

## **Non-instructed Advocacy in Focus**

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## **Introduction**

This article aims to stimulate debate about the relative merits of what has become known as 'non-instructed advocacy'. At present there is hardly any available literature on the subject. Little is known about where the term 'non-instructed advocacy' originated; how it is defined; what it involves and how it differs from 'instructed advocacy'. The lack of information resources is surprising given the prominence of the issue within advocacy circles. In addition, it is at the heart of proposals for advocacy contained in the Mental Capacity Act 2005 (Department for Constitutional Affairs, 2005). The Act makes provision for Independent Mental Capacity Advocacy (IMCA) to be available for people lacking capacity who are faced with life-changing decisions. The new IMCAs will very often be acting without permission or instruction from the service user.

### **What is non-instructed advocacy?**

Although the term non-instructed advocacy is widely used by both advocates and those within the wider health and social care sector, there is currently no nationally agreed definition of what constitutes non-instructed advocacy. Part of the problem is that there is very little literature on the subject, either academic or 'grey' literature. An Internet search using the keywords 'non-instructed advocacy' and 'non-directed advocacy' produced the following definitions:

“[Non-instructed advocacy is] redressing an abridgement of a legal right or therapeutic or social entitlement that imperils the incapable client's health, estate, personal security or human dignity.”

***PPAO Toronto***

“[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***

There is much cause for concern here. It is apparent that there is confusion and inconsistency in the above definitions, both in terms of *aims* and *methodology*. On the one hand, the role of non-instructed advocacy is to *safeguard* the basic human rights of the service user, by adopting a 'best interests' approach to advocacy. Here, the advocate is acting as a **'Watchdog/Negotiator'** whose primary function is to ensure the person has access to appropriate services and support. The Watchdog/Negotiator role is one that requires little in the way of relationship between the advocate and service user. 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.

#### **Case Study: Watchdog/Negotiator**

An advocate visits John in the residential home. Whilst observing John in the dining room, the advocate notices that John is not given a pudding although all the other residents get one. When the advocate asks staff about this, she is told that John is a slow eater and takes longer to eat his main course. Hence, there is insufficient time for John to eat his pudding before the dining room is cleared. The advocate takes this up with the catering manager and requests that John be given a) extra time in the dining room b) support to eat more quickly or c) the option to take his pudding to his room. The advocate argues that John is being treated less favourably than his peers are as a

result of his disability. The catering manager agrees to try the various options put forward by the advocate.

The above case study clearly illustrates the potential benefits of the advocacy role. By intervening on John's behalf, the advocate ensures a 'level playing field' in which John is not unfairly disadvantaged because of his disability. The catering manager agrees to change his position towards John and try other options. However, the intervention required little of the advocate by way of forming a relationship with John. She simply observed an injustice and acted accordingly. No effort was made to seek instruction from John, nor to check that he actually liked or wanted pudding.

In contrast, a number of the above definitions also imply that non-instructed advocacy is deeply rooted in the *relationship* between the advocate and service user. Here the role of the advocate can be characterised as the '**Articulate Friend**'. The function of the Articulate Friend is to ensure that the person is healthy, happy and feels, to the extent that it is possible, *in control* of their own life and circumstances. This can only be achieved effectively if there is a long-term, trusting relationship between the advocate and service user. The advocate needs to know the person well enough to be able to comment on their preferences, likes and dislikes and the meaning of their expression whether verbal or non-verbal. Similarly, the service user should feel able to place their trust in the advocate and know they are on their side.

### **Case Study – Articulate Friend**

Rob has been Jodie's advocate for the past 6 years. During that time Jodie has been in and out of a number of unsuccessful residential placements and has now settled happily into her own flat with 24-hour support. Rob has been able to observe Jodie's behaviour and interaction with others in a range of settings and has learned to interpret her gestures and body language (Jodie has no formal communication). When a second resident is moved into the flat, Rob notices that Jodie becomes very agitated and upset when they are in the same room together. She is becoming aggressive towards the other resident and has broken several household items. Rob explains to the Manager that Jodie does this when she is unhappy or feels threatened by people around her. He recommends that a review of the situation be carried out immediately.

### **Seeking a Common Definition**

The above section describes two distinct approaches to non-instructed advocacy that on the face of it appear to have little in common. However, both approaches result in a positive benefit or outcome for the service users. In this sense there is no right or wrong approach to non-instructed advocacy, simply differences in interpretation. Hence, any attempt to develop a common definition needs to reflect and accommodate such differences rather than favour one over another. Both the Watchdog/Negotiator and Articulate Friend approaches are *legitimate* in the context of non-instructed advocacy.

In seeking a common definition, it is essential to incorporate a description of:

- *who* the advocate works with (ie who is the service user)
- *what* the advocate does with and on behalf of the person
- *why* the advocate acts in this way (ie the benefit or outcome for the service user or the problem the advocate is attempting to solve).

Consider the following definition:

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

**(Henderson, 2006)**

### **NIA in Context**

Non-instructed advocacy is not new; in fact all advocacy has its roots in a common desire to safeguard the rights and interests of the most vulnerable people in society. During the 1980s, as advocacy began to emerge as a force for change in the United Kingdom, much of the focus was on the plight of the many thousands of people incarcerated in long-stay institutions. The first generation of advocacy groups were at the forefront of exposing the appalling

conditions inside institutions for people with learning disabilities or mental health problems (Henderson and Pochin, 2001). A great many of these people could by modern standards, be described as being unable to give instruction or lacking the capacity to make informed decisions. The paucity of opportunities to develop communication skills and a stark lack of choice and control over day to day decisions led to people being disempowered and isolated within the institutions. Hence, non-instructed advocacy was out of necessity the *de rigeur* approach: advocates were either unable to obtain instruction from service users or felt compelled to act in advance of receiving it. In addition many institutions operated on a 'culture of fear' which effectively silenced even the most articulate of service users, who were afraid of reprisals from staff if they complained. Early advocates were often faced with a stark choice – act without instruction or collude with the system.

The move away from institutions and towards community based services meant that advocates, in theory at least, had more flexibility of approach. The growth of the user/survivor and self-advocacy movements in the 1990s brought greater focus on the importance of advocacy as a means of empowerment. The role of the advocate was now to support the service user in finding and using their own voice, rather than 'speaking for' the person. In this model, advocates take their instruction directly from service users and do not take any action without the person's express permission. However, for a significant minority of individuals with severe or complex needs, this level of instruction was beyond their reach. This may be because they lacked either

the capacity or the communication skills to be able to fully engage an advocate in this way.

### **What is the difference between NIA and instructed advocacy?**

Essentially the difference lies in the advocates' ability to receive instruction from the service user. With Instructed Advocacy (IA) the advocate is clearly instructed by the service user and works to an agenda set out through a process of negotiation between the two parties (although always user-led). In IA the role of the advocate can be defined as:

- Establishing an open, trusting relationship with the service user
- Ascertaining what the service user wants from the relationship
- Identifying goals and desired outcomes from the advocacy process
- Gathering information on behalf of the service user
- Representing the person's views, wishes and concerns to third parties
- Reviewing progress/ redefining goals in light of experience.

With non-instructed advocacy there are significant differences in the way the advocacy process is *established, led* and *enacted* (Wells, 2006). There is a requirement of advocates to use a far greater level of judgement than in instructed advocacy. The issue of *judgement* is a key factor in defining non-instructed advocacy. Without a clear steer from the service user, the advocate is obliged to *judge* the precise nature of the person's concerns; the best

methods for seeking redress; and the criteria for a successful outcome. This level of judgement places a degree of burden on the advocate which does not exist in instructed advocacy, where each of the above criteria is agreed and assessed by the service user through negotiation. There are implications here for the non-instructed advocate in terms of training and skills, supervision, support and accountability. For advocacy schemes, funding bodies and other stakeholders such as relatives, there may be a case for greater scrutiny of the advocate's practice. As levels of judgement increase, so the potential for acts of *poor judgement* also rise exponentially. The advocate should be able to clearly explain how and why they came to a particular conclusion or pursue a particular course of action. What criteria did they use? Was this based on the views and wishes of the service user? What factors were taken into account (eg social, cultural, behavioural?). What options were considered and discounted and why? These and other questions are legitimate in the context of judgement-based actions.

At the heart of the non-instructed debate are the interrelated issues of *communication* and *capacity*. The lack of a formal communication system (for example speech or via sign language) does not in itself warrant a non-instructed advocacy approach. In this instance, the challenge for the advocate is to establish a system of communication that enables the service user to give instruction. Much work has been done on alternative forms of communication such as pictures and symbols; assistive technology such as computer software; and personal communication 'passports' (Lawton, 2006). Advocates need to be aware of and competent to use these various

technologies to establish a rapport with the service users wherever possible. There are training and resource issues here as many of these alternative communication methods require time and practice to get right.

However, it is not always possible to establish a system of communication that enables the person to give instruction or express choices and concerns.

Often, people lack the capacity to make decisions on complex issues.

Although seeking instruction from the service user should always be the advocate's starting point, it is important not to get 'stuck' or feel unable to act simply because no instruction is forthcoming. People who lack capacity have as much, if not more, of a right to independent support and representation as other people. Advocates should feel entirely comfortable in adopting a legitimate, non-instructed role where all efforts have been made to establish a rapport with the service user.

#### **Four Approaches to Non-Instructed Advocacy**

During the course of our work we have identified four distinct yet complementary approaches to NIA. Each has similarities and differences to the other approaches. Taken together, these approaches represent a sophisticated framework for developing best practice in this area. The approaches described are not mutually exclusive and are best seen as being different points on a continuum of non-instructed advocacy approaches. There are time, resource and skills implications for advocates and advocacy schemes in each of the various approaches. A balance needs to be struck between the resources available (time, money, skills, priorities); the perceived

importance of a long-term relationship between the advocate and service user; and the urgency or severity of the service user's situation. There may be other approaches that we are currently unaware of, or it may be that one or more of the approaches below are deemed inappropriate or 'not advocacy'. We hope to stimulate debate in this area with a view to identifying emerging best practice that can be disseminated nationally.

### **Approach 1: Human Rights Approach**

This approach begins with the premise that we all have certain fundamental human rights that can be clearly defined and explicitly measured. Where the advocate is of the view that an individual's 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. This may be the case where the service user is being denied food or drink, is being restrained or held captive, or is the victim of abuse. With a non-instructed advocacy approach, the role of the advocate is to ensure, using a variety of means, that the basic human rights of service users are promoted, defended and where necessary used to take affirmative action on behalf of the service user. Where the advocate believes that the injustice being done to the service user may be illegal, they should seek appropriate legal representation for the person.

### **Approach 2: Person-Centred Approach**

This approach is based on a long-term, trusting and mutually respectful relationship between the advocate and service user. In spending time with the service user, the advocate builds up a picture of their lifestyle, preferences and needs which is aided by the advocate's independence from service systems. The advocate is in a unique position to describe and, where necessary, represent the person's views. In doing so the advocate is raising the profile of the service user's unique perspectives, and as such is promoting a person-centred approach to service delivery and decision making.

### **Approach 3: The Watching Brief Approach**

'Watching Brief' was devised by advocates from ASIST advocacy scheme in Staffordshire. This approach centres around 8 quality of life domains which are used as the basis for a series of questions that the advocate can put to the decision maker on behalf of the service user. Watching Brief provides a framework for challenging the decision maker in a non-confrontational way and encourages service providers to put the service user at the centre of the decision making process.

### **Approach 4: Witness-Observer Approach**

There is a real value in the advocate's role in being an observer or witness to the ways in which services interact with the service user. The advocate may see or hear things that are unacceptable or which pose a threat to the person's well being. Conversely, the advocate may also pick up on the service user's preferences and pleasures, which can in turn be used to enhance

positive relationships. The witness-observer approach does not require the advocate to make judgements or assumptions, merely to report on the facts of his or her observations. In doing so, the advocate may be bringing to the attention of service providers or decision makers factors that they had not previously been aware of or taken into account. Examples would be lack of stimulation; dislike of certain people, foods or activities; appropriateness of routines and systems; the communication function of key behaviours or actions.

## **Conclusion**

Non-instructed advocacy is an emerging form within the wider advocacy context, not least because of the implementation of the Mental Capacity Act 2005. Advocates faced with people who lack capacity to make certain key decisions or do not have formal communication systems are faced with a choice – advocate using non-instructed techniques or walk away from a potentially vulnerable person. 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.

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