

Approaches to Independent Representative Advocacy

Definition: By "Approach" we mean a particular emphasis or focus that is taken when supporting a person who communicates differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication) to have the life they prefer.

Four internationally recognised approaches to independent, representative advocacy are set out below:

- 1. Person-Centred
- 2. Witness Observer
- 3. Ordinary Life Principles
- 4. Rights Based Approach

Practitioners report that an integrated approach is often most effective in delivering advocacy. With continuous training, education, and development NAS advocates and managers are competent and confident in using all of the approaches, either separately, or in combination.

1. PERSON-CENTRED APPROACH

Definition: By "person-centred approach" we mean a process of continual listening and learning, focussing on what is important to someone now and in the future, and acting upon this, being led by the client and where required in alliance with the circle of support. [Thompson J. Kilbane J. Sanderson H. (2008) Person Centred Practice for Professionals, Open University Press]

NAS seeks to work always in a person-centred way, in the sense that advocates strive to keep people at the centre of decisions and the issues that affect them.

From the perspective of the person, who is advocated for, being person-centred could mean:

You could take time to get to know me, learning about the way I communicate, gaining a deep understanding over time of what is important to me. You could spend time with me in places I spend my time and you could talk to people who say they know me well. Then you may feel you can relay my perspective with confidence so other people listen and you can represent what is important to me well.

Overview of the approach

This approach is based on a medium/long-term trusting and mutually respectful relationship between the advocate and person. In spending time with the person, 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 'as if they were the advocate's own' (O'Brien, 1981). In doing so the advocate is raising the profile of the person's unique perspectives, and as such is promoting a person-centred approach to service delivery and decision making.

NAS acknowledges that for some people there may already be others in their life taking a person-centred approach. NAS advocates, in some situations, learn about what is important to and for the person by listening to the people they know and trust, in order to build up a picture of the relevant factors from their point of view.

2. ORDINARY LIFE PRINCIPLES [OLP] APPROACH

From the perspective of the person being advocated for:

You could think about the quality of my life and think about how changes or decisions about my life will affect me. You can ask questions of powerful people who are making decisions about me to make them really think about the decision from my point of view – this keeps me at the centre of the decision, so decisions are made which are in my 'best interests' from my point of view.

Overview of the approach

This approach centres around eight quality of life domains which are used as the basis for a series of questions that the advocate may put to the decision maker or service provider on behalf of the person. OLP provides a framework for questioning and challenging the decision maker or service provider in a non-confrontational way. It encourages services to put the person at the centre of the decision making process. OLP places the person at the centre of this process so as to support them to live their life in a way which reflects their own preferences and values and reflects generic ordinary life principles.

Using this model advocates must:

- make services aware that they are protecting ordinary life principles and not expressing their own personal view
- be clear in their own mind as to the difference between advocating for the person's ordinary life principles and disputing the service provider's methods of care implementation.
- refrain from actively arguing for or against a particular support package; or any element of it. The advocates' role is to use the elements within the 'eight domains to a quality of life' to question and seek justification to promote services which undeniably meet the wishes and needs of the person. See Toolkits for relevant OLP approach documents.

3. WITNESS-OBSERVER APPROACH

From the perspective of the person being advocated for:

You could just watch me in my world and see what you can find out about my life, the way I am treated, the environments I spend my time in. You can see how people relate to me. You won't make any judgements on what you see. What you see and report to people in my life could make them think differently about me and my life – it could lead to things getting better in my life. You could come back after a while to see if things have got better.

Overview of the Approach

There is a real value in the advocate's role in being an observer or witness to the ways in which the person lives their life. The advocate may see or hear things that indicate the person's preference will and preferences which can in turn be used to represent the person. Conversely the advocate may see or hear things that are unacceptable or which pose a threat to the person's rights.

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, surroundings or activities; appropriateness of routines and systems; the communicative function of key behaviours or actions. See Toolkits for documents supporting this approach.

4. RIGHTS-BASED APPROACH

From the perspective of the person being advocated for:

You could think about my rights (which are the same as yours) and make sure I get what I am entitled to, that I'm safe and that my rights as a person and user of health and community services are upheld. If you think something is happening in my life which breaks law or infringes my rights, you may need to get legal advice or ensure there is effective representation.

Overview of the approach:

This approach begins with the premise that we all have certain fundamental rights that can be clearly defined and explicitly measured.

The advocate will work to ensure that the person's rights are:

- Respected [that is, having the right recognised, stopping people and institutions from denying or limiting the right]
- Protected [that is, having laws and measures to ensure the right is not violated and prevent its violation]

• Fulfilled [that is, given sufficient recognition, funding, and other positive acts that enable and assist enjoyment of that right]

Where the advocate is of the view that an individual's fundamental rights are being limited, he or she is empowered to intervene on behalf of the person to challenge such limits and seek redress.

This may be the case where the person is being denied food or drink, is being restrained or held captive, or is the victim of abuse, neglect, mistreatment and exploitation. With this advocacy approach, the role of the advocate is to ensure, using a variety of means, that the basic human rights of the person are promoted and defended. These imposed limits are motivation to take affirmative action on behalf of the person. Where the advocate believes that the injustice being done to the person may be illegal, they should seek appropriate legal representation for the person. See Toolkits for documents supporting this approach.

Integrating Approaches

Effective advocates are skilled at working in an integrated way so that they do not rely solely on one or two of the approaches outlined above. Instead they are able to combine the approaches to represent the perspective of the person, and raise issues on their behalf in a credible way.