



Information from Counsel and Care: 25

# Independent Advocacy

Like everybody else, some older people can sometimes feel unable to speak out, to make sure their voice is heard in relation to any difficult issues affecting them.

Independent advocacy can be, amongst other forms, a one-to-one partnership between an independent advocate and an older person who needs support in order to secure or exercise their rights, choices and wishes. This guide looks at what independent advocacy is, and what it is not, when it may be needed, the importance of the relationship between the Independent Advocate and the older person (advocacy partner), how others (professionals/carers/family) may respond to advocacy, and how and when to access it.

**Counsel and Care is the national charity working with older people, their families and carers to get the best care and support. If you have found our service helpful, please consider making a donation or leaving a legacy in your Will. You can arrange either by telephoning 020 7241 8555 or using the secure service on our website [www.counselandcare.org.uk](http://www.counselandcare.org.uk).**

Counsel and Care is a national charity; however the creation of the Scottish Parliament, and the Welsh and Northern Ireland Assemblies means there are differences in the ways each region cares for and supports older people. The information in this guide applies essentially to England although there may be similarities with Scotland, Wales and Northern Ireland.

We also produce five separate guides for both Scotland and Wales covering the community care assessment of need process; paying care home fees and making a formal complaint which are the key areas where the policy and legislation differ significantly to England. All of the guides we publish can be downloaded from [www.counselandcare.org.uk/helping-you/guides](http://www.counselandcare.org.uk/helping-you/guides) or posted to you by calling our guide orderline on 020 7241 8522.

This guide has the following sections:

<b>1</b>	<b>The importance of independent advocacy .....</b>	<b>5</b>
<b>2</b>	<b>Who is an Independent Advocate? .....</b>	<b>7</b>
2.1	Lack of mental capacity .....	8
<b>3</b>	<b>'Independent' or independent? .....</b>	<b>10</b>
<b>4</b>	<b>Types of independent advocacy .....</b>	<b>11</b>
4.1	Crisis advocacy .....	11
4.2	Citizen advocacy .....	12
4.3	Self-advocacy .....	12
4.4	Independent Mental Capacity Advocates (IMCAs) ....	13
4.5	Independent Mental Health Advocates (IMHAs) .....	14
4.6	Advocacy under the Mental Health (Care & Treatment) (Scotland) Act 2003 .....	14
4.7	Non-instructed advocacy .....	14
<b>5</b>	<b>Independent advocacy – what it is and what it is not.....</b>	<b>15</b>
5.1	Independent advocacy is .....	15
5.2	Independent advocacy is not .....	15
<b>6</b>	<b>The independent advocacy relationship.....</b>	<b>16</b>
6.1	How it is formed? .....	16
6.1.1	Whose problem is it? .....	16
6.1.2	After a referral is received .....	16
6.1.3	Permission to advocate your views.....	17
6.2	How it works .....	18
6.2.1	Defining the difficulty and taking control.....	18
6.2.2	Speaking out.....	18
6.2.3	Who is in charge of the advocacy relationship?.....	19
6.2.4	Summarising the advocacy relationship .....	20
6.3	Advocacy and human rights .....	20

<b>7</b>	<b>Where and when might independent advocacy be beneficial to an older person? .....</b>	<b>23</b>
<b>8</b>	<b>Barriers to independent advocacy.....</b>	<b>27</b>
8.1	Valuing independent advocacy .....	27
8.2	Some examples of barriers.....	27
8.2.1	Failure to recognise conflicts of interest .....	27
8.2.2	Resisting the concept of independent advocacy.....	28
8.2.3	'Shooting the messenger' .....	29
8.2.4	'Paying lip-service' .....	29
<b>9</b>	<b>Who can refer for independent advocacy? .....</b>	<b>31</b>
<b>10</b>	<b>Accessing independent advocacy .....</b>	<b>32</b>

# 1 The importance of independent advocacy

As an older person surrounded by family or professionals (who each may have an opinion on what is best for you) who you are dependent on for your care and support, you may feel powerless or unable to voice your opinions. In such circumstances, you may find it daunting or feel unable to influence or challenge the decisions that are made about your life. In some cases, if you feel particularly isolated you could be faced with having to challenge the individual or an agency causing the problem in order for things to change.

An Independent Advocate can devote time to you as an individual and be on hand to respond to the changing circumstances of your needs and situation. The advocate is able to talk one-to-one with you and is then able to support you to voice your views and wishes or can represent your views and rights on your behalf, in person, to those involved with your care. This support should be free of charge.

There is now some legislation and policy guidance surrounding the provision of advocacy, notably with the Mental Capacity Act 2005, which applies in England and Wales. This Act creates a new role of Independent Mental Capacity Advocate (IMCA). For more information about IMCAs, see section 4.4 of this guide and 4.5 for Independent Mental Health Advocates (IMHAs) – a result of the

2007 changes to the Mental Health Act 1983. In Scotland, the Mental Health (Care and Treatment) (Scotland) Act 2003 finally established a legal right to independent advocacy for people with a mental disorder. The Adults with Incapacity (Scotland) Act 2000 did not address the legal right to independent advocacy.

## 2 Who is an Independent Advocate?

An Independent Advocate is a person who has been asked by or given permission by you to represent you. (If the Independent Advocate represents you, then he or she will be known as your advocate, see section 6, the independent advocacy relationship.) Representing you means they will help you to speak out, to have your voice heard and to have your views, wishes and rights taken into account by your family, carers and the professionals in any decision that affects your life. The Independent Advocate will make sure at each point in the advocacy relationship that you have all the information you need about the situation so that you can make informed decisions and choices (if you are able to). The Independent Advocate will then support you to voice these decisions and choices or speak on your behalf. Independent advocacy is not usually about legal representation, or paying a solicitor or lawyer to be an advocate. However, it could involve your independent advocate appearing in court to speak on your behalf, at a guardianship hearing, for example.

**Tip:** If someone is trying to influence you to make a particular decision, is not listening to your views or wishes, is trying to make decisions for you rather than letting you make them yourself (if you are able to), or is not saying the things that you asked them to say, this person is not advocating independently for you.

## 2.1 Lack of mental capacity

Where an older person is unable to give permission (or their views) because they are unable to understand information, also known as 'a lack of mental capacity', it is still possible for the independent advocacy relationship to work. It is very important that lack of mental capacity is always assessed by psychiatric services that specialise in mental health for older people. Lack of capacity, by law, must never be assumed, as to do so may deprive someone of their rights. Sometimes, older people who lack capacity and have dementia or another mental health problem are denied access to independent advocacy. This is because those in a position to refer them to advocacy incorrectly assume that this support will not be of value and, that it will not work because the older person cannot (or probably cannot) give instructions or make choices. However, it can work for a person who has dementia or another mental health problem, and is sometimes known as non-instructed advocacy. Contact Westminster Advocacy Service for Senior Residents (WASSR) (tel.: 020 7439 3131; [www.wassr.org.uk](http://www.wassr.org.uk)) for information on non-instructed advocacy in England, or the Scottish Independent Advocacy Alliance (SIAA) (tel.: 0131 260 5380; [www.siaa.org.uk](http://www.siaa.org.uk)) if you live in Scotland.

There are Independent Advocates trained specifically to communicate and work with people who have dementia and other mental health problems.

This is important because:

- If you have dementia or other mental health problems you may not be able to process complex information, but despite

this, you may be able to make 'one-off' important decisions, such as where you wish to live or who you live with.

- Your past wishes, by law, should be taken into consideration, for example, you may have regularly stated you wished to remain in your own home rather than move into a care home.
- If your 'problem' has been identified by someone else (because you are not able to voice this), such as professionals or family, having an Independent Advocate to represent your views is important. This will ensure you are supported to try to reach a solution to the difficulty should there be any conflict of interest. For example, a doctor, nurse or social worker may need to balance your needs against the money in their budget or their workplace policies. You may not have anyone else to help you advocate your wishes and the Independent Advocate will ensure your rights, views and wishes are taken into account by those involved in your care.

### 3 'Independent' or independent?

An Independent Advocate must be truly independent if advocacy is to be as effective as it can be for older people. Although some professionals, such as a social worker or nurse, can have an advocacy-type role as part of their overall job, if your 'problem' is connected to the policies, guidelines or practices of the local council social services department or NHS hospital, then it may sometimes be inappropriate for the social worker or nurse to 'advocate' on your behalf. This is because in order for you to get your chosen outcome, the social worker or nurse has to 'risk' challenging their own manager or their agency's practices and policies. Although some professionals have attempted to do this, it is difficult because, ultimately, they are employed by that organisation. Your voice may never be heard properly or it may be brushed aside due to a conflict of interest.

There are many independent advocacy organisations that can be accessed by older people now, where the advocates are not employed by, for example, the council, NHS, home care agencies or care homes. Details of how to access these organisations can be found in section 10 at the end of the guide.

## **4 Types of independent advocacy**

There are several types of independent advocacy, the main three for individuals being crisis (or issue-based) advocacy, citizen advocacy and self-advocacy. There are also now specific independent advocacy services set up to represent people subject to the Mental Capacity Act 2005, Mental Health (Care & Treatment) (Scotland) Act 2003 and Mental Health Act 1983 – extended in 2007 (see below).

### **4.1 Crisis advocacy**

This tends to be short-term in nature lasting anything from one day to six months (although it can be longer depending on the complexity of the case and the responses of the other people involved). The advocacy relationship would focus on one issue or aspect of your life, for example, your wish to challenge the decision to discharge you from hospital to a care home. The Independent Advocate would stay involved until the outcome that you want (for example, to go back home from hospital) is achieved, or until all avenues have been exhausted to try to achieve this. The Independent Advocate then ends their involvement. Hopefully, after this experience you would feel more able to advocate your own needs in the future. There is also the option of referring yourself in future for further advocacy support about a similar or different issue.

## **4.2 Citizen advocacy**

This can be more long-term in nature than crisis advocacy. This is the type of advocacy that is traditionally linked to people with mental health difficulties and should be rooted in communities. In this form of advocacy, the partnership takes more time to form as the Independent Advocate has to be 'matched' to you. As you will be spending more time together (perhaps even every day) it is important that you and the advocate feel comfortable together. Citizen advocates may be involved in advocating on many issues on behalf of their advocacy partner (you). The relationship is designed to support you in some or many aspects of your life. The citizen advocate may not 'belong' to a specific advocacy scheme, for example, it may be a neighbour or a volunteer from the community you live in.

## **4.3 Self-advocacy**

This is the term used when someone speaks up for themselves. It may be interesting to note that when someone not considered vulnerable or disabled expresses their views, it may be called being assertive. When some people, especially the more vulnerable people in society, are excluded or have their right to choice and self-determination taken away it can then become difficult for them to find the confidence to speak out. This is one example of where independent advocacy can be of benefit. It can support you to speak up for yourself as well as speaking on your behalf. Self-advocacy may lend itself to group advocacy (where a group of people rather than one individual are affected by the same issue)

more than the other two types mentioned above, although both been used in group advocacy.

#### **4.4 Independent Mental Capacity Advocates (IMCAs)**

The Mental Capacity Act 2005 introduced a new role of Independent Mental Capacity Advocate (IMCA). This is the first time that advocacy has been enshrined in legislation in England. The Act was designed to give a framework for acting and making decisions on behalf of someone who lacks the mental capacity to do so themselves. An IMCA would be involved in a serious care and welfare decision if an older person is regarded as not having the capacity to make that decision themselves. The IMCA would become involved if a decision related to serious medical treatment or a possible change of residence. Members of staff in local council social services or NHS Trusts have a duty to refer individuals who need to make such a decision to an IMCA in their area.

The IMCA will meet with the individual to gather as much possible information from them about what their wishes are and what they would like from the decision. In the cases where it is not possible to establish what the individual thinks about a decision, the IMCA will act in their 'best interests' in a similar way to non-instructed advocacy, and will represent the person's rights and past wishes (if known) to the professionals involved in the care and treatment of the person.

#### **4.5 Independent Mental Health Advocates (IMHAs)**

As of April 2009 some people using mental health services in England will have a legal right to an IMHA. This has come about through the Mental Health Act 2007 which updates the Mental Health Act 1983 and the Mental Health Act 1983 (Independent Mental health Advocates) (England) Regulations 2008. Those people receiving compulsory treatment, those receiving supervised community treatment and 'informal' or 'voluntary' patients considering serious treatment, such as neurosurgery, can access an IMHA to support them independently, help make their wishes heard and have their rights protected. For more information contact Action for Advocacy. Their contact details can be found in section 10 of this guide.

#### **4.6 Advocacy under the Mental Health (Care & Treatment) (Scotland) Act 2003**

Under the 2003 Act everyone in Scotland with a mental disorder has a legal right to an independent advocate. You do not have to be subject to the powers in the Act. Local Authorities and Health Boards in Scotland have a duty to ensure advocacy provision. The person with the mental disorder may want or require independent representation so that their views and rights are taken into account at, for example, a mental health tribunal. For more information please contact the Scottish Independent Advocacy Alliance (SIAA) whose details can be found in section 10 of this guide.

#### **4.7 Non-instructed advocacy**

Please see section 2.1.

# 5 Independent advocacy – what it is and what it is not

## 5.1 Independent advocacy is ...

- Being on your side
- Believing in you
- Speaking on your behalf or supporting you to speak
- Providing information (though some advocates such as citizen advocates may dispute this and prefer to direct the person to other organisations for information) and discussing options
- Enabling you to make informed decisions and choices
- Ensuring that your rights, views and wishes are acknowledged and taken into account by others
- The Independent Advocate placing their own values aside
- Exhausting all avenues to try to achieve the outcome you desire.

## 5.2 Independent advocacy is not ...

- Influencing you to make a decision
- Making a decision for you
- Advising you on the course of action to take
- Persuading you to do what other people want you to do
- Doubting what you say or the outcome you want
- Counselling you
- Speaking for you when you want to speak for yourself.

## **6 The independent advocacy relationship**

### **6.1 How it is formed?**

#### **6.1.1 Whose problem is it?**

Is there really a 'problem' and, if so, is it really your 'problem'? The 'problem' may be defined or explained in various ways depending on who is describing it (for example, you, a family member, a professional). That person may have a personal view of, or stake in the problem being resolved in a particular way. It may be easier for that person if the problem was resolved to their advantage and that you were to agree with them. For this reason, it is important to have your view of the problem from your perspective acknowledged. Your stated or known views and your rights should always be at the centre of the advocacy relationship.

#### **6.1.2 After a referral is received**

When you are referred to an independent advocacy organisation (or if you refer yourself), an advocate should arrange a meeting with you. This meeting should be held in private and the contents of the discussion should be as confidential as possible or as confidential as you want it to be. The Independent Advocate should, for security reasons, notify the care home manager, charge nurse or warden and so on, of their planned visit if you live in a care home or sheltered housing, or are a patient on a hospital ward.

The Independent Advocate should explain their role to you and explain what the advocacy organisation does and how it maintains its independence. At this point, the conversation should be completely confidential, which may enable you to speak openly to the advocate about your difficulty.

### **6.1.3 Permission to advocate your views**

Although the Independent Advocate should listen to the views of others (GP, carer, social worker, family) your definition of the difficulty or issue should be at the centre of the advocacy relationship. That is your view of the problem and what you would like to see happen. This should be central to the whole advocacy relationship.

Once the Independent Advocate knows your views or wishes, the advocate then needs to get your permission to advocate for you (see section 2.1 for a description of the advocacy relationship where the older person may not be able to give permission). If you give permission, then and only then, do you become the advocacy partner. The Independent Advocate should then ask you what outcome you want – how you would like the problem to be resolved. This outcome is the ultimate aim of the advocacy partnership and is not negotiable as far as social services, the NHS etc are concerned unless you decide it is based on the ongoing information and circumstances which you should be kept fully informed of.

## 6.2 How it works

### 6.2.1 Defining the difficulty and taking control

You should be in charge of the relationship. You have given your view of the problem and decided the outcome you want. You can also end the advocacy partnership at any time and in any circumstances, whether the outcome has been achieved or not.

### 6.2.2 Speaking out

The Independent Advocate should support you to speak out or should represent your views, wishes and rights to all those involved in your care (for example, professionals, carers and family). The advocate may also put these views, wishes and your rights enshrined in law and government policy within the context of the problem – for example, you have a right to decide where you want to live because you have the mental capacity to make decisions about your own care.

The Mental Capacity Act 2005 in England and Wales, and in Scotland, the Adults with Incapacity (Scotland) Act 2000, enshrine your rights to decide about your own welfare issues in law unless you have been assessed formally as incapable of making such decisions. The Act in England introduces the new role of Independent Mental Capacity Advocates which will work with people who lack mental capacity, have no family or friends to advocate for them, and who need to make a serious decision about health treatment or accommodation. See section 4.4 for more information about Independent Mental Capacity Advocates.

The Independent Advocate's role is to ensure that what you feel is important to you is conveyed to the people you want to say it to (or to support you to be able to say it yourself if you want to). This could be done by letter, telephone or in person – for example, attending a case conference or meeting on your behalf or supporting you to attend the meeting.

### **6.2.3 Who is in charge of the advocacy relationship?**

Where the Independent Advocate is representing you and talking to those involved, there is likely to be a response to your views or wishes. This response may come from a social worker or care agency – for example, in relation to the agency's policies and practices. It is the role of the advocate to take this information back to you so that you can continue to make informed choices and decisions in the face of the sometimes changing nature of the issue. It is important that the Independent Advocate asks about your views and wishes and the outcome you want on an ongoing basis. This is because your views and wishes may change as a result of the information coming back to you via the Independent Advocate from the other people involved. The Independent Advocate then continues to make clear your continuing or changed views or wishes.

Tip: It is not the role of the Independent Advocate to make or take decisions for you. It is also not the role of the Independent Advocate to negotiate the outcome. The outcome that you have requested is only negotiable if you decide that it is.

## 6.2.4 Summarising the advocacy relationship

The relationship is a process of:

- Discussing the difficulty or issue with you
- Taking your wishes or views forward, while keeping you informed so that you can continue to make informed decisions; and
- Taking any changed wishes or views forward again.

The relationship continues until the outcome is achieved or until all avenues have been exhausted to try to achieve it. The process can also end at any time if you do not wish to continue it.

Tip: It is not the role of the Independent Advocate to persuade you to continue the process, whatever stage you have reached. You have the right to make the decision to end the advocacy relationship and your decision should be respected.

## 6.3 Advocacy and human rights

The Human Rights Act 1998 establishes that there are certain levels of conditions and treatment which it is unacceptable for people to receive or endure. This is important for people who are in receipt of care from other people, and also those who find it difficult to express their views and opinions. Those people who cannot express their opinions and who are involved in an advocacy partnership are also entitled to have their human rights adhered to. It may be possible to challenge the decisions of organisations felt to be in breach of the Human Rights Act 1998,

particularly public bodies like the local council or the NHS, through the courts.

Key points in the Act include:

- “No-one shall be subjected to ... inhuman or degrading treatment.” (Article 3)

For example, people being cared for in a hospital or residential care home are entitled to treatment which maintains their dignity and respect. However, it should be noted that at this time, while council-funded residents in private care homes are covered by the Human Rights Act, private residents paying for their care in private care homes are to a large extent outside of its remit.

- “Everyone has the right to respect for his private and family life, his home and his correspondence. There shall be no interference by a public authority with the exercise of this right ... (except in certain circumstances, such as in accordance with the law and the needs and protection of rights of others).” (Article 8)

For example, it may be possible to challenge circumstances where an older person is having pressure put on them by a council to go into a care home rather than helped to maintain their independence at home because care in a care home is the cheaper option. This challenge was successfully upheld in a Court of Appeal decision: *Khana (by Official Solicitor) v. the Mayor and Burgess of Southwark* (2001).

- “Everyone has the right to freedom of expression.” (Article 10)

Independent advocacy can assist someone who has problems expressing themselves to do so.

- “Rights and freedoms ... should be enjoyed without discrimination on any ground.” (Article 14)

For example, discrimination experienced due to age, like someone having a care package denied to them because they were thought to be too old. No-one should receive treatment or experience attitudes which treat them differently simply as a result of their age.

If you are affected by any of the above issues you should seek further advice from an agency such as Counsel and Care, who can advise you on your rights and direct you to an organisation that can work with you to challenge the situation you face. You may also want to take legal advice from the Community Legal Advice Service (tel.: 0845 345 4 345; [www.communitylegaladvice.org.uk](http://www.communitylegaladvice.org.uk)) or Liberty, a charity specialising in human rights law (tel.: 0845 123 2307; [www.liberty-human-rights.org.uk](http://www.liberty-human-rights.org.uk)).

## 7 Where and when might independent advocacy be beneficial to an older person?

### Scenario 1

Some older people are supported by other people (carers, social workers, family) who they are dependent upon for their care and quality of life. It may be difficult in such circumstances for you to voice any concerns you have regarding your care and treatment. For example, you may be faced with a situation where you want to complain about the person or people that are responsible for your personal care. You may also want to make a complaint to an agency, such as the local council social services, or the Care Quality Commission (CQC) (tel.: 03000 616 161; [www.cqc.org.uk](http://www.cqc.org.uk)), the government body responsible for inspecting community care services and care homes in England. In Scotland, contact the Scottish Commission for the Regulation of Care (SCRC) (tel.: 0845 603 0890; [www.carecommission.com](http://www.carecommission.com)). In Wales, contact the Care and Social Services Inspectorate Wales (CSSIW) (tel.: 01443 848 450; [www.cssiw.org.uk](http://www.cssiw.org.uk)). You may feel frightened that if you complain your care and treatment could suffer, or feel frightened that you are being seen as unappreciative by those caring for you. Therefore, you may be reluctant to say anything and your quality of life may continue to be adversely affected.

An Independent Advocate can help you to voice your views and ensure these are respected.

## **Scenario 2**

You may be living alone with no family or other support. You may reach a stage where you think you are 'at risk' and need access to care and support, but have no idea where to start. You may not know of any entitlement to services from the council, including how to begin the process – by obtaining an assessment of your care needs. Sometimes, the processes involved and the information provided to you can appear complicated or confusing. In these situations it may be that you feel unable to make your voice heard and unable to deal with the professionals and the information or processes involved.

An Independent Advocate can help you through the complicated community care process by ensuring that you understand the information and what your rights are, and that the professionals involved 'hear' what you are saying.

## **Scenario 3**

You may be in hospital when you no longer need treatment. The NHS or local council social services may be applying pressure for you to move on from hospital to another setting. It may be that you or your family are concerned that the services are not in place for the discharge to be safe. It may also be that you or your family (if you are unable to make your wishes known) are in dispute about the decision to discharge you, for example, from hospital directly to a care home. In such circumstances, it is not

uncommon for many of the professionals involved (and, in some cases, family too) to decide that your physical needs (sometimes described as 'a risk to you') carry more weight than your emotional, social or psychological care needs. Therefore, you are denied the right to take 'risks' that you understand, accept and have a right to take.

An Independent Advocate can ensure that your voice is heard by all those making plans on your behalf.

#### **Scenario 4**

You may be feeling concerned about your treatment, the quality of your care or that you are being abused in some way. This lack of care or abuse may be happening, for example, at home, in hospital, or in a care home. You may have no independent support to be able to voice your fears or concerns. It may even be that you are not aware of or are unable to understand that the abuse is taking place.

An Independent Advocate will be able to talk to you in confidence about the circumstances. You could decide whether to take up the offer of independent advocacy to help you feel protected and stop the abuse. Please also see our guide **Abuse - older people at risk** (guide number 20).

#### **Scenario 5**

Within Local Authority Circular LAC (DH) 2008 1 the Department of Health has set out how it intends to support councils with social

services responsibilities to transform their existing systems of social care to make them more person-centred. This is to give older people more choice and control over the type of care they access and how they access it. The initiative is called 'Putting People First' and it introduces the concept of 'personal budgets' for people eligible for care services from their local council. The idea is that the 'personal budget' will allow more flexibility and choice for the older person in finding and securing the care they feel is best to meet their own care needs. Central to the initiative is that older people who require it have access to independent advice, information and advocacy to enable them to be fully informed of the care options available and support to access it. You can read more about the personalisation of social care in England in our guide **Home Care: using Direct Payments and personal budgets** (guide number 23).

As a result of the personalisation of social care, the creation of personalisation advocates is beginning to emerge to support older people to identify care options and try to secure them to meet their care needs. This would be a different and distinct role from the care brokerage role that some social workers or care managers may have. To find out more about this you may want to contact Kath Parson who is the National Programme Manager at OPAAL ([kath@opaal.org.uk](mailto:kath@opaal.org.uk)), as she is monitoring this development.

## **8 Barriers to independent advocacy**

### **8.1 Valuing independent advocacy**

Independent advocacy may not always prove successful in achieving the outcomes that you want and you may have no absolute right to your desired outcome. However, it is important to know that the success of independent advocacy, according to some older people, should not be judged solely on its ability to achieve desired outcomes. The value of the experience of independent advocacy may still be judged positively by you even if the outcome you wanted is not achieved. This is because research has found that it is not necessarily the outcome of the independent advocacy experience that was the most important aspect for some older people. Additional values were felt to be:

- That the older person felt that someone was on their side
- That the Independent Advocate believed what the older person was telling them, and
- That the Independent Advocate supported the older person to try to achieve the outcome wanted.

### **8.2 Some examples of barriers**

#### **8.2.1 Failure to recognise conflicts of interest**

Independent advocacy grew partly from the recognition that where the older person was supported by a professional there may not be a completely impartial advocacy service. This is because of

the conflict of interest we looked at in section 3, 'Independent' or independent?

The professional or carer may simply not recognise that such a conflict of interest exists or they are unable to grasp that the older person has a right to have the issue taken further than the professional/carer can take it.

Tip: The Independent Advocate could point out that a conflict of interest may be taking place and explain why this is felt. They may also want to use any available policies or legislation to reinforce your (as the advocacy partner's) rights.

### **8.2.2 Resisting the concept of independent advocacy**

Some professionals, carers and family members may not understand how the independent advocacy relationship should work. They may also not recognise your right or need to have an Independent Advocate. Therefore, they may not respond appropriately or may resist working with the Independent Advocate. Independent advocacy is about redressing the power imbalance that often exists between professionals, informal carers, care services and you when difficult decisions need to be made.

Tip: In this situation the Independent Advocate, with your permission as the advocacy partner, should continue to endeavour to seek a response from those involved. This may involve taking the issue to a more senior person. The Independent Advocate could also provide an opportunity to those involved to discuss the

role of the Independent Advocate so that any misunderstandings about the purpose of independent advocacy can be addressed.

### **8.2.3 'Shooting the messenger'**

When the actions of professionals, carers and other people who feel they are acting on your behalf and in your 'best interests' are challenged, they may try to prevent themselves feeling challenged by excluding the Independent Advocate. They may do this by failing to keep the advocate involved or even refusing to engage with them, therefore, effectively dismissing your views as part of the decision-making process.

Tip: The Independent Advocate may wish to acknowledge that it is understood that those involved feel they are working in your best interests. The advocate can then ensure the focus of their work on your behalf is centred on how the policies or practices may have contributed to the situation. The Independent Advocate may again also wish to reinforce what the role of the Independent Advocate is and how their views are actually those of the older person.

### **8.2.4 'Paying lip-service'**

Sometimes professionals and other people involved in your life may express a willingness to work with an Independent Advocate. However, it may become apparent that no improvement to your situation is taking place. This may be because a professional feels concerned about the impact independent advocacy may have on

their work. Or they may feel anxious about something negative they have done becoming known.

Tip: The Independent Advocate should quickly become aware that this is an issue and address it in a way that both ensures your views and wishes are acknowledged and that the person 'paying lip-service' is made aware that this is unacceptable.

## 9 Who can refer for independent advocacy?

You can refer yourself to an independent advocacy organisation if you feel you may benefit from this support. Or a member of your family, a friend, neighbour or carer who supports you, but feels unable to 'challenge the professionals' on your behalf can, with your permission, make a referral or assist you to make a referral. Or, alternatively, a professional who feels that you may benefit from 'an independent voice' can make a referral.

If you are living in a care home, you may also be able to ask the care home manager and/or care workers in the care home for assistance to access independent advocacy. This complies with Standard 14.3 of the National Minimum Standards – Care Homes for Older People (there is a similar requirement under the care home standards in Scotland), where older people living in a care home should be “informed of how to contact external agents (e.g. advocates) who will act in their interests.”

## 10 Accessing independent advocacy

This section includes the contact details of independent advocacy organisations and umbrella groups (some of whom have a database of independent advocacy provision) in England, Scotland and UK-wide, as well as those specific to older people living in a care home and older people in hospital and using NHS services.

### **Action for Advocacy**

Website: [www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)

Email: [info@actionforadvocacy.org.uk](mailto:info@actionforadvocacy.org.uk)

Tel.: 020 7820 7868

An established resource and support agency for independent advocacy schemes across the country. They are involved in the promotion and development of independent advocacy and promotion of advocacy at a strategic level.

### **Advocacy Resource Exchange**

Website: [www.advocacyresource.org.uk](http://www.advocacyresource.org.uk)

Email: [enquiries@advocacyresource.org.uk](mailto:enquiries@advocacyresource.org.uk)

Helpline: 08451 22 86 33

Advocacy Resource Exchange supports learning from and development of advocacy by providing specialist training. They are involved in the exchange of news and information about advocacy and sharing and development of good practice. They have a national database and helpline for advocacy provision.

## **Dementia Advocacy Network**

Tel.: 020 7297 9384

Website: [www.wassr.org/dementia.htm](http://www.wassr.org/dementia.htm)

Email: [dan@wassr.org](mailto:dan@wassr.org)

For more information about advocacy and dementia, including non-instructed advocacy.

## **National Coalition of Citizens Advocacy Schemes**

Website: [www.cacoalition.org.uk](http://www.cacoalition.org.uk)

Tel.: 0151 733 6705

Email: [enquiries@cacoalition.org.uk](mailto:enquiries@cacoalition.org.uk)

They can give more information about citizen advocacy and can signpost to particular services.

## **Older People's Advocacy Alliance (OPAAL)**

Website: [www.opaal.org.uk](http://www.opaal.org.uk)

Email: [jo@bjf.org.uk](mailto:jo@bjf.org.uk)

Tel.: 01782 844 036

Database of advocacy schemes. They are involved in projects aimed at developing, promoting and defending advocacy as well as quality and benchmarking work. They are the contact point for and have built links between national (UK wide) advocacy groups.

## **Scottish Independent Advocacy Alliance (SIAA)**

Website: [www.siaa.org.uk](http://www.siaa.org.uk)

Email: via the website "Contact us" page

Tel.: 0131 260 5380

They hold a directory of independent advocacy provision in Scotland and provide training as well as promoting provision of advocacy in Scotland.

**Age UK** branches often provide advocacy for older people. They may also be able to direct you to independent advocacy organisations in your area.

You could either contact your local office (details in your telephone directory) or the national office for your area.

- Age UK (tel.: 0800 169 65 65; [www.ageuk.org.uk](http://www.ageuk.org.uk))
- Age Scotland (tel.: 0800 169 28 28; [www.ageconcernandhelptheagedscotland.org.uk](http://www.ageconcernandhelptheagedscotland.org.uk))
- Age Cymru (tel.: 0800 169 33 99 or 029 2043 1555; [www.agecymru.org.uk](http://www.agecymru.org.uk))
- Age Northern Ireland (tel.: 0800 169 36 36; [www.ageni.org](http://www.ageni.org))

**Counsel and Care** can search its database for independent advocacy organisations in your area. If you are looking to find or refer someone to independent advocacy, you may want to call the advice service on 0845 300 7585 – Monday to Friday 10.00am to 4.00pm every day except Wednesday afternoons.

### **Care home and hospital residents**

The National Minimum Standards in England (and Scotland) make it clear in Standard 14.3 that each care home has a requirement to be aware of the independent advocacy provision available to older

people in the local area. Residents of care homes should be assisted to access independent advocacy, if they request this.

**Care home residents** may, alternatively, want to contact the above named national organisations for details of organisations that provide independent advocacy for older people in residential care.

### **People with complaints about the NHS (including hospitals)**

The Independent Complaints Advocacy Service (ICAS) can help anyone with a complaint about the NHS (including hospitals) in England. Three different charities (The Carers Federation, POhWER and South of England Advocacy Projects - SEAP) provide this service on behalf of the Department of Health. To find your local ICAS, tel.: 0300 456 2370. (POhWER has been contracted by the Department of Health to provide this part of the ICAS service.)

In Scotland, some NHS Boards have contracted with Citizens Advice Scotland offices to provide an Independent Advice and Support Service (IASS) which can provide independent advice and help to make complaints about NHS and social care services. Contact your local Citizens Advice Bureau (CAB) to find out if this is offered locally (look in your phone book, or tel.: 0131 550 1000 or visit [www.cas.org.uk](http://www.cas.org.uk) to get details of your local CAB, or phone Citizens Advice Direct on tel.: 0844 848 9600 for telephone advice; [www.citizensadvisedirect.org.uk](http://www.citizensadvisedirect.org.uk)), or contact the Scottish Independent Advocacy Alliance (see details above). This service was introduced to replace the functions of Local Health Councils. The service also offers help and representation with making

complaints about health and social care services including  
Continuing NHS Care.

Our advice workers can advise on a wide range of issues affecting older people, their relatives and carers. Counsel and Care produce a range of guides which can be downloaded from our website [www.counselandcare.org.uk](http://www.counselandcare.org.uk), or requested by calling our guide orderline on 020 7241 8522.

This guide is not a full explanation of the law and is aimed at people over 60.

Counsel and Care  
Twyman House  
16 Bonny Street  
London NW1 9PG

Tel.: **0845 300 7585** (local call rate)  
Email: [advice@counselandcare.org.uk](mailto:advice@counselandcare.org.uk)  
Website: [www.counselandcare.org.uk](http://www.counselandcare.org.uk)

Registered Charity No. 203429 Counsel and Care for the Elderly

We are a member of the Federation of Information and Advice Centres (FIAC)

**As a charity we rely on donations**

© Counsel and Care May 2010