Scoping review of the research and evidence base relating to advocacy services and older people’s entry into care homes in England

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This is an independent report commissioned by the Department of Health. The views expressed are not necessarily those of the Department.
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Introduction

The purpose of this review is to scope the literature on advocacy in relation to the decision to enter a care home on a long-term or permanent basis. The focus is on older people since these are the main users of care home services. At 31 March 2008 Councils with Adult Social Services responsibilities were funding 236,100 residents in Council-provided and independent residential and nursing homes.\(^1\)

The review seeks to inform planned work on the development of independent advocacy services being considered as part of the Independent Living Review by the Office for Disability Issues. While the government’s personalisation agenda (Department of Health (DH) 2007) envisages that the promotion of choice and control, together with initiatives promoting prevention of abuse and reablement, may support older people in their own homes, there may still be numbers of older people who are considering care home support. Older people’s access to information and advice services in the UK is variable (Age Concern 2008). Four reasons why advice, advocacy and information are essential for older people, especially those considering care home entry, have been identified by Platt (2006):

- It helps people to understand their options
- It enables people to make their voices heard
- It ensures that older people enjoy the same rights as everyone else
- It leads to value for money—people’s own, as well as public money.

Similarly, while the government’s End of Life Strategy promotes the development of community-based services in palliative care in people’s own homes (DH 2008a) this may impact upon choices to remain in care homes to die. The number of people aged 85 and over, one of the key groups who consider care home entry, is projected to grow to 1.7 million people by 2031, leading to predictions that the number of adults overall seeking residential care may rise to 450,000 by 2010 and 670,000 by 2031 (Wittenberg et al. 2004). This review is set in this context.

Currently, it is estimated that about 600 organisations make up the advocacy sector (Department of Health 2008b). It is possible that this number may rise with the recently instituted Independent Mental Capacity Advocate (IMCA) service and the development of Mental Health Act advocates, as well as the increased interest surrounding advocacy groups supporting older people. On the other hand it may be that the number of organisations providing advocacy services may decline as economies of scale lead to commissioners funding organisations that provide services across local authority areas. One key factor in the development of advocacy will be the extent of legal obligation to involve and advocate in any decision making. Another is the extent to which indicators of dignity in care, that is, those factors that should be measured to assess whether health and social care services support the dignity of older users, include access and availability of advocacy services as relevant (Help the Aged 2008). The introduction of the Mental Capacity Act 2005 has been a

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major spur to the development of statutory advocacy (IMCAs). With implementation in 2007, there are as yet few accounts of the scope and effect of this service. The service is restricted to people lacking specific decision-making capacity around care home moves and medical treatment (see below). It is not therefore available to all—though this is the call from several campaigning organisations (Moulin 2008, p6).

In the context of adult safeguarding, access to advocacy is reported to be patchy and inadequate (Commission for Social Care Inspection 2008) despite its crucial role in the prevention of and early intervention in instances of abuse and neglect. In a recent CSCI inspection, 58 percent of councils inspected noted shortages of advocacy in their areas and of the 250 services noted, more were available to young people in care homes (23 percent) than older people in care homes (10 percent). This picture is not confined to England. A recent survey of advocacy services for older people in Wales (Age Concern Cymru 2007) tracked down 45 organisations that said they had an advocacy role but established that only 23 actually offered advocacy services, and many of these had funding problems. The recommendation that there should be advocacy services for inpatients of learning disability services was made by the Healthcare Commission following its review of these services (Secretary of State 2008) and it may be that similar arguments become voiced more often in respect of older people who are unrepresented.

A scoping review aims both to map the range of literature in a particular field and to envisage where gaps in the evidence base may lie. This entailed conducting a literature search, but given the dearth of studies in this area we also generated a projects and contacts list, which provides a picture of activity in advocacy in England at present. The material in the review may appear dry and impersonal. The extract below provides an example of the use of advocacy around proposed care home admission (Box 1).

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**Box 1: Extract from British Institute for Human Rights (2008 p.13)**

‘Older woman to be moved from hospital to residential care home against her wishes

*Source: Independent Living Advocacy (Essex)*

An older woman was staying in hospital following a number of strokes. She had been interned as a Japanese prisoner of war during the Second World War and suffered a range of trauma related mental health problems. She was observed re-enacting various behaviours from this period including washing her clothes with rocks and hanging them to dry on the hospital fences. Against her wishes, the hospital sought to discharge her and move her into residential care on cost grounds. Her advocate was concerned that being in an institution was what was causing this regression. After receiving BIHR training, he used human rights language to argue that she should not be placed in residential care and that she should instead be allowed to return home in accordance with her wishes. As a result, funding was secured to support her care at home’.

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International developments

There are many examples of individual advocacy schemes but their range is wide and evaluations rare. In Australia, the National Aged Care advocacy program is funded under the Aged Care Act 1997 and is available to people receiving Australian government funded aged care services in care homes or at home. Advocacy services are supported by government funding in each territory and state (Australian Government n/d). In contrast, the community advocacy movement in the United States, where focus is mainly on the quality of care in nursing homes, is highly variable (Phillips et al. 2008). In a recent survey, 21 states had no operating consumer advocacy group (CAG). Nearly a quarter of a million nursing home residents—roughly one-sixth of all residents—do not have support from local CAGs. Most (63%) CAGs have been active for more than a decade but their funding is precarious, relying on donations, memberships and foundation grants in the main with only 16 percent of funding coming from state agencies.

Methods

This scoping review was in four stages, and was initiated with a search of the references from three studies already known to the researchers (Scourfield 2007a, 2007b; Margiotta et al. 2003). This helped to inform the search strategy stage: studies were sought published in English since 2000, where the topic was advocacy in relation to the decision to enter a care home. Family members and other supporters acting as advocates were excluded, as well as professionals in care and treatment roles, and this review was conducted in relation to adult service users, particularly older people. The following electronic bibliographic databases were searched:

Applied Social Sciences Index and Abstracts
Social Care Online
Social Services Abstracts
Sociological Abstracts

The third stage involved the searching of the following websites for relevant studies:

Better Government for Older People (BGOP)
IMCA web pages on Department of Health website
Older People’s Advocacy Alliance UK (OPAAL)
Action for Advocacy (A4A)
Westminster Advocacy Service for Senior Residents
Making Decisions Alliance
Centre for Policy on Ageing
Get Heard
National Advocacy Network
Thomas Pocklington Trust
National Advocacy Network
Beth Johnson Foundation
Finally, a list of current projects and individuals with particular interests in this field was generated, building on information provided by Kath Parson of Older People’s Advocacy Alliance (OPAAL) in advance of a national advocacy conference being held in spring 2009.

A total of 60 studies and reports were retrieved. However, none is directly focused on the question of advocacy and entry into care homes. Both the 60 references and the list of current projects and individuals are presented below.

**Commentary**

*Absence of research*

There is a lack of research in the area of advocacy and entry into care homes. The recent major literature review of quality of life in care homes conducted for Help the Aged (National Care Homes Research and Development Forum 2007) contains a chapter on entry into care homes, but concentrates on the carer/family perspective and available sources of information rather than the actual or potential role of advocates in facilitating the decision to be made. Other authorities in this area, notably Andrew Dunning (2005) and Peter Scourfield (2004; 2007a; 2007b; 2007c), highlight the need for further research in relation to advocacy and older people generally and in their reviews of the field do not report any particular studies considering care home entry. Where care homes and advocacy are considered together at all this is in relation to instances where the older person is already at the home, as in the case of Wright (2005). Advocacy in these cases may involve issues such as breakdown in the relationship between the resident and care home staff or complaints about the standard of care, but not about the decision to enter the home. This paucity of evidence is reflected, too, in the findings of a Cochrane review of interventions in this area (Gravolin et al. 2007). Here, the objective of the review was to assess the effects of various decision-support interventions delivered by health or social care providers on the outcomes of older people facing the possibility of entering long-term residential care. The reviewers found no studies (in a field that could have included examinations of advocacy) that met their relatively stringent inclusion criteria, although Reed and Morgan (1999), among others, have identified the vulnerability of older people in hospital to having decisions made for them about care home entry. Finally, while the focus here may be on advocacy and entry into care homes, there is also the question of the potential need for advocacy when care homes close. Williams et al. (2003) noted the variability of information, advice and help available to residents whose care home was closing voluntarily, particularly those paying for their own care.
Independent Mental Capacity Advocate service

The Independent Mental Capacity Advocate (IMCA) service was created by the Mental Capacity Act 2005. It is of relevance to this review because one of the duties the Act imposes on NHS bodies and local authorities is to instruct the IMCA service when a decision is being made in relation to an individual who lacks capacity with regard to a move to, or change in, longer term accommodation.

The IMCA service started on April 2nd 2007 and its first annual report was published by the Department of Health in June 2008. The report found that 5,175 people who lacked capacity were represented by the IMCA service in its first year. Of these the majority, 3,047 referrals, were in relation to accommodation moves (as opposed to the other category, serious medical treatment). Of these referrals, 1,165 decisions involved people in hospital at the time, 859 involved people moving from care homes, and 679 involved people moving from their own homes. The report does not engage in fine-grained analysis, but does make clear that this new form of advocacy has had a great impact in individual instances:

‘Some people did communicate that they wanted to go back to their homes, and sometimes the IMCAs’ reports assisted the development of a very ‘person centred’ intensive home based care package. There were some remarkable outcomes where some people were enabled to return home despite having limited capacity to look after themselves without very intensive support. In many other situations it was a case of finding the most appropriate care home setting. One IMCA service, fed up of being told there was no choice and that people needed to move into the first available bed, negotiated a situation where best interests decisions needed to bring two specific options to the table. They were unwilling to rubber stamp ‘best interests decisions’ without a genuine choice of placements occurring.’ (Department of Health 2008: 11)

To balance this positive account, the report considers that referrals are at too low a level and unevenly distributed, geographically, indicating that awareness of, or compliance with, the Mental Capacity Act 2005 is inadequate, a concern that first arose at the pilot evaluation stage (Redley et al. 2006).

Future research

As Scourfield (2007a) remarks, advocacy with older people has developed significantly only over the last decade. The Older People’s Advocacy Alliance (OPAAL) UK was formed, for example, in 1999. And advocacy in relation to those without mental capacity is on a statutory footing for only its second year. As the first annual report of the IMCA service points out, ‘Only relatively recently have advocacy organisations been coming together under a number of umbrella organisations. Some exciting work has taken place in relation to the development of an Advocacy Charter identifying advocacy principles and values and Advocacy Quality Standards.’ (Department of Health 2008: 7). Ferment is also indicated by the current survey being conducted by the Advocacy Consortium UK into the idea of developing a National Strategic Framework for advocacy.
Such increased activity in the advocacy sector was recognized by the Office of Fair Trading’s 2005 market report into care homes. The report recommended that the Department of Health (and the devolved administrations) should run pilot projects to measure the benefits to older people, care homes and local authorities of advocacy services being provided to older people entering or living in care homes as well as the costs of providing such services (Office of Fair Trading 2005: 13).

Given this increased interest, the lack of research is all the more remarkable. The Cochrane review in this area speculates as to the reason for the lack of work in this area. In particular, the authors consider whether the process of entering care homes may be thought to be routine and inevitable or whether the service users concerned may be seen as ‘passive players’ (Gravolin et al. 2007: 6).

Future research should consider what impact, if any, the use of advocates would have on this decision-making process. There is, for example, some evidence of inappropriate decisions being made: the Help the Aged report on quality of life in care homes quotes one study that conducted a retrospective audit of nursing home placements and found that 31 percent of the sample would have been more appropriately placed in residential or community care (National Care Homes Research and Development Forum 2007: 36). Would the use of advocates have a positive effect here?

Future research should address the question of what impact the nature of the decision-making process has on the service user’s adjustment to life in the care home. As Lee et al. (2002: 25) comment in their review of the literature 1970-2000 ‘adjustment to residential care is more than just a discrete event. It begins well before placement actually occurs and continues beyond.’ If this transition is to be performed successfully then anything that improves the process of decision-making is likely to have a positive impact on the individual’s future and potentially their carers’ wellbeing.
**References (see also annotated bibliography)**


Activity / Contacts in Advocacy for older people

The following list contains projects being undertaken or recently completed in the field of advocacy in the UK, and individuals and groups with particular interests within advocacy. It was developed—by making contact where possible—from information supplied to researchers by OPAAL (Older People’s Advocacy Alliance).

**Action for Advocacy**
Rick Henderson, Chief Executive
Tel: 020 7820 7868
Independent Mental Capacity Act Advocacy
http://www.actionforadvocacy.org.uk/articleServlet?action=display&article=796&articletype=40
- 2007: Four-day Independent Mental Capacity Act Advocacy training developed and rolled out across the country – over 600 IMCAs trained.
- 2008: First national IMCA conference launched; advanced IMCA training launched.

*Also:* work on materials for the national advocacy qualification.

Martin Coyle, Head of Quality and Development
Tel: 07971 314747
martin@actionforadvocacy.org.uk
Quality Performance Mark (QPM) – from September 2008
http://www.actionforadvocacy.org.uk/articleServlet?action=list&articletype=44
- The QPM is the only national advocacy specific quality assessment system which applies to all forms of one-to-one advocacy.
- QPM is a three stage process consisting of self-assessment, desktop assessment and site assessment.

**Action on Elder Abuse**
Daniel Blake
Policy Manager
Tel: 020 8765 7000

**Advocacy Alliance Luton and Bedfordshire**
Heena Yadav
Tel: 01582 355041
heena.yadav@advocacyalliance.co.uk
- In process of starting an advocacy and older people programme Dec 2008.
Advocacy Alliance Scarborough  
Judith Kershaw, co-ordinator  
Tel: 01723 363910  
Advocacy in care homes  
- Three-year project started 2007, funded by Comic Relief.  
- Going into 24 care homes each month to see if advocacy is required by residents.  
- The project was the subject of independent evaluation at 18 months (a funder condition).

Advocacy Consortium UK (ACUK)  
acuk@advocacy-network-leeds.org.uk  
- This group is conducting a survey (closing date for a response was 28 November 2008) of advocacy schemes in England about the proposal for a National Strategic Framework for Advocacy.  

Age Concern Devon / Living Options Devon  
(information from Les Bright)

Age Concern England  
Neil Mapes  
Mental Capacity Advocacy Project Co-ordinator  
Tel: 07767 693357  
- Mental Health Advocacy – working with volunteer non-instructed advocates through Age Concern groups funded by DH and Age Concern England. Project runs until October 2009.  

Age Concern England / PASSION  
Nick Pizey convenes PASSION, providers of advocacy services support and information.  
nick.pizey@ace.org.uk

Age Concern Slough & Berkshire East  
Tel: 01753 822890  
- Comic Relief funded project.
**Autistic Society**
Sue Mulcahy  
Tel: 020 7903 3763  
Advocacy for autism

**Beth Johnson Foundation**  
Betty Machin, National Development Officer  
Tel: 01782 844036  
‘National Advocacy Support Project’
- Peer support for managers of advocacy for older people.
- Three-year project, started May 2008.
- Aiming to work in 5 local authorities across England.
- Department of Health section 64 funding.

**Brent Advocacy Concerns**  
Richard Downes  
Tel: 020 8459 1493
- User-led advocacy for disabled people.
- 3 members of staff.
- 67 volunteers on books.
- Funding: London Borough of Brent; City Parochial Foundation; Local Government Disabilities Development Fund.
- Provides advocacy service once the disabled person is in a home or wanting to leave, but does not assist with entry into homes.
http://www.brentadvocacy.co.uk/pages/contact-us.php

**Les Bright**  
Independent consultant  
Tel: 01392 424 696  
Regional approaches to strategic development of advocacy services – Devon and Newcastle upon Tyne with OPAAL (UK)

**Carers UK**
Tel: 020 7378 4999
http://www.carersuk.org/Home
- Carers Strategy and Advocacy.

Kate Mercer
National Independent Advocacy Qualification Manager
**Care Services Improvement Partnership (CSIP)**
Tel: 07876 158 276
- Work on the National Advocacy Qualification.
Kay Steven  
National Advocacy Development Manager  
**CSIP/Department of Health**  
Tel: 0161 351 4920  
http://www.northwest.csip.org.uk/kay-steven.html  
- Current work includes preparing services for the implementation of Independent Mental Health Advocacy.

**Comic Relief**  
Gilly Green, Head of UK Grants  
Tel: 020 7820 5566  
http://www.comicrelief.com/elder-abuse/  
‘Comic Relief Older People’s Grant Programme’ 2005-January 2009  
- £4 million programme comprised 50 grants with specific focus on advocacy and older people.  
- Of these 50, 11 grants funded advocacy services relating to people in care homes or supporting the move to a care home.  
- Of these 11 projects about half were run by local Age Concerns, the remainder by advocacy networks.  
- An example of the 11 grants was one for Herefordshire People’s Advocacy Network (the funding of an advocacy co-ordinator in a number of care homes).  
- A new programme is proposed commencing May 2009.  
- While all projects operate with a monitoring framework, there is no more strategic overview evaluating advocacy as a service.

Tim Gunning  
**Equality and Human Rights Commission**  
- Advocacy developments within the Commission.

**Greenwich Advocacy** – over 55s only.  
Eleanor Gibson, Director  
Tel: 020 8269 0298  
http://www.afop.org.uk/  
- c. 15% of Greenwich Advocacy’s work is in entry into care homes.  
- Samantha Everson has been the lead on two projects in relation to care homes: 1. Five years ago in relation to two care homes closing down. 2. Six month project ending January 2009: involves two advocates setting up advocacy groups in care homes to see if there are any issues that need to be addressed. Funded by Help the Aged and Greenwich Council.

Andrew Dunning  
**Interdisciplinary Research Centre on Ageing, Swansea University**  
Tel: 01792 602563  
http://www.swan.ac.uk/applied_social_sciences/ADunningbio.html  
- Continuing work on advocacy with older people. *Includes:* Benchmarking Advocacy Pilot Report.  
- *Also:* Speaking Up for Our Age programme in Wales – evaluation.
Leeds Gate
Claire Graham
Tel: 0113 240 2444
http://www.opforum.webeden.co.uk/#/leedsgate/4525616805
Advocacy with Gypsies and Travellers.

Tom Hore
Bristol MIND
Tel: 0117 980 0386
advocacyinaction@bristolmind.org.uk
Advocacy in prisons

Norah Fry Research Centre, Bristol.
Dr. Ruth Townsley
Tel: 0117 331 0987
http://www.bristol.ac.uk/norahfry/staff.html
  • Independent advocacy for older people – ODI Costs and benefits study.

Older People’s Advocacy Alliance (OPAAL)
John Miles
Treasurer
  • Advocacy and the Personalisation Agenda. Also World Class Commissioning in the DH and its impact on advocacy services.
  • Conducted workshop on personalisation 9/7/2008 at Community Care conference on adult social care green paper.
    http://www.helptheaged.org.uk/NR/rdonlyres/25CB9124-D4D5-4B5E-81B4-E7C5C3015269/0/right_care_conference_200608.pdf

The Relatives & Residents Association
Dr Gillian Dalley, Chief Executive
Tel: 020 7359 8148
http://www.relres.org/index.php
  • Three advice workers.
  • Topics covered: Financial; Care; Admissions/evictions; Legal; Human rights; General; Management; Interpersonal; Daily life; Inspection.
  • Funders: Department of Health; a group of care home providers; a county council.
  • Work in relation to entry into care homes constitutes about a sixth of their work.
  • Recent projects include: ‘Assessment Denied’ concerning the position of self funders going into care.

Scottish Independent Advocacy Alliance (SIAA)
Tel: 0131 260 5380
http://www.siaa.org.uk/
  • Advocacy Stories.
Sefton Pensioners’ Advocacy Centre
Andrew Booth
Tel: 01704 538411
andrew@spacadvocacy.org.uk

Westminster Advocacy Service for Senior Residents (WASSR)
Irene Kohler
Tel: 020 7439 3131
http://www.wassr.org/index2.html
WASSR Service:
- 4.5 paid advocates; 7 volunteer advocates.
- Funded by Big Lottery; Comic Relief; Westminster Council; Westminster PCT.
- Covering: dementia; mental health; community care; housing; BME; any other issues.
- Covers entry into care homes, often in relation to client/relatives conflict.
- Also: runs National Dementia Advocacy Network (two staff members) – funded by Department of Health and Tudor Trust.

WASSR projects:
- ‘Adding Value through Advocacy’ 2004. This is a report showing the benefits of WASSR advocacy to statutory providers (council and PCT) in Westminster based on two years of case files and interviews with (then) current clients. Has lead to increased funding for WASSR from those providers.
- Learning and Assessment Materials for the new advocacy qualification.
- Survey of all London Boroughs’ advocacy for older people (current project).

Paul Swann
Commissioning and planning officer (leaving post Feb 2009)
Wrexham County Borough Council
Tel: 01978 298 612
paul.swann@wrexham.gov.uk
http://www.wrexham.gov.uk/english/council/social_services/advocacy_works.htm
‘Advocacy Works’
- Project in development since early 2004 and due to be operational February/March 2010 with the goal of improving access to independent advocacy.
- Funding: Joint funding – Wrexham County Borough Council and Wrexham Local Health Board. Also: a ‘critical contribution’ (Paul Swann) made by ‘Voices through Advocacy’ (a 2005 Big Lottery funded project - £0.5m). 10 local authorities were sought for Voices through Advocacy – Wrexham was a leading example, for whom the key benefit was that John Macarthy of Voices through Advocacy became the co-ordinator of Wrexham’s work in this area.
- Main outcome will be the renewal of contracts at existing levels for advocacy in mental health, and new funding for generic advocacy (which will include care home entry advocacy, though Age Concern also works on this locally).
<table>
<thead>
<tr>
<th>Author/s</th>
<th>Year</th>
<th>Title</th>
<th>Journal / organisation</th>
<th>Summary</th>
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<tbody>
<tr>
<td>Abbott, S., M. Fisk and L. Forward</td>
<td>2000</td>
<td>'Social and democratic participation in residential settings for older people: realities and aspirations.'</td>
<td><em>Ageing and Society</em> 20(3): 327-340.</td>
<td>—Explores some of the experiences of older people living in residential settings (sheltered, very sheltered housing and residential care), in the context of theories of participation, consumerism and citizenship. —Residents did not participate in deciding how the residential settings where they lived should be organised and managed, except for helping with simple domestic tasks. There is a need to change both attitudes and practice to enable older people to participate more fully in these settings. Personal interviews undertaken with over 100 older people in England and Wales, and also from discussions with staff. Two-thirds of respondents were aged over 85.</td>
</tr>
<tr>
<td>Action for Advocacy</td>
<td>2002</td>
<td><em>The Advocacy Charter</em></td>
<td>London: Action for Advocacy.</td>
<td>Charter launched in 2002 – over 75 organisations contributed to its development. Charter is a set of core principles for advocacy aiming to: —To inform advocacy practice and training —To raise awareness of the value of Advocacy —As a tool for negotiating with funding and commissioning bodies —As a quality assurance mechanism</td>
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<td>Action for Advocacy</td>
<td>2008</td>
<td><em>Here for good? A snapshot of the advocacy workforce.</em></td>
<td>London: Action for Advocacy.</td>
<td>—To provide snapshot of advocacy workforce —Online survey; semi-structured interview; focus group —Demographic make-up; average pay; backgrounds; satisfaction; pathway —321 online; 56 interviewees</td>
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<td>Barnes, M.</td>
<td>2005</td>
<td>'The same old process? Older people, participation and deliberation.'</td>
<td><em>Ageing and Society</em> 25(2): 245-259.</td>
<td>Considers the potential of older people’s participation in policy processes for both transforming the policy process and for achieving socially just outcomes. —3 case studies —The conclusion suggests that attention needs to be given to the process of participation as well as to outcomes.</td>
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<td>Brandon, T. and D. Brandon</td>
<td>2001</td>
<td>'Stand by me.'</td>
<td><em>Community Care</em> 13: 26.</td>
<td>Suggests that social care has always had mixed feelings about its advocacy role, and this is one reason why training courses pay so little attention to it.</td>
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<tr>
<td>Cantley, C., K. Steven and M. Smith</td>
<td>2003</td>
<td><em>Hear What I Say. Developing Dementia Advocacy Services.</em></td>
<td>Newcastle upon Tyne: Dementia North, Northumbria University.</td>
<td>Guidance on how to set up a service, and good principles to underpin it with.</td>
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<td>Cheston, R., M. Bender and S. Byatt</td>
<td>2000</td>
<td>'Involving people who have dementia in the evaluation of services: a review.'</td>
<td><em>Journal of Mental Health</em> 9(5): 471-9.</td>
<td>Reviews five methods of gathering the experiences of people with dementia as those experiences relate to the services that they receive, including advocacy. Notes Dunning’s classification of advocacy.</td>
</tr>
<tr>
<td>Counsel and Care</td>
<td>2005</td>
<td><em>Independent Advocacy.</em></td>
<td>London: Counsel and Care.</td>
<td>Factsheet about independent advocacy: what it is; (NB CtA decision re wanting to stay at home, despite being more expensive than care home: Khana (by Official Solicitor) v. the Mayor and Burgess of Southwark (2001).)</td>
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<td>Dawson, J. and M. Ryan</td>
<td>2004</td>
<td>'She won't let us help her.'</td>
<td><em>Community Care</em> (1532): 42-43.</td>
<td>News story about advocacy</td>
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<td>Department of Health</td>
<td>2008 b</td>
<td>The first annual report of the IMCA service</td>
<td>London: Department of Health</td>
<td>See note in Report</td>
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<td>Disability Rights Commission</td>
<td>2006</td>
<td><em>Delivering the Choice and Voice Agenda: The role of independent advocacy services.</em></td>
<td>London: Disability Rights Commission.</td>
<td>DRC consultation paper seeking views on DRC opinion that public bodies such as councils, NHS Trusts, etc should fund advocacy services.</td>
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<td>Dunning, A.</td>
<td>2005</td>
<td>Information, Advice and Advocacy for Older People: Defining and developing services.</td>
<td>York: Joseph Rowntree Foundation.</td>
<td>— Looks at information, advice, and advocacy and the ways in which they may overlap in practice, as well as the differences between them. — Explores definitions, core principles, forms, roles and relationships. Information, advice and advocacy are also discussed in terms of skills, services and processes of empowerment. The report focuses on five key themes – accessibility, independence, involvement, strategy and standards. It highlights good practice, and critically examines different ways of thinking about the development of information, advice and advocacy for older people.</td>
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<tr>
<td>Finlay, W. M. L., C. Antaki and C. Walton</td>
<td>2008</td>
<td>'Saying no to the staff: an analysis of refusals in a home for people with severe communication difficulties.'</td>
<td>Sociology of Health &amp; Illness 30(1): 55-75.</td>
<td>People with severe communication difficulties may attempt to exercise control over their lives by verbally or non-verbally refusing an activity proposed by supporters. Details examples in which such refusals are treated by care home staff as a temporary reluctance, warranting further attempts to persuade the individual to co-operate. Identifies the following conversational (and bodily) practices by which staff achieve their institutional ends: appreciating a resident’s behaviour as something other than refusal; formulating the invitation again in a no-blame format; minimising the task required; escalating the invitation to a request and an order; moving the person bodily; and positively glossing the proceedings. Dealing with refusals illustrates the dilemma faced by institutional personnel in health and care settings in accepting choices which might disrupt the efficient management of the service.</td>
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<tr>
<td>Gare, J. and S. Orchard</td>
<td>2004</td>
<td>'Independence days.'</td>
<td>Community Care (1522): 48-49.</td>
<td>Case study involving Knowsley Older People’s Voice</td>
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<td>Author(s)</td>
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<td>Glasby, J.</td>
<td>2002</td>
<td>'Independence at a price.' <em>Community Care</em> 29: 30-1.</td>
<td>In relation to direct payments</td>
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<tr>
<td>Hayes, D.</td>
<td>2007</td>
<td>'Following the Imca trail.' <em>Community Care</em> (29 March).</td>
<td>Describes the IMCA service and notes its importance as the first statutory national advocacy service</td>
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<tr>
<td>Department of Health</td>
<td>2005</td>
<td><em>Consultation on the Independent Mental Capacity Advocate Service.</em></td>
<td>Government consultation of scope of IMCA service</td>
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<td>Department of Health</td>
<td>2007</td>
<td><em>The Mental Capacity Act 2005: the Independent Mental Capacity Advocate (IMCA) Service.</em></td>
<td>Outlines role and remit of IMCA services</td>
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<tr>
<td>Gravolin, M., K. Rowell and J. de Groot</td>
<td>2007</td>
<td><em>Cochrane Database of Systematic Reviews</em> (3): Art. No.: CD005213.</td>
<td>A Cochrane review seeking studies of the decision-making process for older people facing the possibility of long-term residential care. No studies fitting the selection criteria were found, although many related studies that did not reach the threshold were found.</td>
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—addresses key issues facing the contemporary advocacy movement, such as the need for independence, developing quality standards and security of funding;  
—suggests viable ways forward;  
—moves beyond the partisan tendency to champion one kind of advocacy to offer an inclusive account of different styles. |
| Hocking J | 2006 | Advocacy and Older People – special report | Community Care website dated 28 July | Commentary on the OPAAL report listing examples in brief |
| Hussein, S., J. Rapaport, J. Manthorpe, J. Moriarty and J. Collins | 2006 | 'Paying the piper and calling the tune? Commissioners' evaluation of advocacy services for people with learning disabilities.' | *Journal of Intellectual Disabilities* 10(1): 75-91. | —Examines how local authorities evaluate the outcomes of advocacy schemes and reports on and discusses the findings of a survey of local authorities.  
—Concludes that monitoring and review systems are not well known or extensively used, that while user involvement in evaluation is seen as appropriate this is not well developed, but that advocacy services themselves are interested in contributing to processes of improvement and accountability. |
<p>| Joseph Rowntree Foundation | 2004 | <em>Older People Shaping Policy and Practice.</em> | York: Joseph Rowntree Foundation. | Report summarises the key themes from the 18 research projects with priorities defined by old people |</p>
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<tr>
<th>Author(s)</th>
<th>Year</th>
<th>Title</th>
<th>Publisher</th>
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<tr>
<td>Joyce, T.</td>
<td>2007</td>
<td>Best Interests: guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves (England and Wales)</td>
<td>British Psychological Society</td>
<td>Guidance with reference to ‘best interests’ in the eyes of the courts in light of MCA.</td>
</tr>
<tr>
<td>Kerr, L. and V. Kerr</td>
<td>2003</td>
<td>Older People Doing it for Themselves: Accessing information, advice and advocacy.</td>
<td>York: Joseph Rowntree Foundation.</td>
<td>The project aims to establish the perceived and actual needs and requirements of two groups of older people: —those who are currently pensioners —those who will become pensioners in the next 15–20 years. It also looks at the provision and means of delivery of information, advice and advocacy. Considers instances—Barnet; WASSR</td>
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<td>Author</td>
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<td>Keywood, K.</td>
<td>2003</td>
<td>'Gatekeepers, proxies, advocates? The evolving role of carers under mental health and mental incapacity law reforms.'</td>
<td>Journal of Social Welfare &amp; Family Law 25(4): 355-368.</td>
<td>This article explores the potential impact of the mental health and mental incapacity law reforms on carers. The reform proposals anticipate a number of overlapping and at times conflicting roles for carers (including those of gatekeeper, decision-making proxy and advocate), which is suggestive of an ongoing ambivalence toward the caring role at the level of ethics, policy and strategic planning.</td>
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<tr>
<td>Kitchen, G.</td>
<td>2006</td>
<td>Mapping Older People’s Advocacy in the English Regions.</td>
<td>Stoke-on-Trent: Beth Johnson Foundation/OPAAL.</td>
<td>Mapping exercise and literature review providing picture of older people’s advocacy in the English Regions. OPAAL defines advocacy as: “a one-to-one partnership between a trained, independent advocate and an older person who needs support in order to secure their rights, choices and interests”. Examined 11 commissioning documents of which 7 were specifically concerned with older people stemming from 5 organizations — Survey generated directory of 136 organizations. (including London)</td>
</tr>
<tr>
<td>Kitchen, G.</td>
<td>2007</td>
<td>Commissioning Advocacy for Older People: A Common Lack of Approach?</td>
<td>Southport: Get Heard.</td>
<td>— Findings strongly suggest that the development of a National Commissioning Framework for Advocacy with Older People may be helpful in providing a context in which commissioning should take place. (As a result of widely divergent approaches.)</td>
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<tr>
<td>Leason, K.</td>
<td>2005</td>
<td>'More than just a fad?'</td>
<td>Community Care (1565): 28-30.</td>
<td>Re introducing statutory advocacy</td>
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<td>Author(s)</td>
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<td>Lee, D. T. F., J. Woo and A. E. Mackenzie</td>
<td>2002</td>
<td>'A review of older people's experiences with residential care placement.'</td>
<td><em>Journal of Advanced Nursing</em> 37(1): 19-27.</td>
<td>Literature review covering 1970-2000. Notes that transition to the care and environment of a residential home has been identified in the literature as the most significant relocation affecting older people. However, little effort has been made systematically to review and synthesize the body of knowledge relating to older people's experiences with such placement. This has led to lack of concerted effort in the development of strategies to help residents adjust with dignity and success. Authors found minimal literature on the actual experiences of older people when making their day to day adjustment after placement. There is a need for future research to identify the dynamic processes of how older people come to terms with residential living. Future research should also focus on developing an accurate understanding of the adjustment experiences of elders with different ethnic background.</td>
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<tr>
<td>Manthorpe, J., J. Rapaport, S. Hussein, J. Moriarty and J. Collins</td>
<td>2005</td>
<td><em>Advocacy and People with Learning Disabilities: Local Authority Perceptions of the Scope of its Activity, Extent and Effectiveness. A Report to the Department of Health</em></td>
<td>Social Care Workforce Research Unit, King’s College London.</td>
<td>The study consisted of a review of the published and unpublished UK literature on advocacy, details about 97 separate advocacy schemes obtained through a postal questionnaire sent to local authorities in the UK and 27 semi-structured interviews with key stakeholders involved in commissioning and developing advocacy schemes. A consultation event attended by groups representing people with learning difficulties, advocacy organisations, service providers and social work practitioners was held to validate the findings. The work was undertaken between 2004-2005.</td>
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| Margiotta, P., N. V. Raynes, D. Pagidas, J. Lawson and B. Temple | 2003 | *Are You Listening? Current practice in information, advice and advocacy services for older people.* | York: University of Salford; Joseph Rowntree Foundation. | - Older people should be provided with information about local advocacy services – their availability and ease of access.  
- The older vulnerable person must be central in the advocacy process.  
- Advocacy must be individually led by the person in need.  
- Older people should be involved at all levels, whether in planning, organising or acting as volunteer advocates.  
- Volunteer citizen advocates should be drawn from the many diverse groups and cultures within a community.  
- Health and social care practitioners should receive training about advocacy and the role of volunteer advocates.  
- Funding should be made available to support advocacy schemes to maintain their independence.  
- National standards and codes of practice should be established. These would include guidelines for recruitment, training and supervision of volunteers. |
<p>| National Care Homes Research and Development Forum | 2007 | <em>My Home Life. Quality of life in care homes.</em> | London: Help the Aged. | This survey of quality of life in care homes is broken down into sections on: Contexts and concepts; care home life; enhancing quality of life in care homes. Includes a section on Transitions into a care home, and associated literature. |</p>
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<td>Office of the Deputy Prime Minister/Social Exclusion Unit</td>
<td>2006</td>
<td>A Sure Start to Later Life: Ending Inequalities for Older People - A Social Exclusion Unit Final Report.</td>
<td>London: Office of the Deputy Prime Minister.</td>
<td>As part of reducing social exclusion of older people, the government has agreed to ensure that advocacy services are included in the piloting of the Sure Start to later life approach through the ‘Link Age Plus’ programme and as part of the Individual Budgets pilots.</td>
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<tr>
<td>Office of Fair Trading</td>
<td>2005</td>
<td>Care Homes for Older People in the UK. A market study.</td>
<td>London: OFT.</td>
<td>Found that older people and their representatives face significant problems in finding information about moving into a care home, often at a time of difficult and distressing circumstances. Argues that prospective residents need better information and advice when considering entry to care homes. Proposes a central information source or one stop shop for information. Recommends that the DH run pilot projects to measure the benefits and costs of advocacy services for older people entering and living in care homes.</td>
</tr>
<tr>
<td>Pati, A.</td>
<td>2006</td>
<td>‘Older people and advocacy.’</td>
<td>Community Care(24 August 2006)</td>
<td>Being ignored is a common experience for older people. Part of the solution is advocacy, but research suggests many older people have never heard of it - and many social care staff are unsure of what it entails.</td>
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<td>Pritchard, J.</td>
<td>2001</td>
<td>'Let residents speak out.'</td>
<td>Community Care, 5.4.01, p.28.</td>
<td>Ways care home residents can make their voices heard.</td>
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<tr>
<td>Rapaport, J., J. Manthorpe, S. Hussein, J. Moriarty and J. Collins</td>
<td>2006</td>
<td>'Old issues and new directions: perceptions of advocacy, its extent and effectiveness from a qualitative study of stakeholder views.'</td>
<td><em>Journal of Intellectual Disabilities</em> 10(2): 191-210.</td>
<td>This article describes and discusses 27 interviews that explored perceptions of the effectiveness of advocacy services for people with learning disabilities in the UK. The views of stakeholders on the current position of advocacy services, how services are evaluated and recommendations for change are central themes in the analysis of the interviews. The discussion suggests that although evaluation of effectiveness is increasingly important in the light of policy change and funding constraints, it is not universally in place and available tools are considered to be inadequate for the task. The explanation of this may lie in the continuing debates over the meaning and purpose of evaluation and fears that it is one-dimensional. Future investment and commitment to advocacy schemes will need to address these issues.</td>
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<td>Rapaport, J., J. Manthorpe, J. Moriarty, S. Hussein and J. Collins</td>
<td>2005</td>
<td>'Advocacy and people with learning disabilities in the UK. How can local funders find value for money?'</td>
<td><em>Journal of Intellectual Disabilities</em> 9(4): 299-319.</td>
<td>Advocacy schemes have been established throughout the United Kingdom (UK) but their evaluation by funders is varied. This article reviews the literature in respect of models of evaluation of advocacy schemes for people with learning disability. It discusses the six main models and the issues that arise in evaluation. The advantages and disadvantages of each model are analysed. The article concludes that whilst fears exist about the potential for evaluation to infringe advocacy schemes’ autonomy, funders need to undertake such a process for reasons of public accountability. Advocacy schemes may find it useful to consider which model of evaluation works best for them and will be appropriate and useful for their funders.</td>
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<td>Redley, M., L. Luke, H. Keeley, I. Clare and A. Holland</td>
<td>2006</td>
<td><em>The Evaluation of the Pilot Independent Mental Capacity Advocate (IMCA) Service.</em></td>
<td>Cambridge: University of Cambridge.</td>
<td>The pilot IMCA service raised many operational questions. Foremost was whether the decision-focused approach to advocacy could actually protect people lacking decision-making capacity? With casework experience, both IMCA case-workers and their managers said that it could. Health and social care practitioners also saw the pilot IMCA service as better at safeguarding the ‘best interests’ of people lacking decision-making capacity than current best practice. However, the research revealed that many health and social care practitioners using the IMCA service had little understanding of the relevant parts of the Mental Capacity Act (not implemented at the time of the pilot). Additionally, many social care practitioners lacked confidence in assessing a person’s decision-making capacity.</td>
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| Robinson, J.          | 2006 | *Making a Real Difference.*                                                                                   | Stoke-on-Trent: Beth Johnson Foundation/OPAAL. | The Department of Health funded OPAAL in a 3-yr development plan to implement its aims viz.  
— Promote independent advocacy with older people  
— Contribute to the development of standards  
— Improve access to advocacy for older people  
— Develop better practice in the field  
— Build the involvement of older people in the organisation  
— Develop links with minority ethnic communities |
<p>| Robinson, J. | 2006 | <em>Advocacy. Who Cares for Older People?</em> | Older People's Advocacy Alliance (OPAAL) UK. | Considers four discussion topics raised at meetings in the English regions: 1. on guidance on good practice and quality frameworks 2. evidence base for advocacy 3. independent advocacy for older people as a right, and examples of older people’s involvement in promotion of independent advocacy 4. on funding sources and the problems of sustainable funding. |
| Sang, B. | 2004 | 'Choice, participation and accountability: assessing the potential impact of legislation promoting patient and public involvement in health in the UK.' | <em>Health Expectations</em> 7(3): 187-190. | Recent legislation enabling increased patient and public involvement in health decision-making will increasingly interact with the maturing independent patient movement to open up accountability systems across healthcare. Lay people will develop new roles, building on learning from the independent advocacy sector, self management, and wider active participation. Inevitably, this means a profound cultural challenge for healthcare organizations, and for citizens, as they begin to understand the implications of the new policies, including patient choice. |
| Scourfield, P. | 2004 | 'Questions raised for local authorities when older people are evicted from their care homes.' | <em>British Journal of Social Work</em> 34(4): 501-516. | This article asks whether the necessary work required to minimize the harmful effects caused by the stress of relocation is actually being carried out properly. It also raises the questions of what exactly should be offered to older people when they are given notice to quit, who is best qualified to do the work and whether care management as it has developed with the ‘purchaser/provider framework’, is adequate to the task. In short, where can social work for older people be found when it is needed? |
| Scourfield, P. | 2007a | 'A commentary on the emerging literature on advocacy for older people.' | Quality in Ageing - Policy, practice and research 8(4): 18-27. | This paper comments on emerging themes derived from recent official publications on older people's advocacy in the UK. There is an examination of relevant policy documents and the responses from service user groups. Discussion includes: clarity in defining advocacy; the nature of the advocacy relationship; sustained and reliable financing of advocacy services; the uneven nature of provision; lack of inter-agency connectivity; the need to establish national standards for advocacy; problems of mental capacity; and advocacy for care home residents and for minority groups. The need for and direction of further research is proposed. |
| Scourfield, P. | 2007b | 'Helping older people in residential care remain full citizens.' | British Journal of Social Work 37(7): 1135-1152. | As most older people living in residential care are there following the intervention of a social care professional, ensuring that they have access to advocacy must surely be a key task. This paper argues that this is frustrated by the lack of suitable services. Without Government significant investment in independent advocacy services, not only is the social work task impossible, but the Government cannot deliver on its own agenda of empowerment, active citizenship and inclusion. |
| Scourfield, P. | 2007c | 'Reviewing residential care reviews for older people.' | Practice, 19(3), September 2007, pp.199-209. | Care home residents are one of the most powerless groups in society with few opportunities to gain control over their living circumstances. The discussion raises the issue of whether care home reviews should always seek to involve independent advocates; as policy allows but seldom happens in practice. If this is the case, then this raises further issues of how to ensure such a service is available to all. |</p>
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|                                 |      | Advocacy is currently viewed highly favourably by the government and moves are afoot to further professionalise it. Advocates - people who "support, speak in favour of, or plead for" someone else. The voice of the service user is being given unprecedented importance in decision-making, and advocates are increasingly being relied upon to ensure that individuals' wishes and needs are represented.
| Williams, J., Netten, A. and Ware, P. | 2003 | Closure of Care Homes for Older People                                             | Canterbury, PSSRU                                                              |
|                                 |      | DH funded study covering *inter alia*, local government guidelines on voluntary care home closures and case study of 15 closures that interviewed residents, relatives, care home staff and care managers. |
| Wright, F.                      | 2005 | 'Explaining about...advocacy and care home residents.'                            | Working with Older People 9(1): 9-12.                                          |
|                                 |      | Overview of advocacy                                                               |                                                                                   |
| Wright, F.                      | 2006 | The role of advocacy for older people resident in care homes.                      | Institute of Gerontology, King’s College London                                 |
|                                 |      | A postal questionnaire sent to the 29 administrators of local Age Concern advocacy schemes with a service for elderly care home residents elicited 19 responses (66%). Twelve administrators agreed to discuss issues at greater length in a telephone follow up interview. |
| Wright, M.                      | 2006 | A Voice That Wasn’t Speaking.                                                      | Stoke-on-Trent: Beth Johnson Foundation/OPAAL.                                  |
|                                 |      | This report presents a summary of the main findings of a consultation with older people who have had contact with and/or received advocacy services. |