

# Advocacy for Unpaid Carers, Guidance

March 2016



# **Advocacy for Unpaid Carers, Guidance**

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## Foreword

We are pleased to introduce this Guidance which seeks to promote best practice in Scotland in relation to advocacy for adult carers.

We recognise the important role advocacy plays in helping safeguard people who may be at risk of being treated unfairly as a result of individual, social and environmental circumstances that make them vulnerable. We also recognise that some carers, especially the most vulnerable, benefit from independent advocacy support to help them in many different ways, including supporting them in dealings with health and social care and other professionals.

The Guidance is primarily intended for use by independent advocacy organisations, independent advocates, carer advocacy projects and carer advocacy workers to support a wide understanding of the role and boundaries of advocacy for carers. We envisage that it will also be helpful to carers in both understanding best practice as well as sign-posting them towards self-advocacy techniques.

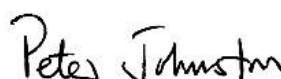
Various types of advocacy are highlighted which may be offered and the importance of each is acknowledged. The Guidance recognises the value of local information on advocacy and provision of advocacy. In doing so it compliments these existing initiatives.

Carers should be involved in decisions about their own care and support. They can also be involved in decisions about the care and support of the people they care for. Advocacy helps ensure that people's rights are upheld, by ensuring that their views, opinions and wishes are expressed and listened to when decisions are made about their lives. Advocacy should provide an environment where people can confidently raise issues, knowing that it is free from conflict of interest.

This Guidance would not have been possible without the dedicated work of the Carers' Advocacy Guidance Working Group. We thank them for their valued contribution and hard work.



Jamie Hepburn MSP,  
Minister for Sport, Health Improvement  
and Mental Health



Councillor Peter Johnston,  
COSLA Health and Wellbeing  
Spokesperson

<b>Contents</b>	<b>Page Number</b>
<b>What is advocacy?</b>	Page 3
<b>The purpose of advocacy</b>	Page 3
<b>Carers and advocacy</b>	Page 3
<b>Who this Guidance is for</b>	Page 4
<b>Commissioning advocacy</b>	Page 5
<b>Why a carer may need advocacy</b>	Page 6
<b>Benefits of having an advocate</b>	Page 7
Case study	
<b>Advocacy is, advocacy is not</b>	Page 8
Advocacy is - Case study	
Advocacy is not - Case studies	
<b>Managing conflict of interest</b>	Page 11
What is a conflict of interest?	
The organisation	
The advocate	
Cases where a carer support organisation offering advocacy also offers other support/advice services	
Case study	
Cases where both the carer and service user have an advocate	
<b>Boundaries and expectations</b>	Page 15
General boundaries and expectations	
Confidentiality	
One-to-one or individual advocacy	
Collective advocacy	
Self-advocacy	
Case studies	
<b>Accessibility in advocacy</b>	Page 18
Minority groups and advocacy	
Case studies	
<b>Professional practice</b>	Page 21
Training and professional development	
Support and supervision	
Policies	
Additional reference tools	

<b>Advocacy and duty of care</b>	Page 23
Case study	
<b>Evaluation and outcomes</b>	Page 24
<b><u>Appendix 1</u></b>	
<b>Carers advocacy guidance glossary</b>	Page 25
<b><u>Appendix 2</u></b>	
<b>Different types of advocacy</b>	Page 29
Independent advocacy	
Advocacy delivered by wider support organisations	
Advocacy provided through carers centres	
One to one or individual advocacy	
Group or collective advocacy	
Self-advocacy	

## What is Advocacy?

### Advocacy:

- safeguards people who are vulnerable or whom services find difficult to serve
- empowers people who need a stronger voice by enabling them to express their own needs and make their own decisions
- enables people to gain access to information, explore and understand their options and to make their views and wishes known
- speaks up on behalf of people who are unable to do so for themselves, or who choose not to do so<sup>1</sup>. This is different from legal advocacy where an individual is represented by a legal professional.

There are many different types of advocacy and these are briefly described in Appendix 2.

The accepted and commonly used term for a person who uses advocacy is 'advocacy partner'. The Scottish advocacy movement has used this term for a number of years. It conveys a message about the equality of the relationship between the advocacy partner and the advocate and the fact that the relationship should be a partnership. In the context of advocacy for carers, many organisations will simply use the term 'carer'. Throughout this document the terms 'carers' and 'advocacy partner' are both used where appropriate.

### The purpose of advocacy

The value of advocacy has been recognised for many years, and has played a major role in helping people have their voices heard and ensuring access to appropriate help and support. Advocacy supports people to gain access to information and to explore options and consider possible outcomes. Most importantly it helps ensure that people's views, opinions and wishes are listened to and taken into account when decisions are made about their lives.

### Carers and advocacy

The Scottish Government and COSLA recognise carers as equal partners in the delivery of care<sup>2</sup>:

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<sup>1</sup> [Principles and Standards for Independent Advocacy, SiAA, 2008](#)

<sup>2</sup> [Caring Together: The Carers Strategy for Scotland 2010 - 2015](#)

Carers should be recognised and treated as equal partners in care with other care and support providers. This means being involved in decisions affecting the person they care for and engaged in decisions about the development of /or changes to services in their area.

Carers should be able to make decisions about how much unpaid care they wish to provide to the person they care for.

In decisions with health and social care services relating to a cared-for person the views of the cared-for person are essential. However, carer involvement in decision-making processes regarding the cared-for person should be sought.

There is no right in law for carers to access advocacy. However, Caring Together: The Carers Strategy for Scotland 2010 – 2015 recognises that:

*“Some carers, especially the most vulnerable, benefit from independent advocacy support to help them in many different ways, including supporting them in their dealings with health and social care and other professionals.”*

Advocacy provision for carers varies throughout Scotland and is not available in every area. In some areas the local carers’ centre has a separate advocacy project with dedicated workers or volunteers providing advocacy support.

Other areas have independent advocacy projects with a dedicated carers’ advocacy worker or protocols to ensure that any advocacy for carers is separate to advocacy provided to the person they care for.

## **Who this Guidance is for**

This Guidance is primarily intended for independent advocates, independent advocacy organisations, carer advocacy workers and carer advocacy projects. These advocacy workers are based in independent advocacy organisations or wider carer support organisations. The Guidance aims to support good practice in the delivery of advocacy for adult carers.

This Guidance will be of interest to everyone involved in working with and supporting carers to promote a wide understanding of the role and boundaries of advocacy for carers. It demonstrates the benefits of advocacy for carers and gives guidance on best practice in planning, commissioning and delivery.

For advocacy workers working with carers, the Guidance will ensure full understanding of the role and its challenges. It also aims to ensure that best practice is adhered to, thereby ensuring a consistently high quality of advocacy practice across Scotland.



For independent advocacy organisations and for carer advocacy projects the Guidance sets out advocacy best practice. It provides clarity around what may constitute a conflict of interest in delivering advocacy and how such conflicts may be avoided.

For carers the Guidance promotes understanding of what advocacy is, how it may help and what to expect from an advocacy service. It also provides information for health and social care professionals working with carers and with those they care for to understand the role and boundaries of advocacy for carers.

This Guidance helps ensure that conflicts of interest do not arise in the provision of advocacy for carers. Where there is the potential for a conflict of interest the Guidance helps both independent advocacy organisations and carers' support organisations to recognise this and to put in place policies and procedures to mitigate against this.

This Guidance relates to adult carers. The Scottish Independent Advocacy Alliance (SIAA) is producing guidelines for advocates about working with children and young people. Where young carers have additional support for learning they will have access to an advocacy service.

## **Commissioning advocacy**

The Scottish Government Independent Advocacy Guide for Commissioners (2013)<sup>3</sup> reflects Commissioners' statutory responsibility under the Mental Health (Care and Treatment) (Scotland) Act 2003. It provides commissioners with an understanding of good advocacy practice and management to be considered when commissioning advocacy services. This Guidance can be used alongside the Guide for Commissioners. Material produced by the SIAA such as the *SIAA Principles and Standards for Independent Advocacy*, and the associated *Code of Practice and the Independent Advocacy: An Evaluation Framework (2010)* also provide benchmarks against which advocacy practice can be measured. These can be used in evaluation of advocacy organisations or projects.

## **SIAA Principles and Standards**

The advocacy movement, with stakeholders, developed the *SIAA Principles and Standards for Independent Advocacy* (2008). Commissioners can use the Principles in the commissioning of advocacy services if they so wish and some do. The Principles, which represent the core beliefs about independent advocacy outlined within the SIAA document and reflected in the Scottish Government Guide for Commissioners (2013) are as follows:

**Principle 1:** Independent advocacy puts the people who use it first

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<sup>3</sup> [Independent Advocacy - Guide for Commissioners \(2013\)](#)

**Principle 2:** Independent advocacy is accountable

**Principle 3:** Independent advocacy is as free as it can be from conflicts of interest

**Principle 4:** Independent advocacy is accessible

These Principles are widely accepted and are relevant and appropriate in the provision of quality independent advocacy services. They are reflected in this Guidance.

## **Why a carer may need advocacy**

*‘Even within the broad community of people using adult social care services, different people have different levels of power over their lives, over the decisions made about them and the choices and risks they can take.’<sup>4</sup>*

*Principle 1: Advocacy puts the people who use it first*

There are many reasons why a carer may need advocacy including the nature and complexity of caring roles and the difficulties of balancing the carer’s needs with those of the person they care for. Carers can also find it difficult to access the support they need when they need it.

Advocacy may be provided to a carer at any stage of their caring journey. This includes, for example, where the person they care for has moved into residential or nursing care, as the carer may still play an ongoing role in relation to their care and support.

After a person’s caring role has come to an end, the former carer may still require advocacy support. This is because the end of caring may have implications, both financial and practical. It will be a matter for advocacy organisations to prioritise the advocacy requirements of carers and former carers, depending on conditions attached to funding and legislative requirements.

Many carers are able to speak up for themselves, but others find it more challenging to do this for a number of reasons:

- stress, fatigue and social isolation can undermine a carer’s self-esteem, making it much more difficult for them to ask for things before they reach crisis point
- carers can often find themselves in situations where they are speaking on behalf of the person they care for and also trying to get their own views

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<sup>4</sup> [Joseph Rowntree Foundation Programme Paper, Risk, trust and relationships in an ageing society, 2012](#)

across. Sometimes the carer's views will differ from those of the person they are caring for so it is possible that they will not ask for the things they need.

- carers may have family members, friends or other professionals who will help them represent their views. However, in situations that are complex, or where there is a conflict of interest a carer may need support that is independent.
- the size and complexity of the system can be off-putting for a carer who doesn't know where or to whom to address their needs – and the jargon used in the system, unintentionally, can act as a barrier for a carer in understanding what professionals mean.
- a carer is often the expert in the care of the person they are caring for. If this is not acknowledged by professionals carers may need support to gain recognition as equal partners and be involved in decisions affecting them.
- employers and education providers may not always be aware of the full extent of the caring responsibilities of their employees or students and how these are impacting on their attendance and performance
- a carer may have difficulties in expressing the magnitude or intensity of how their caring role affects their physical, mental or emotional well-being
- a carer can be so overwhelmed with paperwork and dealing with multiple agencies and may simply not have time to search out what information and support is available or to keep asking for help
- a carer may not know how to access the information about services that can support them
- even though a carer may also have Power of Attorney, or be in the role of Welfare or Financial Guardian for the person they care for, it is also possible that they may need someone to discuss the options or to help them get their voices heard, without in anyway influencing decisions they may make

## **Benefits of having an advocate**

An advocate can:

- ensure the carer's rights are upheld
- help carers to access early-intervention support to prevent crisis
- get the carers' voice heard when dealing with professionals and others. They can do this by giving the carer clarity and confidence in relation to their rights and choices

- speak on behalf of the carer or support the carer to get their voice heard, in writing or in person
- offer the carer independence and trust as the advocate is wholly on the side of the carer with the sole focus on getting the carer's views heard
- represent the carer as a distinct voice from the person being cared for
- help the carer navigate 'the system' by finding the right person for the carer to present their views to
- support a carer in meetings and clarify the carers' needs to professionals
- explain to the carer the reasons around professionals' decision making
- help translate jargon and terminology used by professionals

### **Case study**

Janet cares for her husband, Phil, who has early onset dementia. She had found it difficult at times to get help such as additional hours of day care and occasional short breaks. Her health was suffering and she was concerned that her ability to continue to care for Phil was being affected by her worsening health and levels of stress.

Her friend told her about the local advocacy service that provides advocacy for carers. Janet contacted them and met with Sue, an advocate.

Sue now goes to meetings with Janet and with her support Janet has been able to access more support to care for Phil. Janet feels that the additional hours of day care and short breaks have led to a reduction in her levels of stress and believes that she will be able to maintain her caring role. Janet is now able to spend time with family and friends and to enjoy time in her garden.<sup>5</sup>

### **Advocacy is, advocacy is not**

#### **Advocacy is...**

- about standing alongside potentially marginalised people
- about ensuring the rights of a person or group are upheld
- a process of promoting natural justice

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<sup>5</sup>All case studies in this document are based on real life situations, but some details have been changed to ensure confidentiality

- listening to someone and trying to understand their point of view
- finding out what makes them feel good and valued
- understanding their situation and what may be stopping them from getting what they want
- offering the person support to tell other people what they want or introducing them to others who may be able to help
- helping someone to know what choices they have and what the consequences of these choices might be
- enabling a person to have control over their life but taking up issues on their behalf if they want you to
- being non-judgemental

### **Case Study**

Marion is the main carer for her son who is affected by mental health issues. Marion was referred to Independent Advocacy for support by the Mental Health Officer, who felt that she may benefit from someone independent to discuss and understand her options and rights with regards to her sons care and treatment as he had been detained in hospital.

The Carers Advocate gave Marion information about her rights as she had become the “named person” for her son by default, and she was provided with her options regarding participation in discussions surrounding her sons care. The Carers advocate also explained the conditions of her son’s detention under the mental health act and supported her to access a solicitor.

Marion was supported to prepare her views for the upcoming tribunal, and the process was explained so that she had knowledge of what to expect. Marion was supported by advocacy to attend the tribunal and put forward her views; the Carers Advocate collected information from the professionals around the table and asked any questions that Marion wished answered.

After the tribunal Marion met with the Carers Advocate to go over the information given at the tribunal and to discuss what options were available to her. Marion’s son was discharged from hospital later that month, and the Carers Advocate supported Marion to make contact with local carers services as her son was residing with her. The Carers Advocate also supported Marion to make contact with social services regarding a carers support plan and regular respite.

Marion continues to receive the support of advocacy for care reviews.

The feedback from Marion was that Carers advocacy allowed her to have a voice, and understand a system she had never had experienced before. She felt that she was valued, listened too and granted to opportunity to engage in the process.

### **Advocacy is not...**

- making decisions for someone
- mediation
- counselling
- befriending
- care and support work
- consultation
- telling or advising someone what you think they should do
- solving all someone's problems for them
- speaking for people when they are able to express a view
- filling all the gaps in someone's life
- acting in a way which benefits other people more than the person you are advocating for
- agreeing with everything a person says and doing anything a person asks you to do
- providing an alternative for poor or inadequate service from another agency

### **Case Studies**

Julie is the advocate for Graeme, a carer for his 28 year old daughter who has cerebral palsy. Graeme tells Julie that he wishes to make a complaint about the short break service his daughter attends, however Julie's husband works for the short break service. Julie declares this conflict of interest to her manager so that they can discuss the best course of action.

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Sandra is a carer for her mother, and her advocacy worker, Colin is helping her prepare for a review meeting. The day before the review is due to take place, Colin receives a phone call from the social worker suggesting that he attends early tomorrow for a 'pre review meeting' with professionals as there is sensitive information which will be discussed and they feel it may be best if Sandra is not

aware of this information yet. Colin clarifies with the social worker that as an advocate he is unable to give any opinion, professional or otherwise, or withhold any information from Sandra.

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## **Managing conflict of interest**

*Principle 3: Independent Advocacy is as free as it can be from conflict of interest*

### **What is a conflict of interest?**

These may be, but are not limited to, the following scenarios:

- a service provider attempts to direct or control the actions of an advocate
- the cared-for person attempts to exert influence over what views they wish the carer to express in relation to the carer's own needs
- the carer wishes their advocate to express the cared-for person's views as well as their own
- an advocate is requested to withhold information from the carer receiving advocacy, for example, by a professional or by the cared-for person
- an advocate is asked to give their own opinion or advice rather than representing the view of the carer
- there are several people involved in the care of the individual. For example, two parents looking after an adult child with a disability. The advocate is asked if they can advocate for both parents.
- an advocate feels drawn into a mediation role between the carer and service user
- there is an expectation on the advocate, either from the carer/service user or other professionals, to take on responsibilities outwith the advocacy role
- an advocate discovers they have a personal connection to their advocacy partner
- the advocate is involved in providing a different service to the carer in addition to their advocacy role
- there is an expectation on the advocate, from parties outwith the advocacy relationship, to withhold information from the carer

**The advocate should ensure that the carer's rights are upheld and their actions only directed by the carer's needs, interests, views and wishes. In order to do this successfully and avoid any conflicts of interest it is necessary for both the organisation and the advocate to have clear guidelines for best practice.**

**The organisation:**

- should have clear guidance and procedures on how they declare a conflict of interest, including to their funders and commissioners and how this will be managed. The purpose of having such a policy is to highlight and illustrate the potential conflict situations, some of which are not obvious. The policy should also set out which conflicts can be managed (and how they can be managed) and those which the organisation considers unmanageable (and therefore cannot allow).
- and/or the advocate should identify and document any potential conflict of interests, noting how these are managed
- must in extreme cases restrict an advocate from pursuing an activity which creates a fundamental and unmanageable conflict of interest
- must provide an advocate with appropriate training for their role, including understanding of the policies and procedures in place which set out what advocates should do when presented with situations which may pose a conflict of interest for them
- must ensure the provision of advocacy to carers is kept separate from advocacy for the service user. This may be done by using a dedicated carers advocate, either based within an existing advocacy project or employed by a carer support organisation.

**The advocate:**

- must be free from conflicts of interest or perceived conflicts of interest that could adversely influence their judgment, objectivity or loyalty to the organisation or their advocacy partners
- may take part in legitimate financial, business, charitable and other activities outside their advocacy role, but any potential conflict of interest raised by those activities must be disclosed promptly to their manager. Examples of such activities could be that the advocate fulfils an advisory role elsewhere. This should be subject to on-going review.
- should be aware of any relationships that might conflict or appear to conflict with their advocacy role, responsibilities, or the interests of the organisation. Examples of this may be that the advocate has a relationship with another professional who they may come across in their advocacy role. An advocate may have a relationship with another organisation which must be declared in



case they are seen to recommend it or face a conflict of interest if their advocacy partner wishes to complain about that organisation.

- should be aware that even the appearance of a conflict of interest can cause concern and can damage the employee and the organisation's reputation if they are not already aware of it and/or have procedures in place to manage it.
- must not enter into any agreements which unduly direct, influence or restrict their advocacy role. This includes agreements, informal or otherwise, with other professionals who may be involved in their advocacy partner's situation.
- should be clear during discussions with third parties that they are obliged to pass on to the carer any information which is disclosed. An advocate is unable to withhold information from the person they are supporting. This is because making a judgment about what information should be passed on could be considered to be giving an opinion. Equally, withholding information might be seen to be not supporting the carer.
- in circumstances where there is more than one carer involved in caring for an individual, the advocate must agree who they are advocating for. Where more than one carer in these circumstances requires an advocate, a second advocate will need to be identified.

### **Cases where a carer support organisation offering advocacy also offers other support/advice services**

*"In order to be able to ensure the individual's views are heard and understood and that they receive support to ensure their rights are not infringed, advocates have to be structurally and psychologically independent of the service system<sup>6</sup>."*

In some cases carer advocacy services are provided by organisations which deliver a range of services and support to carers, in addition to the advocacy service.

In these circumstances it is essential that organisations develop measures to minimise the potential for conflict of interest that can arise as a result of being both service providers and delivering an advocacy service.

The Carer Advocacy Service should endeavour to maintain its independence of action with separate governance and service management arrangements, the development of specific workplans and targets, and dedicated funding to support the development of advocacy support.

In addition, the service should aim to promote best practice and address any potential conflict of interest through:

- the development of advocacy-specific policies and procedures to support the

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<sup>6</sup> Scottish Government Guide for Commissioners, November 2013

independent work of the service

- asking advocates to declare any potential areas of conflict, both before they take on the role and throughout their employment or volunteering role
- keeping roles separate and ensuring advocacy workers do not provide other support services
- providing training, support and supervision to make advocates aware of the need to keep a separation with other services provided by the organisation and ensure they are able to recognise and minimise conflicts.
- ensuring agreements around funding and service provision protect the ability of the service to challenge the activities of the funder
- ensuring that when carers are referred to other services and supports, that the carer is supported to explore all available options. This may include referring to other services within the organisation and externally where appropriate.

### **Case study**

Elaine is an advocacy worker employed by a carers support service that offers several types of support for carers, as well as advocacy. The advocacy service has just recently started, and Elaine is the first and only advocacy worker.

As a lone advocacy worker, Elaine has been feeling a bit isolated, and her manager feels that it would be beneficial for her to attend the team meetings so that she can get the support of her colleagues. At the first team meeting that Elaine attends, it is agreed that boundaries are necessary in order that Elaine is not put in a position which may be a conflict of interest. This could happen if she unwittingly hears discussion regarding one of her advocacy partners, which she would then be obliged to pass on to them.

For example, at the team meeting one of Elaine's colleague's, Susan, a carers support worker, mentions that she has received information regarding one of the carers she supports. Susan has been told by a social worker that they have concerns the carer is not physically coping with providing the level of care her husband needs. The social worker has said they intend to look into what options are available to support the carer and broach the subject with sensitivity. However, Susan did not want this mentioned to the carer at the moment as it would cause undue stress and anxiety. Elaine recognised the carer as one of her advocacy partners and is now privy to information about her advocacy partner, which as an advocacy worker she has to pass on to her.

To avoid this type of difficulty, all the staff agree that the meeting will be split into two parts, one where Elaine can freely participate and receive information and where general carers' issues can be shared. Elaine will then leave before the second part of the meeting where case-specific issues may be discussed. However all staff agree

that caution is still needed to ensure even general issues are not attributable, including during informal discussions in a shared office. In addition to the one-to-one support and supervision meetings held between Elaine and her manager, it is agreed that Elaine will research other forums where she can meet with advocacy workers to share advocacy specific issues.

### **Cases where both the carer and service user have a separate advocate:**

In these cases:

- it is particularly important to be aware of and manage the potential for conflict of interest when both the carer and service user have their own advocacy worker. It is possible that these advocates may be from separate carer/service user led organisations, or from the same organisation and based in the same advocacy office.
- where it is the case that there is more than one advocate involved in a situation it is important to not disclose details of individual cases or share information, including electronic information, between advocates
- the importance of the separation of these advocacy roles should be explained to both the carer and service user, and boundaries maintained, irrespective of whether the views being expressed on behalf of the two advocacy partners appear to be similar or not
- such cases highlight the importance of supervision, effective management and the need for clear policies and procedures to be in place

## **Boundaries and expectations**

The boundaries and expectations of the carer advocacy relationship should be clear from the outset.

### **General boundaries and expectations**

Common to all forms of advocacy, the advocate should:

- discuss the carer's objectives with them in getting their voices heard
- be aware of the unique role of carers and the complexities of the caring role
- make it clear to the carer if the advocacy relationship will be on-going or will be related to a specific issue(s). Typically citizen advocacy may be on-going, whereas one-to-one advocacy is generally time limited
- share all information disclosed by a third party with the carer and the advocate must explain this to any third party that discloses relevant information to the advocate

- safeguard the rights of the carer(s) and inform others of their rights if need be
- where required, signpost carers to other appropriate sources of support

### **Confidentiality**

- The boundaries of confidentiality within the advocacy relationship should be explained to the advocacy partner at the outset.
- The advocacy partner's case notes and files should be locked away and electronic information held securely. The holding of all data must comply with current data protection legislation. The advocacy partner has the right to access their own case notes.
- At an organisational level, the advocacy partner's information should be kept confidential between the carers' advocacy worker and their line manager. It is important that information about their case is not made available to other members of the team. For an advocacy organisation, disclosure of information about a carer could lead to a conflict of interest if the cared for person also has an advocate from the same organisation. For a carers' centre if a carer receiving advocacy also receives other support where there personal information is shared between staff, e.g. at a team meeting, this could lead to a conflict of interest.
- When a carer discloses, or the advocacy worker becomes aware, that there is a risk of harm to themselves or others, the advocate will be required either by law or by their own organisational policies to act on such information

### **One to one or individual advocacy**

(A full description of the different types of advocacy can be found in Appendix 2.)

The advocate should:

- ensure that carers have an understanding of what advocacy is and that this is what they require
- have sufficient knowledge of local support and services for carers e.g. welfare rights, condition specific support organisations, local carer services, to refer or signpost carers on to
- at the outset and throughout the advocacy relationship the advocate and carer will identify and record the advocacy issues, desired outcomes and planned course of action
- ensure the carer understands the process and options and can help them think through the likely consequences of their preferred course of action, without giving them advice

## **Collective advocacy**

Collective advocacy development workers should:

- explain to the group what advocacy is and how it can help them
- be clear on the objectives of the collective advocacy group and ensure group members are clear on their respective roles
- ensure that the work of the group is directed and prioritised by its members and at the pace set by the group
- ensure that their personal opinions, choices and values do not influence the decisions of the group
- act within the law and the rules of the organisation
- ensure all group members have the opportunity to have their say
- support the group to regularly review the way it works and if this could be changed or improved

## **Self-advocacy**

Advocacy workers helping carers self-advocate should:

- help the carer(s) equip themselves with the tools and techniques to feel confident enough to get their voice(s) heard. This would include giving them options on ways of communicating, negotiating, and approaching stressful situations.
- explain good practice in self-advocacy, such as recording information and accessing the right person to speak to
- offer to be a 'mentor' for them – but being careful not to advise on their personal situation – as they begin to self-advocate with systems or if they experience difficulties
- for carers who have successfully self-advocated, provide them with the opportunity to pass on their experiences and good practice to carers who are just about to start making their own voices heard

Carers Scotland have produced 'Being Heard' a self-advocacy guide for carers which provides information and suggests techniques to help carers advocate for themselves

## **Case studies**

Advocacy worker Marion visits Catherine, who cares for her daughter who has physical disabilities, for an initial assessment. Catherine discloses information about her own experiences of being abused while growing up in a social care setting, and how this influences her relationship with professionals involved with her daughter. The next time Marion visits, Catherine attempts to discuss the abuse again, going into more detail, and Marion reiterates the boundaries of the advocacy role. It becomes clear that what Catherine is actually looking for is an outlet to discuss her own past experiences. Marion is able to offer Catherine help to make contact with a local counselling organisation which could help her with her feelings, leaving the advocacy worker freer to help Catherine to get her voice heard in meetings about her caring role.

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Sarah is the advocacy worker for David who cares for his wife. David has asked for advocacy to help him express his views to the local housing office that the couple would like to move to a property in another area of the city, as he says they are not listening to his needs but expects they will listen to someone with some 'clout' like Sarah. Once Sarah contacts the housing office it becomes clear that David's views have been heard and taken account of, but there are no properties currently available in his desired area. As the couple's move is not for medical reasons they are not a priority for rehousing. Sarah explains to David that advocacy workers do not have any 'clout' to change procedures or qualifying criteria that are in place.

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Carly is the advocacy worker for Jack, a frail gentleman who cares for his mother. Each time Carly contacts Jack he asks her to pick up some shopping for him, and when she leaves his house he will ask her to drop him off somewhere or post mail. Carly needs to be clear with Jack each time she speaks to him about the extent of her advocacy role and maintain her boundaries. Carly offers to help Jack find out about local services which may be able to help him with his shopping or transport issues.

## **Accessibility in advocacy**

*Principle 4: Independent advocacy is accessible*

Advocacy reaches out to the widest possible range of people, regardless of ability or life circumstances.

There are many issues and situations that may present barriers to accessing advocacy. These may be as simple as not being aware of advocacy, of what

support can be provided by it and where to go for advocacy locally. However there may be more complex barriers to access for some. Accessibility can be limited by geography, communication, language barriers, cultural issues or perception.

Carers may themselves be users of services, because of their own health or social care needs and may already have access to advocacy in relation to these needs. In addition, their caring role may have an impact on many areas of their life and they may benefit from being able to access a specific carer advocacy service.

However, for those carers who have not had any previous contact with services, advocacy may not be something they consider would be for them. Professionals, while accustomed to referring people accessing services to advocacy, may not consider also referring a carer. Organisations providing advocacy need to think about how they can spread awareness and understanding of the role of advocacy for carers.

To ensure that advocacy is as accessible as possible organisations should make referral processes as straightforward as possible. Organisations should have multiple referral routes and should accept self-referrals. Awareness of advocacy and how it can help is often spread amongst service users by word of mouth; this is also likely to be the case for carers.

Organisations may have differing eligibility criteria which reflect the Contract or Service Level Agreement agreed with the funder. For example, they may be funded to provide advocacy only in a specific area or to carers caring for someone with a specific disability e.g. mental health. It is important that these eligibility criteria are made clear to referrers and to potential service users. If the organisation operates a waiting list with a system of prioritising referrals then prioritisation criteria must be clear and transparent. An organisational policy should be made available detailing referral routes and eligibility and prioritisation criteria.

Demand for advocacy can exceed the resources available. In such a situation the clarity around referral and prioritisation criteria along with robust recording methods of referrals and delivery can provide evidence on gaps in advocacy which can be collated to inform planning and negotiation with commissioners.

### **Minority groups and advocacy**

Carers from minority groups, which may include for example people with disabilities, people from Black and Minority Ethnic (BME) communities and people from Gypsy/Traveller communities, will have many of the same requirements as carers within the majority community when it comes to providing advocacy but there will also be additional issues to consider.

Work undertaken on behalf of the Kings Fund (2002)<sup>7</sup> suggests that advocacy providers should have a statement of equal opportunities or a statement of the organisation's commitment to challenging discrimination and providing a culturally competent service.

Advocacy can play a crucial role in overcoming or minimising disadvantage and potential will need to be reassured that both the advocate and the service has an understanding of the specific needs of carers where such additional issues arise .

For many BME carers, language and the ability to communicate effectively, continue to present many challenges. It is in this context that bi-lingual advocacy has developed. Bi-lingual advocacy fuses two sets of skills or functions, that of the interpreter and of the advocate to provide a broader understanding of the carer's cultural, religious and social norms. It is important to recognise however that this approach may not be suitable for everyone and some carers may prefer to keep the two roles separate recognising that:

- advocacy sees things from the carer's perspective and ensures their rights are not infringed
- the role of the interpreter is recognisably different from that of an advocate, as an interpreter is paid to be impartial and communicate a message between professionals and carers
- carers with disabilities may have specific support needs outwith their caring role and may require advocacy for issues arising from those needs

### **Case studies**

Jim is 73. He is visually impaired and has mobility problems. He is also the main carer for his wife, Anne who has multiple sclerosis. The couple had paid care workers coming in every day to their home but when Jim had to go in to hospital for an operation Anne had to go into a residential care home.

When Jim was due to be discharged from the hospital after his operation he was told that it had been decided that he could not look after Anne any longer and that she would be remaining in the care home.

Jim contacted his local advocacy organisation. He told the advocate that he would be happy to move out of his home but that he did not want to live apart from Anne. The advocate supported Jim in meetings with Anne's social worker making sure that Jim's views and wishes were heard. The advocate also helped Jim to look into supported accommodation options. Jim found a place that was suitable where he and Anne preferred to live.

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<sup>7</sup> [Advocacy Standards Framework for Black and Minority Ethnic Communities SILKAP Consultants and OPM 2002](#)



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Saima lives with and cares for her elderly mother. Recently her mother's health has deteriorated and she has needed much more help day to day. Saima was working and struggled to manage caring for her mother as well as keeping up with her job. She asked the local social work department for support but they were unable to provide care workers who could speak Punjabi, her mother's first language, or prepare the food she eats.

The family felt stuck and didn't know what else they could do, until someone suggested contacting a local carer's organisation. An advocacy worker met with Saima to find out about her situation. After talking through her available options, Saima decided the best option for her would be to employ her sister as her mother's Personal Assistant, meaning she could keep working, knowing her mother was being well looked after while she was at work.

The worker supported Saima in arranging this with the local authority, and in making contact with another organisation who could assist with contracts and payroll. This arrangement is as easy as possible for Saima to manage, and her mother gets the support she needs.

## **Professional practice**

*Principle 2: Independent Advocacy is accountable*

### **Training and professional development**

There are no specific professional qualifications for advocacy workers. Instead both advocacy workers and the organisations they work for have a joint responsibility to ensure they are adequately trained and adhere to principles of best practice.

There are various training tools available, such as those provided by SIAA and information courses on carer advocacy, such as those provided by Carers Scotland. As well as being an essential part of any induction process, training is an important element of the continuous professional development of all advocates.

In addition to this, advocacy workers have a responsibility to keep their knowledge and practice up to date, particularly in relation to the following areas:

- current policy and legislation, such as health and social care policy and equalities legislation
- an understanding of local support services. Advocacy workers should also aim to develop good working relationships and referral protocols with local agencies and other professionals working with carers.

## **Support and supervision**

Organisations have a responsibility to provide workers with regular support and supervision and should have a policy to support this. In relation to advocacy workers, this is particularly important in helping workers to talk through and resolve any conflicts of interest, or situations where they wish to talk through the clients chosen course of action. This should also be used as a time to explore any difficulties advocates are experiencing.

## **Policies**

Organisations have a responsibility to ensure they have robust policies in place, both in relation to normal working practice and also policies specifically related to providing an advocacy service. For organisations providing advocacy, these may include but are not limited to:

- avoiding conflict of interest
- the storage of confidential information
- maintaining boundaries in the advocacy relationship
- comprehensive referral policy, including information on access policy, waiting lists and prioritisation protocols
- record keeping
- equality of access
- lone working

## **Additional reference tools**

In addition to this Guidance, other useful reference tools are available and can be of great assistance in developing an advocacy service for carers. These include:

- [Scottish Government Independent Advocacy Guide for Commissioners \(Nov 2013\)](#)
- [SIAA Principles & Standards for Independent Advocacy](#)
- [SIAA Code of Practice for Independent Advocacy](#)
- [SIAA Independent Advocacy: An Evaluation Framework](#)
- [SIAA Non-Instructed Advocacy Guidelines](#)
- [SIAA A Voice through Choice, stories of independent advocacy](#)
- [Carers Self Advocacy toolkit for professionals](#)

- [Equal Partners in Care \(EPiC\)](#)

## **Advocacy and duty of care**

Unlike other professionals and service providers, advocates do not make judgements on what is the 'best interest' for their advocacy partner. This means therefore that they cannot work from a 'duty of care'. Their role is to express the views their advocacy partner wishes them to, whether they are considered to have unacceptable risks or not be beneficial for them. An advocate's obligation to not withhold from the carer any information, pertaining to the carer, that they are privy to is a further extension of this, since to do so may be to make a judgement on what information is in their best interests to know about.

This also extends to the information and options which an advocate presents to their advocacy partner. The advocate can discuss the likely consequences of different options so that the advocacy partner may make an informed decision, but will ultimately not exclude choices which may be considered 'unwise' for them.

The absence of duty of care does not mean that advocates put people at risk because a request made on behalf of the advocacy partner can be turned down. What it does mean is that the person has had the opportunity to ask for or say what they want, and to receive a response that they can understand.

*NB\* It should be noted that this is different to the advocate's professional and legal obligation to report any child or adult protection concerns they may have to the relevant authorities which should be explained to advocacy partners at the outset.*

## **Case study**

Margaret is a carer for her husband Brian who is in the advanced stages of dementia. As his illness has progressed Brian has become increasingly aggressive toward his wife, which has escalated to physical violence in recent months. After a serious incident, Margaret moved out of the couple's home temporarily, however now feels ready to return. Other professionals and family members concerned for Margaret's safety feel this course of action is not in her best interests and try to discourage her from doing so. Margaret's advocacy worker has talked through the various alternatives available to her without being required by a 'duty of care' to advise her against this course of action. Having explored other options Margaret is adamant that she still wishes to continue living within the home and wants her advocacy worker to help her express that wish. As Margaret's advocacy worker does not need to work from a position of 'duty of care', they are able to express on her behalf that she wishes to return to the marital home, irrespective of any potential risks. The advocacy worker also provides Margaret with information about a local dementia specific carer support group.

## Evaluation and outcomes

It is important to build in processes for evaluation of the advocacy provided, measuring the delivery against recognised standards. To support evaluation, organisations and projects delivering advocacy should consider both internal and external evaluation.

The Scottish Government's Guide for Commissioners and the SIAA Principles and Standards recommends that an external evaluation should be commissioned every three years. When organisations are seeking funding to provide advocacy for carers an element for external evaluation should be built in. Consistency in approach and standards against which the advocacy is measured will help towards ensuring consistently high quality in the advocacy provided across Scotland.

The SIAA Evaluation Framework provides tools to allow the measurement of advocacy practice against the advocacy Principles. This can be used for both independent and non-independent provision. It should be noted, however, that some of the Standards within the Guide for Commissioners reflect Commissioners' statutory responsibility and differ from the SIAA Principles and Standards. Completion of the self-assessment tool should reflect and be measured against the relevant Standards applied in the commissioning of the service. Completion of the assessment annually can allow organisations to measure quality of provision and progress against previous years.

When considering measurement of outcomes it must be remembered that desired outcomes identified at the start of the advocacy process by the carer may not be achieved. This may be for a number of reasons; however this does not necessarily mean that advocacy outcomes have not been achieved.

Advocacy outcomes are likely to include:

- being supported to make informed choices
- having views and wishes heard and considered.
- being involved in planning and decision making
- feeling more able to speak up
- having one's rights observed

To measure outcomes organisations should gather feedback from carers at the completion of the advocacy relationship. The feedback request should be designed to gather information on the carer's views on the advocacy outcomes. Such consultation will build evidence supporting proposals for on-going or increased provision of advocacy for carers.

## **APPENDIX 1**

### **Carers advocacy guidance glossary**

Accessibility	The extent to which a service can be obtained by an individual in terms of local proximity, cultural competence and eligibility.
Advocacy Partner	The person who uses advocacy. Some advocacy organisations use the term 'client' or 'service user'.
Advocate	An advocate helps people express their views and make informed decisions. An advocate helps people to find out information, explore options and decide for themselves what they want. Advocates can be a voice for the person and encourage them to speak out for themselves. There are different kinds of advocacy, though they all share things in common. Advocates will never tell people what to do, or allow their own opinions to affect the support they provide. All advocacy tries to increase confidence and assertiveness so that people can start speaking out for themselves. Advocates are as free from conflicts of interest as possible.
Befriending	Where a person is paired up with a trained worker or volunteer to offer company or social interaction and the development of life-skills.
Boundaries	The concept in advocacy that provides clarity on the role and activities of an advocate, to ensure that objectives are clear and the advocate's loyalty is wholly with the person they are advocating for.
Care and support work	Practical support to someone to live independently, including personal care, independent living skills, household support and social support.
Carer	A carer is someone of any age who supports a family member, friend or neighbour who is ill, frail or disabled.
Carer's Assessment	A carer's assessment is a plan prepared by a responsible local authority setting out an adult carer's identified outcomes and needs and the support to be provided to the carer to meet those needs, where applicable. Some areas have different names for a carer's assessment, such as a carer's journey or carer support plan. The Carers (Scotland) Act 2016 which was passed by Parliament on February 4 2016 will extend the availability of carer's assessments and change the name to an adult carer support plan. Commencement of the Act's provisions will

begin 2017-18.

Carers Rights	Rights that carers have in law for example the right to ask to be assessed as a regular and substantial carer, to ask for flexible working. For more information, contact Carers Scotland <a href="http://www.carersuk.org/scotland">http://www.carersuk.org/scotland</a>
Commissioning	A term used to describe when a local authority or health board 'buy' a service to be provided in the local area. There is specific guidance for commissioning advocacy services
Condition-specific organisation	An organisation, usually a charity or trust or varying sizes set up to support individuals who have a particular health condition. Alzheimer Scotland, Parkinson's Scotland, MS Scotland are all examples.
Confidentiality	The principle where discussions between two or more people are not disclosed to anyone else, in order that trust in the relationship is maintained. There may be exceptions where the advocate becomes aware that harm may come to the advocacy partner or someone else.
Conflict of interest	This is anything that could get in the way of an advocate being able to fully represent the person they are advocating for. For example, it would not be appropriate for an advocate volunteering for a mental health organisation to also work in the local psychiatric hospital because this would affect their ability to be on the side of the person. It would also affect their relationships with hospital staff. Other conflicts of interest could include relationships as well as financial investments.
Contract	Legally binding agreement between two organisations that specifies a service one has pledged to provide to another.
Consultation	Where individuals or service users are asked for their views on the development of policy or legislation that affects them. Consultation period usually is time-limited
COSLA	(Convention of Scottish Local Authorities) is a collective voice of local authorities in Scotland and negotiates with the Scottish Government on behalf of its members. <a href="http://www.cosla.gov.uk/">http://www.cosla.gov.uk/</a>
Counselling	Process where by an individual, couples or families can discuss problems and difficult emotions in a confidential and trusting environment with a trained counsellor, who will help them understand their feelings and move

forwards.

Cultural competence	The extent to which a service meets the cultural needs of those from minority ethnic groups and specific communities. These can include needs around language and religious observance and cultural traditions.
Duty of care	The principle in social care that says that a social worker, or any other local authority representative, always has to act in the best interest of the person they are supporting, i.e. in a way that keeps them safe.
Eligibility criteria	<p>Rules that are applied to decide who can access a service and who cannot. For advocacy, these can be on factors such as the 'type' of disability of the cared-for person and where the person lives.</p> <p>This definition is distinct from eligibility criteria used by health and social services to determine the allocation of services to a service user.</p>
Equal partners	The Carers Strategy 2010 – 2015 recognises that carers are “equal partners in care” (Para 2.11) alongside professionals. This is in the sense that their expertise is as valid as other professionals who are involved in the care of someone.
Equality of access	The extent to which a service is accessible in practical ways to all the users who may be eligible to use a service, regardless of age, gender, ethnic group, location and other factors.
Financial Guardian	A Guardian appointed by the court with property and/or financial powers to act or make decisions on behalf of another adult.
Independent Advocacy Guide for Commissioners	A document produced by the Scottish Government which sets out how local authorities and health boards purchase advocacy services that are good quality and fit for purpose.
Kings Fund	<p>An charity that seeks to improve health and healthcare in England that carries out research and analysis on health issues</p> <p><a href="http://www.kingsfund.org.uk/">http://www.kingsfund.org.uk/</a></p>
Local Authority	A local organisation funded by national and local taxation to provide services to its residents, including social care, education and housing services.

Local Strategic Advocacy Plan	A local authority plan of the advocacy services that are to be made available and to whom in their area.
Mediation	Where two parties that are in disagreement with each other come together voluntarily with a mediator – who is independent of either party - to try and resolve the problem in practical ways.
Mentor	When a person with certain knowledge and experiences offers support to someone else who is going through a comparable experience.
Natural Justice	This comes from the legal concept for a person to receive a fair hearing.
Negotiation	A Process whereby two parties, usually with different aims and viewpoints work out a given course of action. Negotiation usually involves compromise and ‘give and take’.
NHS Board/Health Board	An NHS organisation that is responsible for providing health services in a specific area, including GP services, hospital services and mental health services.
Power of Attorney	A legal power an individual has to delegate decisions on their welfare and or finance to someone else, when the individual is not able to make decisions for themselves.
Prioritisation criteria	The process by which an organisation decides the order in which they offer a service to a group of individuals on a waiting list. This is usually around need, how long the person has been on the waiting list and the availability of workers.
Professionals	Trained individuals who are paid to provide specific expertise and services to service users, e.g. doctors, nurses, social workers, OTs, psychiatrists, teachers. Commonly employed by large organisations.
Referral protocols	The internal process of an organisation used to assess whether an individual is suitable to access their service, or whether signposting on to another service is appropriate.



## **APPENDIX 2**

### **Different types of advocacy**

*Principle 1: Independent advocacy puts the people who use it first*

*Principle 4: Independent advocacy is accessible*

This document provides guidance for the delivery of advocacy for carers. There is no best model of advocacy for carers, no 'one size fits all'. The most appropriate model for any carer is likely to depend on the carer's preferences, circumstances and situation and this may vary from time to time. In practice advocacy models available for carers will depend on what provision there is in their area. General guidance for advocacy providers on the delivery of one-to-one and collective advocacy can be found in the SIAA Code of Practice for Independent Advocacy.

### **Independent Advocacy**

Independent advocacy is structurally, financially and psychologically separate from the agencies providing services for the carer. Such independence helps to ensure that there is no possibility of any conflict of interest arising in relation to any other services accessed by the individual carer.

### **Advocacy delivered by wider support organisations**

Advocacy is also sometimes provided to carers as part of wider support offered by condition-specific organisations that are supporting them or the person being cared for. This is not independent advocacy as it is part of more general support. However it is nevertheless valued by carers where they are comfortable with the staff and where this may be the only advocacy accessible to them.

### **Advocacy provided through carers centres**

Some, though not all carers centres have a dedicated advocacy project where carers can be referred if they need support in resolving issues with services. While this is not independent advocacy, efforts are made to keep the advocacy separate from wider services provided by the centre. Some centres that do not have an advocacy project may still offer support to a carer in voicing their concerns about a particular issue.

### **One to one or individual advocacy**

This includes professional or issue based advocacy. It can be provided by both paid and unpaid advocates. An advocate supports an individual to represent their own interests or represents the views of an individual if the person is unable to do this themselves. They provide support on specific issues and provide information but not advice. This support can be short or long term.

Another model of one to one advocacy is citizen advocacy. Citizen advocacy happens when ordinary citizens are encouraged to become involved with a person who might need support in their communities. The citizen advocate is not paid and not motivated by personal gain. The relationship between the citizen advocate and their advocacy partner is on a one-to-one, long term basis. It is based on trust between the advocacy partner and the advocate and is supported but not influenced by the advocacy organisation. The advocate supports the person receiving advocacy using their natural skills and talents rather than being trained in the role.

Peer advocacy is also individual advocacy. Peer advocates share significant life experiences with the advocacy partner. The peer advocate and their advocacy partner may share age, gender, ethnicity, diagnosis or issues. Peer advocates use their own experiences to understand and have empathy with their advocacy partner. Peer advocacy works to increase self-awareness, confidence and assertiveness so that the individual can speak out for themselves, lessening the imbalance of power between the advocate and their advocacy partner.

### **Group or collective advocacy**

Collective advocacy enables a peer group of people, as well as a wider community with shared interests, to represent their views, preferences and experiences. A collective voice can be stronger than that of individuals when campaigning and can help policy makers, strategic planners and service providers know what is working well, where gaps are and how best to target resources. Being part of a collective advocacy group can help to reduce an individual's sense of isolation when raising a difficult issue. Groups can benefit from the support of resources and skilled help from an advocacy organisation.

### **Self-advocacy**

The aim of all models of advocacy is to help individuals gain increased confidence and assertiveness so that, where possible, they will feel able to self-advocate when the need arises. It is important to remember that, while carers may feel able to self-advocate in certain situations, in others they may wish to be supported by an advocate.

Carers self-advocacy is about the carer speaking up for themselves, making choices and being independent. Where any advocacy is provided, moving towards carer empowerment is seen as a key goal.

Self-advocacy can be done via one-to-one work with an advocate, who enables the carer to learn techniques around assertiveness, effective communication and negotiation or via written materials or group training sessions. Self-advocacy learning can also include an exploration of self-awareness and how to optimise coping strategies in difficult situations. A carer with self-advocacy skills will be able

to understand or challenge, if necessary, the language of professionals and be able to be more prepared for interactions with services.

Self help resources can be a useful tool to enable carers to have their own voices heard carers to get their own voices heard.

5 Resources to help carers self-advocate are being developed as part of the Scottish Government's carer policies. The resources will help carers get their own voices heard with systems and services and also provide tools for personal coping strategies and self confidence'. Contact Carers Scotland for more details at <http://www.carersuk.org/scotland/training-resources/self-advocacy>



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