



## **Good practice 4: Improving access to forms of advocacy such as citizen and non-instructed advocacy to all who are unable to represent their own views and feelings easily**

As long ago as 1995 the vital role of trusted advocacy in facilitating access to complaints procedures was highlighted by Ken Simons.<sup>1</sup> He suggested (1995a p69-70) the role of the advocate could include

- Providing reassurance
- Crystallizing the complaint
- Dealing with correspondence
- Offering informed, independent advice
- Speaking for a complainant
- Chasing the progress of complaints
- Acting as a witness

**The role of advocacy:** Because of its independence and objectivity, advocacy can have a very clear role to play in supporting people who face barriers in complaining. It can be of particular value where staff, family carers or others may try to influence (or may be *perceived* as trying to influence) the person or to have an interest in whether or not they make the complaint.

**For example:** staff might see that changes in day services are clearly distressing to Teresa but if they support her to make a complaint they could be seen as using her to voice concerns about their jobs. An advocate may seek information and clarification from other people who know Teresa well but will then look at the situation simply from Teresa's perspective.

**About advocacy:** Information about advocacy can often be confusing because of the different forms it might take or the words people use to describe it. In terms of making complaints, we probably need to think about:

- **Self-advocacy** – someone 'speaking up' for themselves
- **Representational advocacy** – someone speaking on behalf of another person



- **Non-instructed or non-directed advocacy** - where someone cannot ask an advocate to raise issues on their behalf. The advocate uses different ways of finding out what they *might* want to say
- **Peer advocacy** – where someone with similar experiences or using the same services acts as an advocate for others in the same situation

In addition, a person might be supported by a paid ‘professional’ advocate for a specific, crisis or time limited issue. Alternatively, they might be supported by a volunteer ‘citizen’ advocate who might work with them over a longer period of time. For both of these types of advocacy, there will be a referral process and possibly a waiting list. The Mental Capacity Act<sup>2</sup> sets out some situations where people who are assessed as lacking capacity have a statutory right to support from an Independent Mental Capacity Advocate<sup>3</sup>.

**Advocacy and Complaints:** Making a complaint involves self-advocacy, but most definitions of self-advocacy really don’t sound like they apply to people with complex communication needs:

- Speaking up for yourself
- Standing up for your rights
- Making choices

Advocacy can support people to challenge the assumption that only people who use words have something to say. However, the advocate must be very clear about how they are doing this and what their role is in supporting the person. Other sections of this pack discuss ways of interpreting and supporting communication for people who may not use words. The role of an advocate is to support this self-advocacy by ensuring that others not only ‘hear’ but ‘listen to’ and act upon what the person may be communicating.

**For example:** Others might recognise that Andy’s body becomes rigid and he holds his head when there is shouting nearby. The role of the advocate might be to bring this communication to the attention of others and request that Andrew eats his lunch in a quiet area of the day centre or to complain to the housing association about noisy neighbours.

**Non-instructed advocacy:** If advocacy is about giving people control by enabling them to direct how their wishes and feelings are represented, there is



a dilemma when someone is unable to instruct an advocate. A person may not be able to instruct for a number of reasons, including:

- Communication difficulties.
- Lack of comprehension.
- Severe learning disability.
- Dementia.

There is a national debate around both **if** and **how** an advocate can represent the thoughts, wishes and feelings of a person unable to instruct<sup>4</sup>. However, we believe that everyone, no matter how profound their needs, should have the same rights to involvement and to protection as everyone else. This includes the right to complain.

There are a number of commonly accepted approaches to Non-Instructed Advocacy and these are discussed in more detail below.

**Advocacy in practice:** Advocacy as a tool to support people to complain will only be credible if the advocate can demonstrate that they:

- Know the person well and understand their likes and dislikes (or can 'evidence' what leads them to believe they know what the person wants)
- Can represent them or support them to self-advocate without bringing in their own views or agendas

When working with a person who faces barriers in communicating, the advocate must be very clear about their own role and what leads them to suggest a particular course of action. The key is to spend time getting to know the person, understanding what their likes and dislikes might be and feeling confident to represent these to others. Non-instructed or non-directed advocacy is often used to describe this type of advocacy. Advocates will always assume that the person can communicate their wishes in some way but there are a number of different approaches to non-instructed advocacy that advocates might use to support this:

- Person-centred
- Witness-observer
- Rights-based
- Watching Brief



Citizen advocacy is a good example of a **person-centred approach** where a volunteer works with someone over a long period of time. This enables them to build a picture of what life might look like from their perspective and what their hopes and aspirations might be. For any advocate, and in nearly every situation, the key is to spend time with the person rather than feeling they have to immediately rush into action and demonstrate that they are doing something.

**For example:** An advocate might observe that Peter is very alert and communicative when supported by particular members of staff. With others he behaves very differently and keeps his eyes closed and his head turned away. Over time, and by watching him with different people and in different settings, this suggests to the advocate that Peter prefers to be supported by young male workers. When Peter is allocated an older female key-worker with whom he does not appear to interact, the advocate feels confident to challenge this on his behalf and explain why he might prefer a male to support him.

In many cases, the advocate is pulling together what other people might be saying but these messages become really powerful when they are backed up with examples of events that show how this has been found out or by referring to photographs, life story work or a person centred plan (see more information on person centred planning in **good practice suggestion one: getting to know the person really well**).

There may be some situations where there is an urgent need to keep the person safe or establish what their view might be in relation to a more abstract decision. Where there are no opportunities to observe and build a picture of what might be important to the person, the advocate must clearly demonstrate their neutral view while questioning what is happening. A **rights-based approach** can provide a good starting point where there is no time to build up an in-depth picture of the person's likes and dislikes. The advocate focuses on the person's legal and moral rights, particularly in relation to the Human Rights Act (1998)<sup>5</sup>. The advocate also thinks about the responsibilities that other people and services have towards the person and whether they are being treated fairly and without discrimination. The advocate will look at any situation or proposed decision and ask:



- Have all the options been considered?
- Where the person's preferences and dislikes can be identified, have these been taken into account?
- Are there any particular agendas being pursued?
- Are the person's civil, human and welfare rights being respected and upheld?

**For example:** Sarah is not able to attend art classes at the local college, as they do not have facilities to support her personal care needs. Her family do not know whether Sarah wants to go or not but her interest in art at the day centre suggests she might enjoy it. The advocate could challenge the college under the Disability Discrimination Act and also remind them of her human rights to access education. Once she is able to attend, the advocate can observe Sarah in sessions and decide whether she enjoys this particular class or not.

The **Watching Brief**<sup>6</sup> has been developed by Asist to provide a framework for advocates to raise questions on behalf of a person in situations where they cannot understand or find out what they might want. It is based on eight domains to a quality of life and is a way of suggesting questions that advocates might ask.

**For example:** In relation to Sarah accessing college, the advocate might take the heading of 'community presence' and ask why she can only do art in specialist provision at the day centre, rather than a mainstream facility. By doing this the advocate makes it clear that they are not suggesting a view or a particular course of action – merely raising a question on Sarah's behalf.

**Summary:** The role of the advocate is to be independent and objective and very clear about their role. Supporting someone to complain will involve either referring to human and legal rights or knowing the person well enough to suggest that they may not be happy with a particular decision or situation. The advocate will need to be clear about the approach they are taking and the 'evidence' on which they base any questions or assumptions about what the person might want to happen. As in any other work with people who face significant barriers to communication, the complaint will usually be based on learning about the person over a long period of time, rather than an instant



judgement. Advocacy can work with and support other strategies discussed in this pack in order to ensure people listen to those who are 'seldom heard'.

## Some conclusions

The role of advocacy in all its forms is increasingly recognised as important.

All Trust Boards should ... have effective systems in place to deliver effective, 'reasonably adjusted' health services. This should include arrangements to provide advocacy for all those who need it ...

### **Recommendation 10 Healthcare for All 2008**

There are specific rights in law for advocacy in some circumstances ... The Independent Mental Capacity Advocate (IMCA) service supports people who lack capacity and who have no family or friends to support them when serious decisions are taken in their lives ... Independent Mental Health Advocates (IMHA) for 'qualifying' patients in England from April 2009 ... independent advocacy should always be provided where children are the subject of a child protection plan and/or care proceeding. It also says that advocacy and self-advocacy should be made available to help parents engage with, and access, services.

### **Valuing People Now, page 102**

Being able to speak up about decisions which affect your life relies on being given the right information to make those choices. For this reason *Putting People First* says that people who need support in their lives should have access to better support, information and advocacy so that they are able to navigate the health and social care systems.

### **Valuing People Now, page 102**

Regional Valuing People leads will drive a programme of leadership support involving the national and regional forums to build and strengthen self-advocate leaders ... will support service commissioners to help them commission a broad range of high-quality advocacy services and support .... The National Directors will appoint a programme lead for advocacy to ensure that the national advocacy programme and funding focuses on supporting advocacy to achieve a greater impact.

### **Valuing People Now, page 103**



However advocacy is not without controversy, particularly when non instructed advocacy is involved, as the two quotes below illustrate.

... we have not had a situation where we would use non-instructed advocacy in a formal complaint; this is because we feel that to take forward a complaint we would have to have instruction from our advocacy partner .... Our concern about complaining on behalf of people is that this would involve us having an opinion on such issues as quality of care, appropriate placements/treatment, etc. We spend such an amount of time explaining to providers that we do not have an opinion and cannot give advice that we believe that this would be confusing and outside of the advocacy role.

**Manager of advocacy organisation**

There is sometimes a hesitation from some advocates to take children's issues to the level of a formal complaint due to not definitely knowing it is what the person wants you to do. However, complaints systems also entail representation on behalf of children and young people who use services, which means that many issues can be pursued from a children's rights agenda and enable valuable insights and experiences to be heard and acted upon

**Martin Goodwin, D.I.C.E**

There is no single simple answer to the question of whether advocates can ever be involved in complaints on behalf of an advocacy partner who is unable to make a formal instruction. Advocacy organisations have taken different stances on this issue whilst adhering to similar general principles of conduct. Some of this is explored in the recent SCOPE publication 'When communication gets tough'<sup>7</sup>. However we believe that people who are seldom heard have the same rights as anyone else to have their 'complaints' heard and so we must not exclude them from a process simply because they lack capacity or formal means of communication. We offer the following thoughts to guide further thinking on this matter

1. The rights of the individual with learning disabilities concerned must always be paramount and central to decision making.
2. Advocates have a responsibility and duty of care in relation to safeguarding vulnerable adults and in some circumstances may be the only person available to act on their behalf.



3. The decision making framework of the Mental Capacity Act (2005) is relevant to consider. There is a legal requirement to uphold the principles of the Act for all paid workers. The Act provides a legal framework for decision making on behalf of people who are unable to demonstrate capacity for a particular decision providing the best interest checklist is applied.
4. The regulations of the joint complaints procedure (section 5.2<sup>8</sup>) make it clear that there are circumstances where somebody may make a complaint on behalf of another person, including when the person lacks capacity to formally consent to this.
5. It is important that an advocate is clear about the role they are taking in any situation. Reference to the code of practice<sup>9</sup> and standards<sup>10</sup> for advocates found on the A4A website is useful in this respect.

Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice.

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.

Advocates should be clear about the nature and extent of their role. They should understand the boundaries of their own advocacy role and non-advocacy roles such as mediation and advice giving. Advocates should not act outside of these boundaries. Advocates should seek permission to refer people on to other agencies where appropriate.

**Action for Advocacy Code of Practice**



6. An advocate who find themselves in the position of wanting to make a formal complaint on behalf of a person who is unable to instruct them has various options open to them. This includes making the complaint whilst making it very clear that they are doing this in the person's best interests and not as part of their formal advocate role **or** referring to and liaising with other agencies that will instigate the complaint on their behalf.

Some advocacy services provide specific services for people with profound and multiple learning disabilities. You can read more about them in **resource 3**.

### **Further resources:**

#### **Advocacy organisations**

**Action for Advocacy** [www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)

**Advocacy Resources Exchange (ARX)** [www.advocacyresource.org.uk](http://www.advocacyresource.org.uk)

**Coalition of Citizen Advocacy Schemes** [www.cacoalition.org.uk](http://www.cacoalition.org.uk)

**Department for Constitutional Affairs, Human Rights Team**  
[www.dca.gov.uk/hract](http://www.dca.gov.uk/hract)

**Valuing People Support Team Resources: Toolkit about advocacy**  
<http://valuingpeople.gov.uk/dynamic/valuingpeople62.jsp>

**Valuing People Support Team Resources: Toolkit involving people with high support needs** <http://valuingpeople.gov.uk/dynamic/valuingpeople70.jsp>

**A Voice of Their Own: A toolbox of ideas and information for non-instructed advocacy** Annie Lawton (2006) BILD Publications

**Making Advocacy Count: a toolkit for evaluating the effectiveness of advocacy** Written by Asist Advocacy Services. Available from BILD  
[enquiries@bild.org.uk](mailto:enquiries@bild.org.uk)

**When communication gets tough: a guide to non instructed advocacy** written by the Voices through Advocacy project © Scope, November 2008  
[www.scope.org.uk](http://www.scope.org.uk)



## Resources to accompany this recommendation

1. Non Instructed Advocacy in Focus by Rick Henderson
2. Watching brief by ASIST
3. Advocacy services working with people with profound and multiple learning disabilities

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<sup>1</sup> **I'm not complaining but ... Complaints procedures in Social Services departments**, Joseph Rowntree Foundation Simons, K (1995a)

<sup>2</sup> **Mental Capacity Act** <http://www.dca.gov.uk/menincap/legis.htm>

<sup>3</sup> **Independent Mental Capacity Advocates**  
<http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/IMCA/index.htm>

<sup>4</sup> **Non-instructed Advocacy in Focus**. Rick Henderson. Action for Advocacy. March 2007 (see resource one)

<sup>5</sup> **Easy Guide to the Human Rights Act 1998**. Implications for people with learning disabilities. Andrea Hughes and Phil Coombs (2001). Bild Publications

<sup>6</sup> **Watching Brief**, ASIST advocacy (see resource two)

<sup>7</sup> **When communication gets tough: a guide to non instructed advocacy** written by the Voices through Advocacy project © Scope, November 2008 [www.scope.org.uk](http://www.scope.org.uk)

<sup>8</sup> **The Local Authority Social Services and National Health Service Complaints (England) Regulations 2009** (February 2009 No. 309) <http://www.opsi.gov.uk/stat.htm>

<sup>9</sup> **A Code of Practice for advocates**  
<http://www.aqv59.dsl.pipex.com/Code%20of%20Practice%20booklet.pdf>

<sup>10</sup> **Quality standards for advocacy schemes**  
<http://www.aqv59.dsl.pipex.com/Quality%20Standards%20Doc.pdf>