



The Scottish Independent Advocacy Alliance

Non-Instructed Advocacy Guidelines

A companion to the Code of Practice for Independent Advocacy



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'Life's most urgent question is: what are you doing for others?'

Martin Luther King Jr.

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Contents

Acknowledgments	1
Introduction	4
How to use these Guidelines	8
Advocacy Examples	9



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

Standard 1.1	12
<i>Independent advocacy is directed by the needs, interests, views and wishes of the people who use it</i>	
Standard 1.2	13
<i>Independent advocacy helps people to have control over their lives and to be fully involved in decisions which affect them</i>	
Standard 1.3	14
<i>Independent advocacy tries to make sure that people's rights are protected</i>	
Standard 1.4	15
<i>Independent advocacy values the people who use it and always treats people with dignity and respect</i>	
Advocacy Examples	16



Principle 2: Independent advocacy is accountable

Standard 2.1	17
<i>Independent advocacy is accountable to the people who use it</i>	
Standard 2.2	18
<i>Independent advocacy is accountable under the law</i>	
Standard 2.3	19
<i>Independent advocacy is effectively managed</i>	
Advocacy Examples	20

●	Principle 3: Independent advocacy is as free as it can be from conflicts of interest	
	Standard 3.1	21
	<i>Independent advocacy cannot be controlled by a service provider</i>	
	Standard 3.2	22
	<i>Independent advocacy and promoting independent advocacy are the only things that independent advocacy organisations do</i>	
	Standard 3.3	23
	<i>Independent advocacy looks out for and minimises conflicts of interest</i>	
	Advocacy Examples	24
●	Principle 4: Independent advocacy is accessible	
	Standard 4.1	25
	<i>Independent advocacy reaches out to the widest possible range of people, regardless of ability or life circumstances</i>	
	Advocacy Examples	26
	Appendices	
	1. Advocacy is, advocacy is not	27
	2. Glossary	29

Non-Instructed Advocacy Guidelines

This document was developed following the decision made by the *Principles and Standards for Independent Advocacy* and the *Code of Practice for Independent Advocacy* 'Good Practice Working Group' that these documents should not include extensive detail on non-instructed advocacy. It was felt that, as it is a complex area, it would be better to have a separate document to look at the advocate's role in greater depth.

These guidelines work alongside the *Principles and Standards* and *Code of Practice for Independent Advocacy*. They have been written to apply to all types of advocacy. Throughout Scotland advocacy organisations share the same core Principles although they might do things in a slightly different way.

The document lays out guidelines for advocates when advocating for an individual who may lack capacity, for example, someone in advanced stages of dementia or someone with severe learning difficulties, or for someone who has severe communication difficulties. This is known as non-instructed advocacy. The responsibilities for organisations in the case of non-instructed advocacy are the same as for instructed advocacy and can be found in the *Code of Practice for Independent Advocacy*.

The *Principles and Standards for Independent Advocacy* apply to non-instructed advocacy in the same way as they do to instructed advocacy. Advocacy is about safeguarding people who are vulnerable and disadvantaged. People who have difficulty communicating their views and wishes and who cannot give instructions are extremely vulnerable and may be even more disadvantaged than others. Non-instructed advocacy can happen when a person has complex communication needs or has a long term illness or disability that prevents them from forming or clearly stating their wishes and desires.

The Mental Health (Care & Treatment) (Scotland) Act 2003 Code of Practice states:

"Where a patient has a degree of incapacity, or cannot for any reason clearly say whether or not they would like an independent advocate, an MHO/hospital managers/appropriate person should consider how an independent advocate may be involved... The right of access to independent advocacy is for each patient and is not limited only to those who are best able to articulate their needs."

“Non-instructed advocacy is... taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person’s rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives.”
(Henderson, 2006)

The spirit and principles of the Adults with Incapacity (Scotland) Act 2000 can be considered in informing the non-instructed advocate. The five general principles on which the Act is based are that:

- An intervention must benefit the individual
- An intervention must be the least restrictive option
- Account must be taken of the past and present wishes of an individual
- There must be consultation with significant others in an individual’s life
- An individual should be encouraged to exercise their own will and self-determination

In instructed advocacy an advocate agrees an agenda with the advocacy partner and represents the partner’s views and wishes or supports the partner to do so. In non-instructed advocacy the advocate will observe the partner and their situation, look for alternative means of communication with the partner, gather information from significant others in the partner’s life, if appropriate, and ensure the partner’s rights are upheld. The advocate should be aware of relevant legislation and ensure that service providers follow such legislation. Advocates will not give professional opinions in the same way as Mental Health Officers, CPNs, Consultant Psychiatrists and other health and social care professionals.

Non-instructed advocacy is about:

- Where possible, spending time getting to know the advocacy partner, observing how the partner interacts with others and their environment and building a picture of the partner’s life, likes and dislikes.
- Trying different methods of communicating with the partner.
- Gathering information from the advocacy partner through a variety of measures. This may include identifying ‘past wishes’ or any Advanced Statement made.

- Speaking to the significant others in the partner's life.
- Ensuring that the partner's rights are respected.
- Ensuring that account is taken of the partner's likes and dislikes when decisions are being made and that the partner is enabled to make choices as far as is possible.
- Ensuring that all options are considered and no particular agenda is followed.

For individuals with severe communication difficulties a non-instructed advocate will, where possible, spend time finding out if a person is able to express a view and how they communicate, getting to know the partner's preferred method of communication. If it is clear that a partner lacks capacity to understand options or form views a non-instructed advocate will have a safeguarding role, ensuring that the partner's rights are upheld.

In a situation where an advocate does not have the opportunity to spend much time getting to know the partner their role is to safeguard the basic human rights of the partner. The advocate acts as an observer ensuring that the person is receiving appropriate services and support. The advocate needs to consider how the partner would feel in the situation, taking account of as much past and present information as is available and keeping in mind the partner's human rights and Human Rights legislation. The advocate should also encourage service providers to appreciate how the partner might feel.

In general an advocate would expect to represent the partner's views to decision makers or to support the partner to express these views. Non-instructed advocacy considers the following question:

'How can we (advocates) best advocate for people who cannot tell us clearly what they want or need?'

To help provide an answer to this there are a number of questions which a non-instructed advocate should consider:

- What is life like for this person?
- What is important to them?
- What might their wishes, feelings and desires be?
- What are their rights?

- What do other people who know this person well think?
- What responsibilities do other people or organisations have towards this person?
- Is this person being treated fairly?
- How can we increase this person's involvement in decisions made about them and their life?

This is by no means an exhaustive list but by considering all of these questions, by observing the advocacy partner and by trying to find the partner's preferred means of communication an advocate will be prepared to speak up for the partner.

*Muriel Mowat
Research and Quality Officer, 2009*





"[Non-instructed advocacy is] where an advocate represents what he or she feels a person's wishes would be, if they were able to express them."

Mind

How to use these Guidelines

The first section gives examples of non-instructed advocacy in a range of situations. These examples are used to illustrate the application of the Principles and Standards of independent advocacy.

The following four sections are divided into the four main Principles of independent advocacy.

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

Principles are the core beliefs about independent advocacy. These are the ideas that guide everything that advocates and advocacy organisations do.

Standards outline what should happen in order to meet the Principles.

Indicators are the evidence of how advocates meet each standard.

Each Principle is divided into sections covering the related Standards. For all these Standards there are sets of indicators for advocates. These indicators are relating to non-instructed advocacy and build on the indicators from the *Code of Practice for Independent Advocacy* which should also be considered. Indicators for organisations can be found in the *Code of Practice for Independent Advocacy*.

Advocacy Examples

Example 1

Beth is a young woman with severe learning and communication difficulties. She shares a house with two other people, one of whom has only very recently moved into the house. All the residents have 24 hour support. During the week she attends a day centre, travelling there and back in a taxi with two members of support staff.

Adita has been Beth's advocate for some time and has spent time getting to know her. While visiting and spending time with her Adita has observed Beth's home situation and the interactions between her, staff and other residents. Over the time she has spent with Beth Adita has learned that, although Beth cannot tell people about what she is feeling, she shows her feelings in other ways. When she is relaxed and with people she likes and trusts she is calm and smiles a lot. When she is stressed or anxious she often cries and her behaviour can appear to be aggressive.

The support staff have reported to their manager that Beth has become aggressive towards staff and the other residents and she is now very difficult to manage in the taxi travelling to and from the day centre. A meeting is arranged to discuss this which Adita attends. At the meeting Adita tells staff that she observed the change to Beth's behaviour start after the new resident moved in to the house. She suggests that Beth may be unhappy about the new person who has moved in to the house or that she is worried about change. Adita believes that, in this situation, Beth feels disturbed and anxious about changes to who she shares her home with. The manager says that they have to consider all the residents and that Adita should think about how the new resident feels. Adita explains that, as Beth's advocate, Beth's feelings and wishes are her only concern in this situation.

The manager and support staff agree to look into this situation and consider what can be done to help Beth and her housemate be more comfortable with each other. They also agree to review the situation regularly to check if things have improved for Beth. A further meeting is arranged in two weeks.

Adita feels that the two other residents of the house should have their own advocates to speak up for them. She refers both residents to the advocacy project.

Example 2

John is an 87 year old man with severe dementia. His ability to understand what is said to him is limited and he is no longer able to communicate clearly. John's wife died 6 years ago. He has no children, and no surviving siblings.

When the care home in which John had lived for 6 years (he moved there when his wife died) closed three months ago, he moved to another care home. Staff at this home are concerned that John is not settling, but they are unsure why. They refer him to the advocacy service and Lucy begins working with him. Initially, Lucy finds it difficult to gauge John's feelings, but over time she gets to know him and finds ways of communicating with him. John frequently alludes to a fear of being alone, and twice refers to being scared at night. Lucy speaks with one of the night staff, who tells her that John is usually awake for some time after he goes to bed, and often looks quite anxious.

Lucy contacts the person who was manager of the home John lived in previously, to ask about John's sleeping pattern while he lived there. She learns that John was known as "a good sleeper" in this home. It also transpires that John shared a room for his entire 6 year stay, due to having requested this when he first moved there. This was not considered to be particularly significant when alternative accommodation was being sought for John, because he and the other resident spent their days apart and gradually stopped communicating at night due to their respective health problems.

Lucy considers what she has gleaned from John directly along with what she has learned from those involved in his care now and in the past. She knows that it was John's *past* wish to share a room, and thinks his current behaviour indicates that this is his *present* wish as well. She relays this to the staff, and asks if it would be possible for John to move to a shared room on a trial basis. The staff promise to do this as soon as there is a vacancy in a shared room. Lucy says she will continue working with John during the transition phase. She and the staff also agree to meet 6 weeks after John moves, to review the situation.

Example 3

Tom is in his 80's and since he had a stroke he has been unable to communicate verbally. He has recently been moved into a care home after having an accident at home. Tom was referred to the local advocacy organisation and Sarah, the advocate, visited him. Over the course of several visits Sarah noticed that Tom appeared to be very angry and upset most of the time, she explained who she is and what she does and gradually he seemed to relax in her presence.

To help her find out more about Tom and his situation Sarah contacted his son in Canada and discovered that Tom had always been adamant that he wanted never to go into a care home. During her visits to Tom she noticed that some of the care home staff didn't seem to engage with him or give him a choice about anything such as food or where he wanted to sit. When challenged on this they said it was because he couldn't communicate. Sarah believed that Tom felt that he no longer had any control over his life in even the smallest way and that this was making him angry and upset.

A case meeting was called and Sarah advocated for Tom, on the basis of what she had learned from spending time with him, observing him in the home and speaking to his son and the care home and social work staff. She suggested that, although Tom couldn't speak, he could indicate what he would like if offered choices of food, activity, where he would like to sit etc. The care home staff agreed that they would make sure that Tom be given the chance to make choices.

Sarah continued to visit Tom over the following weeks and noticed that he seemed to have become more relaxed.

Principle 1

Independent advocacy puts the people who use it first

✓ Standard 1.1

Independent advocacy is directed by the needs, interests, views and wishes of the people who use it

Advocates must:

- a** Where possible, spend time getting to know the advocacy partner, observing how the partner interacts with others and their environment and build a picture of the partner's life, likes and dislikes.
- b** Try different ways of communicating and speak to significant others in that person's life where the advocacy partner has severe communication difficulties or lacks capacity.
- c** Gather information from the advocacy partner through a variety of measures. This may include identifying values, 'past wishes' or any Advance Statement made.
- d** Not let their personal opinions, choices and values interfere with any identified choices their advocacy partner may have made. Advocates should be aware of their own prejudices.

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

✓ **Standard 1.2**

Independent advocacy helps people to have control over their lives and to be fully involved in decisions which affect them

Advocates must:

- a** Try to enable their partner to make choices as far as possible.
- b** Ensure that account is taken of their partner's likes and dislikes when decisions are being made.

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

✓ **Standard 1.3**

Independent advocacy tries to make sure that people's rights are protected

Advocates must:

- a** Participate in training on the different laws that apply to what they do.
- b** Keep up-to-date with changes to the law and policy, as appropriate.
- c** Know how to apply the law to what they do.
- d** Act within the law.
- e** Act in a professional manner at all times.
- f** Ensure that their partner's rights are respected.
- g** Ask the appropriate people to explain why an action is being taken.
- h** Know the relevance of the law and policy, what their advocacy partner's rights are and know how to access appropriate information.

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

✓ **Standard 1.4**

Independent advocacy values the people who use it and always treats people with dignity and respect

Advocates must:

- a** Always treat their advocacy partner with dignity and respect.
- b** Not be unduly influenced by views and wishes of significant others in their advocacy partner's life.
- c** Give their partner the opportunity to communicate their wishes in a number of ways.
- d** Always show their partner in a positive and respectful way.

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

Advocates' examples:

Example 1

1.1 – indicators **a** and **b**

1.2 – indicators **a** and **b**

1.3 – indicators **f** and **g**

1.4 – indicators **a**, **c** and **d**

Adita has got to know Beth, spending time with her and observing her and her situation. She has learned some of the different ways Beth communicates her feelings and wishes. By challenging decisions made on Beth's behalf and by explaining what she believes Beth is communicating Adita is trying to ensure that Beth has some control over her life and is involved in the decisions made about her. While attending Beth's meeting Adita asks questions and tries to make sure that Beth's rights are protected.

Example 2

1.1 – indicators **a**, **c** and **d**

1.2 – indicators **a** and **b**

1.3 – indicator **g**

1.4 – indicator **c**

Lucy has spent time with John which has allowed her to gather from him that he does not like being alone and is scared at night. She speaks to staff about how John reacts and to the manager of the home he had lived in previously. Having considered all this information gathered from a range of sources she suggests to the staff of the new home that John might prefer to share a room with another resident.

Example 3

1.1 – indicators **a**, **c** and **d**

1.2 – indicators **a** and **b**

1.3 – indicators **f** and **g**

1.4 – indicator **c**

Sarah visited Tom several times and spent time observing him and staff interacting with him. She contacted his son in Canada to find out more about Tom and discovered his past wishes about not going into a care home. She challenges the staff about Tom's lack of choice over food and other things in his life and makes sure that he will be supported to make choices in the future.

Independent advocacy is accountable

✓ **Standard 2.1**

Independent advocacy is accountable to the people who use it

Advocates must:

- a** Be accountable to their partner and the independent advocacy organisation.
- b** Ensure that they work according to any known past values and wishes and observations of their partner's responses to different situations.
- c** Consider the views of friends and family of their partner where appropriate.
- d** Ensure that they work according to relevant legislation.
- e** Safeguard the rights of their advocacy partner and inform others of their advocacy partner's rights.

Principle 2: Independent advocacy is accountable

✓ Standard 2.2

Independent advocacy is accountable under the law

Advocates must:

- a Be aware of and act within the law at all times.
- b Know what the organisation's policies and procedures are and act on them if they are aware of their advocacy partner being in danger of harm.
- c Ensure that they have regular, appropriate support and supervision when acting as a non-instructed advocate

Principle 2: Independent advocacy is accountable

✓ Standard 2.3

Independent advocacy is effectively managed

Advocates must:

- a** Act within the *Principles and Standards for Independent Advocacy* and *Code of Practice* and the policies and procedures of the organisation.
- b** Be aware of who the organisation is funded to provide advocacy for.
- c** Be clear on what their role and responsibilities are and the role and responsibilities of their manager or co-ordinator.

Principle 2: Independent advocacy is accountable

Advocates' examples:

Example 1

2.1 – indicators a, c and d

Adita does the best she can to ensure that she is voicing Beth's wishes and feelings as far as possible and understands that she is accountable to Beth. She makes sure she knows about legislation and any changes which might affect Beth and makes sure that staff take account of them.

Example 2

2.1 – indicators a, c and d

Lucy has considered John's past wishes in his request on entering the previous care home that he share a room. Having relayed her thoughts to the staff about what she believes is the reason for him not settling she says that she will continue to work with him during the transition phase. She agrees a review meeting with the staff to take place after 6 weeks.

Example 3

2.1 – indicators b, c and e

Sarah has discovered Tom's past wishes by contacting his son. She also challenges the care home staff about Tom being denied choice.

Principle 3

Independent advocacy is as free as it can be from conflicts of interest

✓ Standard 3.1

Independent advocacy cannot be controlled by a service provider

Advocates must:

- a** Be aware of the Service Level Agreement or Funding Contract of the organisation and the organisation's policies and procedures.
- b** Be clear about their role as an advocate and where their responsibilities lie, including the boundaries of relationships with people other than their advocacy partner.
- c** Understand that they must not take the side of the service provider or try to influence their partner's wishes on behalf of the service provider.

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

✓ **Standard 3.2**

Independent advocacy and promoting independent advocacy are the only things that independent advocacy organisations do

Advocates must:

- a Be clear about their role and responsibilities.
- b Follow the organisation's policies and procedures and the *Code of Practice for Independent Advocacy*.
- c Only act within the boundaries of their role descriptions and those of the organisation.
- d Refer back to their line manager or co-ordinator if unsure about what they are being asked to do.

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

✓ **Standard 3.3**

Independent advocacy looks out for and minimises conflicts of interest

Advocates must:

- a** Be aware of their relationships with other people who may be connected professionally or personally to their advocacy partner and be conscious of the possible consequences of entering into relationships that may compromise their advocacy role.
- b** Be aware of the boundaries set by the organisation and what will happen if these boundaries are not upheld.
- c** Declare any potential conflict of interest to the organisation and, if appropriate, inform their advocacy partner.

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

Advocates' example:

Example 1

3.1 – indicator **b**

3.2 – indicators **a** and **b**

Adita makes it clear to the support staff that she is only there for Beth and not for other residents. She knows that she could not advocate for the other residents as that would be a conflict of interest. She refers the other residents to the advocacy project to ensure that they have someone there to speak up for them.

Independent advocacy is accessible

✓ **Standard 4.1**

Independent advocacy reaches out to the widest possible range of people, regardless of ability or life circumstances

Advocates must:

- a** Support their advocacy partner whatever the person's abilities, skills and life experiences.
- b** Be aware of their own opinions, prejudices and discriminatory practices, and actively work to minimise these in their advocacy partnerships.
- c** Fulfil their role within all the policies and procedures of the organisation.
- d** Be clear that advocacy is free to the people that use it.
- e** Promote the organisation and independent advocacy in the course of their work.

Principle 4: Independent advocacy is accessible

Advocates' examples:

Example 1

4.1 – indicators **a and **e****

Adita spends time with Beth observing how she interacts with her environment and with others around her. In this way she has learned a lot about Beth's likes and dislikes which helps her when advocating for Beth. By referring the other residents of the house Adita is ensuring that advocacy is reaching out to people for whom accessing advocacy could be very difficult.

Example 2

4.1 – indicator **a**

Lucy learned a bit about John's feelings and anxieties by spending time with him, listening to his responses to questions and observing how he reacts to his environment. This knowledge, combined with the information gathered from staff and from the manager of the previous home, helped her to understand possible reasons for John's unhappiness.

Appendix 1 — Advocacy is, advocacy is not

Advocacy is...

- about standing alongside people who are in danger of being pushed to the margins of society.
- about standing up for and sticking with a person or group and taking their side.
- a process of working towards natural justice.
- 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.

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.

Appendix 2 — Glossary

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.

Independent advocates are as free from conflicts of interest, as possible.

Advocacy

The process of standing alongside another, speaking on behalf of another and encouraging the person to speak up for themselves. Advocacy can help address the imbalance of power in society and stand up to injustice.

Advocacy partner

The person who uses advocacy. Some advocacy organisations use the term 'client' or 'service user'.

Capacity

Ability to reason, make decisions and consider choices, express views and receive and understand information. The law assumes that people have capacity unless a doctor's assessment shows that a person lacks capacity.

Commissioner

Usually representatives from the Local Authority or Health Board who fund advocacy.

Community of interest

The group of people that the advocacy organisation has been set up to support, for example, people with learning difficulties or mental health issues.

Conflict of interest

Anything that could get in the way of an advocate being completely loyal to their advocacy partner. For example, it would not be appropriate for an advocate volunteering for a mental health advocacy organisation to also work in the local psychiatric hospital, because this would affect their ability to be on the side of the advocacy partner. It would also affect their relationships with hospital staff. Other conflicts of interest could include relationships as well as financial investments.

Dementia

Dementia is the loss (usually gradual) of mental abilities such as thinking, remembering, and reasoning. It is not a disease, but a group of symptoms that may accompany some diseases or conditions affecting the brain. There are many different types of dementia, each with their own causes. The most common dementia symptoms include loss of memory, confusion and changes in personality, mood and behaviour.

Discriminatory practices

Anything that an organisation or individual does that directly or indirectly shows prejudice or favouritism towards an individual or group of people.

Diversity

Differences, for example, in age, gender, sexuality, race, ethnicity, language, nationality or religion among various groups, at different levels such as within a community, organisation, or nation.

Equal opportunities

The prevention, elimination or regulation of discrimination between people on the grounds of, for example, gender, marital status, race, disability, age, sexual orientation, language, social origin or other personal attributes, including, but not limited to, religious beliefs or political opinions.

Financial guardian

A guardian appointed by the court with property and/or financial powers to act or make decisions on behalf of another adult.

Funding contract

The agreement, usually between Local Authority or Health Boards and the advocacy organisation, which outlines how much funding the organisation receives, which geographical areas will be covered, who the advocacy is for and how long the funding is for. (Also see Service Level Agreement).

Independent advocacy organisation

Advocacy organisation that is structurally, financially and psychologically separate from service providers and other services.

Structurally — an independent advocacy organisation is a separate organisation in its own right. For example, they are registered as a charity or company and have their own Management Committee or Board of Directors. Everyone involved in the organisation recognises that they are separate and different from other organisations and services.

Financially — an independent advocacy organisation has its own source of funding that does not cause any conflicts of interest and that does not compromise the work it does. (See conflict of interest).

Psychologically — Everyone involved in the organisation knows that they are only limited in what they do by the principles of independent advocacy, resources and the law. It is important to recognise that although there may be conflicts of interest present, psychological independence is vital.

Safeguard

Ensuring that people's rights are protected.

Service Level Agreement

The agreement, usually between the Local Authority or Health Boards and the advocacy organisation, which outlines how much funding they receive, which geographical areas will be covered, who the advocacy is for and how long the funding is for.

Service provider

A person or organisation involved in giving support or care services to an individual.

Service User

The person who uses advocacy. Some advocacy organisations use the term 'client' or 'advocacy partner'.

Support and supervision

Reflective practice, problem-solving, peer support, individual support and guidance for all members of staff and volunteers in an organisation. Supervision should be a positive experience for all and should take place regularly.