resorting to the crude categories of *critical*, *substantial* and *moderate* which can often serve as de facto eligibility criteria. They were also aware of a lack of precision in many referrals, and the need to clarify the often unfamiliar pressures and opportunities that advocacy presents.

By bringing together health, care, accommodation support and housing needs, rather than placing restrictions on referrals, the pilot service's canvas was very broad. This chimes well with public messaging on preventive health and care.

## Innovation

The team developed a working model to identify factors which influenced their ability to provide a worthwhile response, based on the '3 Ps' of *person*, *place*, and *presenting problem*.

They also identified a range of issues that users may present as problematic, most of which fall outside a narrow interpretation of health, care or accommodation. These included *care, health, well-being, income, housing, mobility, communication, leisure, work, education, citizenship and spiritual and emotional feelings*.

The pilot service needs to be clear about its strengths and weaknesses, time constraints, and the risk that successful outcomes can generate dependencies (rather than supporting independence). Other risks of success include increased demand from all sides, affecting service stability, staff enthusiasm, and the degree of empowerment that the service can provide for service users.

## Added value from volunteers?

The potential benefits of using volunteers to help deliver services were evident throughout the project. It was clear that people making serious offers to volunteer could easily outnumber the staff team (and increasingly absorb the Lead Advocate's time). At the same time, supervision of volunteers could not be 'contracted out' because of the need for an experienced advocate to guide and advise volunteers in managing complex cases.

**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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 Further copies of this executive summary, and of the full report: "*Wheelchair Access? That's a lifestyle choice!*" *Lessons from a Pilot Advocacy Service in South West England*, can be downloaded at [www.opaal.org.uk](http://www.opaal.org.uk)



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