AN ADVOCATE'S GUIDE TO INDEPENDENT NON-INSTRUCTED ADVOCACY

Older People and Dementia

Principles, Practice and Guide to Further Resources

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Contents

Page No

1. Introduction 4

2. Independent Advocacy and the Principles of Advocacy 4
   - *I. 'The Advocacy Charter'* *5*

3. The Development of Non-instructed Advocacy 7

4. What is 'Capacity'? 9

5. The Mental Capacity Act 2005 9
   - *I. Independent Mental Capacity Advocate (IMCA)* *11*
   - *II. Independent Mental Health Advocate (IMHA)* *13*

6. Assessing Capacity 15

7. Deprivation of Liberty Safeguards (DoLS) 16

8. Capacity and Communication 18

9. Communication Tools and Techniques 19
   - *I. Communication and sensory impairment* *20*
   - *II. Capacity to instruct* *20*

10. Approaches to Non-instructed Advocacy 21
    - *I. Definitions of Non-instructed Advocacy* *21*

11. Best-interests Advocacy & the Role of Statutory Advocates 23

12. Being Person-centred 24

13. Rights-based Approach 25
    - *I. Equality Act 2010* *25*
    - *II. Human Rights Act 1998* *26*

14. Observation 28
    - *I. The Watching Brief* *28*
    - *II. The VIPS Framework* *30*

15. Consent to Provide Non-instructed Advocacy 32

Bibliography 34

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This guide is based on experience of providing independent non-instructed advocacy to older people living in care home settings. However, the information here should be of equal interest to any independent advocate providing non-instructed advocacy to any individual.

1. Introduction

All people have a right to express their views and a right to make choices about their own lives. In situations where someone is receiving support, care or services from others, they have a right to a say in how these services are provided. Some people find it much harder to say what it is that they want, or to speak up when they feel things aren't right for them. For some people this can be made even more difficult due to problems with communicating, or because of ill health or disability.

Advocacy is recognised as a way of assisting people to work out exactly what they want, and to speak up and say it. Whilst we all know that nobody gets exactly what they want all the time, the support which is provided by an advocate helps make sure that individual's know what their rights are, are informed about the options available to them, and are supported to express their wishes. More than this, advocacy can help make sure that what people say is taken notice of, and that their wishes are acted upon. If someone is still not happy an advocate can continue to support them to make a complaint or challenge a decision.

2. Independent Advocacy and the Principles of Advocacy

Independent advocacy is a special kind of support and is something which is different to help given by family members or services provided by health and social care workers. Independent **advocates** are professionals who work in a particular way to support someone to express their views, to get what they need and what they have a right to. Some organisations exist to make sure that advocacy is recognised as different from these other kinds of support or services, and that the principles which make advocacy distinct are well known and are followed by everyone who calls themselves an independent advocate.

One of these organisations is called Action for Advocacy and they developed a set of **principles** for advocacy, which most independent advocacy services and advocates in the UK agree with. This is known as the Advocacy Charter. Action for Advocacy also wrote a **code of practice** which explains how advocates work, and importantly also explains what advocates don't do. Agreeing to adopt the same principles and code of practice across all different advocacy schemes helps to make sure that independent advocacy is recognised as distinct from other support and services. It also helps to make sure that independent advocacy schemes provide consistent and really good quality support.

2(i) The Action for Advocacy Principles: 'The Advocacy Charter'

Clarity of Purpose

The advocacy scheme will have clearly stated aims and objectives and be able to demonstrate how it meets the principles contained in this Charter. Advocacy schemes will ensure that the people they advocate for, service providers and funding agencies have information on the scope and limitations of the schemes' role.

Independence

The advocacy scheme will be structurally independent from statutory organisations and preferably from all service provider agencies. The advocacy scheme will be as free from conflict of interest as possible in both design and operation, and actively seek to reduce conflicting interests.

Putting People First

The advocacy scheme will ensure that the wishes and interests of the people they advocate for direct advocates' work. Advocates should be non-judgmental and respectful of peoples' needs, views and experiences. Advocates will ensure that information concerning the people they advocate for is shared with these individuals.

Empowerment

The advocacy scheme will support self-advocacy and empowerment through its work. People who use the scheme should have a say in the level of involvement and style of advocacy support they want. Schemes will ensure that people who want to, can influence and be involved in the running and management of the scheme.

Equal Opportunity

The advocacy scheme will have a written equal opportunities policy that recognises the need to be pro-active in tackling all forms of inequality, discrimination and social exclusion. The scheme will have in place systems for the fair and equitable allocation of advocates' time.

Accessibility

Advocacy will be provided free of charge to eligible people. The advocacy scheme will aim to ensure that its premises, policies, procedures and publicity materials promote access for the whole community.

Supporting Advocates

The advocacy scheme will ensure advocates are prepared, trained and supported in their role and provided with opportunities to develop their skills and experience.

Accountability

The advocacy scheme will have in place systems for the effective monitoring and evaluation of its work. All those who use the scheme will have a named advocate and a means of contacting them.

Confidentiality

The advocacy scheme will have a written policy on confidentiality, stating that information known about a person using the scheme is confidential to the scheme and any circumstances under which confidentiality might be breached.

Complaints

The advocacy scheme will have a written policy describing how to make complaints or give feedback about the scheme or individual advocates. Where necessary, the scheme will enable people who use its services to access external independent support to make or pursue a complaint.

There is a lot more information on the Action for Advocacy website
www.actionforadvocacy.org.uk

The Code of Practice for Advocates can be found here:
http://www.aqvx59.dsl.pipex.com/Code%20of%20Practice%20booklet.pdf

Other useful online resources can be found on the following websites:
www.opaal.org.uk/
www.afop.org.uk/
www.advocacyplus.org.uk/

3. The Development of Non-Instructed Advocacy

When independent advocacy was first described as a way of supporting people to have a voice, it relied very much on **instruction.** That is, the person needing the support of an advocate would tell the advocate what to do on their behalf. This meant that the individual requested the support of an advocate and were able to tell their advocate what was wrong. The advocate would work to support the individual by finding out information relating to their problem, and would help the individual to understand the information and the options open to them. The advocate would then wait to be told what to do next on the individual's behalf; they would wait to be instructed.

A generally held view was that, if an individual couldn't understand what an advocate was, and was unable to instruct them with regard to what they wanted, independent advocacy was not a suitable service. However, there are no other services based so strongly around the principles of independence, confidentiality and empowerment, and which put people first at all times.

This left a big problem with regard to the very many people unable to instruct, but who were facing many disadvantages and difficulties in their lives, and in some cases experiencing poor or abusive treatment. These were often people who really needed the support of an independent advocate most of all, for example, people with a learning disability, older people with a dementia, or people with mental health problems.

Advocates who thought independent advocacy should be available to everyone started to consider how **non-instructed advocacy** might work.

> *At the heart of advocacy is a commitment to safeguarding the rights of the most vulnerable, and non-instructed advocacy is a practical manifestation of that commitment. The challenge is to develop the skills and confidence of advocates to work in this way, and to raise awareness amongst others of the legitimacy of this approach.*
>
> ***Rick Henderson Non Instructed Advocacy in Focus***

Over time different ways of providing non-instructed advocacy have been considered. These started out as different and largely separate 'approaches' to non-instructed advocacy but are now mainly used together in a holistic way. There is now a general acceptance that independent non-instructed advocacy is something which can be provided in a good quality and clearly defined way.

The very important advocacy principles have been developed over time to enable non-instructed advocacy to fit within them. Taking the principle of Putting People First as the most important, this principle is reproduced in full below to highlight how it now also applies to non-instructed advocacy *(see Figure 1 on page 8)*.

Putting People First

a Advocates should ensure advocacy support is appropriate to the service users' needs and/or expressed wishes.

b Advocates should take instruction from service users wherever possible. Advocates should base their actions on mutually agreed plans and preferred outcomes, and work in partnership with service users to achieve this.

(i) INSTRUCTED ADVOCACY:

- Gathering and presenting up to date and accurate information to help service users make informed choices but NOT giving advice.
- Listening to service users and discussing options but NOT imposing views or opinions.
- Talking to and corresponding with family members or other professionals with the service user's permission but NOT making decisions or choices on behalf of service users.
- Representing the person's expressed views and wishes but NOT taking action independently of the service user.
- Agreeing a plan of action and identifying initial outcomes and timescales with service users but NOT being prescriptive or inflexible.

(ii) NON-INSTRUCTED ADVOCACY:

- Where a service user cannot give clear instruction, taking time to get to know them and building a picture of their preferences and lifestyle including their cultural background.
- Seeking appropriate alternative forms of communication which enable the service user to express views and choices.
- Ensuring the person's fundamental human rights are respected and upheld at all times.
- Challenging service providers and decision makers in order to promote a person-centred approach.
- Acting as a 'witness' or observer in the settings in which the service user spends time.

Each of the points in (ii) Non-instructed advocacy, above, will be discussed further in this Guide.

4. What is 'Capacity'?

Capacity is a word which is used to describe the ability someone has to make a decision about something. People may decide they want a particular thing to happen, but they may not have the **capacity** to fully understand the wider implications of this decision.

Because the level of understanding needed to make different decisions is also very different, it is not acceptable to state that someone 'lacks capacity to make all decisions'. For example, someone may be able to decide what they would prefer to eat for lunch, but may not really be able to decide on the best way to manage their income. This is because the capacity which is required to understand the implications of each of those decisions is significantly different.

Sometimes advocates and other professionals are told that the person they are working with 'doesn't have capacity'. As an advocate this should cause you some concern. This is because the people involved in supporting any individual should automatically be assuming they have capacity to make a decision, until it becomes evident through working with them that they do not. This will always be in relation to a particular decision which is to be made.

This assumption of capacity is the first principle of an act called the **Mental Capacity Act.** This Act is often used to help non-instructed advocates make sure the way someone is being treated is right, in principle and in law.

5. The Mental Capacity Act 2005

The Mental Capacity Act sets out different situations which people without capacity may find themselves in. It makes it clear who can take decisions, in which situations, and how this should be done. The Mental Capacity Act provides a statutory framework to empower and protect those who may lack capacity to make some decisions themselves. This can include major decisions about property, healthcare treatment, and accommodation, as well as everyday decisions about personal care or what to eat.

The Mental Capacity Act is underpinned by a set of 5 key principles which aim to:

- Protect people who lack capacity and
- Help them take part, as much as is possible, in decisions that affect them

There are a lot of ways in which the support of an independent advocate can help to ensure that the aim of the key principles and the overall intention of the Mental Capacity Act can be achieved. At a basic level, advocates can ensure that the 5 key principles contained within the Act have been upheld in relation to any decision an individual needs to make.

The 5 key principles in the Mental Capacity Act are summarised as:

1. A person must be assumed to have capacity unless it is established that they lack capacity

2. A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success

3. Just because an individual makes what might be seen as an unwise decision they should not be treated as lacking capacity to make that decision

4. An act done or decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests

5. Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms

The Mental Capacity Act deals with two main things. The first is the assessment of a person's capacity. With regard to this the Act sets out:

1. A single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time

2. A non-exhaustive checklist of factors that decision-makers must work through in deciding what is in a person's best interests

The second main thing the Mental Capacity Act deals with is acts by the carers of people who lack capacity. In regard to this the Act sets out:

1. Statutory protection from liability where a person is performing an act in connection with the care or treatment of someone who lacks capacity

Liability is not incurred if, before doing the act, the carer takes reasonable steps to establish that the person lacks capacity in relation to the matter (Principle 1); and they believe that the act or decision is in the best interests of the person (Principle 4).

There is additional information in the Mental Capacity Act about using restraint against people who lack capacity. This says that restraint is only permitted if the person using it reasonably believes it is necessary to prevent harm to the person who lacks capacity, and if the restraint used is proportionate.

There are also additional safeguards for people who lack capacity and who are deprived of their liberty. These are known as the **Deprivation of Liberty Safeguards** and information about these can be found in Section 7 on page 16.

The Mental Capacity Act also allows people to plan ahead for a time in future when they may lack capacity, so that they can choose in advance who will make decisions for them. This is called *Lasting Powers of Attorney (LPA)*. Sometimes independent advocates provide information and support to people to set up an LPA, especially if they have recently been diagnosed with a dementia.

The Act also creates a new public body and a new official to support the statutory framework. These are the *Court of Protection* and a new *Public Guardian* and an Office of the Public Guardian.

Finally, the Act also includes three further provisions to protect vulnerable people. These are:

- Independent Mental Capacity Advocate (IMCA)
- Advance Decisions to Refuse Treatment
- Introduction of a criminal offence of ill-treatment or neglect of a person who lacks capacity

The Mental Capacity Act is clearly central to non-instructed advocacy. It is the role of an independent advocate to ensure that people involved in the care of someone who is assessed as lacking capacity act entirely in accordance with the 5 key principles. It is therefore important to learn as much as possible about the Mental Capacity Act 2005.

5(i) Independent Mental Capacity Advocate (IMCA)

An Independent Mental Capacity Advocate (IMCA) can be instructed by a professional, most likely working in health or social care, to provide advocacy support to an individual who doesn't have capacity. Whilst this sounds very similar to the independent advocacy services discussed elsewhere in this Guide, there are clear criteria which define which individuals can be supported by an IMCA. In fact, if someone meets these criteria then an IMCA **must** be instructed. See box below for details of when an IMCA must be instructed.

The IMCA will work in very similar ways to any other independent advocate, and can often work alongside independent advocates. The IMCA will use a variety of non-instructed advocacy approaches to communicate with the individual and to find out their wishes, beliefs and values. They will provide information to the decision makers (health or social care professionals) which they must take into account. An IMCA can also challenge a decision which has been made by a professional if they don't believe it is in the best interests of the person they are advocating for.

When should an IMCA become involved?

An IMCA must be instructed for people lacking capacity who have no-one other than paid staff to support them whenever:

- A National Health Service (NHS) body is proposing to provide, withhold or stop serious medical treatment.
- A NHS body is proposing to arrange a stay in hospital lasting longer than 28 days.
- A NHS body or local authority is proposing to arrange accommodation (or a change of accommodation) in a care home for a period of longer than 8 weeks.

An IMCA may also be instructed on behalf of a person lacking capacity for:

- Care reviews, where no-one else is available to be consulted.
- Adult protection cases, whether or not family or friends are involved.

Mental Health Matters Wales (2010)

There are four main elements to the IMCA work:

1. Ascertaining the views, feelings, wishes, beliefs and values of the person, using whichever communication method is preferred by the client. Ensuring that those views are communicated to, and considered by, the decision-maker

2. Non-instructed advocacy. Asking questions on behalf of the person and representing them. Making sure that the person's rights are upheld and that they are kept involved and at the centre of the decision-making process

3. Investigating the circumstances. Gathering and evaluating information from relevant professionals and people who know the person well. Carrying out any necessary research pertaining to the decision

4. Auditing the decision-making process. Checking that the decision-maker is acting in accordance with the Act, and that the decision is in the person's best interests. Challenging the decision if necessary

There are some exceptions to the conditions under which an IMCA must be instructed, and these can include decisions regarding urgent life-saving treatment, or decisions regarding accommodation where the alternative would leave the vulnerable individual homeless.

With regard to the Mental Capacity Act it would be useful to learn more about the following to support you in your role as an advocate:

- The Court of Protection
- The Office of the Public Guardian
- Lasting Power of Attorney
- Assessing capacity and ability to make a decision
- Best interests decisions
- Advance Decisions to Refuse Treatment

For the full Mental Capacity Act and further links to associated material: http://webarchive.nationalarchives.gov.uk/+/http://www.dca.gov.uk/menincap/legis.htm

For a wide range of training resources and video examples associated with the Mental Capacity Act http://www.scie.org.uk/

For more information about the role of the IMCA see:
http://www.imcawales.org

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/IMCA/index.htm

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_073931.pdf

For online learning resources about the Independent Mental Capacity Advocates please see http://www.scie.org.uk/publications/imca/index.asp

5(ii) Independent Mental Health Advocate (IMHA)

In Wales there are also Independent Mental Health Advocates (IMHAs) whose role was introduced by a 2007 amendment to the Mental Health Act 1983. This was redefined for Wales by the Mental Health Measure 2010. Follow the link below to view the 2010 Mental Health Measure:

http://www.legislation.gov.uk/mwa/2010/7/contents/enacted?view=plain
(See Part 4: Section 31 for details of the IMHA role and remit)

IMHAs are specialist paid advocates offering issue specific support in relation to medication, treatment and care. In Wales if someone is:

- Detained in hospital under the Mental Health Act (except sections 135 & 136)
- Subject to a Community Treatment Order or Guardianship
- A Conditionally Discharged Restricted Patient
- Being considered for ECT or neurosurgery
- An informal in-patient in any hospital or registered establishment, being treated or assessed for a Mental Health Condition (this includes dementia)

They are legally entitled to an Independent Mental Health Advocate (IMHA).

The IMHA remit is to ensure the service user's voice is heard, that they are able to make informed choices, and that their rights are safeguarded. IMHAs provide both instructed and non-instructed advocacy, and largely adhere to the same principles as independent, non-statutory advocates. However, as statutory advocates IMHAs have additional rights in law:

The IMHA has the right to:

- visit and interview the patient in private
- access patients records
- visit, interview and get the views of anyone professionally concerned with the patient's medical treatment.

IMHAs should be enabled, as appropriate, to:

- have access to the unit and ward where the patient under detention is staying
- have access to facilities in the community where the patient is a community patient
- attend relevant meetings and ward rounds when asked to do so by the patient.

For more information about the IMHA role and remit please see
http://www.wales.nhs.uk/sitesplus/documents/865/Psychiatric%20Professionals%20leaflet%20pre%20imp%20update.pdf

http://www.mhmbcb.com/IMHA.htm

http://www.ascymru.org.uk/

6. Assessing Capacity

Any assessment of a person's capacity must start with the key principle that the person has the capacity to make the decision in question until this is shown to be otherwise. If all steps have been taken to help and support a person to make a particular decision and this has not resulted in them being able to do so, then they will need an assessment of capacity. When an assessment of capacity must be made it is vital to remember that this assessment is specific to the particular decision which is to be made.

An assessment that a person lacks capacity to make a decision must never be based simply on:

- their age
- their appearance
- assumptions about their condition
- any aspect of their behaviour

When assessing capacity to make any decision, consider all of the following:

- Does the person have a general understanding of what decision they need to make and why they need to make it?
- Does the person have a general understanding of the likely consequences of making, or not making, this decision?
- Is the person able to understand, retain, use and weigh up the information relevant to this decision?
- Can the person communicate their decision (by talking, using sign language, or by any other means)?
- Would the services of a professional such as a speech and language therapist be helpful?

Anyone can make an assessment of capacity, and anyone, including an independent advocate, can challenge an assessment of capacity made by someone else.

It is common to mistake communication difficulties as evidence of a lack of capacity. Take a look at the short case study on page 18. You will see that care home staff had assessed an 82 year old resident as lacking capacity and treated him as such for over 10 months. In just 10 minutes an independent advocate was able to establish that it was not a lack of capacity, but rather a difficulty with communication. This is a common mistake and is one which non-instructed advocates must be very aware of. Advocates must ensure this mistake is not being made in relation to someone they are advocating for.

Further information and a guide to assessing capacity can be found in Chapter 4 of the Mental Capacity Act 2005 Code of Practice.

7. Deprivation of Liberty Safeguards (DoLS)

The DoL Safeguards are a supplement to the Mental Capacity Act 2005. The aims and principles of the Mental Capacity Act (to empower and protect people who may lack capacity) and the tests for assessing capacity mentioned in section 6, must be considered in relation to the Deprivation of Liberty Safeguards.

The DoL Safeguards **only** apply to people who have been assessed as lacking the capacity to consent to the care or treatment they receive **and** who are:

- aged over 18
- in receipt of care in hospital or in a care home setting
- deprived of their liberty through the care they receive
- not detained under the Mental Health Act (sectioned)

If someone is deprived of their liberty this may mean they are:

- over-medicated or otherwise restrained
- not able to leave the hospital or care home where they are living
- not in control of all decisions about their lives
- not allowed to have visitors

As an independent non-instructed advocate working with someone without capacity, if you believe that they are being deprived of their liberty in some ways then you must check that there are ***Deprivation of Liberty Safeguards*** in place. These are intended to ensure the deprivation of liberty is in the 'best interests' of the individual.

What if there are NO SAFEGUARDS in place?

If you believe there is evidence to show that the individual is being deprived of their liberty and there are no safeguards in place, then you must raise this with the Care Home or Hospital Manager. The Care Home or Hospital Manager is known as the **Managing Authority.** After raising the concerns the result should be either:

1. The issue is resolved and the individual is no longer deprived of their liberty
2. The Managing Authority believes that the deprivation is necessary to keep the individual safe

If the Managing Authority believes the deprivation is necessary to keep the individual safe then they have a **legal duty** to apply for authorisation to deprive someone of their liberty. They have to apply to the Local Authority or Local Health Board. These are known are the **Supervisory Body.** There are set timescales for applying for authorisation, and limits to how long the deprivation can continue.

To put in place the Safeguards the Managing Authority will write to the Supervisory Body. The Managing Authority must explain the situation and what they are doing to manage it which is resulting in the deprivation of the individual's liberty.

A **Best Interest Assessor** will visit the individual to decide whether the deprivation of liberty is in their best interests. The best interest assessment will lead to one of three decisions:

1. The deprivation of liberty is thought to be in the best interests of the individual
2. Some of what is happening which is depriving the individual of their liberty is in their best interests, whereas other things are not
3. It is not in the best interests of the individual to be deprived of their liberty

In all cases the Supervisory Body will write to the Managing Authority to explain the decision of the Best Interest Assessor and ask the Managing Authority to explain that decision to the individual concerned.

If some of the things which are happening to deprive the individual of their liberty are found to not be in their best interests then the Managing Authority must remove these deprivations.

If some of the things which are happening to deprive the individual of their liberty are found to be in their best interests then **Deprivation of Liberty Safeguards** will be put in place to help protect the individual.

The DoL Code states:
'Every effort should be made to prevent deprivation of liberty. If deprivation of liberty cannot be avoided, it should be for no longer than is necessary'

If someone has DoL Safeguards applying to them, then they are also legally entitled to have a **Personal Representative.** This may be a family member or other independent person who will monitor the deprivation of liberty to ensure it remains in the best interest of the individual.

If the individual, their personal representative, or anyone else is unhappy with the individual being deprived of their liberty they have the right to ask for a review.

Deprivation of Liberty Safeguards and Code of Practice can be found in full at
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_087309.pdf

DoLS Easy Read version is available from
http://www.cuh.org.uk/resources/pdf/patient_information_leaflets/easy_read/deprivation_of_liberty_safeguards_and_you-easy_read.pdf

8. Capacity and Communication

Sometimes, as mentioned already, what can be taken to be a lack of capacity is in actual fact an inability to use a common communication method, such as talking or writing. Think about this example below, of an advocate working with an 82 year old man who had been living in a care home for 10 months:

After explaining who she was and why she was there the advocate considered that he seemed able to understand what was being said. She tried getting him to squeeze her hand but that was too difficult; when it was suggested he blinked his eyes he did so rapidly. He was then asked to blink once for yes and twice for no. Within 10 minutes it was possible to ascertain that he had some mental capacity. He wept when the [advocate] told him that she believed he understood what she was saying. That alone suggested he had capacity. It was not difficult to establish communication: sadly Andrew had at this point been in this home for 10 months with staff all assuming he lacked capacity and the ability to communicate.

This example is taken from a book called 'Taking their side; fighting their corner'. This is published by the Dementia Advocacy Network, and contains lots more information and case studies about non-instructed advocacy.

The link below will take you to the publication and to the full case study
http://dan.advocacyplus.org.uk/data/files/Taking_their_side/FINAL_COPY_TAKING_THEIR_SIDE_MARCH_2012.pdf

This example shows how crucial it is to distinguish between a lack of understanding and a lack of ability to be understood. Difficulties with communicating can all too often be mistaken for a lack of capacity. Imagine how scared, frustrated and alone this could make you feel.

Advocates who are providing non-instructed advocacy must therefore make every attempt to establish a form of communication with their advocacy partner. In some cases, this will mean that the advocates are actually able to provide at least some instructed advocacy.

Dementia Advocacy Network (DAN) has lots more information on their website
http://dan.advocacyplus.org.uk/index.php

Overall, the most important thing to remember is that you must always assume the individual has the capacity to instruct or to make decisions, until all attempts at communication have been tried unsuccessfully.

9. Communication Tools and Techniques

The extract above describes how an advocate attempted to communicate through squeezing hands or blinking; once for yes and twice for no. This is a common approach to trying to work out if someone understands what you are asking them and highlights how advocates are expected to be creative and persistent when trying to establish communication in order to assess capacity, and receive instruction.

Some useful resources and tools have been developed to help advocates with this. These include packs of picture cards to aid communication, and talking mats which use cards in different sequences to form sentences.

If you are planning to provide advocacy support to older people with a dementia, or to provide non-instructed advocacy in any way, it is worth considering buying or creating your own sets of communication cards and other communication tools, or accessing communication training.

For a basic guide to how to communicate with older people with a dementia see:
http://www.alzheimers.org.uk/site/scripts/document_pdf.php?documentID=130

Advocacy Services in Staffordshire (ASIST) sell a 'Generic Communications Toolkit'. On their website it says:

> The Generic Communications Toolkit enables creative approaches to communication. The Toolkit has been extremely well received by both advocates and workers in health and social care.

You can find out more by following this link http://www.asist.co.uk/gen_tk.html

Talking mats are an extension to basic communication cards, as the Talking Mats website explains:

> Talking Mats is an established communication tool, which uses a mat with symbols attached as the basis for communication. It is designed to help people with communication difficulties to think about issues discussed with them, and provide them with a way to effectively express themselves.

This description highlights the role talking mats could play in providing advocacy.

For more information follow the link to http://www.talkingmats.com/

Body language and behaviour are both very important and a good advocate will learn with experience to read the non-verbal signs which an individual is giving out. Around 90% of communication is non-verbal, involving facial expressions, gestures and touch. Non-verbal communication is increasingly important as dementia develops and as an advocate you need to be increasingly sensitive to body-language. It is also very

important to be aware of your own body language. If you are in a hurry, are upset, or frustrated for some reason, the person you are working with will often be able to sense this quite clearly. In some cases this could cause confusion or distress and make communication even more difficult.

9(i) Communication and sensory impairment

Advancing age is associated with sensory loss including hearing loss and deteriorating eyesight. For older people with a dementia, changes in their ability to communicate, or in their behaviour, can often be misattributed to their dementia. There is some evidence of under-diagnosis of sensory impairment in older people with dementia, and non-instructed advocates working in this field need to be aware of this. Ensuring the individual has the right glasses, correctly fitting dentures, or a fully functioning hearing aid can lead to a stark improvement in ability to communicate, and consequently to instruct.

9(ii) Capacity to instruct

In many cases, with time, commitment and creativity, it will be possible to establish a form of communication. It is only at this point that the advocate is then able to set about establishing 'capacity'. This can be done in a number of ways, by asking questions and assessing responses to these for understanding and consistency. Even if a form of communication can be successfully established it may still be the case that you will be providing non-instructed advocacy, at least in part.

It is useful here to refer back to the list of things to consider when making an assessment of capacity, taken from the Mental Capacity Act:

- Does the person have a general understanding of what decision they need to make and why they need to make it?
- Does the person have a general understanding of the likely consequences of making, or not making, this decision?
- Is the person able to understand, retain, use and weigh up the information relevant to this decision?
- Can the person communicate their decision (by talking, using sign language or any other means)?
- Would the services of a professional such as a speech and language therapist be helpful?

With a method of communication established it will be possible to begin to determine how much the individual understands about the decision they need to make, and the extent to which they can understand the different options and the consequences. That is, you will be able to assess their capacity to instruct.

10. Approaches to Non-Instructed Advocacy

When thinking about non-instructed advocacy different people thought about different ways of doing it and these became known as the different approaches.

It might be useful at this point to consider some of the definitions of non-instructed advocacy which have developed over time. This will help with seeing how different organisations viewed non-instructed advocacy when it was first considered. The definitions highlight the differences between approaches which were common in the early days of non-instructed advocacy. (NB: some of these definitions are no longer used by these organisations).

10(i) Definitions of Non-Instructed Advocacy

"[The non-instructed advocate] works with a client over a period of time by trying to get a sense of how they relate to their environment and the people around them. A crucial part of this process is to get a sense of the client's preferences and develop an understanding of the client's way of life."

POhWER Hertfordshire

[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

"[Non-instructed advocates] take a best interests approach to ensure that the person has the benefit of the full range of entitlements and services."

Mencap

"Non-instructed advocacy is taking affirmative action with or on behalf of a person who is unable to instruct an advocate due to issues of capacity e.g. comprehension or communication issues.

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 all relevant factors which must include the person's unique preferences and perspectives."

Action for Advocacy

You can see from the definitions above that they mention things like rights and entitlement; best interests; preferences; and understanding the individual. These were historically linked to an individual approach to non-instructed advocacy.

These approaches were commonly known as:

- Best-interests
- Person-centred
- Rights-based (including the Equality Act and the Human Rights Act)
- Observation (including The Watching Brief and the VIPS framework)

As independent non-instructed advocacy developed it started to seem that describing and using these approaches separately was not always helpful: focusing on a single approach could mean that the individual receiving the support of an advocate was not benefiting as much as was possible.

As a consequence focusing on adopting a single specific approach to non-instructed advocacy has lessened and it is now much more common to provide non-instructed advocacy in a holistic way. The definition from Action for Advocacy above has become widely recognised as best describing this holistic approach to providing independent non-instructed advocacy.

Advocates working with people who are unable to instruct them will now often use a mix of the different approaches most of the time. This is because the approaches naturally complement each other. Some in particular, like **Person-centred,** are much more about a principle with regard to working with individuals. As such this should be common to all people and all advocacy services, whether these are providing instructed or non-instructed advocacy.

Whatever approach an independent non-instructed advocate may choose to use they will always need to consider the things discussed already in this Guide. These include:

- the advocacy principles and code of practice
- the capacity of the individual to make any particular decision
- the principles of the Mental Capacity Act 2005
- the communication needs of the individual

In some cases, depending on the situation, the non-instructed advocate will also have to consider the Deprivation of Liberty Safeguards.

This Guide will now discuss some of the most important approaches to providing non-instructed advocacy, and how these are used in practice. This will focus on how the different approaches complement each other and should be considered and used together to provide the best possible quality of advocacy support.

First of all, we will briefly discuss the form of non-instructed advocacy called **Best-interests.**

11. Best-interests Advocacy and the Role of Statutory Advocates

When non-instructed advocacy was first talked about it was argued by some people that it was not really advocacy. I hope that what you have read so far in this Guide, and will go on to read below, will lead you to challenge this argument. Even without the capacity to give instruction it is possible to provide non-instructed advocacy which meets the well recognised standards and principles which apply to all advocacy support.

There is just one area within non-instructed advocacy which is still open to the argument that it is not really advocacy as we would understand it. This is the area of **Best-interests** advocacy. This is where the 'advocate' makes a decision about the care or treatment of someone without capacity, based upon what they consider to be in that person's best-interest. This is often a decision made by somebody who is not 'independent', perhaps a health or social care worker.

There are some advocates who have a statutory role, that is, advocates whose role is written in law. These include Independent Mental Capacity Advocates (IMCA) whose role is written into the Mental Capacity Act 2005; and Independent Mental Health Advocates (IMHA) whose role is written into the Wales Mental Health Measure 2010 (see section 5 above for more information). IMCAs play a role in ensuring that 'best-interest' decisions are taken in the proper way, and that the best-interest principles contained within the Mental Capacity Act are upheld.

There are four main elements to the IMCA work, the last of which relates specifically to best-interests decisions, including auditing the decision-making process and checking that the decision-maker is acting in accordance with the Act, and that the decision is in the person's best interests.

Best-interests advocacy is not something which would be used by independent non-instructed advocates, indeed, IMCA's are not best-interest advocates, they are appointed to ensure the best-interest process as laid out in law is adhered to. However, it is important to remember that 'best-interests' meetings often take place amongst health and social care workers, when trying to decide the best course of action for an individual. As an independent non-instructed advocate you may find yourself involved in 'best interests' meetings.

In these situations your role, as in all other situations, will be to reflect the wishes and preferences of the individual you are advocating for. You will do this through finding out about the individual and the kinds of decisions they made in the past, their preferences and their dislikes. The information in the following sections will help to explain how this can be done. It is always good practice to consider whether the individual you are working with is entitled to an IMCA, and to refer to this service as appropriate.

12. Being Person-centred

Whilst person-centred has been recognised as a non-instructed advocacy approach for a long time, it is in fact not a standalone approach but is rather the basic standard of good practice in providing all types of services, including independent advocacy. Being person-centred recognises a person's individuality, their personal history and personality. It seeks to understand the world from the individual's perspective. Being person-centred is something which should happen regardless of the type of service being provided, and regardless of capacity.

"Person-centred support can only exist in a sustained and effective manner when it is underpinned by certain core values such as inclusion, respect, independence and personal choice"

This quote is taken from a guide written for health and social care practitioners. The guide contains some useful information and ideas for independent advocates to consider and can be accessed using the link below:

http://www.shapingourlives.org.uk/documents/SWEx_Practitioners.pdf

Being person centred when providing independent non-instructed advocacy essentially means taking the time to build a full picture of who the person is. Through asking questions, finding evidence, and taking lots of time to communicate in any way possible, the non-instructed advocate will find out as much about the person as possible. It involves finding out what their preferences have been throughout life, in relation to all kinds of things, and then considering, for example, whether these preferences are enabled and supported by their current care providers.

Building up a picture of someone who may not have an easy form of communication, or little capacity to answer your questions can be hard. It requires and lot of time and patience and may require you to use communication tools and techniques. Finding out about someone can require the involvement of third parties, such as family, friends and carers. This is perfectly acceptable practice in independent non-instructed advocacy. However, it is always important to get a full picture from as many sources as possible: don't rely on just one person's views; try not to just listen to the loudest voice; and make sure you use more than one way to find out about the individual.

Finally, the independence of the non-instructed advocate from any service which may be provided to the individual is really important. The independent advocate can find out lots of things and use this information fully, without their judgement being clouded by any conflicting interest.

[1] Croft, S., Bewley, C., Beresford, P., Branfield, F., Fleming, J., Glynn, M., & Postle, K. (2011) Person-Centred Support: a guide to person-centred working for practitioners: Shaping our Lives in association with The Joseph Rowntree Foundation. Pg9.

13. Rights-Based Approach

As with being person-centred, the 'rights-based' approach to non-instructed advocacy is not standalone. All advocacy provision, whether instructed or otherwise, will involve a person's rights in some ways. 'Rights' can help the non-instructed advocate to make decisions, identify poor or unequal treatment and understand and fight for fair and legal treatment. Independent non-instructed advocacy makes sure that universal rights are upheld for all of us.

Rights-based non-instructed advocacy makes use of things such as the Mental Capacity Act 2005 and the Deprivation of Liberty Safeguards, which have been discussed already. These are used to ensure that people are receiving the care and treatment they are legally entitled to in ways which promote their dignity and respect. Rights-based advocacy can also draw upon written standards and procedures regarding quality of care and care provision.

As well as the Mental Capacity Act and the Deprivation of Liberty Safeguards, the other two main pieces of law used in rights-based advocacy are the **Equality Act** and the **Human Rights Act.** These are explained briefly below in order to help you to understand how to use them in your independent advocacy practice.

13(i) Equality Act 2010

The Equality Act 2010 could be useful in cases where you feel someone is being discriminated against. This could be because of:

- Age
- Disability
- Gender reassignment
- Marriage / civil partnership
- Pregnancy / maternity
- Race
- Religion and belief
- Gender
- Sexual orientation

These are known as protected characteristics. It is unlawful to treat a person less favourably than someone else when that treatment is for a reason relating to the person's protected characteristic.

For more guidance on the Equality act please see
http://www.equalityhumanrights.com/advice-and-guidance/new-equality-act-guidance/

For the full Equality Act 2010 please see
http://www.legislation.gov.uk/ukpga/2010/15/contents?view=plain

As an independent advocate, if you believe that someone is being treated unfairly and you have evidence that this unfair treatment is related to their age, gender or religion, for example, you can use the Equality Act to challenge this unfair treatment on their behalf.

13(ii) Human Rights Act 1998

As an independent advocate you will need to have an understanding of the Human Rights Act to be able to use it in your advocacy practice. There are two kinds of rights enshrined within the Articles of the Human Rights Act. These are known as **Absolute** and **Non-Absolute** rights. Included in non-absolute rights are **limited** and **qualified** rights:

- **Limited** rights are those which can be limited under specific circumstances
- **Qualified** rights are those which may be restricted under more general conditions, providing that the interference is lawful, legitimate, necessary and proportionate

Rights which are absolute can never be taken away. This includes the 'Right to Life'. Other rights might have to be balanced because of the rights of others, for example, the right to free speech. Another example is the right to freedom, which might have to be limited if someone breaks the law.

The threshold at which someone's human rights are accepted to have been breached is set very high. However, using the principles of the Human Rights Act can be very powerful when seeking to improve the care or treatment which an individual is receiving from a service provider. As a non-instructed advocate you should not shy away from quoting it! There are many sources of support for you if you are concerned that someone's Human Rights are at risk of being breached. Useful starting points for advice and support would be the Equality and Human Rights helpline or email, or the free human rights advice service run by Liberty:

Helpline: Phone: 0845 604 8810; Textphone : 0845 604 8820
waleshelpline@equalityhumanrights.com

Liberty Advice Service: 0845 122 8621
http://www.yourrights.org.uk/vas/

For more general information about the Human Rights Act and for some user friendly guides please see http://www.bihr.org.uk/resources/guides

For a full copy of the Human Rights Act please see
http://www.legislation.gov.uk/ukpga/1998/42/contents

Within the Human Rights Act there are 16 rights, which are called Articles. Page 27 lists the 9 Articles which are most important in non-instructed advocacy and provides examples of situations in which the Articles could be referred to.

A very important thing to remember is that the Human Rights Act places a **legal duty** on **public bodies** to uphold it. Public bodies include local authorities, local health boards, the police, and other services funded by public money.

Figure 2: Human Rights Act: Key Articles for Advocates & Scenarios for Use

Article 2 'Right to Life'

- Decisions about providing life saving treatment which involves judgements about quality of life
- To take reasonable steps to protect your life

Article 3 'Prohibition of Torture'

- Decisions about how best to safeguard vulnerable people from abuse
- The right not to be treated in an inhuman or degrading way. Degrading treatment means treatment that is grossly humiliating and undignified. The level of inhuman or degrading treatment which must be experienced to meet this Article is extremely high

Article 5 'Right to Liberty and Security'

- Decisions about whether or not to detain someone under the Mental Health Act, or whether to continue to detain them in a secure unit

Article 6 'Right to a Fair Trial'

- Decisions about all kinds of welfare benefits and appeals to benefit review panels

Article 8 'Right to Respect for Private and Family Life'

This is perhaps the most important Article in respect of advocacy for older people. It includes:

- Decisions about monitoring or reviewing care plans
- Decisions about evictions or tenancy hearings, and decisions about housing allocation
- Decisions about continuing artificial nutrition and hydration for some patients
- Decisions about domiciliary care provision
- Being able to live together with your family, and where this is no longer possible, being able to have regular contact with family
- Being able to live your personal life as you choose; being able to establish relationships with others
- Having access to information about your private life which might be in the possession of others; having personal information kept confidential
- Personal choice and dignity in respect of things including personal relationships, cultural needs, physical and mental well-being, and participation in community life
- Privacy concerning your body, including not being changed or unclothed in front of others, and not having a member of the opposite sex washing or undressing you if you have requested this does not occur

Article 9 'Freedom of Thought, Conscience and Religion'

- Decisions about the provision of services as these relate to people's beliefs

Article 10 'Freedom of Expression'

- Decisions about preventing individuals from speaking to the media about certain service issues; or decisions to withhold information from service users

Article 11 'Freedom of Assembly and Association'

- Decisions about allowing protests on the property of public bodies

Article 14 'Prohibition of Discrimination'

- Decisions about access to services and potentially all of the above

14. Observation

There are two views of observation as a tool for independent non-instructed advocacy. One is that observation as an approach to advocacy is different from other approaches in that it doesn't require a relationship to be developed between the advocate and the individual. Whilst in most situations observation would be used as part of wider non-instructed advocacy practice, it is possible for observation to be a standalone approach.

In this first view of the observation approach, it is essentially observing an individual and the way they are treated, or the way services are provided for them. Following the observation "the advocate simply compares the service user's circumstances against an 'ideal' set of circumstances that could be expected to apply to any person in that situation. If it is found that the service user is missing out on a particular service or entitlement, or is being treated less favourably than others then the advocate seeks redress on behalf of the individual".[2]

The second view, which is perhaps more widely held, is that observation is in effect an integration of other non-instructed advocacy techniques: being person-centred; understanding the individual's life and preferences; and examining and upholding the rights of the individual. Observational techniques involve noticing communication and intervention, and observing how the individual responds to different environments and circumstances. Very recent changes to CSSIW inspections have seen a move towards an observational approach, called SOFI, developed by the University of Bradford. This recognises that the lived experience of care home residents is crucial in assessing the standard of care, rather than simply ensuring paperwork and processes are legally compliant.

There are two main 'tools' which can be helpful when providing observational non-instructed advocacy for older people with a dementia. These are the 'Watching Brief' and the 'VIPS Framework'. The Watching Brief is not specifically aimed at this client group although is very suitable, whilst the VIPS Framework is specific to older people with dementia, although initially developed as a self-assessment tool for care homes.

14(i) The Watching Brief

The Watching Brief strongly promotes the second view that observation is something which happens as part of a holistic approach to independent non-instructed advocacy which uses a number of different techniques together.

The Watching Brief is a practice guide for advocates using non-instructed advocacy and was developed by Advocacy Services in Staffordshire (ASIST).

[2] Henderson, Rick 'Non Instructed Advocacy in Focus' (2007)

ASIST describes the Watching Brief as 'a policy for offering advocacy to people who do not have a system of communication that is recognised by the advocate'.

The Watching Brief was developed in part to address the concerns around non-instructed advocacy regarding instruction, which were examined earlier. In relation to this the introduction to the Watching Brief states:

[The Watching Brief] sets out a viable and principled approach to Non-Instructed Advocacy which retains the fundamental practices of advocacy whilst avoiding the necessity to revert to best interest approaches or a temptation to walk away.

The Watching Brief (ASIST)

The Watching Brief should be used as a tool only when all attempts to develop a system of communication and gain an 'instruction' have been made without success. The Watching Brief should also be used only in addition to and not instead of other non-instructed advocacy techniques. Before using the Watching Brief therefore, the following steps must have been taken:

1. **Being person-centred:** focusing on the individual and trying to find out what they want to happen
2. Considering the **rights** of the individual: raising issues where rights or standards are being ignored or infringed
3. Understanding the individual's life: finding out as much as possible about their likes, dislikes and preferences; seeing them as a unique **individual**

The Watching Brief describes '8 domains to ordinary living'. The 8 domains are:

Skills and abilities	Developing and using your skills to be as independent as possible
Community presence	Using, being involved with and contributing to the local community
Continuity	Having a past, present and future with key people and events in your life
Choice and influence	Influencing and making choices about your own life
Individuality	Being a unique and distinctive person in your own right
Status and respect	Being held in esteem and valued for who you are
Partnerships and relationships	Having meaningful contact with other people
Well-being	Feeling physically and psychologically well

If a proposal has been made with regard to the care or treatment of an individual, then the impact of this proposal on the individual can be worked out using the Watching Brief. This works by going through each of the 8 domains and examining the proposal in relation to them.

The Watching Brief is a very simple and effective tool which helps the advocate to 'ask questions that are relevant and effective, and which, most importantly, are questions that any reasonable person would ask'. The aim of the questioning is to establish the impact of the proposal, positive or negative, on the individual's life: to work out 'what's in it for them'?

For a full copy of the Watching Brief, which explains much more about the development and use of the tool, see:
http://www.asist.co.uk/AsistDocuments/the%20watching%20brief%20FINAL.pdf

14(ii) The VIPS Framework

The VIPS framework was developed as a self-assessment tool for care home service providers to measure the way they deliver their services to individuals with dementia. In particular it was designed to assess how 'person-centred' their care services are.

Despite the initial 'self-assessment' purpose, the VIPS framework provides a useful tool for the advocate, as an independent third-party, to assess how services and support are provided to an individual. The VIPS framework, in conjunction with other non-instructed advocacy techniques, provides a form of evidence which can be used to challenge decisions and suggest improvements in the individual's care.

There are four main elements to the VIPS tool:

V Valuing people with dementia and those who care for them
I Individual care and treating people as individuals
P Personal perspectives, looking at the world from their perspective
S Social environment, recognising the importance of relationships

Within each of the four main elements there are six key indicators which the service provided will be scored against. These are:

Valuing People

1. Is there a vision and mission statement about providing care that is person centred?
2. Are systems in place to ensure staff feel valued by their employer?
3. Are management practices empowering to staff delivering direct care?
4. Are there practices in place to support development of the workforce?
5. Are there supportive and inclusive physical and social environments for people with dementia?
6. Are continuous quality improvement mechanisms in place, driven by knowing and acting upon needs and concerns of the individual?

Individual Care

1. Are strengths and vulnerabilities identified in care planning?
2. Are care plans regularly reviewed?
3. Do service users have their own clothes and personal possessions?
4. Are service user likes and dislikes acted on?
5. Are staff aware of service users individual histories?
6. Are there activities available?

Personal Perspectives

1. Are service users asked for their preferences, consent and opinions?
2. Do staff have the ability to put themselves in the service users shoes?
3. What is the physical environment like: noise; temperature?
4. Are service users health needs given due attention?
5. Is challenging behaviour analysed?
6. How are service users rights protected; is there access to advocacy?

Social Environment

1. Are service users included in conversations?
2. Are service users treated with respect?
3. Is there an atmosphere of warmth and acceptance?
4. Are service users fears taken seriously; are they left alone?
5. Do staff help service users to be active in their own care?
6. Are service users able to use local facilities; are the local community involved in the home?

Like the Watching Brief, The VIPS Framework also provides a simple list of questions against which the treatment of any individual service user can be assessed. The VIPS Framework asks that the service provider, or in our case the non-instructed advocate, grade the service against each key indicator as follows:

Excellent
Good
OK
More work needed

As a recognised model of good practice and standards in providing dementia care, the VIPS Framework, like any other recognised standards, can be used by independent non-instructed advocates to promote improvements in the care and treatment of an individual. The sections of the VIPS framework which are most relevant to independent advocates are sections 2, 3 and 4.

15. Consent to Provide Non-Instructed Advocacy

One area which remains of some concern within non-instructed advocacy is that of consent, which is inherently connected to 'instruction', discussed throughout this Guide.

If an individual does not have capacity to instruct an advocate, they will also be unlikely to have the capacity to consent to the involvement of an advocate in their care. The issue of consent in non-instructed advocacy is discussed on the POhWER website, an independent advocacy agency working across the UK:

What about permission for non-instructed advocates to work with clients?

It is recognised that various groups of people, including some who cannot instruct an advocate, should be entitled to independent advocacy; either as a legal right (for example, under the Mental Capacity Act), or as part of 'best practice'. Other clients who cannot access advocacy for themselves may also benefit from independent input which is entirely focussed around understanding and advocating from their perspective.

Non-instructed advocates will be aware that they do not have direct permission for their work from clients, and will often have taken a referral from a third party. They will always try to ensure, as a minimum, that the client is content with their presence when they visit.

By building up a picture of communication possibilities and following leads from clients where possible, they will often be able to take informal direction from clients who cannot formally instruct.

Because they do not have direct consent from their clients, non-instructed advocates are supervised and supported by a line manager, to ensure that they have considered all options for their clients and continue working from an independent perspective.

Advocates' notes will show that they have kept the issue of consent under review.

http://www.pohwer.net/our_services/noninstructed.html

This information discusses the importance of supervision for non-instructed advocates, and of keeping detailed written notes of your advocacy practice. These are important in all aspects of non-instructed advocacy, not just regarding the issue of consent. Other things which have already been discussed as being important in non-instructed advocacy in general, are repeated here again in relation to consent. This includes the importance of making every effort to establish a form of communication, and thereby gain at least some level of consent from the service user.

Once again, in communicating with an individual regarding their consent for an independent advocate to provide support to them, non-verbal communication cues are very important to look out for. As one very experienced independent advocate commented:

'I feel that we are able to gain consent from people with communication difficulties; once again it's all about getting to know the person. Body language and behaviour often lets us know if they are consenting to us working with them or not'

Beverley Davies

The issue of consent is discussed in some detail in Hear what I say; Developing Dementia Advocacy.[3] A list of suggestions are made for dealing with consent and other ethical issues which arise in non-instructed advocacy:

- ☑ Treat consent as an ongoing process not a one-off decision
- ☑ Record how consent is obtained at the beginning and throughout the advocacy process
- ☑ Record the basis on which you form your views about what the person with dementia wants
- ☑ Explain to the person with dementia what you are recording and how this information will be used
- ☑ Try to establish the issue(s) that are important to the person with dementia and agree which to prioritise
- ☑ Continually reflect on what you are doing, why, and in whose interests
- ☑ Ensure that confidentiality is maintained and that you have consent to share information with others in the family or the service system
- ☑ Ensure that you receive regular supervision in which potential and actual ethical issues are identified and discussed with clear recording of agreed action and the reasoning underpinning those actions
- ☑ Ensure you have received appropriate training and education on issues of capacity, consent, human rights and other ethical issues

A full copy of 'Hear what I say; Developing Dementia Advocacy can be found at http://www.bjf.org.uk/web/documents/resources/HearWhatISay.pdf

[3] Cantley, C., Steven, K., Smith, M. (2003) Hear what I say; Developing Dementia Advocacy Services: Dementia North & Northumbria University, Newcastle upon Tyne.

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