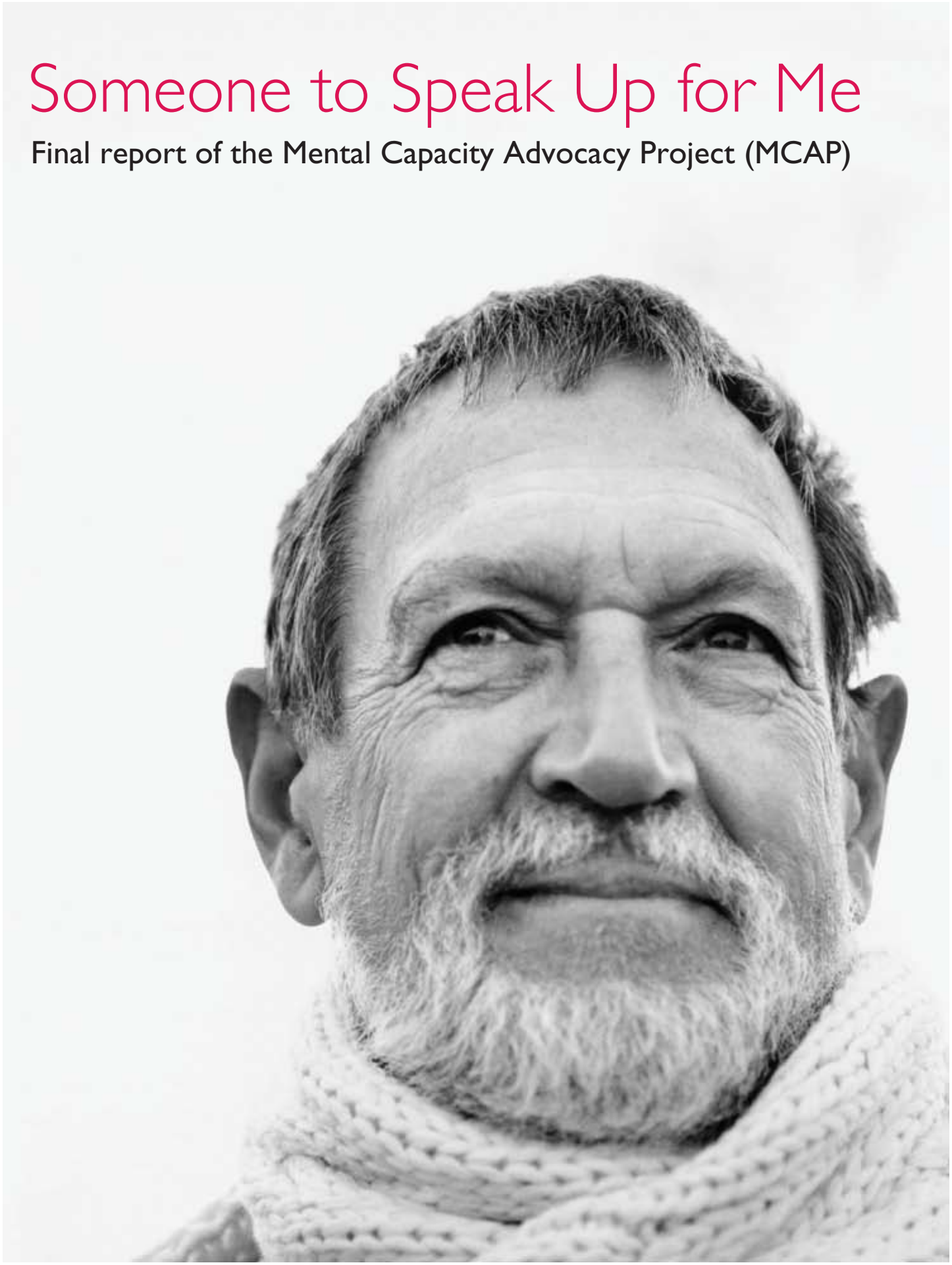
Someone to Speak Up for Me

Final report of the Mental Capacity Advocacy Project (MCAP)



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Final report of the Mental Capacity Advocacy Project (MCAP)

Age Concern and Help the Aged

1 Executive summary

This report has been written by the MCAP Reference Group members at Age Concern and Help the Aged who have overseen the direction of this three-year Department of Health-funded project. It is distinct and separate from *Who I Am Makes a Difference*, the MCAP Independent Evaluation report written by Andy Bradley, Director of Frameworks 4 Change. That report focuses specifically on reporting back against Aims 1 and 2 of the MCAP, looking in detail at the advocacy service from the point of view of the older people and the volunteers who have delivered the advocacy in the pilot sites.

This report is specifically an opportunity for Age Concern and Help the Aged staff to reflect on the success, impact and influence of the project's work over the last three years in relation to Aims 3 and 4 of the MCAP specifically. Thus this report includes information, statistics and interpretation to demonstrate the extent to which we have shared the good practice from the MCAP, and the extent to which we have communicated the needs of older people who lack mental capacity for some decisions to campaigners and policy-makers. This report also reflects on the objectives we set ourselves back in 2006 and the extent to which these have been achieved.

1.1 Key messages from the project

- Older people who lack mental capacity for some decisions have little or no voice and are among the most excluded groups in society today. Developments in communication tools and technology increasingly allow us to explore innovative ways to enable these voices to be heard.
- 'Lacking mental capacity' is a label that many people cannot see beyond, but in spite of it many older people are able to express their views, wishes and choices, given the opportunity and the right support.
- Anxiety and aggression and other 'challenging behaviours' in older people are often wrongly ascribed to a mental illness rather than to potentially treatable causes such as infection control and pain management.
- Problems and crises in the lives of older people do not fall into neat, service-defined pigeonholes. A holistic approach is needed that rebuilds the often lost community connections with the older person.
- Volunteers can bring a fresh pair of eyes to care situations and are often shocked by poor practices with older people, which some care staff seem unable to see.

- Volunteers can provide effective advocacy in areas considered to be difficult and technical with meaningful training and timely support.
- There are numerous people in our communities who are willing to volunteer to advocate for an older person who is experiencing some loss of mental capacity.
- Volunteer advocacy and its benefits and impact are undervalued in the face of 'professional' developments in advocacy in recent years.
- Advocacy providers, commissioners and partners need to work together to ensure that the diverse needs of older people, including those who lack mental capacity, are met by the transformation of social care.
- The Mental Capacity Advocacy Project is personalisation in action.

1.2 MCAP voices

The MCAP has made considerable efforts to capture the voices of older people who lack some capacity and the volunteers themselves so that we can identify and share the issues. Neil Mapes, Project Co-ordinator, was also part of a small team at Age Concern which worked with the RIX Centre to record the views of older people who have experienced a loss of mental capacity about being socially excluded. The report and accompanying DVD (both entitled *Why Don't You Talk to Me about This?*) are available separately. Some of the views of older people who took part in this research are included in section 3.2 (pp. 9–10).

1.3 Summary of lessons learnt

We have learnt a great deal from this challenging and important project. Throughout the report learning points are identified which are summarised here:

- The national role of Project Co-ordinator has been a crucial one in successfully managing and guiding this complex project.
- Engaging independent evaluation early on in the project delivery enabled a holistic approach to the MCAP work and its evaluation, which brought many benefits.
- Core project documents, developed by the team at the outset of the project, were necessary in building an understanding of how to go about successfully delivering this work.

- The MCAP has freely shared the developed resources on volunteer advocacy, which has fostered respect and mutually beneficial relationships. We have learnt that there is a demand for these practice-based materials that enable local providers to translate national policies into practice on an individual level.

- The quarterly reporting and reviewing timescales have been crucial for building in time for reflection, reviewing thinking and changing direction as the work evolved. It has been important to acknowledge from the outset that we don't have all the answers, and to be comfortable with uncertainty and creative with exploring solutions to problems as they arise.

- More work is needed to engage advocacy providers with the commissioners of advocacy so that the benefits and impact of volunteer advocates are clearly understood.

- More work is needed to effectively connect the work of projects of this kind to the Charity's campaigning objectives.

- Stakeholders want to hear directly from older people and the volunteers involved in this project; our work has had most impact when older people and volunteers have represented the work of MCAP.

- We have learnt that resources for effective non-instructed advocacy, being delivered by volunteers, are easily underestimated. The time, training and support involved are different from instructed advocacy, and significant resources are needed if an effective team of volunteers is going to be recruited, trained and supported to deliver non-instructed advocacy.

- There are passionate and committed people willing to volunteer to undertake challenging and important roles in our communities. The impact and influence of these local citizens must not be understated. Project structures and documents are nothing without passionate people.

2 Main report

Age Concern England successfully secured funding through Section 64 monies from the Department of Health for what was originally entitled the Mental Health Advocacy Project (MHAP). The name of the project was changed to the Mental Capacity Advocacy Project (MCAP) following feedback and consultation with stakeholders in year one of the work. The project started in October 2006 and concluded in October 2009. The name change was made for a variety of reasons but primarily to reflect more accurately the remit of the project.

The mission of the project

To develop, explore and evaluate a volunteer advocacy service for older people who lack mental capacity

The specific aims of the project

1. To enable older people who lack mental capacity to access a high-quality advocacy service.

2. To enable volunteers involved in the delivery of advocacy to be knowledgeable, skilled, confident and to have a positive experience of providing advocacy to older people who lack mental capacity.

3. To ensure that providers and commissioners of advocacy services (including local Age Concerns, Independent Mental Capacity Advocacy (IMCA) services, and generic advocacy services) learn the lessons of good practice from the MCAP.

4. To increase communication with key campaigners and policy-makers about the issues faced by older people who lack mental capacity.

2.1 Project structure

The MCAP national Project Co-ordinator, employed by Age Concern and Help the Aged, was Neil Mapes. The brief for the Project Co-ordinator was to develop systems and structures to underpin all aspects of the project and to co-ordinate all aspects of service delivery. In the last year of this work Neil was assisted with the national delivery by Charles Potts, the MCAP Officer.

Critical to the structure of the project was the use of volunteer advocates in working with older people who may lack the capacity to make some decisions. This approach was piloted by four local Age Concerns:

Age Concern Blackpool and District (in partnership with N-Compass);
Age Concern Cheshire;
Age Concern Slough and Berkshire East;
Age Concern Warwickshire.

These Age Concerns enabled the MCAP to work across three different regions in England, with rural and urban communities and with Black and Minority Ethnic groups. There was a Project Manager and an Admin Co-ordinator at each pilot site. Local sites were responsible for recruiting, selecting, training and supporting volunteers for the MCAP. Local sites were also expected to raise awareness of their project with local stakeholders to generate interest in the aims of the project, resulting in referrals from a range of settings. Local project staff worked within agreed guidelines to match volunteers with clients to provide effective advocacy.

The project worked to a fixed reporting time-frame, with pilots submitting reports and holding quarterly meetings to reflect on progress, successes, challenges and the areas for focus and development. This reporting programme was mirrored by the MCAP team, which submitted quarterly progress reports to the funder, the Department of Health.

The MCAP was directed by the Age Concern and Help the Aged Project Reference Group (PRG), which met regularly to receive updates on the development of the project and to decide on and plan next steps.

The MCAP National Advisory Group (NAG) was made up of external, expert representatives who met twice a year to advise the MCAP. The members of the NAG also played a part in disseminating the work of the MCAP project. This group benefited greatly from the perspectives brought by the 'experts by experience', including a person with dementia and a former user of mental health services.

3 Findings – how is the world different as a result of the MCAP?

This section details examples and evidence of work reporting back against Aims 3 and 4, specifically against all the relevant outcomes – how is the world different as a result of the MCAP?

This section also reports back against the objectives or activities that we set ourselves in 2006 – what did we achieve? The findings and work led us to develop a number of key messages, which are identified here. It is important to reference and air the voices of the older people and volunteers to demonstrate the importance of this work.

3.1 MCAP – key messages

- Older people who lack mental capacity for some decisions have little or no voice and are among the most excluded groups in society today. Developments in technology increasingly allow us to explore innovative ways to enable these voices to be heard.
- 'Lacking mental capacity' is a label that many people cannot see beyond, but in spite of it many older people are able to express their views, wishes and choices, given the opportunity and the right support.
- Anxiety and aggression and other 'challenging behaviours' in older people are often wrongly ascribed to a mental illness rather than to potentially treatable causes such as infection control and pain management.
- Problems and crises in the lives of older people do not fall into neat, service-defined pigeonholes. A holistic approach is needed that rebuilds the often lost community connections with the older person.
- Volunteers can bring a fresh pair of eyes to care situations and are often shocked by poor practices with older people, which some care staff seem unable to see.
- Volunteers can provide effective advocacy in areas considered to be difficult and technical with meaningful training and timely support.
- There are numerous people in our communities who are willing to volunteer to advocate for an older person who is experiencing some loss of mental capacity.
- Volunteer advocacy and its benefits and impact are undervalued in the face of 'professional' developments in advocacy in recent years.

- Advocacy providers, commissioners and partners need to work together to ensure that the diverse needs of older people, including those who lack mental capacity, are met by the transformation of social care.

- The Mental Capacity Advocacy Project is personalisation in action.

3.2 MCAP voices

The MCAP has made considerable efforts to capture the voices of the older people who lack some capacity and the volunteers themselves so that we can identify and share the issues. Neil Mapes, Project Co-ordinator, was also part of a small team at Age Concern which worked with the RIX Centre to record the views of older people who have experienced a loss of mental capacity about being socially excluded. The report and accompanying DVD are available separately and are highly significant, helping people to understand the views, experiences and issues that older people who lack mental capacity face. Some of the views expressed in the RIX project are included here.

Older people who have experienced some loss of mental capacity

Extracts from the RIX Centre research commissioned by Age Concern:

> 'Why don't you talk to me about this? How much I've got in the bank or how much I'm paying out for this … I don't even know how much I pay for the rent of the place I'm in! Which, being an independent woman, I always knew these things. Now I don't know anything.'

> 'I'm not really happy … no … no. Yeah, bit dangerously so. That's why I'm coming here, to be with people …'

> 'I always get the feeling he's treating me … not … as if I haven't got all my marbles. I know at first that's how I was … when this first started on me.'

> 'I don't think I've had very good treatment at the hospital … So I had about five visits to the hospital, without seeing anyone at all, without getting any answers.'

A selection of quotations from the MCAP volunteer advocates:

> 'I looked after my parents, and know how hard it was for them … These people have no one. I must speak up for them.'

> 'I am so angry my client doesn't get his personal allowance regularly, that someone has to ask for it, and if no one does then he doesn't get it.'

'How easy it is to be wrongly labelled. I can see how my client's confidence has changed since I have been working with her, she feels someone is on her side. She is not so much in a total fog of doctors, council officials and all the bureaucracy which added to her anxieties and depression.'

'It is sad how families fall out, and communication breaks down, leaving a very vulnerable person – my client just needed a little understanding and I was able to help with this.'

3.3 Aim 3

To ensure that providers and commissioners of advocacy services receive the learning and good practice from the MCAP

This aim was important as it was recognised early on in the project that the work would represent a valuable opportunity to explore volunteer advocacy in a new context, and that lessons from the project should be available to those who provide and commission advocacy .

This aim was focused on the following five specific outcomes:

Outcome 1: Achieved

Findings from the pilots have been analysed to distil learning and good practice

This was intended to explicitly draw out the important lessons and good practice from the pilots. Andy Bradley's work as the independent evaluator has been central in meeting this outcome, as the large proportion of his work has been in analysing the findings from the pilots. *Who I Am Makes a Difference* (the independent evaluation report of the MCAP) gives further detail on this outcome. *Building Up a Picture*, the MCAP interim report published in January 2009, was incorporated into the design of this project so that emerging themes and stories could be shared widely before the project came to a close. The summary of evidence information (see p. 16) is also indicative of the large amount of work which has taken place to analyse the work and convert this into learning and sharing good practice. These included quarterly reflection at pilot site meetings, case-study analysis, publications, networking meetings and speaking at and running workshops at conferences.

Outcome 2: Achieved

Evaluation of the pilots has been used to generate good practice guidance

The work of the pilot sites has throughout the project been used widely to help develop understanding of non-instructed advocacy and share good practice. This has been done informally by speaking at events and formally publishing articles, and has led to the MCAP being featured in various good practice guidance reports by external organisations. *Building Up a Picture* (the interim evaluation report) has been positively received and has been downloaded 329 times from the MCAP website.

Outcome 3: Achieved

Advocates and advocacy providers have received the learning and good practice from the project

The MCAP has made significant efforts to share the results of its work with the advocacy sector in general terms and has been aware of the value and importance of this project for other advocacy providers. The MCAP has freely shared information in a host of spoken and written forms including feedback from older people, volunteers and staff in various formal and creative ways. The website statistics in the summary of evidence (see p. 16) demonstrate the success of these efforts to share information.

Outcome 4: Partially achieved

Providers and commissioners have been informed of the learning and outcomes from the MCAP

A significant amount of work has taken place in order to share the results of the MCAP with service providers and commissioners, as detailed in Outcome 5. The emphasis has been on national networks of local providers as well as on engaging directly with local providers. There has been some direct engagement with commissioners and indirect work, as highlighted in the summary of evidence (see p. 16), but this is an area from which Age Concern and Help the Aged could learn, ensuring that commissioners fully understand the benefits of advocacy. The MCAP Conference has specifically included two discussion seminars on advocacy commissioning to help bring together and understand the issues on both sides of the commissioning process.

Outcome 5: Achieved

Pilot site project managers are skilled and confident in sharing the learning and good practice from the MCAP

Increasingly as the project has developed, the local pilot staff and volunteers have taken a much more prominent role in directly sharing the stories and the importance of the volunteer advocates with a variety of audiences as detailed below. Staff and volunteers have confidently and very skilfully presented their work, which has made a significant impact on the audiences. Audiences commented that it has been good to hear directly from the volunteers engaged with the older people. The MCAP team has resourced specific training for the four pilot managers in, for example, mental health in later life and non-instructed advocacy train-the-trainer. This, combined with weekly information and resource emails, teleconferences and quarterly pilot site meetings and direct visits from the Project Co-ordinator, has enabled the local project staff to skilfully develop the work.

3.4 Aim 4

To increase communication with key campaigners and policy-makers about the issues faced by older people who lack mental capacity

This aim was focused on the following five outcomes:

Outcome 1: Achieved

The key issues faced by older people who lack mental capacity will have been identified

The work of the local pilot sites has raised a number of issues faced by older people who have been deemed to lack mental capacity. These have been distilled in a number of articles and shared widely in writing and in person (see p. 16). The key messages in this report have been developed as a result of examining and exploring the issues with older people. The issues are also explored and highlighted in some detail in *Who I Am Makes a Difference*.

Outcome 2: Achieved

Key campaigners and policy-makers who can make a difference to the lives of older people who lack mental capacity will have been identified

The MCAP has written a number of key documents which have been central to the success of this work. One of the key internal documents has been the MCAP Influence Strategy, which was drawn up in 2007 and revised in 2008 to reflect the changing nature of the mental capacity field and contacts. In this document a wide variety of specific and general contacts were successfully identified and made.

Outcome 3: Achieved

New opportunities for strategic links will have been identified

New strategic links have been made with:

The RIX Centre at the University of East London
Department of Health
Office of the Public Guardian
Social Care Institute for Excellence
Action on Elder Abuse
EVIDEM (Evidence in Dementia Research)
Institute of Rural Health
Action for Advocacy
Older People's Advocacy Alliance (OPAAL)
Volunteer Advocacy in Ukraine (Age Concern Ukraine)
Office for Public Management

Outcome 4: Partially achieved

Relationships will have been established with people who have responsibility for campaigning and policy

There have been a number of relationships developed with key policy-makers at the Department of Health. Advocacy has been increasingly recognised as an essential component of service models to achieve policy goals of transforming services to promote independence, well-being and dignity. Less work has taken place in a tangible sense in terms of public campaigning. We leave it to Age Concern and Help the Aged to effectively connect the work of this project with campaigning objectives.

Outcome 5: Partially achieved

Issues faced by older people who lack mental capacity will have been used to shape campaigns and policy discussions

The MCAP has made considerable effort to bring campaigners and policy-makers face to face with older people, via, for example, the RIX Centre research and its use at various conference presentations and boards, as well as volunteers participating in many conference and workshop presentations. The extent to which these have shaped campaigns and policy discussions is less clear. But the fact that these older people's voices are being aired after previously being unseen and unheard has been a success in itself. We need to ensure that these voices are listened to and that campaigns and policies do genuinely change for the better as a result.

4 Summary of evidence

We have compiled a list of evidence, broken down into two main sections: the spoken word and the written word. Seen as a whole, this list of evidence provides an impressive overview of the significant impact that this project has made. Each of the examples is directly or indirectly applicable to one or more outcomes and all are directly supportive of establishing that we have met our objectives.

4.1 The written word: web-based, printed publications and articles, reports and flyers

Web-based

- The MCAP internet page on the Age Concern and Help the Aged website (www.ageconcern.org.uk/AgeConcern/mhap.asp) has had 5,339 page views and 3,929 unique users (as of 14 July 2009) and associated resources have been downloaded in total 3,426 times (as of 14. July 2009). Given the specific nature of this project these figures are particularly noteworthy.

Breakdown of downloads from MCAP web page (1 July 2007 to 14 July 2009) are as follows:

- *Volunteer Advocate Guidance Pack for MHAP Projects*: 1,033
- *Advocacy Resource Pack to Aid Advocacy Delivery*: 727
- *MHAP Evaluation framework: 1,337*
- *Building Up a Picture:* 329 (1 April 2009 to 14 July 2009)

- The MCAP has logged articles, case studies and good practice material and links on a number of external web pages including: Social Care Institute for Excellence (SCIE), OPAAL, A4A, Care Services Improvement Partnership, Volunteering England, Institute of Rural Health, London Centre for Dementia Care, Relatives' and Residents' Association and the four local Age Concern MCAP pilot sites for local stakeholders.

- Ten issues of the e-bulletin 'Friends of MCAP' have been produced and disseminated throughout the lifetime of the project. Each bulletin has directly reached over 350 people and indirectly reached over 2,000 people, via different advocacy-related network leaders.

- Intranet web page – since 2007 the MCAP has shared information about the work of the pilot and the outputs via its internal Age Concern web page on the intranet.

Printed publications and articles

A variety of published articles have been disseminated throughout the project, including:

- Articles published in the *Elderly Client Adviser* and the Pavilion journal *Working with Older People*.
- Articles in the publications on the Mental Capacity Act produced by the Office of the Public Guardian/Ministry of Justice.
- Articles in *Planet Advocacy* (the journal which is disseminated throughout the advocacy sector) sharing good practice and promoting debate, specifically regarding non-instructed advocacy and volunteer advocacy.
- Case studies fed into City & Guilds learner and trainer packs for new mental health promotion qualifications.
- Articles written and disseminated to all local Age Concerns in *Signpost*, *Network*, and internal newsletters including *BME Newsletter* and *Mental Health and Well-being Newsletter*, *Active Ageing in Focus*, *Inform and Advise*.
- Articles in OPAAL (Older People's Advocacy Alliance) newsletters.

Reports and flyers

- The MCAP has been highlighted as good practice in the following national Age Concern reports: *On the Right Track* – highlighting human rights-focused work; *Out of Sight Out of Mind* – highlighting the social exclusion of older people; and a national briefing of the personalisation of care services.
- Neil Mapes was interviewed as part of the European Commission on Human Rights inquiry report.
- The MCAP has produced three different national flyers, for years 2007, 2008, and 2009 respectively, with 1,500 distributed nationally. Local pilot projects have also produced and disseminated flyers promoting the MCAP work.

4.2 The spoken word: conferences, consultations and networks

Conferences

The MCAP team (staff, volunteers and older people) have developed connections, led workshops and spoken at a wide variety of high-profile national and international conferences, including:

- European Social Services Conference in Paris – MCAP highlighted in workshop.
- International Federation on Ageing Conference in Montreal – MCAP highlighted in workshop on mental health and older people.
- ADASS annual conference in Liverpool – fringe session by MCAP staff and volunteers from Age Concern Cheshire.
- Community Care Live Conference – seminar session.
- National Advocacy Network Annual Conference – workshop held.
- Mental Health Conference with Pavilion – world café presentation with staff and volunteers from Age Concern Slough.
- CSCI Dementia Improvement Board – presentation.
- Alzheimer's Society Annual Conference – workshop held.
- Action on Elder Abuse Annual Conference – workshop held with Speaking Up (IMCA provider).
- Age Concern Joint Networks Development Conference – world café presentation.
- National Council on Ageing – MCAP highlighted by speaker.
- Mental Capacity Act – two separate conference keynote speeches on the MCAP.
- Age Concern Blackpool annual conference – keynote speech.

- The RIX DVD clips of older people talking about social exclusion and mental capacity have been used widely with campaigning and policy audiences, including conferences such as the Alzheimer's Society annual conference, MCA conference keynote speech in 2009, CSCI Dementia Improvement Board, National Council on Ageing and a dementia conference in the North West region.

- Submission to speak at Dementia Congress (4 November 2009) accepted.

Consultations

- Neil Mapes, the MCAP Project Co-ordinator, was asked to submit a section on advocacy for the National Dementia Strategy consultation and was credited in that document as a contributor.

- Contribution and information shared as part of the Deprivation of Liberty Safeguards consultation.

- Neil Mapes was part of a select group of people who informed a delegation from Singapore on the impact of the Mental Capacity Act in England for learning in Singapore.

- Neil Mapes was interviewed by the Office of Public Management on the extent to which volunteers can be part of community-led solutions to social change.

Networks

- Age Concern Advocacy Network meeting – presentations by pilot staff and volunteers.

- Age Concern BME Network meeting – presentations by pilot staff and volunteers.

- Age Concern Mental Health and Wellbeing Network – presentations by pilot staff and volunteers.

- Dementia Advocacy Network (DAN) – steering group member.

- Older People's Advocacy Alliance (OPAAL) – Independent Advocacy National Forum member.

- Advocacy Consortium UK (ACUK) member.

- The MCAP has established contact, presented to teams and made formal links with the following information lines: Advocacy finder online (Action for Advocacy – A4A); Advocacy finder helpline (Advocacy resource exchange); Age Concern information line; Relatives and Residents' Association information line; and Action on Elder Abuse helpline.

- The MCAP has also made extensive efforts to inform a wider audience through attending and presenting at: EVIDEM (Evidence in Dementia Research) – advisory group member; Royal College of Psychiatry Consumer – panel member; Department of Health S64 meeting; and the Mental Health Interfaith Forum member.

- Relationships have been established with IMCA providers, both at all four pilot sites but elsewhere nationally too; for example, with Speaking Up, the IMCA provider in Cambridge.

- Formal relationships have been built with a number of local, regional and national organisations, for example: Alzheimer's Concern Ealing; Bristol and Avon Chinese Women's Group; Hambleton and Richmondshire Advocacy; Hampshire Advocacy Regional Group; OPAAL; R&RA; Dementia Advocacy Network; CSIP and the Department of Health; Mental Health Foundation; Alzheimer's Society; College of Law; and Volunteering England. Connections have been kept up with these links via the MCAP e-bulletin called 'Friends of MCAP' and via the MCAP Advisory Group meetings.

4.3 Did we achieve all our objectives?

The MCAP team set itself six objectives in 2006.

1. To provide an advocacy service delivered and received by a diverse range of groups, populations and communities.

2. To offer a comprehensive and effective training and support package to the volunteer advocates.

3. To provide the four MCAP pilot projects with the information, support and guidance needed to effectively deliver a national pilot at a local level.

4. To provide advocacy organisations and commissioners with good practice guidance, briefings and information on a regular basis throughout the duration of the MCAP.

5. To set up and facilitate an external National Advisory Group.

6. To undertake communication and influencing work with the media, campaigners and policy-makers.

Objectives 1 and 2 are specifically addressed in *Who I Am Makes a Difference*, and further detailed in *A Resource Pack to Aid Advocacy Delivery*, but it is important to describe the training here from a national delivery perspective. Much of the training that volunteers received was sourced and provided at a local level except the following nationally commissioned training:

- in 2007 all four pilots attended a two day training course in mental health in later life; N-Compass provided all four pilots with non-instructed advocacy training and toolkits in 2007;
- Frameworks 4 change further provided 'train-the-trainer' training with all four pilot staff in 2009.

A wide variety of training was provided to the staff and volunteers locally with the MCAP covering advocacy principles, Mental Capacity Act, non-instructed advocacy, mental health law, adult protection and case recording.

Objective 3 has been the main responsibility for the MCAP Co-ordinator and has been achieved in a number of ways. Quarterly pilot site meetings have been held at each Age Concern pilot site in turn to share local learning and context and for support. Conference calls have taken place at key developmental stages of the delivery to facilitate support and agree actions. Weekly emails summarising the key resources and information that have impacted the work have been circulated to all four MCAP pilots. This has enabled pilot staff to focus on the specific issues relevant to the MCAP within the larger picture of change and in a time of information overload. In addition, support and information has also been provided via email and over the phone. Each pilot site has received, on average, a quarterly pilot-site visit from the MCAP Project Co-ordinator for face-to-face support and to devise the work and review it against action and project plans.

Objective 4 concerns information dissemination and has already been established extensively via the summary of evidence (see p. 16).

Objective 5 concerns the National Advisory Group (NAG) for the MCAP. The NAG has met six times (twice in years one, two and three) and comprises 15 experts including a person with dementia, a former mental health service user and representatives from local, regional and national organisations. This group has been integral to the success of the MCAP and has helped the work in numerous ways. The role of advice has been very important in keeping this work relevant to non-Age Concern organisations. At the end of year one and year two, the three support structures of the MCAP – the Reference Group, the Advisory Group and the Pilot Sites Group – all met together to conduct a review of the work and plan the following year. This was not in the original plan but proved particularly useful for all concerned and helped to create a stronger ownership of the success of this work.

Objective 6 concerns the direct communication and with media, campaigners and policy-makers and the extent of the influence the MCAP. There has been a significant amount of direct communication, for example, by the 'Friends of MCAP' e-bulletins, the website statistics and published media articles. The MCAP has been influential and respected within the advocacy sector. Specific invitations to speak at conferences and to contribute to consultations (for example, the National Dementia Strategy) is positive evidence that

the MCAP has had a valuable voice and has been influential in shaping the nature of non-instructed advocacy and sharing good practices in working with the Mental Capacity Act.

It can be said with some confidence that the MCAP has achieved all of the objectives which were set at the beginning of its work. Not only have the objectives been met, but a variety of innovative and creative work has taken place. This project has exceeded the expectations which the Project Reference Group set.

4.4 Key outputs

A number of documents have been produced over the lifetime of the project including flyers, PowerPoint presentations and other communication materials. Here are the key outputs that have been developed by the MCAP team:

1. *Volunteer Advocate Guidance Pack for MHAP Projects* – 2007
2. Advocacy guidance pack – 2007
3. *MHAP Evaluation Framework* – 2007
4. *Why Don't You Talk to Me about This?*, RIX Centre report and DVD film of older people who have experienced some loss of mental capacity talking about social exclusion – 2009
5. *A Resource Pack to Aid Advocacy Delivery* – October 2009
6. *Building Up a Picture*, interim independent evaluation report of the MCAP – January 2009
7. *Who I Am Makes a Difference*, final independent evaluation report of the MCAP – October 2009
8. *Someone to Speak Up for Me*, final report by the MCAP Project Reference Group (this report) – October 2009
9. Web page (www.ageconcern.org.uk/AgeConcern/mhap.asp)
10. E-bulletin – 'Friends of MCAP'

4.5 Conclusion

The specific evidence listed above and the reporting back in general terms against the aims and objectives for the MCAP demonstrates that the MCAP has been successfully completed as a pilot project. The project has been delivered in a time of great change in the policy agenda, has been working with a new piece of legislation (not fully understood by many) and with a specific developing form of advocacy called non-instructed advocacy. This difficult and technical work has also been explored and successfully developed using a volunteer model, a role that individuals and organisations greeted with scepticism at the outset of this work. Volunteers can be effective advocates for older people who have issues with mental capacity, with meaningful training and support.

This project is a timely reminder of the importance of volunteer advocacy in a period when advocacy is increasingly becoming a paid/professional role. The challenges of delivering the MCAP must not be underestimated. Other organisations wishing to embark on similar work would do well to concentrate on aspects of resource allocation for staff and volunteers, key practice documents and strong leadership. They should not expect to know all the answers, instead exploring solutions in creative ways, developing local partnerships and allowing time within projects for thinking and reflecting on the work.

4.6 Discussion

The MCAP has been a relatively well-resourced and well-managed project. It has been delivered at a time when advocacy has been increasingly on the policy agenda. Yet there remains a policy and practice divide. The direct lived experience of older people who have an issue connected to mental capacity is still routinely poor despite the strong policy picture. The resources developed by the MCAP team relate to specific practice and have been made freely available. The MCAP resources have been downloaded 3,426 times, an extremely high number given the specific nature of the material. This demonstrates the demand for practice-based materials that enable local providers to translate national policies into practice on an individual level.

If we had an opportunity to run this project again what would we do differently?

There are opportunities to more fully explore how volunteer advocacy and paid advocacy differ and what the comparisons are in terms of costing and delivery. This is something we would focus on if we ran this project again. We would also make stronger links with campaigning and dedicate more time to the crucial role of project manager at the four pilot sites in order to fully recruit, train and support an extensive team of volunteers. We have learnt that in practice this is a full-time role, particularly where the advocacy being provided is non-instructed advocacy. Organisations wanting to expand their provision from instructed to non-instructed advocacy provision would be advised to be fully apprised of the resource demands of this form of advocacy.

This project has been very successful because of the passion and commitment from the volunteers and staff involved. A key point of learning for organisations wanting to expand their provision into volunteer advocacy is that the impact and influence of strong passionate leaders and community citizens cannot be underestimated. Project structures and plans are nothing without the people.

The role of the national Project Co-ordinator in managing and overseeing a complex project is likewise critical. Neil Mapes developed the project from a set of proposals, concepts and ideas into an effective action research project, engaging a wide range of stakeholders and partners and successfully achieving its targets, including directly affecting

the lives of vulnerable older people. This project would not have been as effective, well known and well respected as it has been without the passion, drive, commitment and skills of Neil. The Project Reference Group would like to put on record its thanks and appreciation to Neil for leading the project so well for three years.

To what extent can other local organisations learn from the MCAP and develop more advocacy? How can we enable a high-quality and effective advocacy provision which reaches thousands of people who are in need of advocacy?

The challenge now is to achieve a practical follow-through from the successful work at the pilot sites. Each of the four MCAP pilots is continuing the work in a variety of different directions, and at the time of this report three have secured extra funding to enable a future for this work at their organisations. The fourth is awaiting funding bid outcomes, and remains committed to continuing the work.

Volunteer- and community-led solutions partially answer these questions – by working together we can find a way. The MCAP has reminded the advocacy sector and others of the value of volunteer advocacy, particularly in working effectively with the Mental Capacity Act. It has highlighted the need for a continuum of advocacy provision that values volunteer advocacy equally alongside statutory advocacy in meeting the diverse needs of individuals. The MCAP will continue to share its resources and experiences with Age Concern and Help the Aged and other organisations working to develop volunteer advocacy.

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Appendix

General overview

The MCAP project is framed by general advocacy principles, non-instructed advocacy and the Mental Capacity Act. The general trend in recent years has been for advocacy to be increasingly provided by paid professionals. There is a sense in which advocacy is becoming formalised, with the development of the advocacy charter, codes of practice for advocacy, agreed standards and, more recently, the national advocacy qualification and the quality mark for advocacy schemes.

This project has been an important opportunity to learn about what happens when the advocate is not paid. The context for the volunteers appears challenging and 'technical', as there are a range of principles to consider and practices to know about and adopt.

However, the matching of volunteer advocates with people who are at risk of being marginalised and excluded from decisions about their lives is not new. Citizen advocacy schemes have a history of bringing together local 'ordinary citizens' with people in the same community who may be devalued.

> 'Citizen advocacy is a one-to-one ongoing partnership between a trained volunteer and a person who is not in a strong position to exercise or defend his or her rights and is at risk of being excluded or mistreated.'
>
> **Andrew Dunning – *Citizen Advocacy with Older People*, Centre for Policy on Ageing, 1995, p. 20**

Specifically the advocacy issues of older people and the recruitment of local citizens have been considered for many years by the Beth Johnson Foundation, OPAAL (the Older People's Advocacy Alliance), Age Concerns and others, in conjunction with local independent advocacy organisations. However, the impact of advocacy volunteers on the lives of older people has not been well researched. The origins of advocacy are in the simple notion of one person looking out for another. This advocacy is essentially a human encounter – *Who I Am Makes a Difference*, the independent evaluation report, fully details the successes, challenges and lessons of this type of advocacy, where an unpaid person enters into a relationship with a person who may be devalued.

Mental Capacity Act

The project was concerned with advocating for older people who may lack the capacity to make some decisions. It was therefore framed by the Mental Capacity Act (2005), which establishes principles and a robust code of practice for empowering and protecting all people who are deemed to lack the capacity to make some decisions.

The Act is underpinned by a set of five key principles which it sets out in section 1:

- **A presumption of capacity** – every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.
- **Individuals being supported to make their own decisions** – a person must be given all practicable help before anyone treats them as not being able to make their own decisions.
- **Unwise decisions** – just because an individual makes what might be seen as an unwise decision, they should not be treated as being unable to make that decision.
- **Best interests** – an act done or decision made under the act for or on behalf of a person who lacks capacity must be done in their best interests.
- **Least restrictive option** – anything done for or on behalf of a person who lacks capacity should be the least restrictive of their rights and freedoms.

A new statutory advocacy role has been implemented as part of the Mental Capacity Act. The Independent Mental Capacity Advocacy (IMCA) service provides a statutory right to independent advocacy to people who are deemed to lack the capacity to make decisions about long-term changes of accommodation and serious medical treatment, in cases where there is no one else deemed appropriate to consult.

The MCAP project differs from the IMCA service in that there is no statutory right to a volunteer advocate for people who may the lack capacity to make decisions that fall outside of the remit of the IMCA, and volunteers are not bound to work only with people who have been deemed to lack capacity through a formal capacity assessment. The IMCA service is bound by tightly defined criteria which leave many people who lack capacity, and who could benefit from advocacy, without statutory support. The work of the MCAP has been invaluable in meeting this need – one that has been further highlighted by IMCAs themselves.

General advocacy principles

The MCAP project has broadly operated within the principles set out in the Advocacy Charter developed by Action for Advocacy in 2002, further detailed in the Advocacy Framework paper produced by Age Concern England. These principles have set the work of the MCAP project in a national advocacy context:

- clarity of purpose;
- independence;
- putting people first;
- empowerment;
- equal opportunities;
- accountability;
- accessibility;
- supporting advocates;
- confidentiality;
- complaints.

(The Advocacy Charter is explained in more detail in *A Resource Pack to Aid Advocacy Delivery*, one of the key outputs from the MCAP work.)

Non-instructed advocacy

The volunteers in the MCAP project have worked with older people who may find it difficult to give their advocates clear instruction. As advocacy clients may lack the capacity to make some decisions, they may not be able to instruct their advocate. In recent years the advocacy sector has developed an understanding of a range of approaches to non-instructed advocacy:

Person-centred – where advocates focus their attention on their client and no other.

Rights – where advocates are vigilant about the rights and entitlements of advocacy clients.

Witness/observation – advocates observe the client and their unique way of operating.

Questions – advocates ask questions to represent the client's viewpoint to others in their life.

Good practice in non-instructed advocacy invites advocates to adopt an integrated, holistic approach which enables advocates to represent the client in an empowering way. The MCAP project has placed emphasis on the use of non-instructed approaches in working with clients. Local project staff and volunteers have all been trained in the use of non-instructed approaches.

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