

# Handout: Substantial difficulty

## Introduction

The Care Act 2014 requires that local authorities involve people in decisions made about them and their care and support.

Where people have substantial difficulty in being involved in the key care and support processes of assessment, care and/or support planning, care reviews, and safeguarding enquires and safeguarding adult reviews, the local authority must enable them to be supported in that involvement as fully as possible. Reasonable steps must be taken to enable the person is fully involved. If the person needs support to be fully involved and a friend or family member is available to facilitate the person's involvement that must be arranged. If there is no one appropriate available to facilitate the person's involvement, the local authority must arrange for an independent advocate.

There are also some circumstances which are judged to be so serious that an independent advocate must be arranged even though the person has a friend or relative who can facilitate their involvement.

The Care Act defines four areas, in any one of which, substantial difficulty might be found. These are:

- understanding relevant information
- retaining information
- using or weighing up the information (as part of being involved in the key process)
- communicating their views, wishes and feelings.

## Involvement

Involvement requires the local authority helping people to understand how they can be involved, how they can contribute and take part and sometimes lead or direct the process. The ultimate aim is for people's wishes, feelings and needs to be at the heart of the assessment, care planning and review processes.

People should be active partners in the key care and support processes of assessment, care and support planning and review and safeguarding enquires and safeguarding adult reviews. People who experience substantial difficulty in involvement will need support in understanding, retaining or using information given, or in communicating their views, wishes or feelings.

## Assessing whether someone has substantial difficulty in being involved

Many people can be supported to **understand** relevant information, if it is presented appropriately and if time is taken to explain it. Some people, however, will not be able to understand relevant information, for example if they have mid stage or advanced dementia.

If a person is unable to **retain** information long enough to be able to weigh up options and make decisions, then they are likely to have substantial difficulty in engaging and being involved in the key care and support processes.

A person must be able to **weigh up** information in order to participate fully and express preferences for or choose between options. For example, they need to be able to weigh up the advantages and disadvantages of moving into a care home. If they are unable to do this, they will have substantial difficulty in engaging and being involved in the key care and support processes.

A person must be able to **communicate** their views, wishes and feelings to aid the decision process and to make priorities clear. If they are unable to do this, they will have substantial difficulty in engaging. For example, a person with advanced dementia, significant learning disabilities, a brain injury or mental ill health may be considered to have substantial difficulty in communicating their views, wishes and feelings. But equally a person with Asperger's may be so considered, as may a frail older person who does not have a diagnosis but is confused as a result of an infection, or a person who is near the end of their life and appears disengaged from involvement and decision-making.

## Comparison with the Mental Capacity Act

There are similarities with the Mental Capacity Act but the duty under the Care Act is, however, broader. It defines a wider range of circumstances in which there is a duty to provide independent advocacy. It also provides support to people who have capacity but who have substantial difficulty in being involved in their care and support. Both the Care Act and the Mental Capacity Act (MCA) recognise the same areas of difficulty, but the test with the MCA is whether the person 'lacks capacity' in relation to a specific decision whereas with the Care Act it is having 'substantial difficulty' in being involved in key local authority processes.

**Case Study (given in the statutory guidance)**

Stephen sustained a brain injury in a fall; he has completed six months in a specialist residential rehabilitation setting and the next step is an assessment of need for his continuing support.

Prior to this, the social worker telephones Stephen's treating clinician who confirms that because of his brain injury, Stephen lacks insight into the effects this has had on him and he also has difficulty processing lots of information quickly – this is a common symptom of brain injury.

Therefore the social worker decides on an initial short meeting to determine Stephen's needs and knows her first step will be to evaluate if Stephen has difficulty understanding and therefore being involved in the assessment process. If so, support could come from an Independent Advocate under the Care Act, family member or friend or Mental Capacity Advocate, as she is aware lack of insight does not necessarily determine lack of capacity.

The social worker notes that Stephen is able to retain information about who she is and why she is meeting with him. He is articulate and can converse well about his plans for the future which includes detailed plans to meet up with friends and return to work again. However, a pre-assessment conversation with his mother, confirms that his friendship group has significantly diminished as his friends find it difficult to understand the differences in his behaviour since his fall and doubts whether he will be able to return to full-time employment. The social worker judges that because Stephen lacks insight into his personal relationships and future plans, he may well also have trouble estimating his true care and support needs. At this point the social worker decides that Stephen would have substantial difficulty in being fully involved in the rest of the assessment process and would therefore benefit from assistance.

Stephen is adamant that he wants to act and make decisions independently of his mother, though he is happy for her to inform the assessment process. The social worker decides that Stephen's mother would not be an appropriate individual under the Care Act to support his involvement in the Needs Assessment. The social worker talks to Stephen about how an independent advocate could help him make sure his views, beliefs, wishes and aspirations are taken into account in the assessment, and with his agreement, arranges for an independent advocate with specialist brain injury training to support him. The independent advocate meets Stephen but also talks to his mother to get a good picture of Stephen's current needs and wishes and to ascertain the differences between how Stephen is now and prior to acquiring his brain injury. The social worker carries out the needs assessment with Stephen who is supported by his independent advocate, and with Stephen's approval, input from his mother.

## **When the duty applies**

At the start of the assessment process, which starts at first contact, if it appears to the local authority that a person has care and support needs, and throughout any subsequent part of the process, the local authority must judge whether a person has substantial difficulty in being involved.

There is also a separate duty to arrange an independent advocate for adults who are subject to a safeguarding enquiry or safeguarding adults review.

Where an authority has outsourced or commissioned all or some of the care and support processes, the authority will maintain overall responsibility for this judgement.

The duty to involve applies in all settings, including for those people living in the community, in care homes or (apart from a safeguarding enquiry) in prisons for example.