

ADVOCACY AND OLDER PEOPLE : UNMET NEED

A study of the need for, and issues around providing, an advocacy service for older people with communication and comprehension difficulties, who are using mental health services in the London Borough of Barnet.

Advocacy is a process whereby an individual or group is supported in pursuing their own needs and interests. When people are disadvantaged in some way, or less able to speak for themselves, it can involve an advocate putting forward their case; defending their rights or promoting their interests. An advocate is someone who will represent a person's right to choose.

Advocates offer support for mental health service users on a wide range of issues including problems surrounding their care, financial problems and their rights and choices. Advocacy can be informal or formal, provided by volunteers or paid workers, but it must be independent, putting the needs of the client first.

Advocacy usually involves the client identifying the problem or issue, saying what they want, and agreeing to any action taken on their behalf. This research report looks at the issues around providing a service to people over 65 who have communication or comprehension problems, who cannot always ask for what they want or need, and who are often excluded from advocacy because of their difficulties.

'Independent advocacy can be invaluable in helping a patient to express his or her views if there are difficulties in communication. As the advocates are neither a relative or associated with the health facility, they can offer assistance without being influenced by conflicting interests.'

The British Medical Association and The Royal College of Nursing 'The Older Person: Consent and Care', 1995.

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Introduction

Mind in Barnet Advocacy Service

The MIND in Barnet Advocacy Service was set up in 1995 with the specific brief of providing advocacy support to patients affected by the closure of Napsbury Mental Hospital and the resulting resettlement programme. At the time, a significant proportion of the patients were older people, many of whom had a considerable degree of communication and comprehension difficulties.

Although the advocacy service has greatly broadened the scope of its service since the closure of Napsbury, a part of our work has continued to be aimed specifically at providing issue-based support to older people who use mental health services.

Resources limit our work and we have been aware for some time that there is a larger group of older people who have communication and comprehension difficulties, including dementia sufferers, that we are not reaching. These people are unlikely to seek out the services of an advocate, and are rarely referred to advocacy by mental health professionals. There is, therefore, a danger that they may get overlooked, with the result that their needs and wishes will never be fully heard.

Recent years have seen growing calls for advocacy to be made available as a basic right in older people's lives. At government level, there is interest in the role of advocacy, and in listening to older people's views. Over the last decade or so the rights and representation of older people in health and social care settings have been promoted in government reforms of person-centered care, choice and participation. Advocacy is mentioned in a number of official charters, notes of guidance and quality standards documents.

From the outset we have been aware that, although the basic philosophy and principles of advocacy remain valid, their application in the support of older people frequently requires new skills and a different approach.

An issue such as confidentiality, for example, is relatively straightforward, when working as an advocate in a short-stay mental health admissions ward. It becomes much more complex when working to support someone whose capacity to understand, remember or speak, varies greatly from day to day or even hour to hour.

We have also had the experience of working with clients whose 'issue' has taken many months to resolve, requiring frequent visits from the advocate. This has raised our awareness that developing a longer term relationship not only enhances communication and understanding, but also enables concerns to emerge over time that were not apparent initially.

These experiences have raised many questions for us. Confidentiality, capacity, the relationship with carers and issue-based versus long term work are just a few of them. Our concerns gave us the impetus to undertake a deeper exploration of the issues as they relate to this group of older people.

In April 2000, MIND in Barnet secured a small amount of funding from the Trustee Savings Bank for a research project on advocacy and older mental health service users. We are also grateful to Barnet NHS Healthcare Trust for their financial support in the publishing of this document. In May 2000, a freelance researcher, Geraldine Cooney was commissioned to work with Lee-Ann Frampton (Advocacy worker) on this

project.

The aims of the research were to identify the extent of the unmet need for advocacy within this client group, and to explore the issues around providing this type of service. We also aimed to look at the type of advocacy needed by this particular client group and the training and support needs of advocates working with them. Our ultimate aim is to gain funding to expand our existing advocacy service to provide a properly resourced service for this client group.

We see this document as useful in three ways: for those considering the establishment of advocacy support for this group, as a contribution to the excellent work on the rights of older people already being undertaken by other groups in the UK, and as a contribution to the further development of general service provision.

Philip Reilly
Advocacy Service Manager
Mind in Barnet

Background

Communication or comprehension problems in older people may be due to a range of causes including depression, confusion, anxiety, physical problems such as hearing loss or stroke, or dementia. They can be temporary, like depression, or the result of permanent and degenerative conditions like dementia.

Mental health involves a complex range of factors, and mental illness is not an inevitable part of the ageing process. Older people may have mental ill health alongside the normal problems of ageing such as arthritis and increasing poverty. These problems profoundly affect not only the individual, but also change the lives of family and friends.

Depression is the most common psychiatric problem amongst people aged 65 and over. It can affect concentration, speech and cause delusions, low energy, sleep problems and suicidal thoughts¹. As well as being mistaken for dementia, depression can also be a symptom of dementia and can make the difficulties caused by dementia even worse.

Advocacy for older people with communication and comprehension difficulties, including dementia, is a relatively new concept. It works on the principle that everyone has needs that are fundamental to their well-being – even if they cannot express them. Although a person may not be able to get their opinion across to others, or simply may not have an opinion on the choices and issues involved, their right to a good quality of life is not any less.

“Glad to see you are taking this seriously – it has been a neglected area up to now”

(Barnet Social Work Manager)

Our Research

Research Methods

The starting point for this research was networking with, and learning from, the small number of organisations and projects nation-wide, already working with this client group.

Most of these projects, and the published work in this area, is on elderly people with dementia. Although our remit was broader than this, and included any older mental health service users who had difficulty communicating or understanding, the experiences of the dementia projects we contacted were highly relevant. They willingly shared their work and experiences with us, enabling us to bring together a wide range of work into this one research document.

We also interviewed professionals, user groups and carers in Barnet, in order to deepen our understanding of the issues and to discover the extent of unmet need locally.

¹ Older people and mental health, Mind Information Unit Factsheet, 1997.

We then built on the research evidence gathered and the issues raised. We developed a toolkit of good practice principles and skills needed for providing a service to this client group. This gives us the means to consult with service users themselves to discover what their needs and wishes are.

See Appendix One for details of organisations consulted, and Appendix Two for a copy of our questionnaire.

The research involved three stages:

Stage One: National information gathering and consultation

- We carried out a national literature search for background information on the issues. We collected information in the form of reports, books and journal articles.
- We made contact with 10 national organisations, including advocacy umbrella bodies, government and university departments with an interest in this area.
- We received completed questionnaires from 10 projects throughout the country who provide an advocacy service to older people with communication and comprehension difficulties (mainly dementia).

Stage Two: Local information gathering and consultation

- We interviewed and/or received completed questionnaires from 9 Barnet mental health professionals including residential care staff, hospital staff and social workers. This helped us identify need locally, and identify staff views on, and awareness of, issues involved.
- We interviewed and/or received completed questionnaires from 5 Barnet voluntary organisations including carers and user groups with an interest or involvement in this area. This gave us their perspective on need and the issues involved (see Appendix One)
- We made contact with some carers of people with communication and comprehension problems.
- MIND in Barnet Advocacy workers wrote up their experiences of working with this client group in the form of case studies.

Stage Three: Analysis and write up

- Analysis of the questionnaires and other consultation, and exploration of the issues raised by interviews and case studies.
- Writing of draft report (end September/October), out for comment in November/December, report published early 2001.

Research Questions

Our research asked the following questions:(see Appendix Two for the questionnaire)

- **Do older mental health service users with communication and comprehension difficulties have a need for advocacy?**
- **In what areas of life is advocacy needed by this client group?**
- **What are the specific issues for advocacy with this client group?**
- **What types or models of advocacy work best with this client group?**
- **How does an advocate deal with specific issues in practice? e.g. consent, instruction, confidentiality, role of carers and professionals.**

Research Findings

Do older mental health service users with communication and comprehension difficulties have a need for advocacy?

“There is a vast unmet need for advocacy. There is still a feeling that people with dementia have no opinion....”

(Barnet Alzheimer’s Disease Society)

“Older people with dementia are doubly disadvantaged by age and their cognitive impairment.... This level of vulnerability in itself indicates a need for advocacy”

Brighton MIND (service provider)

We found a large unmet need for advocacy among this client group, both in Barnet and throughout the country. Mental Health Professionals, service providers, and individuals locally and nationally were unanimous in identifying the need and vulnerability of this client group. The message emerging from our research was that people who cannot communicate well or understand easily are often ignored, and that they are unlikely to ask for help or support themselves.

Studies have shown that the large amount of unmet need for advocacy among older people increases dramatically for those who have mental health problems or some form of dementia.² These older people face enormous difficulties in getting across their views and wishes. People living at home or in an institution can become socially isolated and their emotional well-being ignored. Resources are stretched and sometimes the physical needs are the only ones catered for.

Several voluntary organisations in Barnet said they could identify many potential advocacy clients with communication and comprehension difficulties in a number of settings: hospitals, residential and nursing homes, and in the community. The main barriers to advocacy were identified as negative attitudes towards people who cannot easily make themselves understood, and the fact that this group is unlikely to ask for advocacy themselves.

Barnet mental health professionals agreed with the voluntary organisations that this client group were sometimes overlooked because of their communication and comprehension difficulties. Many stressed the need for befriending, particularly for isolated people or those without supportive relatives, and highlighted the benefits of a long-term relationship where trust can be built up.

² K Reilly, Sparkbrook Profile, Birmingham Citizen Advocacy, page 10,1996

In what areas of life is advocacy needed by this client group?

We found that the areas of life where advocacy is needed by older people with communication and comprehension difficulties, are as diverse as any other group. They include finances, residential care issues, concerns over housing and property, conflict with relatives and carers, issues around the delivery of care, Mental Health Act support, treatment of physical problems and abuse (physical, emotional and financial). There was agreement that advocacy is important when things are about to change for a person, and it was pointed out that not all change is bad. Assessment and reviews of care are also stages at which advocacy should be involved.

Advocacy can help to empower older people, especially those living in institutions, by seeking out and giving individuals information. An advocate can make sure procedures are properly used, all options explored and sufficient attention given to individual circumstances. Advocacy can also offer some protection to older people who are vulnerable to, or victims of, abuse. It can prevent mistreatment as well as support to those who have been mistreated. It can challenge discrimination, ageism or stereotyping.³

Some user groups felt that advocates could have a role in discussions around capacity where their role would be preventing misinterpretations or abuses;

“Capacity is about a specific issue at a specific point in time...advocates can make sure that capacity testing is done and understood correctly.” (National MIND).

Voluntary organisations highlighted a need for advocacy in all the above areas, whereas mental health professionals were more likely to identify some and not others as within the advocate’s remit. There was a feeling that advocacy could duplicate their role and become interference in some areas. Some residential care home staff hoped that advocates could help them by ‘advising on activities’; displaying a lack of understanding of an advocate’s role.

Existing projects pointed out that for many people the above areas of life overlap, and several felt that advocacy should be provided in a holistic or whole person framework, where the individual’s emotional, physical and spiritual needs are looked at together.

Independent advocacy should be made available to all older people who are:
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- | |
|--|
| <ol style="list-style-type: none"> 1. At the point of discharge from hospital 2. Directly affected by a change in the management or running of their care service 3. At the point of accessing continuing care and community care services 4. At the point of being assessed for continuing care and community care services; and 5. At all reviews affecting care services in hospital and in the community.⁴ |
|--|

³ OPAAL /Help the Aged, Dignity on the ward, A Dunning, July 2000, page 9

⁴ STATEMENT OF INTENT. OPAAL (UK), Newsletter 1, Spring 2000

What are the specific issues for advocacy with this client group?

The national organisations we consulted told us that working with older people with communication and comprehension difficulties presents an advocacy service, and individual advocates, with particular challenges and problems. Basic advocacy principles such as confidentiality and client control are difficult to adhere to if the advocate and the client cannot communicate meaningfully with each other. Simply getting access to an advocacy service is a major issue – self-referrals by this client group are low and they tend not to be referred by staff. Projects working with this client group stressed the importance of:

- ❑ advocates having different advocacy tools at their disposal
- ❑ training and supporting advocates in their work, and
- ❑ building good relationships with hospital and care staff to encourage referrals. (see below for an exploration of the main issues and 'Advocates Toolkit' pages 17 - 26 for how advocates can deal with the issues in practice).

Capacity and choice

“Dementia Sufferers can give an opinion”

(Barnet Social Work manager)

“Older people with dementia can communicate and consistently express what they want” (Derby MIND)

People with mental health problems can make decisions about their lives like anyone else, but there are times when their capacity to make decisions is affected. Under current law, a person has capacity if he or she can understand and retain the information relevant to a decision, can believe that information and can weigh it up, to arrive at a choice.

Mental health problems and incapacity are not necessarily linked. However, a person who is detained in hospital under the Mental Health Act 1983 can be given treatment without their consent regardless of their views, if it is deemed in their best interests. One of the dangers for people with mental health problems is that incapacity in all areas is assumed, whereas all of us have different levels of understanding, and this will change from day to day and over time.

We found support nationally and locally for the view that capacity should not be treated as an all or nothing concept.⁵ Very few people lack all decision-making capacity; they may be able to understand an issue, or make a choice if someone takes the time to carefully go through things at their own pace. If someone cannot or does not make a choice about their food, it does not follow they should not be given a choice about what clothes they wear. UK law recognises this, and states that capacity must be viewed in the context of the particular decision to be made.⁶

Some organisations appear to offer a 'hierarchy of choice'⁷ where a limited choice in some areas is allowed, for example, choosing between two set meals, but there may be no choice in matters of ward routine such as bathing or toileting. In matters

⁵ Citizen Advocacy with older people: a code of good practice, Andrew Dunning, CPA 1995

⁶ Simon Foster, Principal solicitor MIND, comments on draft report 8/12/00

⁷ Advocacy for people with a progressed Dementia, Beth Johnson Foundation, June 2000

regarding treatment and care, individuals may be seen as unable to participate in decision-making.

Our research highlighted the fact that legal definitions of capacity can sometimes be a narrow view of a person's abilities. Several organisations and individuals told us that they felt there were inconsistencies in the way capacity is currently determined; although they agreed it was a difficult issue to resolve, and few were able to come up with a better method. One advocacy service felt that client-centred assessment over time, involving observation and interaction, would be a better system, whilst some felt there was a role for advocates in ensuring that capacity assessments were correctly applied.

Consent, Instruction and Confidentiality

“Problems around consent arise because the person may no longer have an understanding of what is being offered to them, and the alternatives.”

“Staff can refer or commission an advocate, but must not instruct.”
(Dementia project, Beth Johnson Foundation)

The basic principles of advocacy rely on getting clear instructions from the client, and consent for any action taken on their behalf. When working with confused or disorientated people it may not be clear whether they wish an advocate to act or not. Whether it is acceptable to impose a service on an individual who does not have the ability to accept or refuse is debatable, but if they are unable to give consent and do not receive a service, what is the alternative? It may be unethical to pass over someone who is vulnerable and apparently unable to agree to the appointment of an advocate but whose quality of life might be vastly improved by the attention of such a person⁸.

Confidentiality between the client and advocate is also a ground rule of advocacy – non-factual information should not be given to, or gained from, third parties. Confidentiality may be compromised if an advocate is commissioned or instructed by professionals or carers, or if information is volunteered by them. This is a difficult area for an advocate. If communication is limited, they may be dependent on other people for vital information about their client. They must work on a ‘need to know’ basis, treating the views and opinions of others with respect, but remain focussed on the needs and wishes of the client.

Relationship with Mental Health Professionals

“I would be very interested in what...advocacy...can offer...we have never considered this a possibility.”
(Barnet hospital ward manager)

“liasing with staff is key as they best understand the client.” (Barnet residential home manager)

Most of the Barnet mental health professionals we spoke to were committed to the idea of advocacy in principle, although some were unclear about how advocacy could work with this particular group. There was also some misunderstanding of the function of an

⁸ Advocacy and Dementia, Jan Kileen, Alzheimer Scotland, Action on Dementia, 1998

advocate, with many seeing it simply as a befriending role. Some staff saw themselves as the client's advocate. Staff can sometimes act as advocates, but it can cause conflict, for example if a colleague is part of the problem. Advocates should be free of conflicts of interest, whereas staff may have pressures in terms of workload, colleagues, management and organisational priorities.

It was agreed that developing and maintaining good relationships needed tactful handling. Our research uncovered some areas of possible conflict and tension:

“Advocates sometimes want to be responsible for everything, including things that are the managers responsibility.” (Barnet residential home manager)

“staff should always take the side of the consultant...these are the people who are responsible for the client.”
(Barnet nursing home manager)

Lack of knowledge and expertise among health and social services workers on the needs and potential of this client group (particularly dementia sufferers) was highlighted as a problem by some existing projects⁹. Education and training of some service providers is needed to promote the rights of people with communication difficulties.

“if an advocate has had specific training in dementia awareness, communication skills etc it is possible that they have greater knowledge than the service providers.”¹⁰

The importance of advocates working co-operatively with professionals was stressed by existing projects. Leaflets explaining the nature of the advocacy service can help, as can clear contracts/protocol with host agencies (for more on this see Advocates Toolkit page 17). Existing projects have found that as advocacy projects gain credibility by dealing well with clients referred to them, mental health professionals become more supportive and positive about the service.

Relationship with Carers

“Relative’s opinions are often given greater weight to the exclusion of the person.” (Derby MIND).

“Treat relatives with respect; they have information.”
(Brighton MIND).

“Relatives are providers, they have opinions we don’t.” (Asist, Advocacy service provider)

Carers often play a vital role in the process of advocacy for this client group. For many older people, their carers or family members may be the best people to represent their interests. But, despite good intentions or because of pressures they are under, relatives and carers may lose touch with the wishes and preferences of the older person. Carers may hold strong opinions on what is in the best interests of the individual, or there may be conflict between family members.

⁹ questionnaire from Sally Wells, Westminster Advocacy Service for Senior Residents (WASS)

¹⁰ Speaking up for people with dementia, WASS, page 10

Some carers and relatives who feel unable to support their relative themselves may welcome advocacy. Others may get confused and upset with the advocate, finding their non-judgemental position hard to deal with. Some carers groups have experienced advocacy as a threat rather than as a source of support.

Referrals

“Someone who is confused and disorientated may be seen as being beyond advocacy intervention, whatever the dilemmas or conflicts involved.” (Brighton MIND, Service Provider)

Advocacy projects have found that getting clients can be a slow process. Few people refer themselves, and it can take a long time to get access to this group, especially in nursing and residential care. Staff and carers saw themselves as advocates for the person and many did not understand the advocacy role. They saw people who could communicate as more able to benefit; and the needs and potential of those with communication or comprehension difficulties were not always understood. Some professionals made referrals as a ‘last resort’ in the hope that the advocacy project could find a solution to an entrenched problem.

Several projects found that referrals were often for befrienders, not advocates. The most frequent reason for referral to one project¹¹ was that the client was isolated or withdrawn and needing stimulation. Although the process of advocacy is stimulating in itself, they realised that emphasising activities and befriending in their promotional literature had led to confusion about the role of an advocate.

One project¹² found it fairly easy to get referrals to their advocacy service once they made it clear what they were offering and developed good relationships with staff. This involved giving talks as well as producing written information. They found that once good working relationships were established, referrals followed.

Training and support of advocates

“Training in the issues for this client group is essential.” (Barnet hospital consultant)

“Volunteers can only work with this client group if they are given lots of support and monitoring.” (Age Concern, Barnet)

Mental health professionals, user groups and existing projects all stressed the importance of training, support and professional guidelines for advocates, both paid workers and volunteers, who are working with this client group. A great deal of input is needed to achieve and maintain a good quality advocacy service.

Working with this client group is probably the most challenging and demanding area of work with older people. There may be few tangible rewards for the advocates, particularly if communication and comprehension is greatly impaired. Some professionals in the field of dementia care see a need for advocacy at a much earlier stage in the illness. For advocates, it is inevitably more rewarding to work with someone who appears to get some pleasure out of the advocacy partnership.

¹¹ Westminster Advocacy Service for Senior Residents (WASS)

¹² Beth Johnson Foundation

It can be hard attracting and retaining volunteers to this type of advocacy; existing projects discovered that softening this challenge when trying to attract volunteers was counter-productive – volunteers soon left if their expectations were unrealistic. All advocates will need ongoing support and training, backed up by strong policies, procedures and protocols (see Advocates Toolkit page 17).

Long-term befriending or issue-based advocacy?

“a one-off visit will not resolve any problems or identify issues....[advocacy] must be ongoing...it will be time consuming.” (Pohwer Advocacy, Hertfordshire)

“it does require longer term and life history work.....at present we rely too much on relatives.” (Social Work Manager, Barnet)

Mental health professionals and advocacy projects we spoke to agreed that older people with mental health problems and communication problems often become isolated because of their difficulties; and that many are simply in need of a friend.¹³ Many advocacy projects found the reasons why this client group were referred were isolation and befriending rather than specific advocacy issues.

Most of the ten projects we talked to used ‘Citizen Advocacy’ with this client group – where volunteers supported by paid workers are matched with an advocacy client or ‘partner’. Using a pool of volunteers gives a choice of advocates and allows some ‘matching’ with clients, and volunteers can spend time getting to know their partner and developing trust. The paid or professional advocates we spoke to tended to have a small case-load and deal with emergency or crisis situations, handing over for long-term work to a volunteer.

Some projects felt that advocacy relationships must be long-term, with a focus on getting to know the personality and background of the person, and developing an understanding and appreciation of their former life. However, experience has shown that it could be hard for advocates to get beyond this befriending role, and that getting to know the partner sometimes became an end in itself.¹⁴ It can be difficult to move on to advocacy or issue-based work.

Other groups felt differently. The Beth Johnson Foundation’s Dementia Project found that a long-term relationship with a person was not always necessary in order to hear their views and preferences. They felt that a skilled independent advocate coming into a situation for the first time, could bring objectivity and recognition of the changing needs and wishes of a person.

Offering a combination of short-term issue-based advocacy and long-term volunteer support, according to the needs of each client, might best meet the complex needs of people with communication and comprehension difficulties. This has led us to the same conclusion as several other organisations working in the field; that a combination of paid advocates doing case-work, supported by a befriending service staffed by volunteers, may be the most appropriate and financially sustainable way of delivering a service to this client group (see conclusion. page 26).

¹³ Dementia Project Evaluation, WASS, 1999

¹⁴ op cit above

Resources and funding - The national picture

There are a small but steadily growing number of voluntary sector services offering advocacy to older people. But at present, advocacy has no legal status in the UK and there is no requirement on statutory authorities to support local advocacy schemes.¹⁵ The current NHS reforms provide an ideal opportunity for ensuring that older people are listened to and supported. Some advocacy schemes are looking to the new primary care groups and trusts for recognition and resources.

Help the Aged's Health and Older People (HOPE) group¹⁶ has called on the government to provide resources for a comprehensive, properly funded independent network of advocacy organisations. They argue that advocacy is essential to promote older people's autonomy, to enable them to access appropriate services, and to protect their interests and well-being. Advocacy is needed at home when people need extra support, in care homes, in hospital, and at any time of crisis or major change.

In a joint report by OPAAL (The Older Peoples' Advocacy Alliance) and Help the Aged, published earlier this year,¹⁷ the authors concluded that advocacy can make a positive difference, but that advocacy with older people generally lacks the recognition and resources it needs to flourish. Possibly because of this, it also lacks co-ordination and its own commonly agreed set of standards and quality framework. They argue for government promotion of advocacy backed up by legislation. OPAAL introduced an Early Day Motion to parliament in January 2000, calling for independent advocacy to be made widely available to older people who require it. It has received 80 signatures to date.

¹⁵ OPAAL/Help the Aged, Dignity on the ward, A Dunning, July 2000

¹⁶ Our Future Health: Older People's Priorities for health and social care Health and Older People's Group (Hope/Help the Aged, May 2000)

¹⁷ op cit above

Basic Values for an advocacy service with older mental health service users with communication and comprehension difficulties.

- ❑ **All health and social care organisations should aim to give people choice in all aspects of their living circumstances.**
- ❑ **Advocacy is a basic right and organisations should make sure it is built into any change process.**
- ❑ **Advocates should make sure that everybody involved has a proper understanding of what advocacy is.**
- ❑ **An advocate aims to find out the views of the individual, however difficult this may be.**
- ❑ **The experiences and views of carers should be considered, but this should not overtake the wishes of the individual.**
- ❑ **The knowledge and understanding of staff should be taken into account when reaching decisions, as well as, not instead of, the views of the individual.**

Adapted from Beth Johnson Foundation¹⁸

¹⁸ Advocacy for people with a progressed Dementia, Beth Johnson Foundation, June 2000

ADVOCATES TOOLKIT

HOW TO PROVIDE AN ADVOCACY SERVICE TO OLDER PEOPLE WITH COMMUNICATION AND COMPREHENSION DIFFICULTIES

Introduction to the Toolkit

Our research locally and nationally found that advocacy for people with communication or comprehension difficulties is a specialist area requiring a different style of service. How much the service differs from standard advocacy depends on the extent of the older persons' difficulties, and on their ability to make choices and decisions. This will vary over time and from day to day.

At an early stage of dementia, or when somebody can still communicate their preferences, advocates can work in their usual way. But as communication and comprehension diminishes, the advocate is presented with the choice of withdrawing their service, or offering a different type of advocacy.

Many of the projects we contacted were involved in an on going process of evaluating their work and exploring different ways of working with people whose communication and/or comprehension was severely reduced. Examples of different ways of providing advocacy for people with severe communication or comprehension difficulties are given below (see 'Different Approaches'). See the Toolkit pages 20-24 for good practice points on advocacy principles of inclusion, empowerment and independence.

Different Advocacy Approaches

If there is little or no meaningful communication between the advocate and the client, the advocate cannot represent an opinion that has not been given or has not been understood by the advocate. However, each person has fundamental rights and needs, even if they cannot express them.

The following methods can be used where there is little reliable or no communication, or when empowered permission from the client is not available.¹⁹ They should not be used as an alternative to developing communication with a service user, but are additional tools an advocate could use in appropriate circumstances.

Substituted judgement /best interest decision-making

The Law Society's Report No 231 on Mental Incapacity gives guidance on making decisions for someone unable to decide for themselves. Substituted judgement is a flexible approach to capacity and decision-making. It aims for a decision which best reflects the person's choice if he or she had capacity, and is sometimes called 'as if it were me' advocacy.

The role of the advocate using the substituted judgement approach is to:

- ❑ Encourage the person to participate or improve their ability to participate as much as possible (capacity is seen as something that can alter).
- ❑ Have regard to past and present wishes, and feeling and factors the person would consider if they could (including the effect on carers, family etc).
- ❑ Gain the views of other people, whom it is appropriate and practicable to consult, about what the person's wishes and feelings might be.
- ❑ To look for the least restrictive option.

Advocates can feel uncomfortable with this approach as it involves making decisions on behalf of somebody else. It can become paternalistic, with advocates anxious to 'do the right thing' for the person irrespective of what they might want.

Personal story

Ward staff approached the advocacy service when they became aware that the mother of a patient (Mr P) was becoming increasingly concerned about her son's financial matters. As she was getting old, she wanted her son's finances to be controlled by someone other than herself. The ward staff felt that it would not be appropriate for them to become involved. The advocacy service made contact with the client's mother and recommended that the Court of Protection's receivership division should deal with Mr P's finances. The advocate helped with the application procedure and the receivership division eventually accepted the case. Since then, the court of protection has had control of Mr P's finances so that in the event that something happens to his mother, there will be an independent organisation taking care of his money.

¹⁹Watching Brief, Information Leaflet No 16, Asist, Advocacy Service in Staffordshire

Comment

This was an unusual case, as the client was never aware of the decisions that were being made about his finances. Staff, parent and advocate all worked together to make decisions about Mr P's affairs without consulting with him as he was not able to understand the impact or nature of the procedure. It is extremely unusual to support a client without having decisions sanctioned by them at some level.

An independent person with a 'watching brief'

Asist (Advocacy Services in Staffordshire) state that everyone has certain basic needs, or ordinary life principles which are fundamental to their well-being, They have developed the 'Watching Brief' approach for people who have little or no communication skills. It involves applying eight 'domains to a quality life' to an existing situation or a proposed change, to question and promote services which meet the user's needs. These eight domains are: competence, community presence, continuity, choice and influence, individuality, status and respect, partnership and relationships, and well-being.

This watching brief method aims to be more objective than the 'as if it were me' approach. The advocate does not give the service users view or their own opinion, but aims to make sure that the institution is working in the best interest of the client in all areas of their life. Brighton MIND has developed a version of this approach, based on the areas of daily life that most people with capacity would deem it reasonable to have a choice about. These approaches have the potential for conflict as staff may see the advocate in an inspection role.

Personal Story

Mr W has little ability to communicate and his ability continues to deteriorate in his nursing home. The advocate learns from his long-stay hospital that he has a very keen interest in football. He visibly brightens when football is on TV. The advocate encourages the nursing home staff to organise a special, individual visit to a local amateur football match, accompanied by a member of staff who also enjoys football. The advocate also goes to the match and they all enjoy it. The advocate feeds back to the manager what a success the trip has been. The nursing home staff and the resident population are predominantly female and there is little apparent interest in football, so the advocate encourages continued contact between Mr W and the male staff member who went on the football trip. The advocate also encourages this member of staff to talk about football to Mr W. As most staff and residents are not interested in football there is a tendency for football not to be selected on TV. The advocate encourages staff to remember that Mr. W enjoys football and asks that he can watch it on TV from time to time, with the male member of staff.

Comment

This is one aspect of choice, continuity, dignity and respect. It demonstrates a 'watching brief' for the advocate - there is a tendency for football to drop off the agenda because of lack of interest by the majority of staff and residents.

Observation Tools

Dementia Care Mapping (DCM) is one type of observation tool, part of the 'person centred' approach to dementia, developed by the late Professor Tom Kitwood at Bradford University's Dementia Research Group. DCM puts an individual with dementia at the centre of a qualitative assessment of their care; it is used in a group setting to evaluate how care services are being delivered. Trained practitioners spend time recording what happens to, for and around any individual at five minute intervals, noting the person's responses. Activity or lack of it is given a value. This builds up a picture of the content of the person's time and aims to give a focus to care providers for considering improvements in the quality of life they offer service users. It is a very skilled approach requiring in-depth training. Some advocacy projects have used it, but found it very time consuming, and more appropriate for evaluating the delivery of care to people with dementia. Again, the advocate can be seen in an inspection role.

Good Practice Principles

The Older Persons Advocacy Alliance (OPAAL) have identified three key advocacy principles for work with older people: inclusion, empowerment and independence.²⁰ Practical pointers for good practice in advocacy involving people with communication and comprehension difficulties are given under these headings below. The sub-headings relate to the advocacy issues raised earlier in this report.

Inclusion

Advocacy projects must make efforts to be accessible to 'hard to reach' older people including those with communication difficulties and those from black or minority ethnic communities. This may involve using better communication skills, different advocacy tools, providing accessible information and publicity. It relies on gaining the understanding and respect of professionals in a position to refer.

Blocks to advocacy might include language differences, or a general mistrust of mainstream services. Birmingham Citizen Advocacy run an advocacy group for Asian older people, including people with mental health problems, which provides a culturally sensitive service. For further information on how cultural issues might impact on advocacy services see the research by Asha-Rai Atkins, 'Coming in from the Cold', best practice in mental health advocacy for African, Caribbean and South Asian Communities.

Advocacy should be available by right at the point of discharge, change or assessment so that individuals are not dependent on good-will or a well-informed person identifying their need and linking them with a local project.

²⁰ Dignity on the Ward, OPAAL and Help the Aged, June 2000

Need and Consent Toolkit

- ❑ Advocates should be pro-active in offering a service and in arranging meetings – people with communication and comprehension difficulties are unlikely to self-refer. Where possible, the client will commission and instruct the advocate, but staff and relatives or carers can also refer or commission an advocate on their behalf.
- ❑ When working with confused or disorientated people it may not always be clear whether they wish an advocate to act or not. Where it is uncertain what the wishes of the client are – or whether they have the capacity to consent to the partnership - the advocate can still have a role (see ‘Different Approaches’ page 18).
- ❑ Passive consent - when an intervention is assumed to be acceptable unless the recipient indicates it is not - may sometimes be the only option. An advocate should consider what the options are for somebody who may not receive a service because they cannot consent to it.

Referrals Toolkit

- ❑ Advocacy projects must raise awareness of what advocacy is, why it is needed and how it relates to the mental health professional and carer’s role. If everybody understands the advocate’s role, both professionals and carers are more likely to refer people with communication difficulties to the service.

The key to getting referrals is to get the understanding, support and enthusiasm of workers in a position to refer. Giving talks and producing good written information about the service is vital, as is gaining the respect from people ‘at the top’ such as consultants.

Personal Experience

MIND in Barnet’s advocacy service noticed that the number of referrals of older people from residential care homes and hospital wards was quite low. This was partially due to the lack of understanding of the role of an advocate, and the fact that the residents/patients were not aware that the service was available.

The advocates therefore spent more time with the staff, holding regular meetings, informing them of ways to access the service and giving details of the type of work done. This improved working relationships and staff later used the advocacy service to raise issues around the closure of a day service that affected a group of their residents.

Advocates also focussed on outreach work with service users, at first in a befriending role (to build rapport) and later, making them aware of the help that was available to them. Advocates were in a position where they could identify advocacy issues themselves and were able to pick up issues on the wards and in residential homes that had existed for many months before.

Empowerment

The advocate's role is to empower the client, redressing the balance of power in relation to professionals and others, and exercising their rights and interests. Advocates will encourage professionals to share information fully with the client in order for them to make truly informed choices, and they will encourage them to listen carefully to the client's wishes and concerns. Advocates should be aware that older people may be frightened to speak out and criticise a service they are dependent on.

Somebody with communication difficulties may be unable to instruct the advocate or control the advocacy relationship. In reality they may not understand what is happening or be able to express their dissatisfaction to the advocate. Different approaches (see page 18) where the client does not have any involvement in the advocacy process run contrary to the basic principles of advocacy. However, it is arguably unacceptable to pass over someone who is vulnerable, and could be helped by advocacy, simply because they cannot understand or control the process.

Capacity, Choice and Communication Toolkit

- ❑ Older people with communication or comprehension difficulties will often be able to express their feelings and opinions in response to clear, concise information.
- ❑ The advocate will present information in a way that enables the client to respond as freely and clearly as possible. The information will be repeated and their opinions/instructions checked and re-checked at appropriate times (e.g. when taking a particular course of action or before a meeting).
- ❑ The advocate will work at a pace which is comfortable for the client, and encourage others to do likewise. An advocate will have the time and ability to discover a person's views when others cannot.
- ❑ Advocates can help raise awareness that a person may have the capacity to make certain decisions, but not others; or may have capacity on some days and not others. Choices must be offered and incapacity in all areas must not be assumed.
- ❑ Developing trust and rapport is vital. As far as possible, the advocate should get to know the personality of the person and perhaps their life history. If they knew the client before the loss of capacity, they may feel able to say what their views would have been.
- ❑ Special techniques may be used to open up communication, such as life story work, reminiscence and creative therapies.
- ❑ Advocates can also work alongside or learn from techniques used by speech and language therapists.
- ❑ Westminster Advocacy Service for Senior Residents have produced a booklet called Speaking Out: Guidelines for Good Practice. It is helpful for understanding the behaviour of people with dementia, giving guidelines and practical tips on ways of opening up communication (see page 28 for details).

Personal Story

Mrs A has been living in a staffed residential home for almost 5 years; as she was suffering from dementia her family had full control of her finances. Nursing staff at the home alerted the advocacy service when they became aware of the family's intention to move Mrs A from her own room to a shared room. Staff suspected that the family's primary concern was to preserve Mrs A's considerable capital as opposed to her welfare. They felt that a move to a shared room would cause her distress.

When the advocacy service became involved and looked at the options available to Mrs A, the family reassessed the situation, and she continues to reside happily in her own room.

Comment

Mrs A's ability to engage with the advocate varied. However when she was able to communicate, it was clear that she felt anxious about the idea of having to leave her own room. As she was not aware of her financial situation, the advocate relied on members of staff for this information. This client did not instruct the advocate, but was empowered through the advocacy process to express her feelings about a move to a shared room.

Independence

Advocacy must be free of conflicts of interest and be independent in seeking to meet the needs of the older person. Service providers in the statutory, voluntary or private sector can have a multitude of demands which make it difficult to truly represent the interests of the service user. The older person may see the mental health professional as part of the problem, be afraid of losing the service they are dependent on, or of 'bothering' busy staff. Family relationships are complex and relatives may have their own agendas, or feel strongly that they know what is best.

Independence and Confidentiality Toolkit

- ❑ Advocates must demonstrate their independence to the client.
- ❑ It should be made clear to staff and carers that they cannot instruct an advocate on a particular course of action or required outcome.
- ❑ Staff and carers may try and give the advocate information about the client. Advocates must try to keep to factual information and will generally work on a 'need to know' basis.
- ❑ Where there is little communication, the advocate will need to gather all the relevant information from staff and carers.

Personal Story

Ward staff contacted the advocacy service about Mr H's section 3 being renewed. The advocate met with the client a few times before the meeting and they seemed to have a good working relationship. During the meeting however a particular piece of information which Mr.H had withheld from the advocate was mentioned. The information was of a sensitive nature and the client responded by shouting that he no longer wanted the advocate present. The advocate met with the client after the meeting and he apologised for his outburst. He explained that he wanted to keep certain aspects of his life private, and that he was not comfortable giving the advocate that type of information. With time the client eventually trusted the advocate enough to divulge the relevant information, and their working relationship has been trouble-free since then.

Comment.

Due to Mr H's dementia, it was necessary for the advocate to spend a lot of time meeting with him to establish a relationship and to remind the client exactly who they were and why they were involved. In this case, particular care was needed around the issue of confidentiality. The advocate needed to demonstrate her independence from the service provider in order for the client to trust her.

Relationship with Carers Toolkit

- ❑ Advocates will treat relatives with respect and diplomacy.
- ❑ An advocate has to consider the views of carers and relatives, but must keep the focus on the client.
- ❑ Advocacy can be helpful to people with communication and comprehension problems even where there are supportive family and friends
- ❑ Carers can be effective advocates. Advocacy projects should enable carers to understand and learn about advocacy and develop their potential as advocates.
- ❑ Where there is a severe conflict of interest with a carer, the advocate will keep the carer involved and informed where possible, but the focus remains on the client.
- ❑ In some cases, mediation or conflict resolution should be considered as an option.

Relationship with Mental Health professionals Toolkit

- ❑ Building a good relationship with mental health professionals is important and needs tactful handling.
- ❑ Exchanging factual information and keeping key workers informed of meetings is important.
- ❑ Giving talks and producing leaflets explaining the nature of the advocacy service is important. Advocates must clarify their role and relationship with mental health professionals.
- ❑ Contracts and protocols (see Management issues below) can help to clarify referral procedures, access to information etc.
- ❑ See Westminster Advocacy Service for Senior Residents (WASSR) booklet for models of good practice in residential care.

Personal Story

Mrs G, who had lived in hospital for 25 years, had been informed that due to the closure of the hospital, she would be resettled into a residential home that was not particularly close to the hospital. The advocacy service became involved when Mrs G expressed to staff that she was not prepared to move. The advocate realised that the client had particular concerns about changes to her routine, and that she was worried about the changes that would take place to her life as a result of the move. The advocacy service worked with the resettlement team and found her a local nursing home. The advocate worked with nursing staff to help Mrs G become familiar with the rules of the new home and arranged several visits before the move to help her settle in. Mrs G lived happily in the home until she died peacefully in her sleep.

Comment

The advocate was free from organisational constraints, and was able to see the client's personal need for a local home.

Management Toolkit

- ❑ Setting, maintaining and monitoring standards of practice is crucial to protect vulnerable people from poor advocacy.
- ❑ Advocacy projects should ideally be independent of agencies that fund or provide services to avoid conflicts of interests. Where they are funded by health providers, the management of the project must be independent and separate.
- ❑ Explicit arrangements with host agencies covering how to refer, access to the ward, access to patient information, attendance at meetings, access to complaints procedures etc are important. (See WASSR booklet for sample contracts/protocol).
- ❑ The position and presence of the advocacy scheme should be made explicit in relevant multi-agency documents.
- ❑ It is important to clarify roles and relationships with other organisations and groups providing support to this client group.
- ❑ Monitoring and evaluating the progress of the project and its policies is vital. Evaluation should not be a number-crunching exercise, but should look at case studies showing how an advocate's intervention led to improvements for an individual.
- ❑ Advocates should be drawn from a diverse group including older people, people from ethnic minorities, and people with diverse experiences and interests.

Support, Supervision and Training Toolkit

All advocates need ongoing support, supervision and training, backed up by strong policies, procedures and protocols. Work with this client group is more challenging and demanding than other forms of advocacy.

In addition to basic advocacy training, for work with this client group training should cover:

- ❑ Person-centred approaches
- ❑ dementia awareness
- ❑ verbal and non-verbal communication and listening skills
- ❑ techniques such as life story work, reminiscence, creative therapies
- ❑ different approaches for people with severe communication/comprehension difficulties

Conclusion - The Way Forward By Philip Reilly, Advocacy Manager, MIND in Barnet

It is clear that the issues facing older people with communication and comprehension difficulties are as diverse as for any other group. As with other groups, there are defined points in service delivery when the involvement of an independent advocate is desirable (see box page 9).

Our concern is that, whilst 'single-issue' advocacy provided at clearly defined points of service delivery is both valuable and vital, it does little to address the kind of support described in a 'watching brief' (page 19). It is recognised, for example, that a person's capacity will fluctuate during any given interval. Assessment of capacity can, therefore, be difficult and imprecise without the luxury of an extended period over which to make such a judgement.

It follows that the evaluation of the application of any such assessment takes time. The input of an informed and independent advocate to this process could have great value. We are aware that some concerns only become apparent when a person's personality and background are better understood and this, also, requires time. We have, however, been reminded of the problem of becoming 'stuck' in the befriending role and of the benefits and objectivity that issue-based advocacy can bring.

Our research has led us to the conclusion that a hybrid service containing the strengths of both befriending and issue-based work would provide the most comprehensive service to this group of older people. One possible model for the interaction of these two roles is as follows:

Diagram 1
Role of the befriender

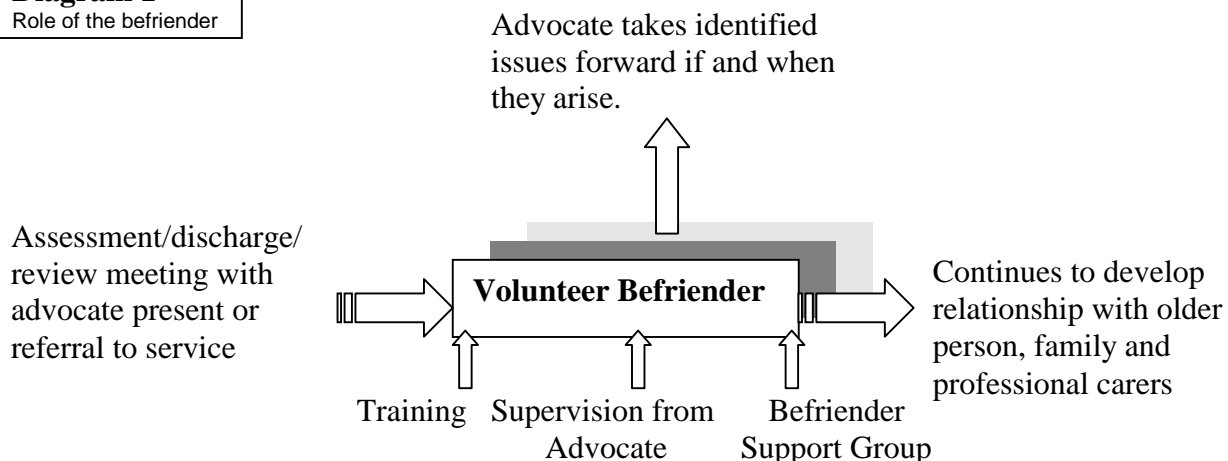
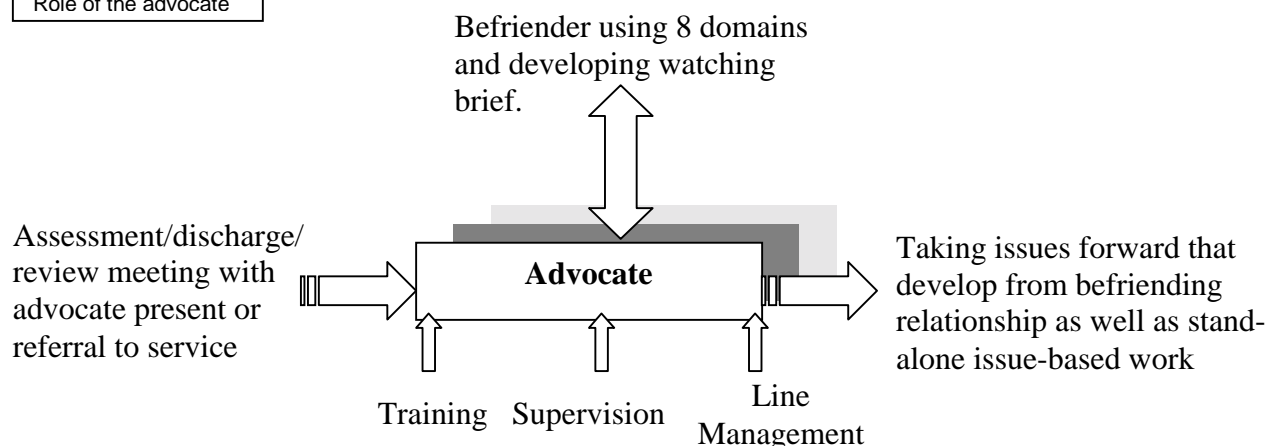


Diagram 2
Role of the advocate



Quality & Monitoring

The tools necessary for managing the development of a flexible and responsive service are outlined on page 25. This covers, amongst others points, the necessity of developing sound protocols and procedures to underpin the development of good working relationships with organisations and groups providing care and support to this group of older people.

The careful collection and collation of statistics can provide useful data about trends in a particular area or service, or the impact of changes in service provision, legislation or benefit rules. The measurement of the advocacy work itself, however, cannot be achieved by 'number-crunching'. The question, "has advocacy made any difference to the life of this older person?" is a tough and complex one to answer. Case studies, using the eight domains (see page.19 – Competence, Community Presence,

Continuity, Choice & Influence, Individuality, Status & Respect, Partnership & Relationships, Wellbeing) and the three key principles of inclusion, empowerment and independence (pages 20 - 23) as measures, can provide a clearer view of the effectiveness of the work at an individual level.

What now?

This research has sought to examine the issues faced by those individuals and organisations offering advocacy support to older people with comprehension and communication difficulties, and to highlight the dilemmas faced in applying the principles of advocacy to this particular group.

The responses we received whilst researching for this document, were mostly enthusiastic. If one considers this alongside the recognition advocacy is receiving in all aspects of health care provision, then the time would seem ripe to further promote the rights of older people. It is important that service commissioners, older people's organisations, advocacy schemes and other relevant groups work together to devise a strategic approach to the development of advocacy for older people. It is our hope that this document contributes to the development of commonly agreed sets of standards and quality frameworks.

We now need the support of government (hopefully via the National Service Framework and other standard-setting documents) and of local funding authorities. But over and above financial provision, service providers need to work in co-operation with advocacy schemes in establishing policies, protocols and procedures for ensuring the effective representation of older people at all levels.

Lee Ann Frampton – local research and case studies
Geraldine Cooney – national research, co-ordination and report writing
For MIND in Barnet Advocacy Service
May 2000-March 2001

Essential Reading when setting up an advocacy project for older people:

Advocacy for Older People: Unmet Need, June 2001, MIND in Barnet, Dove House, 1 Dove Close, Bunns Lane, Mill Hill, London. NW7 2AQ Tel: 020 8906 7511.
See also Website: <http://www.mindinbarnet.org>

Citizen Advocacy with Older People: A code of practice by Andrew Dunning, Centre for Policy on Ageing, 1995
19-23 Ironmonger Row

London EC1V 3QP Tel: 020 7253 1787

Code of practice for guidance and management of citizen advocacy projects. It covers the main legal, ethical and practical issues re: managing projects, training and supporting advocacy partnerships.

Speaking Out: guidelines for good practice.

Westminster Advocacy for Senior Residents (WASSR).

55 Dean Street

London W1V 5HU Tel: 0207 439 3131

Explanation of dementia, exploration of issues for advocates providing service for people with dementia, practical guidelines and tips for advocates especially around communication.

Advocacy and Dementia, Jan Killeen. 1996

Alzheimer Scotland, Action on Dementia

8 Hill Street

Edinburgh EH2 3JZ Tel: 0808 808 3000

Explores why people with dementia need advocacy and the different ways it may be provided.

Coming in from the Cold. Asha-Rai Atkins 2001

Joseph Rowntree Foundation

Policy Press

Best practice in mental health advocacy for African, Caribbean and South Asian Communities.

APPENDIX ONE ORGANISATIONS CONSULTED

National Organisations

We contacted the following organisations, interviewed them by telephone and read their reports and publications.

- Older Peoples Advocacy Alliance (OPAAL), Stoke on Trent
- National Alzheimer's Disease Society, London
- Bradford Dementia Group, Bradford University
- Dementia Services Development Centre, Stirling University
- London Centre for Dementia Care, University College, London
- Centre for Policy on Ageing, London
- Citizen Advocacy Information and Training (CAIT), London
- United Kingdom Advocacy Network (UKAN), Sheffield
- Age Concern, England
- Help the Aged, London
- Better Government for Older People Programme (Department of Health)
- National MIND Legal Department
- Alzheimer Scotland, Action on Dementia Project, Edinburgh

National Service Providers

The following organisations completed our questionnaire. They all provide an advocacy service for older mental health people with communication and comprehension difficulties (mainly dementia).

- Beth Johnson Foundation (BJF), Stoke on Trent
- Asist, Advocacy Services in Staffordshire
- Westminster Advocacy Service for Senior Residents (WASSR), London
- Brighton MIND
- Derby MIND
- Birmingham Citizens Advocacy (BCA)
- Pohwer Advocacy, Hertfordshire
- Advocacy in Barnet

Barnet Professionals

The following completed our questionnaire, and some were interviewed:

- 2 Ward Managers
- 1 Day Centre Manager
- 2 Consultants (we also attended a consultants meeting)
- 2 Managers of Residential Care/Nursing homes
- 1 Social Work Manager
- 1 Occupational Therapy Manager

Barnet Voluntary Organisations

The following completed our questionnaire, and some were interviewed:

- Barnet Age Concern
- Barnet Carers Association
- Barnet Alzheimer's Disease Society
- Action on Elder Abuse Barnet
- Advocacy in Barnet

APPENDIX TWO

ADVOCACY AND OLDER PEOPLE QUESTIONNAIRE

Advocates offer support for mental health service users on a wide range of issues, including problems around their care, financial issues and their rights and choices. Advocacy can be informal or formal, and provided by volunteers or paid workers.

The following questions relate to the provision of advocacy for older people with communication and comprehension difficulties (including dementia) who are using mental health services:

- Does your organisation offer this type of service? If not, would you like to be able to?
- Do you think there is an unmet need or a demand for this type of service amongst this particular client group? Please give reasons for your answer.
- In what areas do you think advocacy would be useful for this client group?
 - Mental Health Act support
 - Delivery of care
 - Housing/property
 - Finances
 - Resolving conflict
 - Safeguarding against abuse
 - Any other areas?
 - Any comments on the above?
- Do you have any views on what models of advocacy or other role, is best suited to this client group? For example:
 - Paid/professional advocacy dealing with casework
 - Citizen or volunteer advocacy offering long term support
 - Independent person/observer

- There are particular problems and differences for advocates working with older people with confusion or comprehension problems, especially in the areas of consent, instruction and confidentiality. Please give your views on the following areas. How could an advocate deal with these issues?
 - Confidentiality
 - who commissions and instructs the advocate
 - What weight is given to the opinion of relatives, professionals or carers
 - How the involvement of a relative, professional or carer affects the client/advocate relationship

- Are there any other issues or problems you would like to raise regarding the provision of advocacy to this client group?

- According to current law, capacity is determined by a person's ability to understand, retain, and weigh up information relevant to the decision, in order to arrive at a choice, and then to communicate that choice.
 - Are you happy with who currently determines capacity and how it is done? Why?
 - Is there a role for advocates here?