Non Instructed Advocacy

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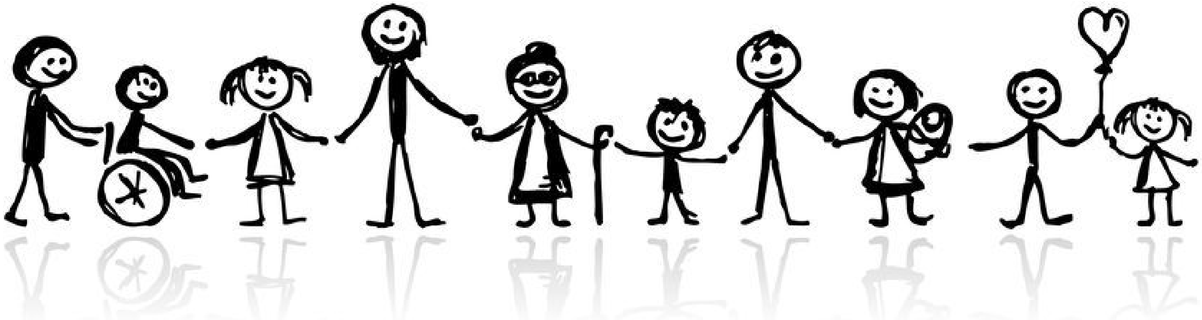
Introduction

Advocacy is often described as helping someone to speak up; to get their voice heard. But what should happen if the person wanting to be heard is unable to clearly instruct their wishes and views – how can the advocate find out and explore what it is they want to say or happen?

Non instructed advocacy is one approach that can be used when the advocate is unable to take instruction or cannot ascertain the person's wishes and feelings.

Non- instructed advocacy initially developed within adult services by advocates working with adults who lack capacity or have dementia. It is "based on getting to know the person and suggesting what their choices might be, rather than being asked by them for support or told how they want to be represented" (Lawton 2006:31). For many people, non-instructed advocacy is the only way an independent person can represent the person's views and preferences to the decision makers.



A non-instructed model recognises that people have fundamental rights and needs, even though it might not be possible to take instruction on their preferred courses of action.

People who experience difficulty in formulating or expressing their opinions are at a greater risk of being excluded from decision making processes, often because it is more difficult to interpret and understand a person who is using non-verbal communication or because the person cannot understand, due to learning disabilities, the choices which are available to them. For many people, advocacy can play an important part in ensuring their rights are treated as equally as others.

It is worthwhile to issue a cautionary word that non instructed advocacy should not be used simply when a person uses non verbal or augmented forms of communication method. Underpinning advocacy is the belief that every person can communicate (Lawton 2006) and has a right to have that communication taken into consideration when decisions are being made about that person. There are a limited number of extreme circumstances (possibly limited to being unconscious) when a person 'doesn't have any wishes and feelings' and the advocate should be extremely suspicious if someone describes any person as they 'can't communicate'. (Morris 2002)

Unfortunately however, there have been occasions when people and staff fail to hear what a person is saying simply because they do not understand the chosen method of communication.   There have been occasions for instance where professionals have completed sections on forms which detail the persons wishes and feelings by entering “he is unable to communicate and therefore his view is not available”. Advocates must take care not to perpetuate the mistaken belief that just because the person has difficulty in expressing her wishes and feelings that they do not have any.

The same is true for people who have a learning disability. Guidance and legislation explicitly asserts that a person who is learning disabled should not be assumed to lack capacity and that care should be taken to present relevant information in an appropriate way. This requires advocates to be creative in their approach in working with disabled people and use a range of augmented communication methods.

Often advocates find themselves asked to advocate with a person and the time limits imposed on them prevent them from undertaking any meaningful work on communication and building rapport, for instance a review meeting is arranged for one week's time. In these instances, good practice dictates that the meeting is postponed until the advocate has had enough opportunity to ascertain and present the person's wishes and feelings. If one week is not an ample period to collect such wishes, the chair should really reschedule; if this does not happen and the person's wishes and feelings are not represented the advocate could consider alternative options including complaints and using human rights legislation to enforce the requirement that the review process considers the wishes and feelings of the person.

The assumption therefore, is that the everybody can communicate and it will take time for the advocate to establish a relationship and communication method to ascertain their wishes and feelings.

Only, after the advocate has exhausted these methods and is unable to confidently represent the person's views and preferences should non instructed advocacy be considered.

What is NIA?

Non instructed advocacy takes place when a person is unable to instruct the advocate on what they want to happen. Similar to instructed advocacy, the advocate using NIA still supports the person to make what decisions they are able to make, can represent their views and takes action to protect their rights. Unlike instructed advocacy, because the person cannot clearly instruct the advocate on what choices they wish to make, the non instructed advocate must speak to others, research information and meet with the person to ascertain what their choices and wishes are likely to be.

It differs from instructed advocacy in a number of ways:

Firstly in instructed advocacy the advocacy would check out with the individual if they wanted advocacy and would explain the advocacy. In other words, they would establish if the person wanted the advocate to be there. In non instructed advocacy, the person may not be able to understand what advocacy is or how an advocate can help. They may therefore not be able to give consent to the advocate offering them support.

The advocate must decide whether to offer advocacy support

Secondly, in instructed advocacy the advocate would only take action with the knowledge and authorisation of the individual. The person receiving the advocacy would stay in control of the advocates action and the advocate would be client led AT ALL TIMES.

In non instructed advocacy the individual may not be able to give clear and consistent instruction which means the advocate has to identify what course of action is most relevant.

Thirdly, in instructed advocacy, the advocate adopts a non judgemental approach which does not judge the clients situation or desires. The advocate is then able to take a position which supports the individual no matter what it is they want. In non instructed advocacy, the advocate is the person deciding what issues should be taken up and as such is required to make judgements about the person's situation and life.

Accessibility

Comparison between instructed and non instructed advocacy (taken from DH IMCA materials):

Issue	Non Instructed	Instructed
Mandate	Advocate self appoints	Person appoints advocate
Consent	None given	Person gives consent for information to be shared or not
Issue	Advocate (decision maker) identifies the issue	Person identifies which issue(s) they would like support on
Process	Advocate decides and leads the process	Person leads the process - including when to end
Outcomes	Advocate identifies desired outcomes	Person decides what they want to happen
Review	Advocate reviews progress with manager	Person and advocate review progress together

Dilemmas in NIA

There are a number of dilemma's within non instructed advocacy which often present challenges to the very nature of advocacy.

Consider Jane who is 14 and lives in foster care. She has cerebral palsy and severe learning disabilities. Jane can make large movements with her arms and head but not fine hand or finger movements. She appears to have favourite people and smiles a lot, particular when other people smile and laugh. Jane also likes to press switches and tends to smile when she can hear the noise a switch makes. Jane cannot concentrate on any activity for long periods and spends a lot of time rocking in her wheel chair.

Sometimes she will vocalise and say recognisable words like “ball” or “tv” but it is not clear whether these words actually mean anything to Jane as she will often turn her head away when these things are offered.

Jane will have regular meetings to review her care and support plan and it is essential that the people making decisions about Jane ascertain and listen to her wishes and feelings. When people feel that they need independent support to have these included, they are able to contact an advocate however Jane is unlikely to understand what an advocate is and will not be in a position to instruct an advocate of her wishes and feelings.

Herein lies the problem; Jane is entitled to an advocate however is highly unlikely to seek advocacy support nor instruct an advocate. If Jane is unfairly denied access to advocacy she will receive unequal access to service which would be an unfair breach of her human rights.

However, a fundamental principle of advocacy is that of taking instruction from the client and having consent to speak and act on their behalf (Wells, 2007). Indeed the first stage of the advocacy process relies on the person taking control and trusting the advocate ‘to take only the action that has been agreed’ (Dalrymple + Hough 1995, p111). The fact that Jane has not consented to the advocacy involvement prevents her from controlling the relationship and making any form of instruction to the advocate.

Furthermore, during the involvement, an advocate may uncover wishes and feelings which Jane may not wish to be made public however since there has been no discussion of confidentiality or agreement Jane will be unable to prevent the advocate from sharing information.

What should an advocate do? Should an advocate even be appointed?

Practice Guidance

There are a number of recognised approaches in non-instructed advocacy that are available to the advocate. All of these approaches require the advocate spending time to get to know the person and how they communicate before approaching the advocacy issue.

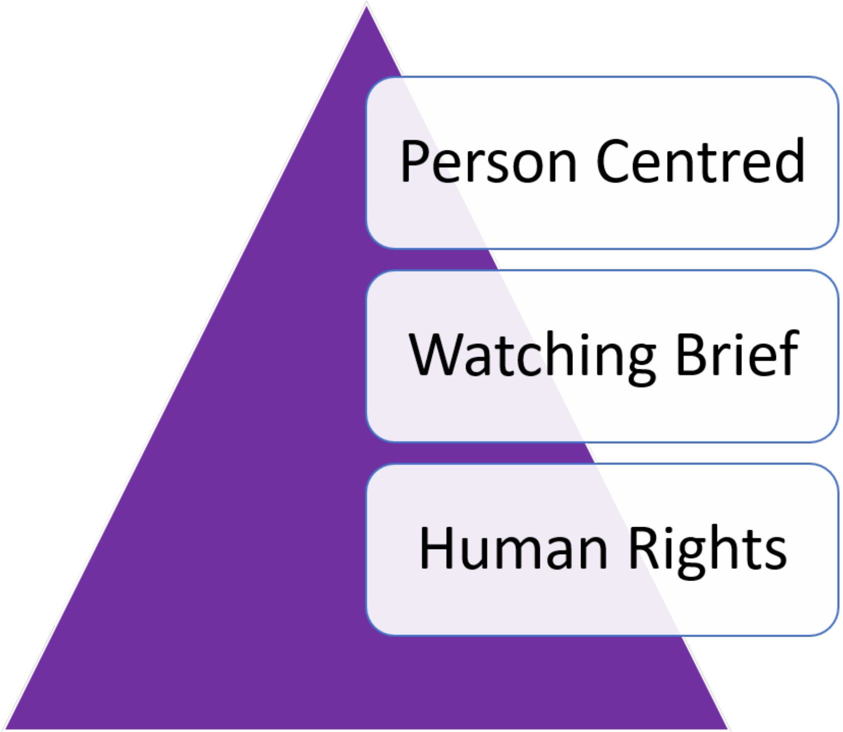
This step should in no way be compromised by logistical difficulties. Often advocates find themselves asked to advocate with a person with time limits imposed preventing any meaningful work taking place on communication and building rapport - for instance a review meeting is arranged for one week's time. In these instances, good practice dictates that the meeting is postponed until the advocate has had enough opportunity to ascertain and present the person's wishes and feelings. If one week is not an ample period to collect such wishes, the chairing officer should reschedule; if this does not happen and the person's wishes and feelings are not represented the advocate could consider alternative options including complaints or using human rights legislation to enforce the requirement that the review process considers the wishes and feelings of the person.

It is up to the advocacy service to establish clear expectations with referring bodies, especially social workers, carers, speech and language therapists and clinical teams, to ensure enough time is given to the advocate.

Advocates and commissioners must therefore recognise that using non instructed advocacy may not happen as quickly as other advocacy relationships and will require additional funding and support.

If after every effort has been taken, the advocate is unable to ascertain their wishes and feelings it may still be possible for the advocate to establish the preferences of the person. An advocate may be able to discover that the person rubs their head and rocks when Coronation Street is shown and when the Beatles is played on the radio. The advocate could then find out from people who knows the person what the head rubbing and rocking means; is it a good feeling or bad? By finding out the person enjoys listening to the Beatles, the advocate is not necessary promoting the views and wishes of the person but they can offer preferences which the decision makers can take into consideration when planning for the person's daily activities.

The three main approaches within Non Instructed Advocacy:



- Person Centred
- Watching Brief
- Human Rights

Person centred approach

The person centred approach is ideal when supporting a person through care planning

The person centred approach encourages engagement, time and patience and relies on the advocate finding out about the person's values and how the world may look like from their perspective. This endorses fundamental principles of advocacy in that it relies on the advocate building a relationship built on trust with the client (Wells 2007).

In the person centred approach the advocate should aim to see the person frequently and regularly to build up a picture of the person and what life is like for them. Once an advocate understands as much as possible about the person they can make suggestions about what the preferences of the person can be (Lawton).

Clearly, the danger is for the advocate to base such statements on their own bias or version of best interests. Advocates must therefore actively demonstrate their neutral view and evidence all claims that are made.

Thomas lives in a care home. He has severe learning disabilities and is currently being treated for depression. The care manager has noticed a lot of scratches on his arm which are bloodied and is concerned that this is a sign of deteriorating mental health. Whenever she asks him to what's happened and tries to clean them, he becomes very agitated and starts shouting at her 'get out' 'get out' 'get out'. A referral is made to the advocacy service to see if Thomas needs any help or information.

The advocate meets with Thomas at 10.00 in the morning and explains the advocacy role. Thomas doesn't look very interested and prefers to ask the advocate questions about their pets. When the advocate asks Thomas if he understands that he has rights and that he can see an advocate if he wants to, he doesn't answer. From Thomas' response, the advocate believes that Thomas doesn't understand what advocacy is and what the advocate can do.

The advocate asks Thomas if he would like the advocate to stay and Thomas shakes his head. The advocate says goodbye and arranges to see him tomorrow.

The next day the advocate sees Thomas at 2.00pm and he seems to be in a quieter mood, but pleased to see the advocate. The advocate tries to explain his role again but Thomas still doesn't seem to understand. The advocate takes time to also explain that the staff are worried that something is upsetting him and explains that he is separate from the hospital and doesn't work for the doctors.

The advocate then spends time every other day with Thomas for 2 weeks. From this he finds out that Thomas;

- *doesn’t like it when anyone sits on his chair in his bedroom*
- *does like looking out of the window in the day room but doesn’t go outside into the garden*
- *prefers to spend a lot of time in the morning with others but in the afternoon tends to be alone and gets agitated if people come into his room*
- *likes watching nature programmes, particularly in the afternoon*

The advocate uses this understanding to build up a picture of Thomas’ life and feeds these observations into Thomas’ care plan. The staff at the home realise that Thomas’ weekly care package often includes activities to take place in the afternoon. They try a new routine where the activities take place in the mornings and that he is given quiet and private time in the afternoon. They agree to review this in 1 months time. The care staff also agree to take Thomas shopping to buy posters of wildlife and gage his reaction.At no point did the advocate take instruction from Thomas about what he wanted to happen or if he wanted something to stop. However by developing a close relationship with Thomas was able to make suggestions about Thomas’ preferences.

Human Rights Approach

The human rights approach is ideal when you don't have a lot of time available

Peter Jenkins defines advocacy as the ‘activity of achieving rights for [people], whether through the process of acting on their behalf or assisting them to act for themselves (Dalrymple, Hough 1995 p36). This explanation sites advocacy as a clear strategy to promote rights and mirrors developments towards the latter half of the 20th Century which increased rights afforded to people notably through the Human Rights Act.

A rights based approach to advocacy involves focusing on the legal rights of the individual. It begins with the premise that we all have certain fundamental human that can be clearly defined and explicitly measured. The advocate can use existing law to ensure that the process undertaken by the decision makers uphold and promote the rights of the person. In instances where the advocate believes the individuals fundamental rights are being violated, he or she is empowered to intervene on behalf of the service user to challenge such violations and seek redress.

Questions an advocate could ask when pursuing the rights based approach;

- Have the decision makers taken every effort to ascertain the wishes and feelings of the person?
- How have these been taken into account?
- How have the opinions of carers, friends and professionals of the person’s wishes and feelings been taken into account?
- Has the advocate had adequate time to formulate a relationship and understand preferred communication methods?
- Who is important to the person and how do they see them?
- Has the person been invited to the meeting?
- What efforts have been made to ensure the participation of the person?
- What efforts have been made to present information in an appropriate manner?
- What needs have been identified?
- How are these being met?
- Are the person’s care plan, education plan and/or pathway plan up to date and current?
- Have contact arrangements been discussed and met?
- If the person has a care plan or treatment plan is it working?
- If the person has specialist communication need do their carers all know this well
- Does the person feel safe?

Watching Brief Approach

The watching brief is ideal when you have a specific decision and a choice of at least 2 options

The watching brief approach, developed by Asist advocacy services in Staffordshire, came in response to dilemma's faced by the advocate when dealing with people who did not have a system of communication that was recognised by the advocate.

Asist developed an approach which tests any given proposal against 'eight domains to a quality life' which are; competence, community presence, continuity, choice and influence, individuality, status and respect, partnerships and relationships, well being (Chris Sterling in Asist 2006). The advocate will ask questions which reviews the proposal against the relevant domains to great effect; "Whilst this technique sounds simple, practitioners often report how powerful just asking 'why' can be" (Asist, 2006).

The eight domains within the Watching Brief

When you use the Watching Brief you look at each option (or proposed decision) and explore how it will affect your partners life in each of these areas.

There are then two questions to explore under each domain:

1. Will the option have a positive or negative impact here. Will it enhance their 'competence' or 'community presence' or 'continuity' etc. How?
2. How important is this domain to the person?

- Competence
- Community presence
- Continuity
- Choice and influence
- Individuality
- Status and respect
- Partnerships and relationships
- Wellbeing

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This approach gives you a very clear framework to research the decision and its likely impact on your partner. It also provides a very robust way to raise concerns if you believe the decision may have an adverse impact onyour partner.

When using the Watching Brief you might ask questions including

- How will the proposal promote the person’s independence?
- How will the proposal manage risk?
- How will the proposal help the person maintain links with their past?
- How will the proposal involve the person in decision making?
- How will the proposal promote individuality?
- How will the proposal reduce prejudice and social stigma?
- How will the proposal provide opportunities for interaction with others?

Taken from Asist The Watching Brief 2006

Using one approach?

There is uncertainty within the sector whether these approaches should be used in isolation – depending upon the individual circumstances of each service user – or whether it is preferable to view the approaches as interchangeable and best used in conjuction with one another.

Our view is that you should use a **single approach**

The approaches were developed for different reasons

Each approach evolved in response to very different needs:

The human rights approach concentrates on looking at the rights of the person and asking questions if the advocate is concerned they are at risk of losing their rights and having any overlooked. It is best used when the 'state' is in power of day to day decisions and there is a clear legislative framework to safeguard the persons rights. It is also an attractive approach when time is tight as the advocate does not need to spend large amounts of time researching the person's life – instead the advocate looks at what rights are particularly relevant.

The person centred approach is very different to the human rights approach as it essentially requires the advocate to consider what life is like for this person. The advocate therefore spends time getting to know the advocacy partner, finding out preferences, needs and values. They are then able to help the professionals who are responsible for providing care, treatment or decision making to be person centred or raise concerns where neccessary.

The watching brief (WB) approach is very different from both of these approaches. Within the WB the advocates considers how a particular decision is likely to impact on a person's life. Thinking about a person's life in terms of 8 specific domains, the advocate looks at how the decision may affect each area. This approach is excellent to use when a decision is being considered (eg an accommodation move, SMT, Tribunal, care review, medication review, to remain at a placement). It is not possible to use the WB unless a decision is being considered.

The temptation to use more than one approach is present as people do not come in neat little boxes – so it is likely that an advocate will work with a person who needs an advocate to get to know them, uphold their rights and also has a decision coming up. It therefore feels appropriate to do a bit of everything.

However, a clear distinction should be made between the *approaches* which have developed within Non Instructed Advocacy and solid advocacy *principles.*These principles mean advocates, both instructed and non instructed, should always be person centred, promote rights and be independent. So it is therefore perfectly okay for the non instructed advocate to promote a person's rights or spend time being person centred whilst using the WB approach.

It focuses the advocates on outcomes

At the beginning of each advocacy relationship where non instructed advocacy is being used, the advocate should take time to consider a) why they are using NIA and b) what they are trying to achieve.

By choosing which approach is best, it will also make the advocate confident about why they are getting involved in this person's life, when the person hasn't explicity asked for an advocate. By spending time thinking about the non instructed advocacy role and which approach is best, there is a clear focus on what you hope to achieve (is it to report on rights, on what life is like or how a decision will impact on the person?). This focus on outcomes will guard against the misuse of NIA and avoid relationships which seem to go on and on without really resulting in anything.

The advocate is clear on when to withdraw

A common challenge within NIA is knowing when to end your involvement. Within IMCA decisions the end point is clear – usually when the report is submitted and the decision maker makes their decision – however in many types of advocacy where NIA can be used, there may not be an obvious ‘end’ point and it is left to the advocate to decide when to end and close their involvement.

By deciding early on which approach is most effective, the advocate is also thinking about their goal and likely timescales.

This should in no way prevent a flexible approach – so changing from one approach to another is entirely possible. However the reason for changing should be clear and not a thoughtless one meandering in between human rights, person centred and WB.

It ensures transparency

Many health and care professionals lack a solid understanding of what advocacy is. Expecting professionals therefore to understand what NIA is a big ask. By deciding early on which approach is most appropriate the advocate can clearly communicate to others what they are doing and why.

This also requires the advocate to talk to the professionals and carers to establish what they think the advocate can do and how the advocacy involvement can be helpful. This helps communicate expectations and limitations to the role and generally advances understanding of what advocates do.

Not only does this make the advocacy work transparent – but it gives the non instructed advocate credibility as they confidently refer to recognised approaches within NIA and can demonstrate they are not just making it up as they go along!

Further reading and references

A Voice of Their Own: A Toolbox of Ideas and Information for Non-instructed Advocacy Annie Lawton, BILD Publications

A lot to say: a guide for social workers, personal advisors and others working with disabled children and young people with communication impairments MORRIS Jenny, SCOPE 2002

Having a Voice: An Exploration of Children's Rights and Advocacy by J. Dalrymple and Jan Hough, Venture Press, Birmingham,

Dementia advocacy, Working with Older People, Emerald Group Publishing Limited Sally Wells 2007,

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