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GOOD PRACTICE GUIDE

Reviewed September 2017

This guide has been updated to reflect key changes to the Mental Health Act implemented on 30 June 2017. This version replaces the previous 2015 version.

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The Mental Welfare Commission

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

Why did we produce this guidance?

In the course of our work, service-users and carers and independent advocates have told us of their concerns about involvement of advocacy.

We have heard of situations where advocates were excluded from important meetings, or were not given the information they needed to fully advocate on behalf of an individual.

We have also heard from practitioners that they are often uncertain about what involvement the advocate should have, especially if an individual has impaired capacity in relation to involving the advocate.

We collected some of the difficult situations that we heard about and used anonymised case studies to consult with a variety of practitioner, advocacy and service-user groups. We also considered the legal framework, notably mental health and incapacity law in Scotland and data protection legislation. We hope that the guidance and case examples we have produced here will help practitioners to understand the role of independent advocacy and provide assistance when dealing with difficult situations.

Independent advocacy - who is it for and why?

Right to advocacy

The Mental Health (Care and Treatment) (Scotland) Act 2003 recognises the importance of independent advocacy in supporting people to *'have their own voice heard in decisions made about their health and wellbeing'*. It enshrines the right of access to independent advocacy for people with a 'mental disorder' in law (section 259). This means that since October 2005, when the 2003 Act was implemented, anyone with a mental illness, a personality disorder or a learning disability has a legal right of access to independent advocacy. It is important to note that this right is for all people with a mental disorder; whether or not they are subject to compulsory measures under the Act; whatever their need for advocacy and whether or not they are incapacitated, or have communication difficulties. The Act gives people a right of access to both collective and individual advocacy. The 2003 Act confers a duty on each local authority and each NHS Board to work collaboratively to ensure that independent advocacy services are available to people with a mental disorder. Ensuring that the services are available is not sufficient though; it is also incumbent upon these two bodies to ensure that staff 'take appropriate steps' to ensure that people are informed about the availability and remit of independent advocacy and have the opportunity to access advocacy services.

The Act defines advocacy services as *'services of support and representation made available for the purpose of enabling the person to whom they are available to have as much control of, or capacity to influence, that person's care and welfare as is, in the circumstances appropriate'*.

The act also stipulates that advocacy must be independent *'because it is vital that the role of*

the independent advocate is not compromised in any way'. It is now widely understood that for advocacy to be effective, there must be no conflict of interest that might jeopardise an advocate's freedom to act. To be able to effectively advocate for a person, advocates have to be structurally and psychologically independent of the service system. An advocacy organisation should not provide any service other than independent advocacy, so there are no barriers to the advocate being wholly able to represent the person's views.

The Mental Health (Scotland) Act 2015 creates new responsibilities for health boards and local authorities to demonstrate that they are discharging their legal responsibilities in relation to advocacy. Boards and local authorities are required to provide the Commission with information about what they have done in the previous 2 years, and what they are going to do in the next 2 years (or a longer period if the Commission requires it) to ensure that independent advocacy services are available for people with mental disorders in their area; and that people are able to access those services.

The Commission will build on the existing map of advocacy services which is prepared by the Scottish Independent Advocacy Alliance, and will periodically produce a publicly-available report analysing the availability of advocacy, and whether the Commission believes that public bodies have done enough to live up to the requirements and principles of the 2003 Act.

Principles of Legislation

The independent advocate's role empowers people to play an integral part in decisions about their care and treatment. As advocacy enables people to know and understand their rights, review the options available and express their needs and wishes, it can play an important part in helping professionals meet their duty to adhere to legislative principles.

The Mental Health (Care and Treatment) (Scotland) Act 2003, the Adults with Incapacity (Scotland) Act 2000 and the Adult Support and Protection (Scotland) Act 2007, all set out principles which must be taken into account by people performing functions under these acts. Independent advocacy has a vital role in assisting in this process; particularly in relation to the following principles (relevant to all the above Acts):

- taking into account the past and present wishes of the person;
- the importance of the person participating as fully as possible;
- ensuring maximum benefit to the person;
- taking into account the abilities, background and characteristics of the person; and
- restricting the person's freedom as little as possible.

Carers can also benefit from the support of advocacy. The principles of the above Acts state that the views of the carer and nearest relative should be taken into account. Carers' advocacy has a role in supporting carers to express their views and informing them of their rights.

People subject to the Mental Health Act have a right to the support of an independent advocate in compulsory proceedings such as tribunals. Their role is to ensure the individual is aware of their rights and support them in exercising these, and, when requested, to represent the views of the individual. Whilst advocacy services may, due to service pressures, prioritise people subject to compulsory measures, they should not limit their service to this group exclusively. The right to independent advocacy extends to people who are not subject to the Mental Health Act. Indeed the involvement of advocacy early on, before compulsory measures are in place, can be helpful in avoiding the need for compulsion. By improving communication with the care team, providing information and helping the person to have their questions answered advocates can assist in building trust, which may enable the person to feel able to access treatment informally.

Named person

People subject to compulsory measures also have a right to nominate a named person, as well as an advocate. The named person also has a role in representing and safeguarding the interests of the person. However the role of the named person differs significantly from that of the advocate. The named person has a right to act independently of the person they represent, with or without the person's approval, and has the right to put their own view forward, even where this differs from the person they represent. The named person has a right to be given certain information concerning compulsory measures being taken and to request and be represented at a Mental Health Tribunal.

Types of advocacy

The Scottish Independent Advocacy Alliance (SIAA) identifies different types of advocacy:

- group, or collective advocacy
- one-to-one advocacy

Appendix 1 contains definitions of the different types of advocacy and the SIAA principles of advocacy.

Role of the advocate

'Advocacy has two main themes:

- *Safeguarding individuals who are in situations where they are vulnerable.*
- *Speaking up for and with people who are not being heard, helping them to express their own views and make their own decisions.'*

[Guide for Commissioners of Advocacy](#) (2013) Scottish Government

The primary role of the advocate is to help people express themselves. When a person is able to direct an advocate this is a relatively straightforward process.

The advocate works with his or her clients to ensure that they fully understand their rights and the situation they are in, the options available to them and helps people to express their views and wishes. The person is always in control of the advocacy process and the advocate only pursues issues of concern if agreed by the individual. An effective advocate has a responsibility to broaden a person's horizons and tell them about options and possibilities that they might never have considered.

If a person lacks the capacity to direct their advocate, the advocate still has a crucial role to play and it is important that professional staff support him or her to access advocacy. As noted in the Code of Practice *'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.'*

Indeed, when a person lacks full capacity it can be argued that they are among the most vulnerable in society and more in danger of having their views ignored. The role of the advocate – when working in a 'non-directed' way with a person who lacks full capacity – is to 'safeguard' a person's rights and promote their interests. The advocate should work to ensure that people are not being exploited for reasons of finance or the convenience of others, that good practice is always followed and that decisions made are consistent with principles, such as that of least restrictive intervention.

The provision of independent advocacy for people who lack the capacity to direct their advocate can cause some ethical dilemmas for professional staff. In particular, there can be concerns about confidentiality and capacity – these dilemmas are discussed in detail later in this guidance.

Independent advocacy organisations in Scotland use the Scottish Independent Advocacy Alliance's Principles and Standards, Code of Practice and other companion guidance. <http://www.siaa.org.uk/resources/best-practice/>

These are clear and concise documents that may aid professional staff's understanding of the advocacy role. The advocate's primary aim is to determine and promote the views of the person being supported.

The advocacy role involves, but is not limited to, the following:

- Helping people to know, understand and exercise their rights;
- discussing things that the person does not understand;
- helping people explore their options;
- giving practical help – e.g. filling in forms, writing letters, assisting people to make advanced statements, make complaints, etc;
- supporting people in meetings, consultations, assessments and tribunals; and
- enabling people to express their views and anxieties and become involved in decisions that affect them.

If it is not possible to ascertain the person's views and wishes due to communication or comprehension difficulties the advocate should follow the SIAA non-instructed advocacy guidelines and offer an opinion based on what they have learned about the person or, as a minimum, ensure that the person's rights are upheld.

An independent advocate does not have a 'professional view' about what is in someone's 'best interests' and should not make judgements, give advice or offer an opinion, except in the specific circumstances outlined above. Consequently, an advocate may support someone to argue for something that the professionals working with that person do not consider as being in the person's interests. This is part of the advocacy role, but it does not change the level of responsibility on other professionals involved with the patient who are still required to exercise their professional judgement in the patient's care.

However, advocacy should lend weight to a person's argument and we hope that professionals will consider what is being argued with an open mind and with a willingness to allow people to take informed, positive, risks.

To get a clear understanding of the role of independent advocacy, it is important also to be aware of what is not advocacy.

Advocacy is not:

- **Counselling/befriending** – although some of the skills used in these roles would be used by advocates.
- **Advising someone what to do** – although advocates should provide sound, impartial information about rights, services and options.
- **Mediation** – Reaching a compromise is not the advocate's primary goal.
- **Unbiased** – The advocate should be clearly on the service-user's 'side'.
- **Creating barriers between service- users and staff** – Advocacy involvement should enhance communication and help build good relationships.
- **Raising expectations unrealistically** – The advocate should ensure that the service-user understands that the advocate has no special powers and cannot promise a particular outcome.
- **Formal monitoring of service provision** – The advocate does not have a view about the individual's situation and should only express the person's views. However, like other people working within the health and care sector, if an advocate witnesses abusive practices he or she would have a duty to inform advocacy management, who may take it up with the service provider's management.

- **Speaking instead of someone** – The advocate’s first duty should be to help a person express him or herself. When speaking on behalf of the person, they should ensure that they are accurately representing that person’s views.

Professional staff who respect the need for an independent advocacy service are demonstrating to service-users that their views are important, that it is acceptable to speak out and to comment on their care and treatment and to challenge professionals’ views.

A good working relationship between professionals and advocates will not be without tension, however there should be a mutual understanding and respect for each other’s roles.

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. Collective advocacy groups work to challenge misconceptions, discrimination and stigma. Groups can benefit from the support of resources and skilled help from an advocacy organization. Collective advocacy groups have been set up in the community, in hospitals and residential units.

The benefits of collective advocacy for the people involved include:

- Raising awareness about rights, policy and legislation
- Increasing confidence
- Improving self esteem
- Reducing isolation
- Strengthening networks
- Sharing skills and ideas

An example of effective collective advocacy

The Patients' Council is run by service users for service users, with the aim of helping patients in the hospital to have a voice that is actually listened to.

Collective advocacy enables people to get together to put forward their views about issues which affect them – for example, issues around mental health treatment and care. The Patients' Council gathers the views of people who use or have used the services of the hospital and ensures that hospital staff and management listen to and respond to them. To achieve this, they work in partnership with the NHS and over the years have become an accepted and respected part of the hospital community.

Most of the work is done by volunteers - people with lived experience of using mental health services. This is invaluable for making a meaningful connection with patients on the wards who feel able to tell the volunteers what they really think.

The volunteers participate in meetings, working groups, seminars and conferences within the hospital, the NHS and the wider community – connecting with people at all levels and from all walks of life. Currently they are involved in the planning for the new hospital.

The Patients' Council has been involved in the design and delivery of training for new NHS staff as part of their induction. They have also been involved in lobbying their MSPs and the Minister for Health regarding changes to mental health legislation. The Patients' Council is a collective voice working to improve services, address stigma and challenge discrimination.

Supporting people to access advocacy services

The Code of Practice for the 2003 Act says:

'All relevant staff should be made aware of the patient's right to independent advocacy and its role, the legal requirements relating to independent advocacy under the act and of best practice. It is important that staff know that advocates may support any patient, including child and adolescent patients, patients with incapacity, and patients with communication difficulties.'

Certain professionals have a specific duty under the 2003 Act to inform people about their right to and the availability of advocacy. For example, Mental Health Officers have a duty to inform people of this right when they are considering consent to detention orders, or when they apply to alter or extend such orders. Similarly, hospital managers have a duty to ensure that patients are informed about advocacy and how to access it. This duty can be delegated to other hospital staff on behalf of the manager. It would be good practice for hospitals and local authorities to have clear procedures for staff to follow to ensure they fulfil the duty to

inform people about advocacy and assist access.

Certainly, posters and leaflets with clear information about local advocacy services should be displayed in a prominent position. Advocacy literature should also be included in information packs that are given to patients on admission to hospital. Such publicity material should be available in a variety of formats to ensure that it is accessible to as many people as possible. For example, if appropriate, it should be made available in different languages, on tape and in Braille; pictorial information making use of symbols such as those used in Makaton might be needed. As it is likely that advocacy organisations will be preparing this publicity material, it might be necessary for commissioning bodies to be aware of the potential costs involved in producing it.

Staff will be required to inform people about independent advocacy at specific times.

Consequently, staff should be able to access information and training about the role of advocacy so they can give out clear and accurate information. There should be a good working dialogue between professional staff and the advocacy service to facilitate this.

Staff should also understand that discussions about the availability of advocacy may need to take place on several occasions, to ensure that the person understands what is being offered and how to access it.

Sometimes it might be necessary for staff to assist a person to contact the advocacy service. Staff will therefore need to understand the referral process of local advocacy services. When a referral is made, it is of critical importance that the staff member does not breach the confidentiality of the person by disclosing too much information.

Advocacy organisations should get most of their information directly from the people they are working with and only request information from professional staff under the explicit direction of the person. Referral information should include the means of contacting the person and a brief summary of the reason the person seeks advocacy assistance.

When a referral is made for someone who lacks the capacity to instruct the advocate, it is still important for staff to be aware of what information should be disclosed. In most cases, the general rule would be that the advocate only requires access to information that allows him or her to undertake the advocacy role effectively.

Welcoming and supporting advocates

Code of Practice for the 2003 Act states:

'As a matter of best practice, where the patient has chosen to use independent advocacy, the independent advocacy organisation or advocate should be entitled to (where the patient agrees):

- *be invited to attend, where practicable, a consultation, interview or meeting about the patient's treatment or care in order to support or represent the patient there;*
- *have access to the patient at any reasonable time to provide any support or representation needed;*
- *correspond or communicate in any other way with the patient on any matter relating to the patient's care and welfare; and*
- *receive such information as would assist them to perform their role.'*

For independent advocacy to offer an effective service to people, it is imperative that advocates and professional staff understand and respect each other's roles and support each other to fulfil these roles. There are a number of things both parties can do to facilitate this.

Advocates can facilitate good working relationships by:

- Providing information about the advocacy service, including hours of work, referral, prioritisation and complaints procedures and the principles and standard to which the advocates adhere.
- Notifying staff who work with the person that an advocate is involved, unless the individual requests otherwise.
- Notifying staff of attendance at any meetings, unless the individual requests otherwise.
- If a person is unable to direct the advocacy worker, information regarding actions taken by the advocacy worker on behalf of the client should be made available to staff, except where the client may be disadvantaged. The purpose of this is to benefit the client and enable the support staff to help the client make best use of their advocate.
- The advocacy service should ensure that all advocates are accountable for their attitude and behaviour whilst carrying out their role as an advocate.
- All written information about service-users should be kept secure in line with the Data Protection Act 1998. Only information directly relevant to the effective provision of an advocacy service should be kept.

Professional staff can facilitate good working relationships by:

- Welcoming the advocate and providing a private place for the advocate to meet with the person if they request this and it is feasible.
- Providing written or verbal information to the advocate only when requested by the person to do so.
- Where possible, support the person to get to and from advocacy meetings.
- Respect the confidential nature of the advocacy relationship.
- Asking if the person wishes to discuss things with his or her advocate whenever a change of circumstances is planned in the person's life.
- At the person's request, inviting the advocate to meetings.
- Ensuring the person sees all correspondence sent to them by the advocate.
- Contacting the advocate as soon as possible, when asked to do so by the person.
- Considering what is being said by the advocate when helping someone to express their views and taking the person's views into account.
- Ensuring that the advocate is aware of any risk posed by meeting a person on their own, including health or medical issues.

It is important that advocates can work effectively with people who are unable to direct their work. As noted above, this can cause ethical dilemmas for staff who are concerned about breaches of confidentiality, but it is important that advocates receive the information that allows them to perform their role. To assist in this process staff should:

- allow advocates access to information that is relevant to their role;
- invite the advocate to meetings about the person's treatment and welfare;
- contact the advocate when there are significant or unexpected changes in the person's life; and
- inform the advocate of any change in behaviour that might indicate unhappiness or anxiety.

All parties should be clear about how to raise issues about the conduct of a worker from any agency. Complaints procedures should be made available and there should be good communication between advocacy service managers and the management of service providing agencies.

Difficult situations - consent, capacity and information sharing

One of the core principles of the health and social care system is that, where an individual has capacity, information gained about a service-user is held to be confidential and cannot be shared with people outside the care team without the individual's consent.

Several regulatory and professional bodies have produced guidance on confidentiality. These include the Nursing and Midwifery Council (NMC) and the British Association of Social Workers (BASW). The General Medical Council (GMC) gives the most detailed guidance on confidentiality. The GMC guidance says: *'Patients have a right to expect that information about them will be held in confidence by their doctors. Confidentiality is central to trust between doctors and patients.'* The guidance goes on to say that, if information is disclosed that could personally affect the patient, he or she must give express consent to the disclosure. The exception to this rule is where disclosure can be justified in the public interest: usually where it is essential to protect the patient, or someone else, from risk of death or serious harm. There is also a statutory requirement for practitioners and service managers to keep personal information confidential. The Data Protection Act 1998 obliges them to follow certain principles in recording and disclosing the personal information they obtain. The provisions of the Act include not disclosing information without the consent of the person concerned, unless that disclosure is legally authorised under specified circumstances.

If the individual has capacity to give or withhold consent to sharing information, the situation is simple. Information can be shared as required between staff and advocacy, based on the individual's consent. However, in many instances things are not as clear cut as this and confidentiality can be a complex issue to manage. Below are some scenarios which illustrate the dilemmas which staff can face.

Staff are generally very aware of the need to maintain confidentiality. There are occasions however, where staff have made a referral to advocacy services without discussing this with the individual. A great deal of detailed sensitive information relating to the service-user's background has been provided without due thought to what information is actually required by advocacy at this stage, or having obtained the service-user's consent to do so.

Where an individual has capacity staff need to seek consent before sharing information and should share information on a need to know basis. Only information which is relevant to the task should be provided.

There may be circumstances where an individual has withheld consent to share information, but to do so may put the advocacy worker at risk. In such circumstances a multidisciplinary discussion should be held at which a decision should be made that takes account the individual's right to confidentiality, as well as the nature and level of risk involved to the advocate if the information is withheld. If it is felt that the risk is significant and the information needs to be shared for reasons of safety, then the service- user should be advised that – in this situation – his or her confidentiality

cannot be maintained. A clear record of the decision and the rationale for this should be documented.

Case example

Steve has a mild learning disability and is on a community-based CTO and living in his own tenancy. He is being referred to advocacy as he is unhappy with the plan to extend his detention. He is in agreement with the referral, but has asked that information about his previous history is not provided by the care team, he wishes to 'tell his own story'. He has a history of being inappropriate and at times aggressive towards females.

As a result of this, female members of the care team do not visit him on their own. Staff are concerned that a lone female advocacy worker visiting Steve may be at risk, but feel that Steve has given a very clear message that staff are not to divulge information to advocacy.

In this situation, staff would have to consider the level of risk which Steve may pose and whether the risks justify a breach of confidentiality. The referrer may decide it is necessary to provide information to protect the advocacy worker from a potential risk, but this doesn't mean they need to give detailed information. As in all situations, consideration should be given to what information is required for the specific task. It may be adequate to notify the advocacy agency that it is advisable to allocate a male advocate, without divulging any detail of Steve's history. This would, as far as is possible, respect Steve's right to privacy without potentially compromising another person's safety.

Information may not relate solely to one individual. The duty to maintain confidentiality for one person may be in conflict with the need to share information that has an impact on the care of another. In such situations, where there is third party information involved staff have to weigh up the competing needs and rights of the individuals and look at ways of giving the advocate enough information to enable them to do their job, without compromising another person's privacy.

Case example

Desmond has a mild learning disability and mental health difficulties. He has recently been admitted to hospital under a short-term detention certificate (STDC) due to his deteriorating mental health and associated behavioural difficulties. Lynn has become his advocate since his admission. It is everyone's expectation that Desmond will return to live with Heather, who has been his carer for five years.

Heather remains in contact with Desmond and has stated that she wishes to continue to support him.

Desmond talks frequently about going home to Heather.

At a case conference the social worker advises the health team and Lynn that Desmond will not be returning to his placement with Heather. He refuses to provide any further information on the reasons for the decision, stating these are confidential.

In this situation the advocate may be frustrated at the lack of information being provided about a decision that has such a profound impact on the person.

However, the reasons for the placement no longer being considered viable may not be solely to do with Desmond, but could also relate to the personal circumstances or health of the carer. In this case, the social worker is faced with having to balance the need to maintain the carer's confidentiality, against the need to provide information to Desmond and his advocate about the basis for such a significant decision. In this situation, while the social worker would clearly be justified in not sharing information that would breach the confidentiality of the carer, a blanket refusal to share any information about the decision to terminate the placement would be hard to justify. In most circumstances there may be some information which can be shared appropriately. For instance, the social worker may choose to discuss the situation with the carer and obtain his or her consent to share information within agreed limits. If this were not possible, it may be that the social worker advises the advocate that returning to the placement would place Desmond at risk, without expanding on the nature of this.

All of the scenarios given here rely on the ability of the individual to withhold or give consent to sharing information. There will, however, be some individuals who do not have the capacity to give consent to staff to share information. Staff can often feel anxious about sharing information in a situation where the individual is unable to give consent and this could be perceived as a break of confidentiality.

Where there are concerns over capacity to consent, it may be appropriate to have a multidisciplinary team discussion to agree what information can be shared with advocacy. In making such decisions consideration should be given to:

- what information is required by the advocate to enable them to effectively fulfil their role;
- whether the information is particularly sensitive;
- whether it is in the best interests of the individual to share the information;
- what is known about the previous wishes of the individual; and
- how the information will be stored and used and who else will have access to it.

Sharing of information doesn't have to be an all or nothing decision with advocates given full access to records. Staff can and will make judgments based on the above factors. Although confidentiality is a key principle in mental health care, staff also need to act in accordance with principles which require that individuals are provided with the support and information they need to maximise their participation in decision making, and the individual's legal right of access to advocacy. It can be argued that failure to share information that is required to enable advocates to fulfil their role, is effectively denying the individual their right of access.

A person may have capacity to make some types of decisions relating to their welfare, but not understand or be able to weigh up the implications of other more complex decisions. Their ability to make these decisions may also vary over time. Therefore capacity is not an all or nothing concept but has to be seen as circumstance specific. Staff should use a 'functional approach' in determining whether a person has the capacity to make a decision. What this approach focuses on is *'whether an individual is able to make a decision at the time when that decision has to be made.'* This means that an individual may be deemed incapable of making a decision at one specific point in time, but capable at another point in time.

In law, adults have the right to make decisions affecting their own life. The reasons given for decisions may be rational, irrational, unknown or, in some cases, possibly even non-existent. There is however a presumption in law in favour of capacity. It is important for staff to remember that just because an individual's decision is thought by others to be unwise, this doesn't in itself mean the individual lacks capacity. If exercising poor judgement alone was taken as evidence of lack of capacity, how many of us would be considered competent to make our own decisions?

The decision to access advocacy services is one that will be within the capacity of the vast majority of individuals. Each individual will vary in their level of understanding of the issues which the advocate is assisting them with and in the level of instruction which they can give to their advocate. Staff should respect the individual's right to have support from advocacy

where they wish this, and actively facilitate this where they can. This could mean including advocacy workers in meetings, or allowing advocacy to accompany the individual to meetings with their clinician, if this is felt to be helpful by the service-user – even if the professionals involved do not feel it is necessary or advisable. There will also be individuals who lack capacity to provide any meaningful instruction to their advocate, for example where someone is suffering from advance stages of dementia or has severe communication difficulties. It is often these vulnerable individuals, who are most in need of someone to advocate for them.

The role of the advocate is normally to work to the direction of the individual, to provide support and representation that enables the person to have as much control or capacity to influence their care as is appropriate. In a situation where the individual doesn't have capacity to make decisions, or can't make his or her wishes known, the advocate has a safeguarding role. It is the advocate's role to ensure that the individual's rights are upheld, the principles of the mental health act are taken into account and that relevant agencies are fulfilling their responsibilities to provide care.

Case example

Tom is in his 80's and suffers from dementia. He has lived in a care home for the past 3 years and has recently appeared to be distressed and angry much of the time. Tom was referred to the local advocacy organisation and Sarah, the advocate, visited him several times over the next few weeks.

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 offer him choices such as what food he would like or where he wanted to sit. When she asked about this some staff members said it was because he couldn't communicate his wishes. Sarah believed that Tom felt frustration at the lack of control over the simplest aspects of his life 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 had dementia and had difficulty with communicating, 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.

In a situation where the individual cannot instruct the advocate, the advocate should follow the guidance contained in the SIAA's Non-Instructed Advocacy Guidelines and has a responsibility to try to find out as much about the individuals past and present wishes as possible. This may mean gathering information from friends, family and carers, spending time with the individual to get to know his or her likes and dislikes, observing their interactions and trying different methods of communication.

Staff should be aware that this is a legitimate part of the role of a non-instructed advocate and should facilitate this, ensuring the advocate has adequate access to the individual, sharing relevant information with the advocate, ensuring the advocate is notified of any significant changes in the person's life, or any significant changes in behaviour which may indicate he or she is unhappy.

Advocacy services are commissioned and funded by local authorities, but remain independent. There may be situations where several providers operate in an area and an individual or group has a choice of services available.

Case example

George has a learning disability, and has had ongoing support from advocacy for some time. He is currently in hospital and advocacy supported him at a discharge planning meeting to express his wish to return to his own home, rather than a care home. The meeting was difficult with the advocate challenging the professionals on their views of the level of risk this would involve for George, and his right to take risks. There are several issues within the unit which George and some other people are unhappy about. George contacted his advocate on behalf of the group and asked that they attend a meeting to support them in taking forward their concerns. The ward manager then contacted the advocate to advise them that the consultant had arranged for another advocacy provider to support the group as he found it easier to work with the second provider. The group had not been consulted about this decision.

Independent advocacy is, by its definition, independent of the services which are delivering care to the individual. Whilst advocacy services are funded by local authorities, hospital and social work services do not have the right to impose an advocacy provider on an individual nor to decide which advocacy service an individual can have access to. The individual has a right to choose whether to engage with advocacy, and which of the available advocacy organisations they wish to use. Should a service have concerns about the conduct or competence of an advocate this should be addressed directly with the advocacy organisation involved.

When decisions have to be made which will mean a major change in someone's life it can be difficult to know what is in the best interests of the person. Sometimes there can be disagreement amongst families about what is the right decision to make. In such cases advocacy has an important role to play in ensuring the individual has a chance to express their views and these are heard.

Case example

Margaret, who has dementia, lived alone with care workers coming in to her home twice a day. She has a son and two daughters. One of the daughters still lives in a nearby town, the other daughter and her son live 50 miles away in Glasgow.

Recently she fell while alone and was admitted to hospital with a broken wrist. In preparation for her discharge her daughters and son met with staff from the hospital and the local authority. All agreed that Margaret needed more care and support than was afforded by care staff visiting her home and there was some discussion about a move to a care home. Margaret's son and one of her daughters wanted her to be moved to a care home in Glasgow. Her other daughter disagreed and wanted her to remain in her home town.

Margaret was referred to her local independent advocacy organisation. The advocate spent some time with Margaret finding out what she wanted to happen. Despite her dementia and confusion about some things Margaret was very clear that she wanted to stay in her own home and close to her friends and the area in which she had lived for most of her life. Her advocate helped to make sure that her wishes were heard and although in the end she was not able to stay in her own home safely she moved to a local care home.

Summary

In our view, the legal right of access to advocacy must include involvement of the advocate to support the person when important decisions about care and treatment are being made. This guidance should help practitioners make sure that advocacy is encouraged and that the advocate plays the important role in care and treatment, as intended by the legislation. We cannot anticipate every possible difficulty and service-users, service providers and independent advocates are welcome to contact us for advice on ethical aspects of care involving advocacy.

References

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Appendix 1 - Types of advocacy

One-to-one or individual advocacy

This includes professional or issue based advocacy. It can be provided by both paid and unpaid advocacy worker. An advocacy worker supports an individual to represent his or her 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 the advocacy partner is on a one-to-one, long term basis. It is based on trust between the partner and the citizen advocate and is supported but not influenced by the advocacy organisation. The citizen advocate supports the partner 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 the advocacy partner may share age, gender, ethnicity, diagnosis or issues. Peer advocates use their own experiences to understand and have empathy with the 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 peer advocate and the 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 help reduce an individual's sense of isolation when raising a difficult issue. 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 with the support of resources and skilled help from an independent advocacy organisation.

Carer advocacy

Carer Advocacy can be provided on an individual or collective basis. Carer advocates can support the carers communication with professionals involved with the person they are carer for; this can include supporting or representing the carer at meetings, hearings, appointments etc. Supporting carer autonomy by providing information and clarification, signposting,

explaining options. Supporting decision making and being a listening ear to support the carer in identifying their own needs.

Principals of advocacy

Independent Advocacy puts the people who use it first.

- Independent Advocacy is accountable
- Independent Advocacy is as free as it can be from conflicts of interest
- Independent Advocacy is accessible





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