## Housing Learning & Improvement Network

Care Services Improvement Partnership CSIP

Health and Social Care Change Agent Team

## Advocacy for Older People in Social Care

By Anita Pati, freelance journalist.

The role of advocates is often poorly understood both by social care staff and clients and their family members. However, many older people find advocacy plays a vital part in preventing them dropping off the social care radar.

This article, published in Community Care magazine 24-30 August 2006, examines the work of two agencies in helping older people with a variety of needs, and highlights the current problems in bringing these services to a wider range of users.

**Mrs Rosetti's story:** "They gave me a walk-in shower when I was saying, no, I hate showers. When I got back home, my bath was gone."

But nobody listened to Mary Rosetti<sup>\*</sup> until she found an advocate. The disabled pensioner with curvature of the spine battled for four years to have her kitchen and bathroom reinstated after her council botched the assessment.

Rosetti had moved out of her flat for what she expected would be three months but which dragged out for 15. In the meantime, the council's contracted housing provider used the wrong specification to adapt her flat. "They made modifications for a wheelchair person. I'm not in a wheelchair - the flat is on the first floor – how would I get there?" The council also fitted a stair lift although she told them this was not part of her care assessment. "I got back and I found this monstrosity. I've been fighting ever since," she says.

In Rosetti's case, despite her assertive nature and strong grasp of the facts, she was systematically dismissed. It was only after her local advocacy service pursued the complaint that she was taken seriously. But not before the experience of being ignored had caused damage.

"They've ruined my life," she says, "but I don't want to forget – I'm very angry about it. Four years out of my life has been wasted, I've been under terrible stress, I'm disabled – it has been hell. If it wasn't for the advocacy service taking this case on I don't know what I'd have done. I've been at the end of my tether".

\*Not her real name

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## THE ROLE OF ADVOCATES

Being ignored is a common experience for older people, says advocate Sarah Reilly of Westminster Advocacy Service for Senior Residents (WASSR): "Older people are discriminated against. I see people not being listened to and not taken seriously. Older people are undervalued in society, as is their contribution."

Reilly has worked as a part-time housing advocate at WASSR for two years, prior to which she was an advocate for people with learning difficulties. She views her role as vital: "It's about nudging the system along. People fall out of the system and it's about putting them back in."

The service uses a multi-disciplinary team of voluntary and paid advocates, including an ethnic minority outreach worker, to support and represent vulnerable older people either at home or in regular community-based surgeries. It offers skills in housing law, dementia and mental health advocacy. At present, Reilly has 10 active cases, mainly women, aged from 60 to 95. Housing is the single biggest issue for clients. "People's housing needs change when they get older. They may need assistance, move into sheltered accommodation, or need adaptations to continue living in their homes," she says. Clients may also have problems with housing benefit, arrears, repairs or disputes with neighbours.

Despite demand, Reilly's funding for the housing part of her role was cut in June – she now officially works as a mental health advocate while continuing to issue housing advice. "The two overlap - we have a lot of clients with mental health needs who also have housing problems".

WASSR's funding issues will be familiar to many who work in the voluntary sector: Reilly says: "It's very difficult to get the key funding to continue a project. The grant-giving bodies want to give money for new ideas and projects but don't want to fund core costs or projects to continue."

The majority of the service's clients are on state benefits or are disadvantaged. But those older people in wealthy Westminster who are either well-off or privileged can also prove vulnerable. One of Reilly's clients is in her 90s and was a GP in her professional life. She had referred herself after her landlord had sought possession of her flat. Another, also in his 90s, had been a psychologist and wrote a book at age 85. His landlord had raised service charges by 700 per cent and, being partially sighted, he needed help with correspondence.

Last month, a mapping exercise by the Older People's Advocacy Alliance UK (OPAAL) found that advocacy services for older people were patchy across England. Of 136 age-specific projects, Age Concern ran 57 with London well resourced but some other counties much less so. The report found a lack of understanding – which sometimes spilled into suspicion - about the role from both service users and other professionals. There was also a misconception that advocacy is advice and information rather than actions taken to represent the client's own wishes.

Contrary to OPAAL's findings that many older people are unaware of advocacy, two thirds of Westminster service's clients self-refer. Reilly believes the level of initiative shown by WASSR's clients is because the project actively promotes the service, particularly among the borough's black and minority ethnic population, at lunch clubs and community groups.

## ADVOCACY FOR PEOPLE WITH DEMENTIA

While the alliance's report found that London and the North-West were well served, there were few such services in the North-East, which was least represented. In Gateshead, Julie McAlpine of the local branch of the Alzheimer's Society is the only advocate for people with dementia in a borough where the charity estimates there are 2,200 people with dementia.

McAlpine has worked as a full time advocate at the society for six years, before which she volunteered for the sitting service. She has a "comfortable maximum" of 20 clients at any one time. "People with dementia are often overlooked and not listened to," she says. "They need someone to talk to in a language they can understand which does not use professional or medical terms, someone to communicate with them at their own pace."

McAlpine frequently encounters suspicion from both social workers and family members when advocating for a person with dementia. Most referrals in Gateshead come from social workers and McAlpine says that her presence can often "help them reflect on their own role. But often they can be suspicious of the advocate and feel threatened by them - they see us as trouble makers," she says. "I would challenge the perception that advocates should only get involved when there's trouble. They are there to represent people's views all the time."

McAlpine agrees with OPAAL's findings that many people, especially family members, do not understand the role of an advocate. But as the only advocacy worker in the office, working to capacity, she is not in a position to promote the service or to pick up extra cases.

She regularly deals with family conflict where members can become "extremely upset". A typical situation is where one partner in an elderly couple has dementia but does not want to be moved to a care home, while the other partner can no longer cope with being the carer. "It's an awful situation," she says. "Because on a personal basis you can see it from both points of view but my role is to represent the person with dementia while acknowledging the carer's stress levels."

Her work with people with dementia can be challenging and time consuming. "It can take twoand-half hours to work with a client. You do have to keep repeating yourself and you have to give them information in a way that they retain it long enough."

Advocacy, for McAlpine, affords job satisfaction despite her efforts often being unacknowledged: "It's good knowing that you have given a voice to people with dementia, who would not have been heard if you weren't there. It does make you feel like you've made a difference but you don't get much feedback from the client because they don't really know what you've done. "You can put an awful, awful lot of work in and the client isn't always aware of that. But you still know that you've done your best." Other Housing LIN publications available in this format:

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Published by: Housing Learning & Improvemen Health and Social Care Change Department of Health		Administration: Housing LIN, c/o EAC 3rd Floor London SE1 7TP

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