



Department
of Health

Directors of
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adult social services

Local
Government
Association

skillsfor
care

Supporting implementation of the Care Act 2014

Providing Independent Advocacy under the Care Act

Self Study Pack for Independent Advocates



Developing skills in supported decision
making

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Chapter 1: The Care Act 2014 – An Overview

Background

The Care Act received Royal Assent on the 14 of May 2014. The Act is in three parts: Part 1 of the Act consolidates and modernises the framework of social care law for adults in England, it brings in new duties for local authorities and new rights for social care service users and carers.

Parts 2 and 3 of the Act deal with recommendations from the Francis report (Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry), quality failure in health care providers and setting up a new performance rating system for health and care providers as well as establishing Health Education England and the Health Research Authority.

The Act is both a reforming piece of legislation (it changes the law) and a consolidating piece of legislation (it repeals many previous laws relating to care and support and replaces them with this Act).

It builds on the government's 'Vision for Adult Social Care' {REF} document and 'Caring for Our Future' {REF} White Paper.

Some of the legislation repealed by the Act – either in whole or in part – includes:

- National Assistance Act 1948, which established the welfare state and abolished the poor laws
- Chronically Sick and Disabled Persons Act 1970 (but only repealed for adults), which introduced major reforms, providing for duty-based entitlement to particular types of community services
- NHS and Community Care Act 1990, a major reform, including an overarching right to assessments
- Carers (Recognition and Services) Act 1995, the first Act to recognise carers
- Community Care (Direct Payments Act) 1996, which included new powers to make direct payments.

The Act also revokes secondary legislation and cancels statutory guidance such as:

- The Delayed Discharges (England) Regulations 2003
- Fair Access to Care Services (FACS): Guidance on eligibility criteria for adult social care (2002 and the 2010 revision)
- Health and Social Services and Social Security Act 1983.



Aims of the Care Act

Put simply, the Act aims to make care and support clearer and fairer for people to access.

The Care Act:

- outlines a single national eligibility threshold for care and support
- requires local authorities to provide all local people with information and advice, related to care and support, to help them understand their rights and responsibilities, and plan for their future needs
- includes protections so that people do not go without care if their provider fails, regardless of who pays for their care
- clarifies local responsibilities for people in prison who have needs for care and support so that they can access the care they need.

The Act also attempts to rebalance the focus of social care on postponing the need for care rather than only intervening at crisis point. The aim is that the care and support system intervenes early to support individuals, helps people retain or regain their skills and confidence, and prevents needs or postpones deterioration wherever possible.

The statutory guidance gives examples of different types of preventative services, including:

- those that promote healthy and active lifestyles (e.g. exercise classes)
- targeted early interventions such as a fall prevention clinic or minor adaptations to housing which improve accessibility
- interventions such as rehabilitation/reablement services.

The Act also recognises carers' vital input and aims to help them maintain their caring role, if they are willing and able to do so, which of course will often help the people they care for to postpone or delay the need for more formal services and preserve choice of setting.

The Act embeds people's rights to certain choices, personalised care and support plans, and personal budgets in legislation. A key aim of the Act is to embed and extend personalisation in social care. Personalisation has a wide agenda encompassing universally accessible information and advice, prevention and early intervention, community capacity building, making greater and more creative use of universal services, and tailoring the formal support people need. The evidence suggests people want to be more actively engaged as planning partners, that services frequently underestimate their willingness, and that the potential impact of harnessing this contribution could have huge economic value

and lead to better outcomes. The Care Act 2014 mandates that all people with an eligible care and support need and carers should have their support planned and managed in this way in future, if they want.

The Act also extends the Human Rights Act to cover people receiving care and support from a regulated provider that is arranged by their council, whether in a residential setting or at home; however, this provision will not apply to people arranging or paying directly for their own care (Section 73).

Wellbeing

Local authorities must promote wellbeing when carrying out any of their care and support functions in respect of a person. This may sometimes be referred to as “the wellbeing principle” because it is a guiding principle that puts wellbeing at the heart of care and support.

The wellbeing principle applies in all cases where a local authority is carrying out a care and support function, or making a decision, in relation to a person. It applies equally to adults with care and support needs and their carers. In some specific circumstances, it also applies to children, their carers and to young carers when they are subject to transition assessments.

Definition of wellbeing

Wellbeing is a broad concept, and the statutory guidance defines it as relating to the following nine areas in particular

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal relationships
- suitability of living accommodation
- the individual’s contribution to society.

A local authority can promote a person’s wellbeing in many ways. How this happens will depend on the circumstances, including the person’s needs, goals and wishes, and how these impact on their wellbeing. There is no set approach – a local authority should consider each case on its own merits, consider what the person wants to achieve, and how the action which the local authority is taking



may affect the wellbeing of the individual in relation to the nine areas listed in the definition of wellbeing. During the assessment process, for instance, the local authority should explicitly consider the most relevant aspects of wellbeing to the individual concerned, and assess how their needs impact on them.

It is likely that some aspects of wellbeing will be more relevant to one person than another. Local authorities should adopt a flexible approach that allows for a focus on which aspects of wellbeing matter most to the individual concerned.

New Duties

The following are new or extension of duties introduced by the Care Act:

Preventing the need for care and support

A local authority is now under a general duty to prevent, delay or reduce the need for care and support of all local people in its area. Local authorities will need to:

- identify what the particular care and support needs in their area are and facilitate a market that delivers appropriate supply to meet those needs
- identify people who may have care and support needs in their area that are not already being met
- identify carers who may have needs that are not being met.

The Act identifies three main strands of prevention – preventing the need for care and support, delaying needs for care and support, and reducing the needs for care and support. There is clear intent in the Act that the care system should help people maintain their independence and improve their wellbeing. Local authorities will need to identify who may benefit from services aimed at delaying the onset of social care needs, including those who may not be in receipt of any care and support services.

Providing information and advice

Under section 4 of the Act local authorities must provide an information and advice service to help all local people understand the care and support system, access services and plan for the future, including enabling people to access independent financial advice to help steer them through the complexities of care funding.

Information and advice on all care and support matters must be accessible to all, so it cannot be simply online, and must be "proportionate" to an individual's needs e.g. a simple, short answer to a simple question or more intensive and more personalised information and advice if a person has more complex issues.

Integration

The Act includes general duties on local authorities to promote integration and on local authorities and “relevant partners” (including the NHS) to cooperate generally and specifically in relation to individuals. The general requirement applies to all the local authorities’ care and support functions, including in relation to preventing needs, providing information and advice and shaping the market of care providers.

Managing provider failure

Sections 48-57 of the Act are about managing provider failure. The aim is to ensure continuity of care, not to prop up failing providers. There is an updated duty for a local authority to temporarily meet needs when a care provider suffers a business failure and the services cease. This duty applies in respect of all people in the area, regardless of their level of need or who was funding the care and support. The guidance recognises that local authorities manage small scale provider failures effectively, and that most exits from the market are handled responsibly by providers. It clarifies the local authority duty to step in to ensure that no one is left without the care they need.

Market shaping

Local authorities’ new market shaping duties mean they should understand the sustainability and capacity of their whole local market i.e. including those elements that they do not directly procure or commission. This should place them in a strong position for developing contingency plans for provider business failure and ensuring continuity of care in the event that a provider does suffer a business failure and the services cease.

The Act also introduces a new market oversight regime and a role for the Care Quality Commission (CQC) in relation to financial oversight of certain “difficult to replace” care providers (due to size, geographic concentration or specialisation). It aims to give Government as a whole early warning if one of these providers is likely to fail. The collapse of the national care organisation Southern Cross in 2011 demonstrated the potential effect of a large provider failing financially and there is now a requirement for CQC to assess financial sustainability of these providers and inform local authorities when failure is imminent, to support local planning.



Independent Advocacy

The Act places a duty (section 67) on local authorities to arrange independent advocacy if the authority considers an individual would experience 'substantial difficulty' in participating in (amongst other things) their assessment and / or the preparation of their care and support plan. The duty does not arise if the local authority is satisfied that there is some other person who is an appropriate representative (provided that person is not engaged in providing care or treatment for the individual in a professional capacity or being paid to do so).

Safeguarding

The Act places on a separate statutory footing (sections 42-47) some of the government's expectations regarding safeguarding co-ordination, that were previously made explicit only in guidance (principally the 'No Secrets' guidance). It includes the duty for the local authority to carry out enquiries (or cause others to) where it suspects an adult (still living or deceased) is at risk of abuse or neglect. An enquiry should establish whether any action needs to be taken to prevent or stop abuse or neglect, and if so, by whom.

Where appropriate, the local authority must arrange for an independent advocate to represent and support an adult who is the subject of a safeguarding enquiry or Safeguarding Adult Review (SAR) where the adult has 'substantial difficulty' in being involved in the process and where there is no other suitable person to represent and support them.

There is also a requirement for all areas to establish a Safeguarding Adults Board (SAB) with core partners of the local authority, NHS and police to bring them together with other relevant partners to coordinate activity to protect adults from abuse and neglect. These boards:

- will carry out safeguarding adults reviews into cases where someone who is experiencing abuse or neglect dies and there is concern about how authorities acted. The Boards will investigate the cases with a view to learn from past mistakes
- have the ability to require information sharing from anyone considered to hold relevant information, to support reviews or other functions – this is a new power
- publish a strategic plan for each financial year that sets out how it will meet its main objective and what each member is to do to implement that strategy
- publish an annual report detailing what the SAB has done during the year to achieve its objective and what it and each member has done to

implement its strategy as well as reporting the findings of any safeguarding adults reviews.

Transition assessments

Children and young people approaching adulthood may need to move from receiving 'children's' services to 'adult's' social care services.

This move, known as transition, can be a vulnerable time for young people and their families. The Act introduces new duties on local authorities to carry out a transition assessment (based on the adult criteria) for young people, young carers and/or the child's carers if they are likely to have needs for care and support, or support, after turning 18, if there is significant benefit to the young person or carer in doing so.

The assessment should be carried out at a time when it is of "significant benefit" to a young person's preparation for adulthood. The purpose is to determine what adult social care a young person might be eligible for so they can make informed choices about their future.



Chapter 2: Advocacy Provision under the Care Act

Introduction

The Care Act signals a general move from engagement and providing information towards full involvement in decision-making. It is not enough for Local Authorities to simply offer information; they must now actively involve people within assessment, planning and review (and safeguarding).

The Care Act introduces the 'assumption that the individual is best placed to judge their own wellbeing' (s1 (3)) and to promote control by the individual over their care and support and the way in which it is provided (s1 (2) (d)).

This means that people should be active partners in the key care and support processes of assessment, care and support planning, care and support review, safeguarding enquires and safeguarding adult reviews. This applies to the following:

- a needs assessment under section 9 of the Care Act
- a carer's assessment under section 10
- the preparation of a care and support plan or support plan under section 25
- a review of care and support plan or support plan under section 27
- a child's needs assessment under section 58
- a child's carer's assessment under section 60
- a young carer's assessment under section 63

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. People should be active partners in the key care and support processes of assessment, care and support planning and review, or safeguarding.

Advocacy is an integral part of this shift – and advocates must remember that their goal is to actively support people to become active participants within the decision making process.

Who can receive independent advocacy under the Care Act?

The duty to provide independent advocacy applies to:

- adults who need care and support
- carers of adults (including young carers)
- carers of children in transition
- children who are approaching the transition to adult care and support

The local authority has a duty to arrange for an independent advocate to support and represent someone when two conditions are met:

- the person has **substantial difficulty** in being fully involved in the key care and support processes of assessment, care and support planning and review, or safeguarding, **and**
- there is no one appropriate available to support and represent their wishes.

The local authority is under a duty to consider and make a determination on a person's need for advocacy under these circumstances.

The Care Act also places a general duty on local authorities to provide an information and advice service that is available to all people. Prior to an assessment with the local authority, there may be some people who require independent advocacy to access information and advice. Local authorities will need to consider such needs in ensuring that the information and advice service is accessible but this will be non-statutory.

Local Authorities should also arrange for an Independent Advocate, even if they have someone appropriate to support their involvement:

- where a placement is being considered in NHS-funded provision in either a hospital (for a period exceeding four weeks) or in a care home (for a period of eight weeks or more) and the local authority believes that it would be in the best interests of the individual to receive advocacy support and representation;
- where there is a disagreement between the local authority and the appropriate person whose role it would be to facilitate the individual's involvement, and the local authority and the appropriate person agree that the involvement of an independent advocate would be beneficial to the individual.



Note that subject to further consultation, the duty may also apply - from April 2016 – if an individual made an appeal against a local authority decision (made under Part 1 of the Care Act).

Substantial difficulty

The Care Act requires the local authority to help people who are likely to experience substantial difficulty in participating in key decision making processes and 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

Understanding relevant information

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 easily able to understand relevant information, for example if they have mid-stage or advanced dementia.

Retaining information

If a person finds it difficult 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.

Using or weighing up the information

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 find it difficult to do this, they will have substantial difficulty in engaging and being involved in the key care and support processes.

Communicating their views, wishes and feelings

A person must be able to **communicate their views, wishes and feelings** - whether by talking, writing signing or any other means - to aid the decision

process and to make priorities clear. If they find it hard to do this, they will have substantial difficulty in engaging and being involved in the process.

For example, some people with mid-stage or 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. Within this context, it is the person's ability to communicate their views, wishes and feelings which is fundamental to their involvement rather than the diagnosis or specific condition.

Who is appropriate to offer informal support to a person?

In general, a person who has substantial difficulty in being involved in their assessment, plan or review, will only become eligible for an independent advocate where there is no one else appropriate to support their involvement. This could be because they do not have any family members or friends who:

- know them very well
- agree to offer this support
- are able to offer this support (for instance they themselves could have learning difficulties or dementia which prevents them from offering support)
- are appropriate (for instance they are suspected of abusing the person)
- are able to help the person put forward their view (for instance they have strong views on what the decision should be and do not support the person to express their aspirations)

The main thing to consider is whether they would be able to facilitate the person's active involvement in the process. With the appropriate individual's support, would the person be able to be an active partner in the process and be involved in decisions made about them and their care and support?

It is not sufficient to know the person well or to love them deeply – the role of the appropriate individual is to support the person's active involvement with the local authority processes. Some people will not be able to fulfill this role easily, for instance:

- a family member who lives at a distance and who only has occasional contact with the person
- a spouse who also finds it difficult to understand the local authority processes



- a friend who expresses strong opinions of their own prior to finding out those of the individual concerned
- a housebound elderly parent.

An appropriate individual cannot be someone who is already providing the person or their carer with care or treatment in a professional capacity or on a paid basis. It cannot be, for example, a GP, or a nurse, a key worker or care and support worker. It will also clearly not be suitable for a person to be regarded as an appropriate individual where they are implicated in any enquiry of abuse or neglect or have been judged by a SAR to have failed to prevent an abuse or neglect.

Practice Example

Adam is 47 years old and has a diagnosis of moderate/severe learning disability and has been using care services since he was a child. He attended a special needs school throughout his education and remained at school until he was 19 years old. He lives in supported living accommodation, works at a community café, and attends the local college once a week. He is in regular contact with his sister who lives nearby.

When his eligibility was last considered (prior to the implementation of the Care Act) his needs were in the substantial band of the Fairer Access to Care Services (FACs) eligibility criteria.

Adam suffers with arthritis and often has pain in his joints and gets very tired easily. He needs support to make sure he remembers to take his medication regularly. He can often become upset and agitated over different things and will lose his temper and throw/break objects or become verbally aggressive. These incidents are increasing in their frequency and recently there have been occasions when he has become anxious and staff have had to leave him in his flat until he has calmed down to prevent themselves from getting hurt.

These incidents have focused on keeping his room clean. He hides away uneaten food and rubbish which sometimes remains undiscovered until it starts to smell. Adam doesn't acknowledge this as a problem, and gets angry when the cleaners discover the food and also when his key worker tries to talk to him about it. It is a condition of his tenancy agreement that a reasonable standard of cleanliness is maintained.

His sister Alice thinks it is the cleaners that he has that are the problem, because they do not communicate with him sensitively. She wants Adam to have a direct payment so he can employ his own cleaner. The manager of the supported living

accommodation believes that the problem needs further consideration before a way forward can be found.

Is Adam eligible for Independent Advocacy under the Care Act?

There is evidence that Adam has substantial difficulty in communicating his views, wishes and feelings to the extent that they are inhibiting his involvement in decisions that need to be made about the management of his care and support. It is possible that he also has substantial difficulty in the other three areas set out in the guidance of understanding relevant information, retaining information and using or weighing the information as part of engaging, but further exploration would be needed to determine this. However, it is only necessary for one of the four areas to be demonstrated to conclude that there is substantial difficulty.

The response to Alice's request for a direct payment must be considered and this would probably be best achieved through a review of his care and support plan. The local authority must make the judgement about whether Adam has substantial difficulty in being involved at this point. It may be the case that the local authority has outsourced reviews or commissioned the care provider to hold them. However, whatever the circumstances the local authority retains the overall responsibility for this judgement.

In general, an individual who has substantial difficulty in being involved will only qualify for an independent advocate where there is no one appropriate to support their involvement. Therefore, the local authority must decide whether Alice can act as an appropriate individual to facilitate Adam's involvement. If she can take on this role then an independent advocate would not normally be appointed. The appropriate individual is expected to support and represent the person and to facilitate their involvement in the processes. So having established that Adam is happy for Alice to support him (assuming he has capacity and that he does), the local authority would have to be satisfied that she understands that it is her role to support his active involvement. In this case the local authority may decide that Alice cannot take on this role - as her opinion about the direct payment to employ a cleaner gets in the way of her supporting Adam to say what he wants and representing his views.

The wishes of the individual at the heart of the decision must be respected: if they do not want to be supported by a particular relative, for example perhaps because they wish to be moving towards independence from their family, then the local authority cannot consider that relative appropriate. The person's wish not to be supported by a particular individual should be respected and if the person has capacity, or is competent to consent, the person's wishes must be followed. If the person lacks the capacity to make a decision, then the local



authority must be satisfied that it is in their best interests to be supported and represented by that individual.

There may also be some cases where the local authority considers that a person needs the support of both a family member and an advocate; perhaps because the family member can provide a lot of information but not enough support, or because while there is a close relationship, there may be a conflict of interest with the relative, for example in relation to inheritance of the home.

Example

Jacinta is 26 and lives with her mother and father. She has 2 siblings aged 28 and 23 who have left the family home. Jacinta would also like to move to living more independently. Jacinta has moderate learning disabilities and finds it hard to retain information. She can look after her personal care needs, and has some very basic cooking skills but is very poor with money. Jacinta's parents are known to be protective and are dead set against her moving. They are adamant that it is their responsibility to look after her, that she won't be able to cope living on her own and that she will be lonely and vulnerable.

In these circumstances Jacinta's parents may not be an 'appropriate individual' who could effectively represent and support her interests and an independent advocate could be offered to support Jacinta.

Sometimes the local authority will not know at the point of first contact or at an early stage of the assessment whether there is someone appropriate to facilitate the person's involvement. They may need to appoint an advocate, and find later that there is an appropriate person in the individual's own network. The advocate can at that stage 'hand over' to the appropriate person. Equally, it is possible that the local authority will consider someone appropriate who may then turn out to have difficulties in supporting the individual to engage and be involved in the process. The local authority must at that point arrange for an independent advocate.

If the local authority decides that they are required to appoint an independent advocate, as the person does not have friends or family who can facilitate their involvement, the local authority must still consult with friends or family members when appropriate. 'Consult' means asking their views. It is the local authority's decision as to whether a family member or friend can act as an appropriate individual and it is the local authority's responsibility to communicate that decision to the person's friends and family where this may have been in question – not the advocate.

Note that a 'best interests consultee' within the Mental Capacity Act 2005 (MCA) has a different role to that in the Care Act 2014. Within the MCA, the individual must be appropriate and practicable to be consulted. Under the Care Act an appropriate individual must be able to support and represent the person and facilitate their involvement. It is a far more active role. It requires that the appropriate individual is willing and able to ensure that the person undergoing the local authority process is themselves involved rather than the appropriate individual merely commenting on their behalf.

Practice example

Mishal is in her early 30's and was diagnosed with multiple sclerosis four years ago. She lives alone in a ground-floor flat. She works as an administrator but is currently off work having experienced a relapse. She has made a good physical recovery but is concerned that she will not be able to return to work because of the fatigue she is experiencing and also poor concentration and memory problems. She has had previous relapses and remissions, but has always managed to return to work successfully.

She telephones the local council's information and advice service to find about what help might be available. From what she has read on the Council website she is unsure about whether she will be eligible for anything because she thinks that she might have too much in savings.

She tells the information and advice worker that she wants to get back to work but feels that everything is "out of control" and that she can't concentrate. When it is explained that she will have to have an assessment to determine whether her needs are eligible needs, Mishal becomes very despondent because she was hoping that the information and advice worker would tell her that she would be getting some help. Despite the information and advice worker's best efforts Mishal does not seem to understand the process of assessment and care and support planning, let alone how financial assessment and charging works. It is suggested that she comes into the information and advice centre for a face-to-face discussion but she says it would be too tiring and stressful and that there is nobody who could help her.

It is agreed that the information and advice worker will get some advice about how to proceed and then telephone Mishal.

Does Mishal face substantial difficulty?

Although Mishal did not understand the relevant information over the telephone, she may well be able to do so with more visual material and careful explanation



in person and might not have a substantial difficulty in this respect. The information and advice worker would have had this in mind when inviting her in for a face-to-face discussion. However, there are indications (poor concentration and memory problems) that at present Mishal may be unable to retain information long enough to weigh up options and make decisions, so she may have substantial difficulty in being involved in the assessment process.

As it is clear that Mishal has the ‘appearance of care and support needs’, the assessment should continue, if she is in agreement. The assessment service is to be advised that Mishal may have substantial difficulty in being involved.

It is up to Mishal to identify if she has someone who could support her as an appropriate person. The information and advice worker did not identify anyone who could act as an appropriate individual - the nature of the discussion meant it was not possible to be certain about whether there is someone who can act as an appropriate individual who could facilitate her involvement in the assessment.

The assessment service receives the referral and makes contact with Mishal.

OPTION A

Based on the information they have received from the information and advice worker and Mishal herself, they have evidence that Mishal will need support to understand the information they send out prior to the assessment to help her understand the process, prepare for the assessment and be able to be actively involved. They establish from Mishal that she does not have any one appropriate to support her. The assessment service decides that they will offer Mishal an assessment with the support of an independent advocate and explains to her how an advocate can help.

The role of the independent advocate will be to support Mishal in understanding the pre-assessment information and preparing for the assessment (for example by making sure that she is able to identify what she wants to communicate), supporting her involvement during the needs assessment & financial assessment (for example by ensuring that she is able to say what she wants and that people are taking notice of this), and in understanding the outcome of the assessments. The independent advocate will also support her during the care and support planning process, and also in accessing universal information and advice as this latter objective was not achieved at the point of first contact. It is anticipated that Mishal’s difficulties in retaining information may well be overcome once care and support is provided.

OPTION B:

Based on the information they have received from the information and advice worker and Mishal herself, they have evidence that Mishal will need support to understand the information they send out prior to the assessment to help her understand the process, prepare for the assessment and be able to be actively involved. They establish from Mishal that she has a sister who is close to her, who she sees regularly and has helped her with her affairs in the past. Once contacted her sister is happy to support Mishal's involvement in the assessment process and Mishal is content with this. The assessment service judges that her sister is an 'appropriate individual' to facilitate Mishal's involvement and proceeds with the assessment on that basis.

The role of the advocate under the Care Act

Advocates appointed under the Care Act have two main functions. Firstly, they are there to support the person to make their own decisions and be as involved as possible within decision making processes. Whilst performing this function, independent advocates will therefore need to:

- be aware of and comply with the rule and regulations under which they operate
- take into account the requirements of the United Nations Convention on the Rights of Person's with Disabilities (UNCRPD) – especially Art 12 (3) which protects the rights of people to have their views effectively communicated '*Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*'
- recognise the different approaches required, dependent on the capacity of the individual and adopt a supported decision making approach wherever possible
- ensure that if the person has been assessed as lacking the capacity to make the decision, the provisions of the Mental Capacity Act have been correctly applied and that anyone charged with making a decision takes it in the best interests of the person.

Secondly, advocates can represent a person, which may involve speaking on their behalf. This is particularly important for people who are not able to self advocate and put forward their own wishes, aspirations and choices. The independent advocate must 'advocate' on the person's behalf, to put their case, to scrutinise the options, to question the plans if they do not appear to meet all eligible needs or do not meet them in a way that fits with the person's wishes and feelings.



Providing Independent Advocacy under the Care Act 2014

The ultimate goal of this representation is to secure a person's rights, promote the person's well-being and ensure that their wishes are taken fully into account.

The advocate must always make arrangements to visit and meet with the individual, wherever possible in private, to offer support in the following areas:

Understanding processes

Advocates will assist people to understand the processes which they are involved in. This could be to understand the key care and support or safeguarding processes and how their needs can be met (by the local authority or otherwise) – understanding for example how a care and support and support plan can be personalised, how it can be tailored to meet specific needs, how it can be creative, inclusive, and how it can be used to promote a person's rights to liberty and to family life.

This requires advocates to understand local authority processes and policies, and other agencies' roles, the available assessment tools, the planning options, and the options available at the review of a care or support plan, and good practice in safeguarding enquiries and SARs.

Understanding rights

Advocates will support people to understand their rights under the Care Act including their right:

- for an assessment which considers their wishes and feelings and which considers the views of other people;
- for the assessment to be carried out in 'appropriate and proportionate' ways
- to have their eligible needs met,
- to have a care or support plan that reflects their needs and their preferences,
- to have their care or support reviewed regularly
- in relation to safeguarding, understanding their right to have their concerns heard and taken seriously
- (subject to policy decisions) to appeal or otherwise challenge the authority's stance

Advocates should also assist the person to understand their wider rights, including rights to liberty and family life, the right to complain and rights enshrined under the Mental Capacity Act such as the right to make advanced decisions.

Making decisions

Advocates will support people to make decisions by assisting them to weigh up various care and support options as well as choosing the ones that best meet their needs and wishes.

Advocates must take great care to ensure the person is supported to make their own decisions – and not be pressured by carers, other family members or professionals into accepting or agreeing to decisions and plans they otherwise would reject. The emphasis must always be on supporting the person to make their decisions wherever possible.

Advocates must also be mindful that they are categorically not to make decisions on behalf of the person to whom they are offering advocacy support. With services increasingly stretched there is a particular risk that pressure will be applied to advocates to make decisions on behalf of those who lack capacity. This should be resisted.

Advocates are not trained to make best interest decisions and should not offer personal judgements about what they consider to be the best interests of the person. Advocates must be very clear in their role of supported decision making and focus efforts on supporting the person to make decisions wherever possible.

There will be times when the advocate will offer support to a person who has been assessed as lacking the capacity to make a specific decision and are unable to weigh up or understand options. Advocates may also support people who lack insight into their own needs and cannot make choices on how their needs are best met. The Care Act Guidance encourages local authorities to invite advocates to put forward choices on behalf of the individual:

*“There will be cases where a person lacks capacity to express a choice for themselves. Local authorities should therefore **act on the choices expressed by the person’s advocate**, carer or legal guardian in the same way they would on the person’s own wishes, unless in the local authority’s opinion it would be against the best interests of the person”.*

This does not mean advocates should make decisions but must always endeavor to establish a person’s likely choices (through researching, consulting others or via a Non Instructed Advocacy approach) to ensure plans and decisions are person centred and reflect the preferences, lifestyle and wellbeing of the individual.

Communicating views, wishes and feelings

Advocates will support a person to communicate their views, wishes and feelings to the staff who are carrying out an assessment or developing a care or support



plan or reviewing an existing plan, or carrying out a safeguarding enquiry or review.

Advocates should be prepared to use creative forms as communication alongside traditional methods for example, supporting someone to show film to help explain their needs, wishes or preferences.

Where the individual does not have capacity, or is not competent, to communicate his or her views, wishes or feelings, the independent advocate must still do everything they can to ascertain them.

Practice example

Kate has profound and multiple learning disabilities. She doesn't use formal communication like words or signs. She communicates using body language and facial expressions. In her assessment, Kate's independent advocate supports her to show some film of her visiting a local market, enjoying the colours and sounds around her. In this way Kate is able to show the assessor some of the things that are important to her.

Understanding plans

Once a plan has been made, the person may need the support of an advocate to help understand the decision or plan reached, what it means for them, who is responsible for what and likely timescales involved.

Advocates should also be prepared to ask for plans to be prepared which are accessible and easy to understand by the person at the centre of the process – for instance easy read or simple jargon-free writing.

Challenging decisions

The Care Act requires advocates to support people to challenge a decision or process made by the local authority where they wish to do so. There will also be times when an advocate will have concerns about how the local authority has acted or what decision has been made or what outcome is proposed. At these times the independent advocate must 'advocate' on the individual's behalf and represent their interests.

Whilst there is no definitive list of situations when an advocate should consider challenging a decision, the following will usually constitute grounds for challenge:

- The person expresses a wish to challenge a decision
- The advocate is concerned the Local Authority has not fulfilled its duty to involve the person in the decision making process(es)
- Representations are necessary for the purpose of securing the individual's rights
- The advocate has concerns about the manner in which the assessment or planning function has been carried out – or the outcomes

The advocate **must** challenge the decision if they consider the decision to be inconsistent with the authority's general duty under section 1 of the Act (duty to promote the individual's well-being).

In all instances, an advocate must prepare a report for the local authority outlining their concerns. The local authority should then convene a meeting with the advocate to consider the concerns and then provide a written response.

The local authority is expected to recognise that an advocate's role incorporates challenge on behalf of the person, and the local authority **must** take into account any representations made by an advocate. The local authority must provide a written response to a report from an advocate that outlines concerns about how the local authority has acted or what decision has been made or what outcome is proposed.

Consult with others

Advocates will be supporting people who may have family, friends, neighbours or carers who know them well but are unable/not appropriate to support their involvement. Advocates should always consider whether it would help the individual to consult any of the following people:

- persons who are, or have been, engaged in providing care or treatment for the individual in a professional capacity
- persons who may be in a position to comment on the individual's wishes, beliefs or values, for example family members, carers or friends of the individual.

Where the individual has capacity, or is competent, to consent to the advocate consulting with a person they must give the advocate permission to approach that person. Advocates offer confidential relationships and must not share personal information without the explicit consent of the person.



Where the individual does not have capacity, or is not competent, to consent, an advocate can approach the person if they are satisfied that consulting with them would be in the individual's best interests.

Accessing records

An advocate can access, and take copies of any relevant records relating to the individual where

- the individual has capacity, or is competent, to consent to the records being made available to the independent advocate and does so consent OR
- the individual does not have capacity, or is not competent, to consent to the records being made available to the advocate but the advocate and Local authority considers it is in the best interests of the individual.

Accessing information recorded about a person, their needs and previous choices is a reliable and useful way to learn more about a person who is now unable to express to the advocate their aspirations, values and preferences. Advocates may want to consider accessing the following types or sources of information:

- previous care or support plans
- previous assessments – and their outcomes
- any recorded evidence of the individual's previous choices, preferences and how they felt their own needs were best met
- any advance decisions
- written evidence of advance statements

The Care Act allows for advocates to access such records if it is in the best interests of the person. Advocates should therefore only access records that are relevant to the current decision making processes and discuss this with the Local Authority.

Issues specific to safeguarding

In terms of safeguarding there are some particular important issues for advocates to address. These include supporting a person to:

- decide what outcomes/changes they want

- understand which actions of their own may expose them to avoidable abuse or neglect
- understand what actions that they can take to safeguard themselves
- understand what advice and help they can expect from others, including the criminal justice system
- understand what parts of the process are completely or partially within their control
- explain what help they want to avoid reoccurrence and also recover from that experience

Conflicts of interests

Where assessments are taking place of two people in the same household, if both people agree to have the same advocate, and if the advocate and the local authority both consider there is no conflict of interest, then the same advocate may support and represent the two people.

If any of the people involved (the people being assessed or taking part in the care planning, the assessor or the advocate) consider that it would be better to have different advocates then separate advocates should be provided.

Working with the Local Authority

The Care Act requires the local authority to take reasonable steps to assist advocates as they carry out their role. For example they should:

- let other agencies know that an advocate is supporting a person, facilitating access to the person and to the records
- propose a reasonable timetable for the assessment and the care and support plan
- keep the advocate informed of any developments and of the outcome of the assessment and the care and support plan.

The local authority may make reasonable requests of the advocate for information or for meetings. Advocates should be mindful that their primary function is to support the person to make their own decisions and be as involved as possible within decision making processes. Any requests for information made by the local authority should be discussed with the individual who is supported to decide what they would like to be shared wherever possible.

Where the individual is unable to take part in such a discussion, for example they lack the capacity to understand the request to share information, the advocate should consider how this opportunity can best represent the individual and



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ensure the decision making process reflects the person's needs and wishes and promotes their wellbeing.

Who can act as an independent advocate under the Care Act?

Independent advocates must have

- *a suitable level of experience: this may, for example, be in non-instructed advocacy or in working with those groups of people who may have substantial difficulty in engaging with assessments and care and support planning*
- *appropriate training: this may, for example, initially be training in advocacy (non-instructed or instructed) or dementia, or working with people with learning disabilities. Once appointed, all independent advocates should be expected to work towards the National Qualification in Independent Advocacy (level 3), including the Care Act module currently in development, within a year of being appointed, and to achieve it in a reasonable amount of time*
- *competency in the task: this will require the advocacy organisation assuring itself that the advocates who work for it are all competent and have regular training and assessments of their competence*
- *integrity and good character: this might be assessed through: interview and selection processes; seeking and scrutinising references prior to employment and on-going DBS checks*
- *the ability to work independently of the local authority or body carrying out assessments, planning or reviews on the local authority's behalf: this would include the ability to make a judgement about what a person is communicating and what is in a person's best interests, as opposed to in a local authority's best interests, and to act accordingly to represent this. The advocate must not otherwise work for the local authority,*
- *arrangements for regular supervision: this will require that the person meets regularly and sufficiently frequently with a person with a good understanding of independent advocacy who is able to guide their practice and develop their competence.*



Chapter 3: Providing Advocacy Support through the assessment process

Introduction

The assessment and eligibility process is one of the most important elements of the care and support system. Under the Care Act, local authorities must ensure that any adult who appears to require care and support, including carers with support needs, has their needs assessed. This is irrespective of their likely eligibility for state-funded care.

The local authority therefore has to:

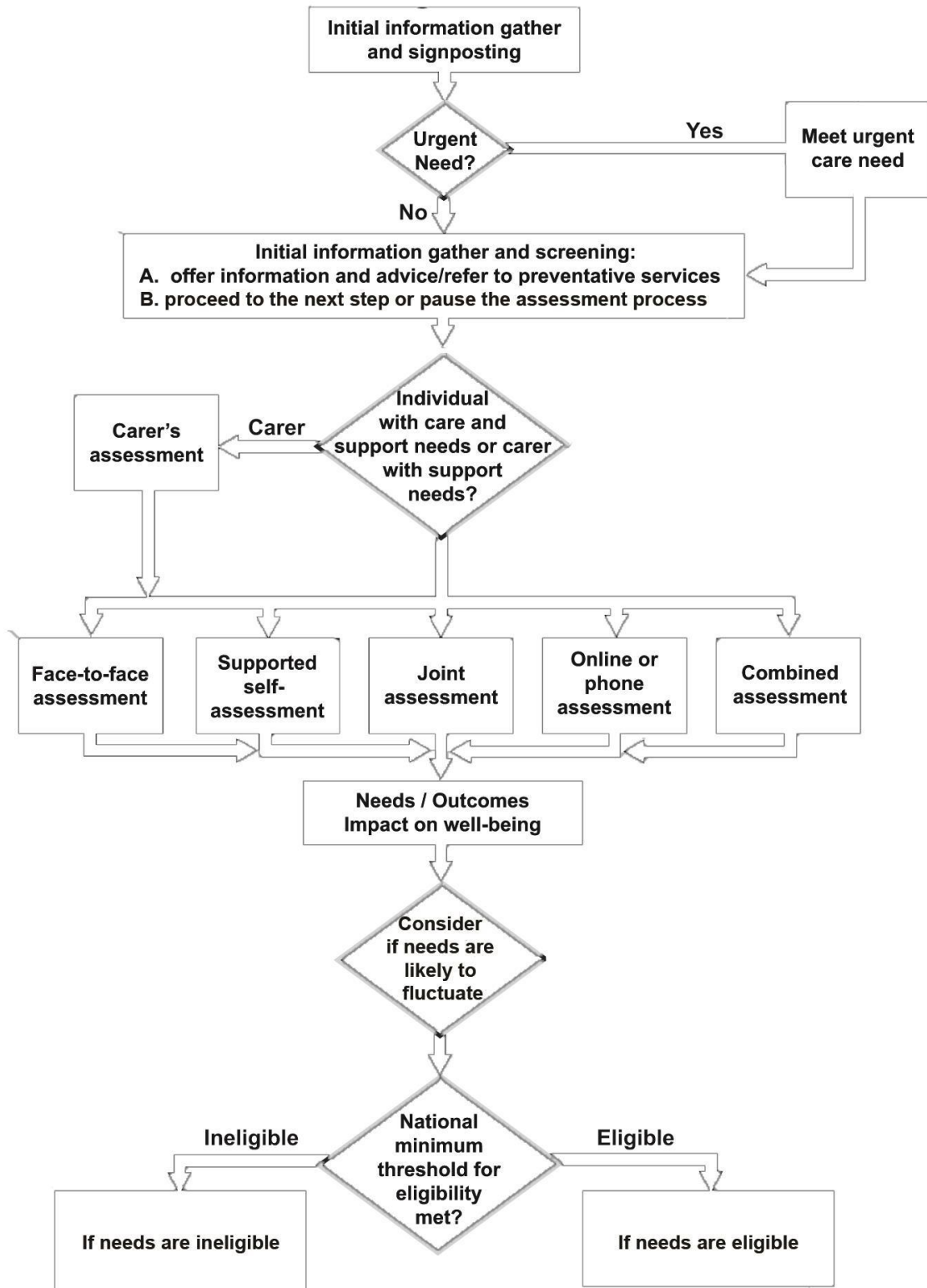
- carry out an assessment for anyone who appears to require care and support
- focus the assessment on the person's needs and how they impact on their wellbeing
- include what outcomes the person wants to achieve
- consider other things besides care services that can contribute to the desired outcomes (e.g. preventative services, community support)
- use the new national minimum threshold to judge eligibility for publicly funded care and support

The following process map reflects the duty upon the local authority to conduct an assessment appropriate and proportionate to the individual's need before any eligibility determination or financial assessment is made – except in cases of urgent need:

Assessment and Eligibility Process

Consider at every stage:

Mental Capacity	Advocacy & Participation Support	Impact on the family and carers	Safeguarding	Strengths - based Approach	Ensuring assessment proportionate and appropriate
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Taken from SCIE: [Assessment and Eligibility Map](#)



The assessment is one of the main interactions between the local authority and an individual. It should not just be seen as a gateway to care and support, but should be a critical intervention in its own right, which can help people to understand their situation and access support when they require it. The process starts from when the local authority first begins to collect information about an individual i.e. their first point of contact with the local authority.

Local authorities must undertake an assessment for any adult who appears to have any level of need for care and support. The aim of assessment is to identify what needs someone has and what outcomes they are looking to achieve to maintain or improve their wellbeing. The approach should look at needs over time and be sustainable. Assessments should be holistic, and consider the impact of needs upon the person's whole family and network.

Assessment is a key element of any prevention and wellbeing strategies as the process can identify needs that could be reduced, or where escalation of needs could be delayed by, for example, accessing preventive services or receiving information and advice about community support.

Assessments should be appropriate and proportionate. The assessment process must be flexible and should be adapted to best fit with the person's needs, wishes and goals. Assessment will not be the same for all people, and depending on the circumstances, it could range from an initial contact which helps a person with lower needs to access support in their local community, to a more intensive, ongoing process which requires the input of a number of professionals over a longer period of time. Assessments may be combined – where the needs of more than one person align – or be joint when different agencies are involved.

Local authorities must undertake an assessment for anyone (adult needing care or a carer) who appears to have any level of needs for care and support i.e. if the person appears to have needs for care and support they will be entitled to an assessment. This is regardless of a person's financial situation, so that question must not determine access to assessment i.e. assessments are available to self-funders. From this assessment the assessor will then determine whether or not the person's needs are eligible.

The assessment process is a means of helping the person to understand their needs, how they can be met, and how they can achieve their outcomes. This might not necessarily be through enabling access to care services, but could also involve networks of support, universal services, or the person's own strengths. For the assessor this means seeking to establish the total extent of a person's needs – including those currently met by a carer - before considering their eligibility for care and support, and what types of care and support can help meet those needs. This must include looking at the impact of the person's needs on

their wellbeing (even if their needs are being met) and whether meeting these needs will help the person achieve their desired outcomes.

This so called ‘carer blinkered’ aspect of assessment is a new requirement in the guidance. It aims to ensure that the entirety of a person’s needs is identified during assessment so that, if the carer feels unable or unwilling to carry out some or all of their caring in the future, the person’s needs have already been assessed and the local authority can take steps to meet them without further assessment.

It is, of course, a basic requirement that people should be informed that they are being assessed and information must be shared about what they might expect from the assessment process – its format, timescales, rights to complain, and the ways in which they can be involved. This should happen in advance, because there is a right to refuse assessment in certain situations.

Carer’s assessment

Where an individual provides care, or intends to provide care, the local authority must consider assessment if the carer appears to have any level of **need for support**. The previous requirement to provide ‘substantial’ and ‘regular’ care (to be defined as a carer) will be removed, as will the requirement to ask for an assessment. Note that in the definition of a carer in section 10 (3) of the Care Act, someone is not considered a carer where care is provided as part of a contract or if they are a volunteer. However, the local authority has the option to view a person as a carer if they feel it is appropriate, even if they provide care on a contractual or voluntary basis, or if part of the care they provide is contractual or voluntary.

It follows from this requirement to undertake a carer’s assessment that carers should be informed that they are being assessed and information should be shared about what they might expect from the assessment process – its format, timescales, rights to complain, and the ways in which they can be involved, once again, in advance.

The exploration of **sustainability** of the caring role (including practical and emotional support the carer provides) must consider whether the carer is currently able – and will continue to be able - and is willing to continue to care for the person. The guidance states that *“Where appropriate these views may be sought in a separate conversation independent from the adult’s needs assessment”* (6.18). This is because such a conversation may be sensitive and difficult to manage with both the adult and their carer in the room. It is important for advocates to think of the dynamic of the situation and talk to the carer about requesting separate meetings especially if they may feel uncomfortable speaking openly about their needs.



A carer's assessment must also consider the **impact** on the carer's activities beyond their caring responsibilities, e.g. their desire and ability to work, partake in education, training or recreational activities, or to have time to themselves. Impact on the carer's activities should be considered both in the short-term and "*over a longer term cumulative sense*" (6.19).

Child's needs assessment

Where it appears to a local authority that a child is likely to have needs for care and support after becoming 18, the authority must, if it is satisfied that it would be of significant benefit to the child to do so and assess:

- (a) whether the child has needs for care and support and, if so, what those needs are, and
- (b) whether the child is likely to have needs for care and support after becoming 18 and, if so, what those needs are likely to be.

The local authority must gain consent from the child (if the child has capacity or is competent to consent to a child's needs assessment being carried out). If the child lacks capacity or is not competent to consent the authority must be satisfied that carrying out a child's needs assessment would be in the child's best interests. If however the child is experiencing or is at risk of abuse or neglect, consent is not required.

The child's needs assessment must include an assessment of:

- the impact of what the child's needs for care and support are likely to be after the child becomes 18
- the outcomes that the child wishes to achieve in day-to-day life, and
- whether, and if so to what extent, the provision of care and support could contribute to the achievement of those outcomes.

A local authority, in carrying out a child's needs assessment, must involve the child, their parents and/or any carer(s) and any person whom the child or a parent or carer of the child requests the local authority to involve.

Once the assessment has been completed the local authority must give the child:

- an indication as to whether any of the needs for care and support are likely to meet the eligibility criteria (and, if so, which ones are likely to do so), and
- advice and information about what can be done to meet or reduce the needs which it thinks the child is likely to have after becoming 18 AND

what can be done to prevent or delay the development by the child of needs for care and support in the future.

Where the child is not competent or lacks capacity to understand this information the local authority is required to give this information to the child's parents.

Child's carer's assessment

Where it appears that a carer of a child is likely to have needs for support after the child becomes 18, the authority must, if it is satisfied that it would be of significant benefit to the carer to do so, assess:

- whether the carer has needs for support and, if so, what those needs are, and
- whether the carer is likely to have needs for support after the child becomes 18 and, if so, what those needs are likely to be.

A 'carer', in relation to a child, means an adult (including one who is a parent of the child) who provides or intends to provide care¹ for the child. It does not include people who provide care by virtue of a contract or as voluntary work. However, where the local authority considers that the relationship between the child and adult providing (or intending to provide) care is such that it would be appropriate for the adult to be regarded as a carer, the adult should be regarded as such and will be eligible to an assessment.

Young carer's assessment²

Young carers are children under 18 with caring responsibilities. As part of the whole family approach, if there is a disabled adult being cared for, then the local council has a duty to consider whether there are any children involved in providing that care, and if so, what the impact is on that child.

The local council have a duty to assess 'on the appearance of need' (i.e. without a 'request' having to be made). They also have a more general duty to 'take reasonable steps' to identify young carers in their area.

¹ The references to providing care include a reference to providing practical or emotional support.

² Taken from Assessments and the Care Act Getting help in England from April 2015 Carers UK 2015



The local council must involve the child with caring responsibilities, their parents and any other person the young carer requests in the assessment process. The assessment itself must look at whether or not the young carer wishes to continue caring, and whether it is appropriate for them to continue caring. When doing this they have to take into account any education, training, work or recreational activities the young carer is or wishes to participate in.

Where a young carer's eligible needs are identified as requiring support, local councils will have to:

- provide support directly to the young carer *or*
- demonstrate that the 'cared for person's' assessment has provided adequate care and support to prevent inappropriate care being required from the young carer

Refusing an assessment

A person with possible care and support needs or a carer may refuse to have an assessment. This could be because, for instance, they do not feel that they **need care** or they may not **want** local authority support. If someone refuses an assessment and has capacity, they are generally entitled to choose to do so.

The local authority must carry out an assessment at a later time if requested by a person who initially refuses assessment. If the local authority later establishes that the person's needs or circumstances have changed, the guidance states that *"... the local authority must consider whether it is required to offer an assessment, unless the person continues to refuse"* (6.21).

Where the local authority has identified that an individual lacks the capacity to refuse an assessment and that carrying out an assessment would be in their best interests, the local authority is required to do so. Similarly, if the local authority believes that an adult is experiencing, or is at risk of experiencing, any abuse or neglect they must begin an assessment, regardless of refusal.

Where a person lacks the capacity to e.g. refuse an assessment, request an assessment, or express their needs, good practice would include appointing an advocate. The guidance states *"The local authority must in these situations carry out supported decision making, supporting the adult to be as involved as possible in the assessment, and must carry out a capacity assessment. The requirements of the Mental Capacity Act and access to an Independent Mental Capacity Advocate apply for all those who may lack capacity"* (6.11).

The Assessment Journey

Before the assessment - contacting the local authority

Advocates must remember that the social care system is not easy to navigate and people can find the system of social care confusing³. Often people are in crisis when they first access social care support and therefore can already find decision-making difficult, especially if they have not foreseen the need for care. This means that people need accessible and good quality information and advice. The more complex the system, the more likely it is that people will need independent advice or advocacy to navigate a way through.

Many people will need help in accessing information and advice even before they contact the local authority and the Care Act places a responsibility on the local authority to provide support through information and advice services. Having access to independent advocacy is part of this range of support which includes:

- Self help information: provided through websites, leaflets, NHS choices etc
- Assisted information: provided through telephone helplines, directories, libraries, one stop shops, CAB, charities, information centres, GPs, frontline staff etc
- Advice: providing through telephone lines, information centres, one stop shops, CAB, support groups, carers' centres, CIL, social workers, GPs, outreach staff/workers etc
- Specialist advice and advocacy: provided through independent financial advisors, legal help on complex matters in specific areas of law, independent advocates.

Advocates therefore need to be able to inform people (or know how to access information) about how the local care and support system works, how to access care and support services, the different types of care and support that are available and the choice of providers. Advocates may also need to provide

³ Karen Windle, et al (2010) [Measuring the outcomes of information and advice services: final report](#). Discussion Paper 2713, Personal Social Services Research Unit, University of Kent, Canterbury. *This research formed part of the 'Measuring Outcomes for Public Service Users' project which aimed to enable the measurement of robust and valid outcomes within and across information, advice and advocacy services. The proposed model covers three levels across which benefit might be measured: societal, organizational and individual.*

³ Think Local Act Personal (2013) Advice and information needs in adult social care: Interim report for the Think Local, Act Personal partnership.



access to financial information relating to care and support including how to access independent financial advice.

The local authority is under a duty to ensure such information is available to all people in its area.

The first response of a local authority

Once a referral has been received, or a person has contacted the local authority, the assessment process begins. The role of staff at the first contact is to gather information. . The nature of the assessment will not always be the same for all people, and depending on the circumstances, it could range from an initial contact or “triage” process which helps a person with lower needs to access support in their local community, to a more intensive, ongoing process which requires the input of a number of professionals over a longer period of time. Note that a person who has any level of need for support cannot be screened out of the process on the basis that they may not meet the eligibility criteria for a service. However first contact staff may offer advice and then signpost or refer a person to preventive services rather than referring to the next step of the assessment process.

At the point of first contact local authorities **must** consider whether the service user or carer would experience difficulty in being involved in the assessment. If they consider this is the case, and there is no one else appropriate to support their involvement, then that person must be offered an independent advocate.

Assessment

If after completing the screening process, it appears to the local authority that the person may need care and support then the local authority must assess whether the adult has those needs and what they are. As part of the assessment the local authority must involve the person being assessed, any carer(s) and any person whom the person being assessed asks the authority to involve or, where they lack capacity to ask the authority to do that, any person who appears to the authority to be interested in the welfare of the person being assessed.

A needs assessment must include an assessment of:

- a) the impact of the person’s needs on their wellbeing,
- b) the outcomes the person wishes to achieve in their day-to-day life, and
- c) whether, or to what extent, the provision of care and support could contribute to the achievement of those outcomes

The assessment a person receives has to be **appropriate and proportionate** – this means it is flexible and adaptable to fit with the person’s needs and is proportionate to the severity of the need and the complexity of the situation. For example the assessment might be carried out on the phone or online where needs are easily recognisable. Questions which should be considered by the local authority when determining what an appropriate and proportionate assessment should look like include:

- How severe/extensive are needs?
- Do needs fluctuate?
- How complex are the circumstances?
- How significant are the impacts of these needs?
- What are the strengths of the person and any carers?
- What are their desired outcomes/preferences?
- Does the person have capacity?
- Does the organisation have historical information that can inform the assessment?
- Does the person have any difficulty engaging in the assessment?

Assessment types

There are a number of ways in which an assessment might be completed and where an advocate could offer support:

Face to face

This type of assessment takes place between the assessor and the person or people concerned. For a person who faces substantial difficulty at being involved in the process, an advocate could work with the person to prepare for the meeting, to identify any questions they have, to think about their needs and decide how best to express these. An advocate should also be present during the meeting to ensure the person being assessed feels able to control the process, can ask questions and is fully supported to participate throughout the assessment.

Practice example:

Jeanne Cissé is 76 and lives in her own house with her husband. Jeanne’s husband Alexis is now unable to get out of bed and uses the only downstairs room as a bedroom. Their only son lives in New Zealand.

Thirteen years ago Jeanne collapsed in the street and was found to have suffered a subdural haematoma which required surgery. She has had to learn to



read and write again, has some word finding difficulties and cannot manage correspondence. She has difficulty retaining information. She has recently had a seizure which is the first time this has happened since her surgery. Her mobility is reducing and Jeanne has difficulty managing stairs, but her bedroom is upstairs.

On meeting with Jeanne and Alexis, the advocate found that both were entitled to an assessment. The advocate felt able to work with both – on the basis that there were no conflict of interests and both the service users, and the local authority, agreed.

The advocate, Carla, identified with Jeanne what her needs were, what she felt her strengths were, the thing that she felt she could do and her desired outcomes.

Carla then worked with Alexis to find out what his needs were, and his desired outcomes. This took several visits as Jeanne found the whole process tiring. Carla found it helpful to use some large templates⁴ with both Jeanne and Alexis so that she could leave them for Jeanne and Alexis to look at and think about between visits. They started by looking at what was working and what was not working for each. Jeanne thought about what made a good day after Carla asked the questions: ‘if you had a magic wand and were going to create a really good day for yourself – what would happen?’ She then asked a similar question about a bad day. With Alexis, Carla took a flip chart to his room, stuck a large template up to look at what was working and not working and wrote his hopes and fears on a piece of flip chart paper so that he could easily see what she was doing.

Carla explained to Jeanne and Alexis what would happen when the assessor visited and explained that the assessor might also contact their GP and possibly other professionals in the NHS. She also explained that while their needs were being assessed the local authority might decide that one or other of them were not eligible for services.

The assessor agreed to visit once Carla had told her that they were prepared and that the work they had done together would answer all the questions that the assessor was likely to want answered. Both Jeanne and Alexis wanted Carla to speak for them at the meeting, but the assessor was able to involve them by talking about the materials Carla presented.

Supported self assessment

⁴ Large templates can be purchased from <http://www.helensandersonassociates.co.uk/>

A person can complete an assessment form themselves which is then checked by the assessor to make sure it is accurate and complete. This may involve asking additional questions or checking with other people such as the person's GP. Local authorities are likely to encourage self assessment for people who are able to do this as this reduces the impact of the assessment process.

People who are competent enough to complete a self assessment are unlikely to need the support of an advocate: if they are able to complete their own assessment they are unlikely to face substantial difficulty in one of the four areas of understanding relevant information, retaining information, using or weighing up the information or communicating their views, wishes and feelings. However this should not be assumed and an advocate could offer support to a person completing a self assessment. Alternatively, a person who does have substantial difficulty in being involved in the assessment process may still wish to complete their own self assessment and the advocate should offer support to enable them to do this.

Practice example

Felipe is 42 and has motor neurone disease. He has received support from his local authority for the past 4 years - however he has been referred for a new assessment as his health has recently deteriorated and his needs have increased.

An advocate was offered to Felipe as he has very limited communication methods. Although he fully understands the process, his needs and options, he is not able to indicate any clear communication without support.

An advocate works intensively with Felipe to understand his communication and establishes a system of eye movements to indicate yes, no, likes, dislikes etc. Using 'talking mats'⁵ the advocate is able to capture Felipe's aspirations, own definition of his needs and what would help promote his wellbeing.

Although the advocate physically completes the assessment forms the content is directed and controlled by Felipe.

Joint assessment

⁵ Talking Mats is a resource using picture and communication symbols. See <http://www.talkingmats.com>



A joint assessment could take place where a person receives support from more than one service – the different agencies work together to undertake the joint assessment and avoid multiple assessments all impacting on the person. For people being assessed this will make their lives easier but also means that the advocate needs to understand what each agency is assessing/able to provide.

Such joint assessments are increasingly being undertaken at people's contact with Accident and Emergency or through hospital discharge arrangements, when there is often an urgency for a needs assessment and care and support arrangements to be in place to prevent hospital admission or a person's timely return to their own home.

Practice example

Ruth is 78 years old and lives alone in a house that she used to share with her husband (who died 6 months ago). She suffers from COPD⁶, is frail and has restricted mobility. She has been admitted to hospital several times for short periods because of respiratory infections. She used to smoke heavily but gave up when she was first diagnosed five years ago.

Ruth's needs are being assessed because the GP has expressed concern about her ability to continue to manage at home on her own without support. She does have some emotional and practical support from a neighbour, but this person is also a full time carer for her partner. She has advocacy support because she has substantial difficulty in retaining information and has not been able to identify anyone who support her (Ruth's neighbour felt that she could not take on this role).

With Ruth's permission, the assessor Ben, contacted her GP and found that Ruth had been referred for pulmonary rehabilitation, but that this would not be available for 3 months. The GP thought the programme would last for about 2 months.

Ben telephoned the advocate to let her know that his plan was to work with the health professionals on the pulmonary rehabilitation team to integrate the care and support needs assessment with theirs. He also thought that Ruth's care and support needs might be less following the pulmonary rehabilitation programme.

⁶ Chronic obstructive pulmonary disease (COPD) is the name for a collection of lung diseases including chronic bronchitis, emphysema and chronic obstructive airways disease. People with COPD have difficulties breathing.

Ben explained that this meant that the assessment of Ruth's care and support needs would be paused, while the potential impact of the pulmonary rehabilitation programme was considered. He also explained that it might be useful to continue the pause until the impact of the programme was evaluated.

The advocate met Ruth and explained the situation. Ruth also asked the advocate to talk to her neighbour as she was worried that she would 'get it all wrong'. She told the advocate that she was anxious that she might have to go into a care home if anything went wrong. The advocate agreed to talk to the neighbour and find out if she felt able to continue to support Ruth over the next five months. She also agreed to pass on Ruth's concerns to Ben.

On-line or phone assessment

Many people can have their needs assessed on-line or via the telephone. This will be particularly appropriate for people whose needs are easily recognisable or less complex. By offering this type of assessment, people can access and complete the assessment process quickly with minimum impact or delay.

If the local authority believes that a person could be assessed via the telephone or on-line they must consider their eligibility for an independent advocate. If a person is entitled to support through a telephone assessment, the advocate could prepare a person for the phone call, what might be asked, what response to offer. An advocate could also help the person to identify their needs and desired outcomes. During the assessment, the advocate could support the person to ask any questions they have and ensure the person expressed all of their needs in a way they wanted.

Practice example

Krista is in the early stages of dementia. She can understand information but has difficulty retaining and weighing it up. She does not like people talking about her. She lives in a flat but she does not know the neighbours and she has no children. Her nearest relative is a nephew who lives in Ireland and has not seen his aunt for several years.

She has an advocate who has helped her prepare for the telephone assessment and arranged for a speaker phone to be used, in agreement with the assessor. Krista would like to speak to the assessor herself but is worried that she might get confused or stressed by the process. She has agreed that the advocate will speak on her behalf if this happens. Krista and her advocate have identified



possible questions that she could find stressful and practised answers for others.

Combined assessment

A combined assessment can take place where the needs of two people align. For instance a husband and wife or a person needing care and support and their carer have very similar care needs. If a combined assessment is being considered, both parties have to agree to be assessed together.

Where advocates are supporting a person who lacks the capacity to consent to a combined assessment, the advocate should consider its appropriateness and raise concerns where it appears the two people have different needs.

Practice example

Jasper has phoned the local authority about his 85 year old father, Mr. Dodd, who has been diagnosed with vascular dementia. Mr Dodd, also has rheumatoid arthritis. His wife died three years ago and his son, Jasper, lives with him. Jasper has bi-polar disorder and suffers from chronic back pain due to sciatica. Jasper has always had a good relationship with his father and wants to be able to continue to care for him.

Jasper does the shopping on line once a fortnight. He cooks all the meals although Mr. Dodd tries to help and make a cup of tea, for example, However, Jasper will find his father pouring milk into the kettle or putting the tea bag into a cup of milk. Jasper usually has to help his father get into bed at night. Mr. Dodd often gets up several times in the night and gets dressed, believing that it is time for breakfast. He then wakes Jasper to tell him it is time to get up. He becomes angry and upset when Jasper tells him to go back to bed. Recently Jasper has had to take him back to his bedroom and help him to go back to bed. Jasper cannot cope with this lack of sleep and, while his father will sit and have a nap several times during the day, Jasper is unable to do this.

Mr. Dodd is aware of his son's concerns but gets frustrated when Jasper tries to talk to him about them. Nevertheless he agrees with Jasper that they need support and they both agree to a joint assessment.

Mr. Dodd finds it difficult to retain information and Jasper has fluctuating needs, which at this point are such that he cannot always retain or understand relevant information. There are no other relatives or people who can be identified to support them through the assessment process.

An advocate meets independently with Mr Dodd and Jasper and establishes that their wishes and needs both align:

- *Both agree that regular respite care for Mr Dodd would help Jasper take some time for himself.*
- *Both agree that Mr Dodd needs help with cooking and cleaning. Whilst they are both happy for Jasper to do most of this, they also feel home help once every other day would relieve the pressure on Jasper.*
- *Both agree that physically Mr. Dodd needs more support than Jasper is able to give due to his own health needs (sciatica)*
- *Both wish to be able to continue to live together in their home*
- *Both agree that they are becoming increasingly isolated and that they would like to have more social contact.*

What are 'Eligible' needs?

The Act introduces a national threshold whereby if a person's needs meet three conditions, then their needs are eligible. The eligibility threshold is based on three conditions, all of which must be met for a person to be eligible:

1. The adult's needs arise from or are related to a physical or mental impairment or illness.
 2. As a result of the adult's needs the adult is unable to achieve two or more of the specified outcomes (which are described below).
 3. As a consequence of being unable to achieve these outcomes there is, or there is likely to be, a significant impact on the adult's wellbeing.
1. The adult's needs arise from or are related to a physical or mental impairment or illness

The first condition that local authorities must be satisfied about is that the adult's needs for care and support are due to a physical or mental impairment or illness and that they are not caused by other circumstantial factors. Local authorities must consider at this stage if the adult has a condition as a result of either physical, mental, sensory, learning or cognitive disabilities or illnesses, substance misuse or brain injury. The authority should base their judgment on the assessment of the adult and a formal diagnosis of the condition should not be required.

2. As a result of the adult's needs, the adult is unable to achieve two or more of the outcomes set out in the regulations



The second condition that authorities must consider is whether the adult is “unable” to achieve two or more of the outcomes set out in the regulations. Authorities must also be aware that the regulations provide that “being unable” to achieve an outcome includes any of the following circumstances, where the adult:

- is unable to achieve the outcome without assistance. This would include where an adult would be unable to do so even when assistance is provided. It also includes where the adult may need prompting for example, some adults may be physically able to wash but need reminding of the importance of personal hygiene;
- is able to achieve the outcome without assistance but doing so causes the adult significant pain, distress or anxiety. For example, an older person with severe arthritis may be able to prepare a meal, but doing so will leave them in severe pain and unable to eat the meal;
- is able to achieve the outcome without assistance, but doing so endangers or is likely to endanger the health or safety of the adult, or of others – for example, if the health or safety of another member of the family, including any child, could be endangered when an adult attempts to complete a task or an activity without relevant support;
- is able to achieve the outcome without assistance but takes significantly longer than would normally be expected. For example, an adult with a physical disability is able to dress themselves in the morning, but it takes them a long time to do this, leaves them exhausted and prevents them from achieving other outcomes.

The Eligibility Regulations set out a range of outcomes. Local authorities must consider whether the adult is unable to achieve two or more of these outcomes when making the eligibility determination.

- **managing and maintaining nutrition** Local authorities should consider whether the adult has access to food and drink to maintain nutrition, and that the adult is able to prepare and consume the food and drink.
- **maintaining personal hygiene** Local authorities should, for example, consider the adult’s ability to wash themselves and launder their clothes.
- **managing toilet needs** Local authorities should consider the adult’s ability to access and use a toilet and manage their toilet needs.
- **being appropriately clothed** Local authorities should consider the adult’s ability to dress themselves and to be appropriately dressed, for instance in relation to the weather to maintain their health.
- **being able to make use of the home safely** Local authorities should consider the adult’s ability to move around the home safely, which could for example include getting up steps, using kitchen facilities or accessing the bathroom. This should also include the immediate environment around

the home such as access to the property, for example steps leading up to the home.

- **maintaining a habitable home environment** Local authorities should consider whether the condition of the adult's home is sufficiently clean and maintained to be safe. A habitable home is safe and has essential amenities. An adult may require support to sustain their occupancy of the home and to maintain amenities, such as water, electricity and gas.
- **developing and maintaining family or other personal relationships** Local authorities should consider whether the adult is lonely or isolated, either because their needs prevent them from maintaining the personal relationships they have or because their needs prevent them from developing new relationships.
- **accessing and engaging in work, training, education or volunteering** Local authorities should consider whether the adult has an opportunity to apply themselves and contribute to society through work, training, education or volunteering, subject to their own wishes in this regard. This includes the physical access to any facility and support with the participation in the relevant activity.
- **making use of necessary facilities or services in the local community including public transport and recreational facilities or services** Local authorities should consider the adult's ability to get around in the community safely and consider their ability to use such facilities as public transport, shops or recreational facilities when considering the impact on their wellbeing. Local authorities do not have responsibility for the provision of NHS services such as patient transport, however they should consider needs for support when the adult is attending healthcare appointments.
- **carrying out any caring responsibilities the adult has for a child** Local authorities should consider any parenting or other caring responsibilities the person has. The adult may for example be a step-parent with caring responsibilities for their spouse's children.

3. As a consequence there is, or there is likely to be, a significant impact on the adult's wellbeing (see definition page 7)

The third condition that must be met is that local authorities must consider whether the adult's needs and their inability to achieve the outcomes above cause or risk causing a significant impact on their wellbeing.

Carers Eligible Needs

The Act also introduces a national carers' eligibility threshold as carers can be eligible for support in their own right regardless of whether the person for whom they care has eligible needs. Carers will be eligible for support if:



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1. they have needs due to providing necessary care for an adult
2. as a result of those needs they are unable to achieve one or more specified outcomes or their health is (or is at risk of) deteriorating; and
3. as a consequence there is a significant impact on their wellbeing.

To be eligible, a carer must be unable to achieve any of the following outcomes:

1. **carrying out any caring responsibilities the carer has for a child** Local authorities should consider any parenting or other caring responsibilities the carer has for a child in addition to their caring role for the adult. For example, the carer might be a grandparent with caring responsibilities for their grandchildren while the grandchildren's parents are at work.
2. **providing care to other persons for whom the carer provides care** Local authorities should consider any additional caring responsibilities the carer may have for other adults. For example, a carer may also have caring responsibilities for a parent in addition to caring for the adult with care and support needs.
3. **maintaining a habitable home environment** Local authorities should consider whether the condition of the carer's home is safe and an appropriate environment to live in and whether it presents a significant risk to the carer's wellbeing. A habitable home should be safe and have essential amenities such as water, electricity and gas.
4. **managing and maintaining nutrition** Local authorities should consider whether the carer has the time to do essential shopping and to prepare meals for themselves and their family.
5. **developing and maintaining family or other significant personal relationships** Local authorities should consider whether the carer is in a position where their caring role prevents them from maintaining key relationships with family and friends or from developing new relationships where the carer does not already have other personal relationships.
6. **engaging in work, training, education or volunteering** Local authorities should consider whether the carer can continue in their job, and contribute to society, apply themselves in education, volunteer to support civil society or have the opportunity to get a job, if they are not in employment.
7. **making use of necessary facilities or services in the local community** Local authorities should consider whether the carer has an opportunity to make use of the local community's services and facilities and for example consider whether the carer has time to use recreational facilities such as gyms or swimming pools.

8. **Engaging in recreational activities** Local authorities should consider whether the carer has leisure time, which might for example be some free time to read or engage in a hobby.

Following assessment – next steps

The person must be given a copy of the assessment. A copy must also be shared with anyone else the individual requests the local authority to share a copy with.

The advocate will then need to ensure that the person being assessed understands the next steps after assessment. There are a number of things which can follow:

1. If the local authority is required to meet needs or decides to do so it must:
 - a) prepare a care and support plan or support plan,
 - b) tell the person which (if any) of the needs that it is going to meet in the person's case may be met by direct payments, and
 - c) help the person with deciding how to have the needs met.

The advocate can continue to support the person through this stage of the process.

2. If the local authority has completed the needs or carer's assessment but is not required to meet those needs and decides not to, it must give the person concerned
 - a) written reasons for not meeting needs,
 - b) advice and information about what can be done to meet or reduce the needs;
 - c) what can be done to prevent/delay development of needs in the future.

If this is the case then the advocate can remain involved under the Act in the following circumstances:

- To help the person understand the decision
- To support a person who wants to appeal [subject to developing policy]
- To challenge the decision if the advocate feels the process or decision was not in line with legislative frameworks.

Advocacy in action

Checking information is accessible



To support the person's involvement, the local authority should establish the individual's communication needs and seek to adapt the assessment process accordingly. This means that local authorities must provide information about the assessment process in an accessible format.

The advocate should always check that the local authority has provided a list of questions to be covered in the assessment in an accessible format. This will help the individual or carer prepare with their advocate for their assessment and consider what their needs are and the outcomes they want to achieve.

Many people are able to give a vivid picture of what is happening in their lives. This is often both an assessment of their situation, which gives clues about their vulnerability and resilience and a chance to identify what services might be needed to make their lives better. This picture may be drawn and presented in a number of ways and advocates will have creative toolkits to do this.

Preparing for a meeting with the social worker

The key things that the advocate and service user or carer will need to convey in the assessment are what their strengths are, what their needs are, what outcomes the person wants (the impacts the person would like to achieve on their quality of life). The advocate will need to spend some time with the person concerned to help them to prepare for the assessment.

Practice example

Jeremy is 50 years old and has a diagnosis of moderate/severe learning disability. He is married to Kate who also has a diagnosis of moderate/severe learning difficulties and has limited speech or understanding. Jeremy works in the kitchen of a local pub four days a week. Jeremy suffers with IBS and has arthritis. He gets tired easily. Jeremy needs support to take his medication regularly.

Kate has glaucoma and problems with swelling in her legs and sees the practice nurse weekly. She manages to prepare a daily meal although this is her sole activity of the day and she spends a lot of time asleep in a chair. Jeremy's sister lives nearby and tries to be supportive but his experience is that she is interfering. Recently Kate has failed to keep appointments and Jeremy's hours have been reduced as the owner of the pub has said that he is too slow.

Jeremy's sister has contacted social services to find out what help is available however the local authority have deemed she is not an appropriate person to support Jeremy and Kate as they are both upset that she has contacted social services and have said they do not want her support. There is evidence that both

Jeremy and Kate have substantial difficulties in communicating their wishes and feelings.

The advocate used Helen Sanderson⁷ tools to work with Jeremy and Kate and helps them each to create a one-page profile. She then went on to use the 'working and not working' person centred thinking tool to think about actions to build on what was working and identify what was not working. The one-page profile and the good day/bad day tools provided information to work out what was working and not working in their lives. Jeremy and Kate both felt they had something concrete and clear to share with the social worker and both felt prepared for the meeting and how to express their needs.

At a meeting with an assessor

Once the advocate has supported the person to identify their needs and desired outcomes, the advocate can then support the person to think about how to manage the meeting. Things to consider include:

- Agreeing how far the person being assessed can speak for themselves and what support the advocate might provide.
- Agreeing how to present information about what their life is like and what their needs are eg on a flip chart, by making a video, developing a powerpoint presentation, using the Helen Sanderson person-centred planning tools.
- Ensuring that the person being assessed understands the limits of the advocate's involvement and what will happen after the meeting.

Practice example

During the assessment Jeremy was able to talk about what he had done with the advocate and present his one-page profile. During their preparation work, the advocate also found out that he was fascinated by computers - although he did not have one and could not use one. Using the advocate's laptop they developed a PowerPoint presentation which Jeremy loved doing and thought was very clever. He talked about what was on each slide during the assessment.

Kate has very little speech and was unable to present her own wishes and views. However she would smile or occasionally say 'Yes that's right' when the advocate

⁷ Helen Sanderson Associates specialise in developing person centred planning tools. See <http://www.helensandersonassociates.co.uk> for more information



checked with her during the meeting. The advocate had learned that Kate also had a look when she did not understand what was being said and a different look when she did not like something. The advocate sat opposite Kate in the meeting so that she could watch her expressions.

After the assessment, the person and anybody else must be given a record of the assessment. The person must also receive a written record of the eligibility determination. There were concerns that Jeremy and Kate would not understand this information, so the advocate arranged to visit again to explain it to them and made sure that they understood what was going to happen next.

Chapter 4: Direct payments and Individual Budgets

What is a personal budget?

A personal budget is an amount of money that the local authority will provide to a person they assess as eligible to enable them to meet their unmet care and support needs. Personal budgets are considered key to making care and support personalised as the preferences and wishes of the person are at the forefront throughout the process in how they would like their care and support arranged.

The personal budget details the cost of the care and support that was drawn up in the support plan and identifies the amount that the local authority will pay towards it. Increasingly it can come from a variety of different funding streams such as the NHS, Education or Social Services depending on the person's needs.

Everyone whose needs are met by the local authority, whether those needs are eligible, or if the authority has chosen to meet other needs, must receive a personal budget as part of the care and support plan, or support plan.

A personal budget enables a person to achieve the outcomes agreed in their support plan and if they have the direct payment form of a budget, to purchase the appropriate services, support, activities or equipment to meet their needs.

If a person is eligible, there are three options in how to receive the personal budget:

1. A local authority managed budget in which the local authority coordinates and arranges all the care and support services for the person – this may be for example respite, day care or transport. It may sometimes be referred to as an individual service fund if it is managed by a service provider.
2. A Direct Payment (DP) in which the person or their representative (sometimes called an authorised person or nominee who is normally a friend or family member) receives an amount of money paid into a bank account to arrange their care and support. NB an advocate would not act as a nominee as this is outside of the advocacy role.



3. A third party receives the money and acts in the best interests of the person, managing, arranging and securing services. This can be via a broker, a Trust, a service provider or authorised person.

Elements of the personal budget

The personal budget must always be an amount sufficient to meet the person's care and support needs, and must include the cost to the local authority of meeting the person's needs which the local authority is under a duty to meet, or has exercised its power to do so. This overall cost must then be broken down into the amount the person must pay, following the financial assessment, and the remainder of the budget that the authority will pay.

The personal budget may also set out other amounts of public money that the person is receiving, such as money provided through a personal health budget. Local authorities should consider requests from individuals to present their personal budget in this way.

Local authorities must carry out their care and support responsibilities with a view to promoting integration with health and other related services (such as housing), and therefore should take a lead in driving the integration of support services for their population. For example, this may involve agreeing with partner organisations how to integrate budgets and to what extent, and the establishment of a lead organisation that agrees to oversee monitoring and assurance of all budgets the person is receiving.

Where a local authority is meeting the eligible needs of a person whose financial resources are above the financial limit, but who has requested the local authority meet their needs, the local authority may make a charge for putting in place the necessary arrangements to meet needs. Where this occurs, the local authority should consider how best to set this information out to the person, in a format accessible to them. This fee is not part of the personal budget, since it does not relate directly to meeting needs, but it may be presented alongside the budget to help the person understand the total charges to be paid. For example, a local authority may wish to specify this in both the plan and the personal budget for the person so all parties are clear on how costs are allocated.

Similarly, there will be cases where a person or a third party on their behalf is making an additional payment (or a "top-up") in order to be able to secure the care and support of their choice, where this costs more than the local authority would pay for such a type of care. In these cases, the additional payment does

not form part of the personal budget, since the budget must reflect the costs to the local authority of meeting the needs. However, the local authority should consider how best to present this information to the individual, so that the total amount of charges paid is clear, and the link to the personal budget amount is understood.

Elements of care and support that are excluded from the personal budget

Regulations set out the cases or circumstances where the costs of meeting the needs of care and support do not have to be incorporated into the personal budget. Because both the care and support plan and personal budget are mechanisms to enable people to have greater choice and control over their care and support, there are not many instances where this exclusion will apply.

The Care and Support (Personal Budget Exclusion of Costs) Regulations 2014 set out that the provision of intermediate care and reablement services, for which the local authority cannot or chooses not to make a charge, must be excluded from the personal budget. This will mean that where either intermediate care or reablement is being provided to meet needs (i.e. under section 18, 19 or 20 of the Act) the cost of this must not be included in the personal budget.

Intermediate care services are usually provided to patients, often older people, after leaving hospital or when they are at risk of being sent to hospital. The services are a link between places such as hospitals and people's homes, and between different areas of the health and social care system – community services, hospitals, GPs and social care. "Reablement" is a particular type of intermediate care, which has a stronger focus on helping the person to regain skills and capabilities to reduce their needs, in particular through the use of therapy or minor adaptations.

Intermediate care/reablement should usually be provided as a free, universal service under section 2 of the Act, and therefore would not contribute to the personal budget amount. However, in some circumstances, a local authority may choose to combine either service with aspects of care and support to meet eligible or ongoing needs, which would require a personal budget to be developed. Removing the cost of provision of intermediate care/ reablement from the personal budget in these scenarios ensures that the allocation of both services is applied uniformly across all local authorities, and in future people progress towards the cap on care costs in a fair and consistent way.



Direct Payments

Direct Payments encourage greater control, flexibility and introduce more creativity in meeting people's support and care needs. People can choose how all or some of their eligible needs are to be met to suit their individual circumstances and preferences. In effect the person in receipt of a direct payment takes charge and becomes a purchaser of their own care and support instead of a relying on local authority provided/arranged care services.

There is a power to provide assistance to manage the direct payment, but no duty; if the authority wishes to fund this help through the direct payment it may allow the money to be paid to a relative in the same household if it thinks it is necessary. Support may also be provided free by way of referral to an in-house or outsourced brokerage or payroll service.

Often people choose a Direct Payment because the services they received from a local authority managed budget in the form of an agency or day centre were not flexible, reliable or suitable to their needs or lifestyle. Also some people with fluctuating needs have found that the control and choices they can make with a DP, allow them to manage their support and care as needed. So it provides a tailored approach to how they can manage their circumstances and needs.

Taking a Direct Payment is a choice but to make a choice, the person must have an understanding of what is involved and how direct payments may or may not work for them. The role of an advocate is to ensure that the person fully understands how direct payments can be used and what the disadvantages and advantages may be for them in managing this to meet their support and care needs.

Practice examples

"The agency tried their best to send the same agency worker during the weekday mornings but often they couldn't and I would have several different agency workers coming to my house throughout the week. Often the agency would not tell me who was coming and they arrived anytime from 8am- 9am. I found it disconcerting that I would not know who was arriving on my doorstep and at what time. This meant I would have to explain to each new care worker what needed doing, how I liked things done (e.g. I like my teabag left in my tea and not weak) and where everything was found. Besides it being tiring repeating myself, it took much longer to get things done and they would rush me towards the end of their shift before going to the next person. I really needed someone who knew me and my routine and was going to be reliable. When I heard that I could employ someone myself by choosing to have a Direct Payment, I jumped at the chance. I now have two very punctual personal assistants who know my morning routine

and just how I like to start my day. It makes a huge difference and more gets done as I am not having to teach the person each day!

Saying this though, finding the right PAs did not happen overnight as I did have to learn how to be an employer and how to recruit and interview as well as take up references and do a criminal record check. There is quite a lot of paperwork initially as you need to have the right contracts for your PAs. You need a payroll service to help you calculate holiday and give the PAs a pay slip each month and deal with the HMRC. However, you soon get used to it and I was lucky to have good support and advice from my local Direct Payments Support Service. I have a bit of system set up now.”

“My son Josh is 19 years old with physical and learning difficulties; however like many youngsters he likes to go to bed late. In addition to this, his evening bedtime routine takes a while due to all the respiratory equipment and checks that need to be done. Unfortunately, the agencies in my area do not provide agency carers after 10pm. The service just isn’t available. So now I am the nominated person who receives the direct payment on behalf of Josh to employ a team of 2 PAs to work from 9 p.m. – 12 am, 6 nights per week. It really works for Josh as he doesn’t have to go to bed at 9:30pm. He is a young man after all!”

“I receive a Direct Payment on behalf of my elderly mother who has had a stroke to engage an agency to look after her when I go work 3 mornings per week. I like the fact that we can change agencies if they do not meet my mother’s needs. We tried several agencies before we found the right one for us. It was great to organise it ourselves rather than relying on the Social Worker and their list of agencies.”

“My Direct Payment included a one off payment to purchase equipment to help me communicate. I am deaf and have speech problems so my Direct Payment paid for a support worker 3 hours per week from an agency. This agency provides support workers with British Sign Language to help me with appointments and face to face things I was struggling with. However, I also received a one off payment in my personal budget to purchase a tablet to help me communicate with people when I am on my own. It is great because it speaks



out the words I struggle to say when I am with people who don't use British Sign Language. I like that it is a piece of equipment that is not special but that everyone is used to and comfortable with when I use it in shops and restaurants."

Fluctuating Needs

One of the many advantages of putting people in control of how they want their care and support to be arranged is that they can find very personal and tailored solutions that fit in with their life and changing needs. This is especially appreciated by people with fluctuating health and support needs. So it is important if a person has fluctuating needs that their support plan should make provisions to accommodate this aspect of their care and find ways to deal with it that work for them.

Practice Example

Martine has Multiple Sclerosis and requires a frame or wheelchair for mobility. She suffers badly with fatigue, but feels able to cope for the majority of the time with daily life with a small amount of care and support. However, during the relapses she has been unable to sit up, walk or transfer, has lost the use of an arm and lost her vision completely. This can last for a few weeks, and happens two or three times per year, requiring 24 hour support for all her needs.

In the past Martine was hospitalized during relapses as she was unable to cope at home. However, in the last couple of years she has received direct payments which allows her to save up to one month's worth of 24 hour care for when she needs it. This is all detailed in her support plan and she has found an agency that can provide this quickly. Martine can now instantly access the extra support she needs without reassessment and has the reassurance that she will be able to put plans in place to cope with any fluctuating needs. This has resulted in no more hospitalisations since her direct payments and has improved her own sense of wellbeing by providing reassurance that she has a Plan B for when her health deteriorates.

Carers and Pooling of Personal Budgets

Personal budgets allow for flexibility and innovation in how care and support can be provided from a diverse range of sources to include Information and Communication Technologies, equipment or club membership. Support plans can be combined and the budgets pooled, either with people in the same household or between members of a community with the similar care needs.

Practice example

The parents of 3 young people with learning difficulties were looking at how they could pool part of their children's personal budgets to pay for the transport to take them to and from the day centre. They all lived close together in a rural area and were finding difficult it to get their children to and from the day centre which was 30 minutes drive away. The parents all had other work and family commitments, so they decided that they would hire a regular taxi service to pick up and take the three adults to and from the day centre. The taxi company billed them individually a third of the monthly taxi bill. The cost of this was written into the support plan.

Carers

Carers now have the same right to an assessment and support as the person that they care for. Following an assessment, a decision will be made whether their needs are eligible and they may be offered a personal budget. The local authority will then be required to work with the carer to draft a support plan to identify how their needs will be met and whether they wish to have this provided by a direct payment. Some examples of support that they may benefit from are:

- Help with housework – such as a cleaning service or even a one off payment to purchase a washer / dryer
- Buying a lap top, phone or tablet to keep in touch with friends and family
- Membership to a gym or swimming pool to ensure their own health and wellbeing
- Classes e.g. leisure or education class, driving lessons



Practice example

Yvonne and John have been married for 25 years. Recently Yvonne had a brain tumour removed which left her paralysed down one side. Yvonne needs assistance to get washed and dressed. John works as a school bus driver which involves him leaving the house at 6:30am every weekday morning. John would like to continue working but this means he is unable to help Yvonne get washed and dressed in the mornings. John would also like to continue to take his grandson to swimming training on a Saturday morning but again this leaves Yvonne without anyone to help her get washed and dressed. Yvonne and John agree to have a joint support plan and pool their personal budgets to pay for a PA to help with the morning routine. This meets the aligned needs of Yvonne (to receive help in getting up, washed and dressed) and John (to go to work and take his Grandson swimming)

Pooling Budgets

Joint funding from the NHS and Social Services

Personal budgets can be combined where a person receives support both from the local authority for their social care and support needs and NHS health care in the form of a personal health budget. This is to reduce duplicating processes and monitoring and to minimise bureaucracy.

Joint Funding with Education

From September 2014 parents will have the right to request a personal budget for their children with special education needs. A statement of special education needs will now be replaced by an Education, Health and Care Plan sometimes referred to as an EHC plan. This is just like a support plan but includes a section on education and how these needs will be met.

A young person aged 16- 25 years may be able to receive funding as part of their personal budget to help them with their special education needs.

Practice example:

Sandra is 18 and has very severe, complex needs. She attends a local sixth form college. Her mother employs a team of personal care assistants (PAs), with two of them going into the college to support her. The morning PA helps her get

up and ready and takes her the short walk to college in her wheelchair. The PA supports her in classes alongside the college learning / teaching assistants who help liaise with the teachers, prepare for lessons and use low tech communication aids.

The second PA arrives at lunchtime to double up for personal care and to ensure a good handover takes place. The afternoon PA then takes over and supports Amy in classes and brings her home. PAs also double up for swimming and any field trips to ensure safe manual handling. The PA hours in school are covered by the Education component of her Personal Budget and the rest of the PA hours at home are covered by the Social Care component.

The PAs have helped Sandra to communicate with her classmates and to be included. This really helps Sandra to be happy and well. She loves attending a college nearby and not having to attend a special school like she did when she was younger.

Rights to request a direct payment

When someone has a personal budget they can request a direct payment. The local authority must inform the person which, if any, of their needs may be met by a direct payment and provide appropriate information and advice as to how to use and manage a direct payment.

Advocates will be involved in helping a person to understand what a direct payment is and to explore how this may work for them in. Advocates may also need to 'advocate on the person's behalf' and request information is provided by the local authority so they can make a choice.

A request for a direct payment must be dealt with in a timely manner and the person does not have to wait until a review is due if they are in receipt of care or support services from the local authority. If a review is due, the Guidance suggests that the date will be brought forward in order to not delay the request and consideration for a direct payment.

There are criteria to meet if a person nominates someone else to receive the direct payment on their behalf. Although a direct payment is a choice, the local authority must be satisfied that the person who will receive or administer the direct payment on their behalf has capacity and is able to manage the monies.



Chapter 5: Providing advocacy support during care and support planning processes.

A person with eligible care and support needs will have a care and support plan which outlines how these needs will be met: carers will be entitled to have a support plan. The plan describes what eligible needs the person has, and which needs the local authority will meet, taking into consideration any needs that are being met by a carer. In addition, it must include a tailored package of information and advice on how to delay and/or prevent the needs the local authority is not meeting.

Everybody will have a personal budget as part of their plan that identifies the cost of their care and support and the amount that the local authority will pay towards it, regardless of their care setting.

Local authorities must ensure that sufficient time is taken to establish a plan that is appropriate to meet the needs of the person, and is proportionate to the needs to be met. The content of the plan must be finalised with the person and any other people that the person requests and be compiled in a format that makes sense to them. The local authority is under an ongoing duty to keep the person's plan under review, to ensure that the needs continue to be met.

If a local authority thinks a person may lack capacity to be involved in making a decision or a plan, even after they have offered them all practicable support, a suitably qualified professional needs to carry out a capacity assessment in relation to the specific decision to be made. Even if lack of capacity is established, it is still important that the person is involved as far as possible in making decisions and when appropriate has access to an independent advocate to support them.

What is a support plan?

A support plan provides the necessary information about what the person wants to achieve with their personal budget and how they will spend it to meet their needs. The support plan offers a clear picture of the person's health, social and wellbeing needs. The support plan should outline how the person's outcomes (goals and aims) are to be achieved, how best to support them, who is going to provide this support, and what resources/funding are needed to make it happen. The final personal budget amount is determined after drawing up the support plan and will need to be agreed by the funding provider.

There are several routes to developing a support plan and it can involve various statutory and community services to include not only social workers but housing,

occupational therapists, clinicians, children's services (for those in transition to adult services) etc.

What good care and support planning looks like:

The person is fully involved

Good plans, that are most likely to work, are those which are owned by the individual they are written for. This means that the person knows what is in their plan, understand what the plan proposes and has had every opportunity to influence its content.

For advocates this will always be the primary focus of their involvement.

The plan is comprehensive

When developing the plan, there are certain elements that **must** be incorporated:

- the **needs** identified by the assessment
- the outcomes the individual is looking to achieve to maintain or improve their **wellbeing**
- the person's own capabilities, assets and strengths and the potential for improving their skills, as well as the role of any support from family, friends or others that could help them to achieve what they wish for from day-to-day life
- whether, and to what extent, the needs meet the **eligibility criteria**
- the needs that **the authority** is going to meet, and how it intends to do so
- for a person needing care, for which of the **desired outcomes** care and support could be relevant
- for a carer, the outcomes the carer wishes to achieve, and their wishes around providing care, work, education and recreation where support could be relevant
- **the personal budget, direct payments** and the amount which the person must pay towards the cost of meeting the needs
- information and advice on what can be done to reduce the needs in question, and to prevent or delay the development of needs in the future
- where needs are being met via a direct payment, the needs to be met via the direct payment and the amount and frequency of the payments.

It is important that these aspects are not viewed as a fixed list. People can influence additional aspects to plans that are important to them i.e. outcomes not necessarily linked to needs the local authority has a duty to meet, etc. Advocates



should check that these elements have been considered and included where appropriate.

Takes a holistic approach

Consideration of how the needs are to be met should take a holistic approach that covers aspects such as the person's wishes and aspirations in their daily and community life, rather than a narrow view purely designed to meet assessed eligible unmet need.

In considering the person's needs and how they may be met, the local authority must take into consideration any needs that are being met by a carer. The person may have assessed eligible needs which are being met by a carer at the time of the plan and the carer remains willing and able to continue caring. In these circumstances the local authority is not required to meet any of the assessed eligible needs, but the carer should be involved in the planning process. These aspects should be recorded in both the care plan and care and support plan.

The local authority should record where they will not be meeting the eligible needs, so that the authority is able to respond to any changes in circumstances (for instance, a breakdown in the caring relationship) more effectively.

Local authorities should have regard to how universal services and community-based and/or unpaid support could contribute to the factors in the plan. The Local Authority should take steps to ensure people who may benefit from a type of preventative support receive information and advice about why it is important, what it might help with and how to access it.

The plan is 'owned by the person'

It should be possible for the person to prepare their plan jointly with the local authority in a format that makes sense to them, rather than this being dictated by the recording requirements of the local authority. There should also be no restriction or limit on the type of information that the plan contains, as long as this is relevant to the person's needs and/or outcomes.

As the support plan belongs to the person it is about, it is essential that the support plan makes sense to them and is in a format that is understood and accessible to them. They can be completed in a variety of ways⁸ that include:

- a voice recording
- the use of pictures and photographs
- a video recording of the person
- a workbook
- a computer presentation such as Power Point

Advocates can make sure the plan is written using the first person “I”: this gives a powerful message that the care and support plan is owned by the individual.

Direct Payments

The Local Authority should include advice on direct payments that should include:

- the difference between purchasing regulated and unregulated services
- an explanation of responsibilities that come with being an employer, managing the payment, and monitoring arrangements and how these can be managed locally without being a burden
- signposting to direct payment support and support organisations available in the area
- an explanation that there is no curtailment of choice on how to use the direct payment (within reason and in light of the statutory purpose for the direct payment), with the aim to encourage innovation
- local examples and links to people successfully using direct payments in similar circumstances to the person

⁸ for resources on different ways of creating support plans also see:

- Helen Sanderson Associates – provide a range of tools and resources on support planning
<http://www.helensandersonassociates.co.uk>
- Cumbria County Council provides a visual support plan that can be written up
http://www.supportplanning.org/Support_Planning_Downloads/Support%20Plan%20Graphic.pdf
- Equal Lives <http://equallives.org.uk/wp-content/uploads/2014/10/mixed-activities-SP-example.pdf>



- the option to have a mixed package of direct payments and other forms of care and support.

An advocate's role is not to provide advice and guidance on how a person can use their personal budget – but rather to help them understand the information the local authority is providing.

Constraints

However the person chooses to have their needs met, whether by direct payment, local authority or third-party provision, or a mix of the three, there should be no constraint on how the needs are met as long as this is reasonable. Above all, the local authority should refrain from any action that could be seen to restrict choice and impede flexibility.

It is important that people are allowed to be very flexible to choose innovative forms of care and support, from a diverse range of sources, including quality providers but also “non-service” options such as Information and Communication Technologies (ICT) equipment or club membership.

Limited lists of ‘prescribed providers’ (often in relation to direct payments and in particular prepaid cards) that are offered as a default only option (or as ‘take it or leave it’) do not fit with the Government’s vision of personalised care and **should** be avoided. If the advocate has good reason to believe this has happened they can challenge this approach.

Challenging Decisions

There may be situations where the amount of money allocated for the personal budget does not seem to meet all of the person’s wellbeing needs or is not enough. For instance:

- the local authority believes that it may be more appropriate to meet the needs of the person via a local authority provided service, rather than making a direct payment to a person. For example providing respite care in a nursing home (due to contracting) rather than through a direct payment where a person can employ a personal assistant to support them at home or they engage an agency which they may find preferable.
- the direct payment may cost more than if the local authority arranged the same support while achieving the same outcomes for the person. This is potentially an area where challenges may occur.

- The Care Act says that the budget must be what the local authority believes it would cost them to procure the services needed to fulfil those duties. The Care Act requires the local authority to fund for sufficiency and meet the cost of 'reasonable preferences'. There may be difference of opinion whether these are objective or subjective preferences. It also makes it clear that the authority is the decision maker and that it will not be possible always to achieve consensus but recognises that it is not always possible to meet every person's wish. The person may then wish to make a challenge by way of a complaint, or a legal process, and a report from the advocate may be the first and best step in resolving the issue. The advocate will have to write outlining the reasons for the challenge and under what part of the Act the decision is being challenged.

What can go wrong when creating care and support plans?

Often the support plan may be written by the person who has carried out the assessment i.e. a Social Worker or Continuing Health care clinician rather than the person themselves or someone they have chosen. In some cases this can result in a person feeling that they have not been fully involved in the care and support plan and that it does not truly reflect their individual requirements or wishes, their communication style (for instance language) and how they understand information.

Difficulties during the development of support plan can also occur in the following areas:

- People can underestimate how much support they actually require to manage well and feel supported when they are trying to maintain their independence.
- Needs that are important to the person may not be considered eligible needs and they may be viewed as wants by the funding provider. Advocates must always make sure however that needs which are important to the person should be included in the support plan, even if they are ineligible for support. This makes the plan person centred and relevant to the individual.
- Outcomes that the person may want to aim for might not be realistic. However by developing an action plan, it can help to focus on what is actually involved and how this can be achieved.



- Differences in terms of viewing risk and how this will be managed safely so that the funding body is happy that this has been openly discussed and the person has considered how to deal with these issues, and is making an informed choice.

Support Planning for People who Lack Capacity

Every adult has the right to make his or her own decisions with regards to their support plan and must be assumed to have capacity unless it is established otherwise. People have the right to make what others perceive to be an unwise or eccentric decision.

If the local authority thinks a person may lack capacity to make decisions about a care or support plan, even after they have offered them practicable support, a social worker or other suitably qualified professional must carry out a capacity assessment in relation to the specific decision to be made. For example this may be whether the person has the capacity to decide on whether a particular support option will meet their needs. Note, an advocate would never assess a person's capacity, but can challenge assessments in certain situations. If lack of capacity is established, it is still important that the person is involved as far as possible in making decisions. Planning should always be done with the person and not for them, should always start with finding out their wishes, feelings, values and aspirations, not just their needs and should always consider their wellbeing in the wider context of their rights to security, to liberty and to family life.

Advocates will need to consider how they can translate all of this information to help the professionals from the local authority to develop a support plan that keeps the focus on what matters to the person and considers their right to family life and liberty.

Advocacy in action

If the person has capacity, the role of an advocate is to work in partnership with the person enabling and empowering them to fully participate in the development of their support plan. Part of this will be to assist the person to discover what is important to them and to explore how their care and support could be provided. This can be enhanced by the following:

- Beginning early and keeping it simple
- Agreeing the best format for the plan
- Letting people do it in their own way in their own environment. Use the tools available to help people think about how best to plan for themselves. Tools could involve devising simple step by step guides, charts or cards

- Allowing sufficient time and being flexible
- Providing clear and simple information on options and choices in a format that is best suited to the person
- Not taking over or over supporting the person
- Supporting the person to think about outcomes and goals that they want to achieve and how these could be best achieved in a way that works for them

Support the person to understand information

Local authorities are required to provide information and advice about the types of care and support services available in their community regardless of whether someone is eligible to receive financial support to meet their needs. However, it takes time to make choices; and information and advice is essential to be able to consider all aspects of a range of possibilities.

Advocates should check that information provided to a person during the creation of care and support plans is:

- provided at the right time.
- clear and makes sense to the person (whether it uses words or pictures or any other method to communicate)
- easy to access and understand with no jargon
- accurate
- consistent with other information available

Advocates should give particular consideration to any factors or needs which impact on the person's ability to understand information. For instance if the person has sensory loss or other difficulties affecting their memory or understanding, the advocate should consider how the person is affected by these factors.

Practice example

Michael has an acquired brain injury from a road traffic accident which means he has epileptic seizures nearly every day. He finds it difficult to concentrate for too long and he can forget details of what is discussed. His assessment identified that he is struggling to live on his own in his flat which is quite isolated (in a rural location). Michael would like to live somewhere where he can receive 24 hrs care and has agreed to look at accommodation options.

His advocate meets him in the afternoons (for no longer than 30 minutes) as his



epileptic seizures happen mostly at night and this gives him time to sleep in the morning.

His advocate prioritises with Michael what he wants to consider and explore. His advocate uses lists to mark off what they have covered in terms of parts of the support plan and to show how they have progressed. She has taken printed pictures of different properties and they have written good and bad points of each location and property. After the meeting the advocate writes a summary of what they have discussed, using bullet points and includes prompts of what to think about before their next meeting. She reminds him before each meeting via text with details of when they are due to meet and what they agreed he will think about.

Michael is working through the options of different accommodation. He is going to visit some of the areas with his support worker and they will take pictures of what he likes and doesn't like with Michael's mobile phone. These will then later be discussed with Michael and his advocate. Michael has given permission to the advocate speak to the support worker to ask for additional information about the visits to then discuss with Michael. The advocate will use this information to support Michael to contribute to his care and support plan.

If there are other people, professionals and/or services involved, part of the role of the advocate is to facilitate and enhance communication and to support collaborative working if this is required. Advocates may find it helpful, with the consent of the person, to work with a number of professionals and others to work out the most effective way to provide information and explore options and preferences throughout the process.

Supporting the person to understand and work out choices

As well as providing information, the role involves supporting the person to think through and reflect on what has been said and to consider their options and what is right for them.

In terms of support planning, advocates will be involved in assisting the person to consider and weigh up options regarding their health and wellbeing needs in their day to day life and also in what they wish to work towards in the long term. Whether the person is completing the support plan on their own or with the professionals from their funding body, they will need to consider the following in order to complete it thoroughly:

- What is important to them?
- What are their likes and dislikes?

- How do they like to spend their time and are they able to do this at the moment? If not, what are the obstacles in the way or what is preventing them from doing this? How can this be integrated into their life?
- What makes them feel supported as well as independent?
- What is their ideal day like?
- Are there times, such as weekends and holidays, when their needs increase or decrease?
- What is working and what do they like about the current care and support arrangements? What would they like more of and what would they like less of?
- What isn't working or concerning them about their current arrangements? For example have there been any incidents such as falling, burning themselves, getting lost or choking that may need to be addressed and discussion of how these can be reduced as much as possible. What would help alleviate this so that these can be dealt with within the support plan?
- Weighing up the pros and cons between a direct payments or local authority managed service to find out what suits them best. Do they fully understand what these different options are and what is involved to manage these in their day to day life? What is their experience of agencies or arranging respite or transport? Are they confident even with some assistance to manage a direct payment? How could they access some support with this, if they chose a Direct Payment?
- What helps and hinders the person's health?
- How can others or their community support them e.g. volunteers or support organisations etc.
- What other types of care and support may be available locally that they could access or may assist them? Is there any equipment, alternative services or telecare assistive technology that can provide some support?
- Where they can obtain further advice, information and support to assist them to meet their outcomes?
- What happens if things fluctuate or change? What contingency plans can be put into place to prepare and manage these situations?
- How will they spend the personal budget to meet their outcomes? Can they meet their health and wellbeing needs within this budget? Does it cater for a broad range of their needs to include their mental, physical and emotional wellbeing? Does it make them feel supported and in control if these were put into place?

These are all important factors to structure any discussions regarding support planning and advocates will have to find the best way to gather and explore this information.



People may face choices they have never had before – or be making decisions which are new. If the person has problems in retaining information or understanding complex choices the advocate must make sure all steps are taken to deal with these difficulties. Consider for instance a person with dementia facing a move into a care home for the first time, how would they know what that choice will be like... or a person with autism trying to imagine what it is like to employ and have a personal assistant instead of an agency carer? Understanding information does not always have to be through a conversation – it could include helping a person ‘experience’ the choice – for instance by visiting the care home or meeting a personal assistant (or someone who already has one).

Supporting a person to identify their outcomes (goals) and how to achieve these

An outcome identifies what the end result will look like or the final goal the person wants to achieve. These can be either short and long term outcomes, as well as big or small changes. For instance:

Mrs Delby has Motor Neurone Disease and she spends a lot of time in bed. She is worried about getting bed / pressure sores and wants to be comfortable in her bed. One of her outcomes is to be comfortable and be free from pressure sores.

Once an outcome has been identified, the second part of the discussion is around developing an action plan describing what the next steps are and what it will take to achieve this. It is helpful to consider who can help the person with this and by when this can be done when drawing up the action plan to attain an outcome.

In Mrs Delby’s case an advocate could support her to build into her care and support plan that:

- *her personal care assistants or agency workers are trained or experienced in providing skin integrity and pressure sore care*
- *she is assisted to move her position regularly – for instance by setting up reminders on her phone and a means for the personal assistants to be reminded*
- *creams are applied regularly to maintain her skin in the best possible way*
- *she can use a suitable mattress to vary the pressure points for when her condition worsens*

Supporting the person to communicate their wishes, aspirations and needs

Once the person has explored their choices, advocates will need to help the person to communicate their wishes, aspirations and outcomes. No matter how complex a person's needs are, there is a requirement to involve them and communicate their views in their voice whatever medium is used. This may involve using creative approaches such as a short film, pictures, a workbook, a recording as to what they like and don't like and want to work towards.

Wherever possible a person should be supported to write their own support plan in their own words. The support plan should provide a clear picture of the person and the voice and personality of the person should come through clearly.

Ensuring the care and support plan takes into account the wishes and preferences of the person

To ensure that the planning process takes a holistic approach, which takes into account people's wishes, feelings, strengths, needs, values and aspirations, the person must be actively involved and influential throughout. Genuine involvement and ownership can both aid the development of the plan and increase the likelihood that the person may achieve the outcomes that matter to them. When involving the person or their carer the local authority has a duty to take all reasonable steps to reach agreement - with the adult or carer for whom the plan is being prepared - about how the local authority should meet the needs in question.

Agreement of the final support plan

The local authority must take all reasonable steps to agree the content of the care and support plan with the person before it is signed off by the funding provider and the personal budget can be arranged. The funding body will want to make sure that all aspects of arranging the person's support and care are explored and that the personal budget is:

- used as agreed to achieve the health, education or social care outcomes
- legal e.g. it complies with employment law if the person wishes to employ PAs
- safe for the person and others involved in their support and addresses any concerns or potential risks. The support plan may outline how these situations can be dealt with
- sufficient – so the personal budget can meet the needs identified



There may be delays and difficulties in coordinating and finalising support plans where there are several funding providers involved at the same time i.e. both Social Care, Education and/or Continuing Health Care funding. There may be difficulties in knowing who to contact and who takes the lead in the process to chase matters up as an advocate.

Often at the support planning stage, it becomes clear that some adjustments to the personal budget amount may be required. This may be for example if specialist training or equipment needs to be arranged, especially for complex conditions. This will need to be approved and agreed by the funding provider potentially creating a delay. There is the possibility that the full amount might not be agreed if alternative funding elsewhere is possible. However, if there is a dispute, support and care arrangements should still be provided while the final support plan is being agreed.

Other delays and difficulties may occur if there is a joint support plan and/or carers are involved and they disagree in how much support is needed or how it is to be provided.

In the event that the local authority decides that it cannot sign-off a care or support plan, or where a plan cannot be agreed with the person, or any other person involved, the local authority should state the reasons for this and the steps which must be taken to ensure that the plan is signed-off. The advocate can check this is done in a timely manner and followed up.

Support plans for carers

The Care Act now provides a right for a carer to have an assessment and to have support provided to meet any eligible needs. The national eligibility threshold for a carer is based on the impact their needs have on their wellbeing. The assessment will look at their day to day life and outcomes that the carer wishes to achieve. These include:

- whether the carer is able or willing to carry on caring
- whether they work or want to work
- whether they want to study or do more socially.

The support plans will be different for each party but the personal budget may be combined.

Practice example

Nora is an 87 years old frail lady with emphysema and the early stages of dementia. Her husband Henry has been her carer for the last 5 years but he

recently had a stroke and is slowly progressing to regain his full speech and mobility. However, he still does what he can with the support of agency 4 times per day. Their Social Worker is now jointly assessing them.

Previously, Nora received a personal budget and Henry was assessed as the carer. Prior to his stroke, Nora used to go to a respite care home 2 weeks per year to give Henry a break. However, she never liked leaving home and was unhappy there. This was provided by the local authority through a block contract as they were told that this was how respite would best meet their needs despite Henry saying he would prefer for care to be provided at home and he asked if he could go away instead.

Henry and Nora require the assistance of an advocate to look at the options and to ensure that both their support and wellbeing needs are provided in the best way for them both as a couple and individually. They wish to remain at home and are nervous that one of them will be put in a home. Henry is not sure if he will still be viewed as a carer or not and whether he will have to pay towards the care.

The advocate helped them to understand the process and what options they had. The advocate got to know both Nora and Henry by spending time with them and accessing the previous support plan for Nora (with her permission). Henry took time to talk and sometimes scribbled down what he wanted to say when he struggled. Henry realised with support from his advocate that he had support needs himself and he was not managing as well as he thought when looking at his needs and how he could help his wife.

Henry was supported to develop his own support plan which reflected some joint outcomes he shared with Nora, but also some which were personal to just him:

- To live at home with support from agency carers via a direct payment. (shared with Nora)
- To have homecooked meals more often. (shared with Nora)
- To go the library with support (Henry was an avid reader and liked to play chess there)
- To purchase a Kindle
- To consider a mobility scooter - but he wanted to see how much he may improve in the next couple of months.

Should advocates write the support plan?



No. It is categorically not the responsibility of the advocate to write, sign off, agree the plan or make decisions about implementation - this is the role of the person responsible for the plan (for instance the social worker).

It is however within the independent advocacy role to support the person to lead the creation of their own plan and this may involve practical help in pulling together different strands of information or writing the plan *taking clear instruction* from the individual about what they want to say and how they want their care and support plan (or support plan) to say this.

If the person is unable to make this decision – for instance they have advanced dementia and lack the capacity to clearly instruct the advocate on what they want included within their care plan –the advocate must then ensure the support plan reflects their views, potential choices, preferences and aspirations. In other words, the advocate should use instructed and non instructed approaches to ascertain (by gathering as much information as possible) how the person would want, or is likely to want, to have their assessed needs met. The advocate should also consider who the person wants (or is likely to want) to be involved in writing and implementing the plan.

Advocates should seek out all opportunities to involve the person and gather their views.

Once the advocate has gathered this information, they should offer this to the person identified from the local authority as responsible for implementation (usually the social worker). They should then take this into account when making the plan.

The advocate is then well placed to check the final care and support plan reflects the individual needs, preferences and likely views and challenge the plan where it does not incorporate these and promote wellbeing.

Chapter 6: Providing Advocacy Support through Review Processes

What the Care Act says about reviews

Reviewing plans regularly is an essential element of the planning process. Without a system of regular reviews, plans can become quickly out of date meaning that people do not obtain the care and support they require to meet their needs. Plans may also identify outcomes that the person wants to achieve which are intentionally progressive or time limited, so a periodic review is vital to ensure that the plan remains relevant to their goals and aspirations.

The Act specifies that plans must be kept under review by the local authority who should establish systems that allow the proportionate monitoring of both care and support plans and support plans to ensure that needs are continuing to be met. This system should also include seeking cooperation with other health and care professionals who may be able to inform the authority of any concerns about the ability of the plan to meet needs. Advocates should ask their local authority about their system of review so they can help service users and carers understand when they should expect their care and support plans to be reviewed and what to expect – the Advice and Information duty covers reviews.

The review should be a positive opportunity to take stock and consider if the plan is enabling the person to meet their needs and achieve their aspirations. The process should not be overly-complex or bureaucratic, and should cover these broad elements:

- Have the person's circumstances and/or care and support or support needs changed?
- What is working in the plan, what is not working, and what might need to change?
- Have the outcomes identified in the plan been achieved or not?
- Does the person have new outcomes they want to meet?
- Could improvements be made to achieve better outcomes?
- Is the person's personal budget enabling them to meet their needs and the outcomes identified in their plan, and
- Is the current method of managing it still the best one for what they want to achieve, e.g. should direct payments be considered?
- Is the personal budget still meeting the sufficiency test?
- Are there any changes in the person's informal and community support networks which might impact negatively or positively on the plan?



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- Has there been any changes to the person's needs or circumstances which might mean they are at risk of abuse or neglect?
- Is the person, carer, independent advocate satisfied with the plan?
- Is there a need to request a re-assessment

As part of the advocacy support on offer, advocates can explore the above areas in the early stages of the review process in preparation.

Types of review

There are several different routes to reviewing a support plan:

A planned review

This is where the date is set with the person during the support planning process. It provides a regular opportunity to ensure the plan is fit for purpose and delivering the right level of support for the person's needs.

Planned reviews of the support plan should take place no later than 12 months after sign-off. However, when a new personal budget / Direct Payment is in place and agreed, a light touch review should take place 6-8 weeks after the agreement and sign-off of the plan and personal budget.

If a person's health is deteriorating or their condition progressive, the local authority may agree with the person to carry out reviews more often. Equally, reviews may take place more often where a person has few friends or family to support them or if risks are higher. Advocates should be informed of when the plans are due to be reviewed so they can plan their support.

An unplanned review

A review can be requested where the person with the support plan, or their carer, family member, advocate or other interested party such as a service provider – has a concern and feels that a review of the care and support plan should be requested – a person's needs may have changed or the care plan may not be meeting a person's current needs. Advocates working with people can make such a request if they feel it is needed – but only after discussion with the person and after seeking their instructions, if they have capacity. Where the person lacks the capacity to make this decision, the independent advocate can request an unplanned review on their behalf.

A review should also be conducted if circumstances have changed in a way that may affect the efficacy, appropriateness or content of the plan; for example if there is:

- A carer who is no longer able to provide the same level of care and support
- Evidence of deterioration of the person's physical or mental wellbeing
- A safeguarding alert

Where a decision is made not to conduct a review following a request, the local authority should set out the reasons for not accepting the request in a format accessible to the person, along with details of how to pursue the matter if the person remains unsatisfied. The role of the advocate includes supporting people to understand this and if appropriate, raise concerns where they exist.

Advocacy in action

A review must first and foremost keep the person at its centre – and this begins with the person leading the review working with the person to agree who attends the review meeting. Advocates can check this discussion has taken place early and the person is supported to understand and make decisions which affect the planning of the review.

A review should be seen as a process and not just a single meeting - if anyone cannot attend the review meeting, they can still contribute by phone, letter, video conference or could consider meeting with the person leading the review outside of the meeting. Whilst there are no legal duties on the Local Authorities to meet separately with the individual there are duties to involve and advocates can be as creative as necessary to ensure the person is supported to make their own decisions and become involved in the review process.

The key elements to a good review are that it:

- Ensures that people are living the life they want to
- Maps a journey
- Is outcome focused
- Gathers and shares information
- Looks at the sufficiency of the budget in the light of market conditions
- Gathers the necessary data
- Is person centred

If following the review, a revision of the support plan is necessary, the local authority should inform the person what this will involve. If a revision is minor, it may not be proportionate to go through the full reassessment process. If a revision is necessary, the local authority should repeat the support planning process and if appropriate the aspects of assessment it thinks are needed. Reassessment should pick up where the last one left off, building on what is already known, rather than conducting a fresh assessment from scratch.



Advocates can check the following aspects of assessments and support planning are followed – and if not, raise concerns as appropriate:

- The person's wishes and feelings should be identified as far as possible and they should be supported to be involved
- The revision should be proportionate to the needs to be met
- Where the plan was produced in combination with other plans, this should be considered at the revision stage
- Any additional elements that were incorporated into the original plan should be replicated in the revised plan where appropriate and agreed by all parties
- There needs to be clarity on the sign off process, especially where the revised plan is developed by the person

Practice example

Ethan is 37 years old and has physical disabilities and severe epilepsy. Ethan receives a direct payment which he uses to pay for a personal assistant to support him with his personal care, accessing the community and a night sitting service due to the frequency and severity of his epileptic fits during the night.

At Ethan's review he shared the good news that he is going to be provided with a dog for the disabled. The dog will be able to ensure Ethan's safety in many situations and thus reduce his need for a personal assistant. A reassessment will be required to fully understand the impact the dog will make. Ethan's support needs and desired outcomes have not changed so these elements will not need to be reassessed. Previously Ethan did not have support from family or friends and therefore required a substantial amount of paid support. The reassessment will focus on the support the dog will be able to give and hence the degree to which paid support may be reduced. The advocate can support Ethan to identify which of his needs can be met through the dog.

Advocates should remember that an impending review can cause stress for people as they may not want their care arrangements to change or be reduced. Advocates may need to offer reassurance to the service user or carer that reviews cannot be used arbitrarily to reduce care and support package as a personal budget amount must be appropriate to meet the person's needs. Any reduction to a personal budget should be the result of a change in need or circumstance.

Representing a person who lacks the capacity to make decisions within the review

Advocates may support people who have fluctuating capacity or have been assessed as lacking the capacity to make decisions about the review of their care or support plan. Local authorities and NHS trusts have the power of instructing an Independent Mental capacity Advocate (IMCA) when they are undertaking reviews for individuals staying in accommodation arranged by a local authority or NHS trust, including care homes and hospitals.[REF] The MCA Code of Practice (10.61) expects local authorities and NHS bodies to have a policy setting out when this discretionary power to instruct IMCAs is used. The appendices provide template policies which can be adopted by local authorities and NHS bodies. An advocate should be instructed to represent a person in these situations if the person does not have anyone suitable to represent them and the local authority believes it is in their best interests to receive advocacy support. A person in such circumstances is likely to have an underlying right to an independent advocate under the Care Act, if they would have significant difficulty in being involved in the review and have no appropriate person to support them.

Advocates are in a unique opportunity to gather information about the person and can access records to establish if the care and support plan has been meeting the person's identified needs in the way the plan intended. It is likely the advocate will have previously supported and/or represented the individual through the assessment and creation of the care or support plan and can use this knowledge of the person to inform the review process.

The advocate is not there to make the final decision on the review or to sign off any amendments or changes to the care or support plan. After checking the assessment of capacity test has been completed correctly and all practicable steps have been taken to support the person to make the decision, the advocate should consider the following activities:

- Checking the person (or people) leading the review have recorded any expressed wishes, views or preferences
- Checking where wishes, views, or preferences have been ascertained these have taken these into consideration
- Checking the review responds to any concerns the advocate (or others) have raised about the person's care or support plan
- Checking the review is completed in a timely fashion and in a way which is proportionate to the care and support needs of the person



Chapter 7: Providing Advocacy through Safeguarding Processes

Adult safeguarding is the process of protecting adults with care and support needs from abuse or neglect. It is an important part of what many public services do, but the key responsibility is with local authorities.

The Care Act puts adult safeguarding on an explicit statutory footing and from April 2015 each local authority must:

- set up a Safeguarding Adults Board with core membership from the local authority, the Police and the NHS (specifically the local Clinical Commissioning Group/s) and the power to include other relevant bodies
- make enquiries, or cause others to do so, if it reasonably suspects that an adult is subject to, or at risk of, abuse or neglect. An enquiry should establish whether any action needs to be taken to stop or prevent abuse or neglect, and if so, by whom
- arrange, where appropriate, for an independent advocate to represent and support an adult who is the subject of a safeguarding enquiry or Safeguarding Adult Review where the adult has “substantial difficulty” in being involved in the process and where there is no other appropriate adult to help them.

An adult at risk of harm is defined as someone who has needs for care and support, is experiencing, or at risk of, abuse or neglect and is unable to protect him or herself by reason of the needs. This means that regardless of whether they are providing any services, councils must follow up any concerns about either actual or suspected adult abuse or neglect.

Safeguarding Adults Boards will be strengthened and have more powers than the current arrangements set up by “No Secrets” but they will also be more transparent and subject to greater scrutiny.

The Act will bring about a major change in practice ensuring a person centred approach to safeguarding and enable people to have the safeguarding outcomes that they themselves want whilst taking into account the holistic circumstances of the safeguarding incident and the circumstances of all involved. For example: - a carer may experience intentional or unintentional harm themselves from the adult they are supporting or they may intentionally or unintentionally harm or neglect the adult they are supporting.

The aims of adult safeguarding are to:

1. stop abuse or neglect wherever possible;
2. prevent harm and reduce the risk of abuse or neglect to adults with care and support needs;
3. safeguard adults in a way that supports them in making choices and having control about how they want to live;
4. promote an approach that concentrates on improving life for the adults concerned;
5. raise public awareness so that communities as a whole, alongside professionals, play their part in preventing, identifying and responding to abuse and neglect;
6. provide information and support in accessible ways to help people understand the different types of abuse, how to stay safe and what to do to raise a concern about the safety or well-being of an adult; and
7. address what has caused the abuse or neglect.

In order to achieve these aims, it is necessary to:

- ensure that everyone, both individuals and organisations, are clear about their roles and responsibilities;
- create strong multi-agency partnerships that provide timely and effective prevention of and responses to abuse or neglect;
- support the development of a positive learning environment across these partnerships and at all levels within them to help break down cultures that are risk-averse and seek to scapegoat or blame practitioners;
- enable access to mainstream community resources such as accessible leisure facilities, safe town centres and community groups that can reduce the social and physical isolation which in itself may increase the risk of abuse or neglect; and
- clarify how responses to safeguarding concerns deriving from the poor quality and inadequacy of service provision, including patient safety in the health sector, should be responded to.

The following six principles apply to all sectors and settings including care and support services, further education colleges, commissioning, regulation and provision of health and care services, social work, healthcare, welfare benefits, housing, wider local authority functions and the criminal justice system. The principles should inform the ways in which professionals and other staff work with



adults and can be used by advocates who need to ask questions, challenge decisions or represent people.

Six key principles underpin all adult safeguarding work

1. Empowerment – People being supported and encouraged to make their own decisions and informed consent. *“I am asked what I want as the outcomes from the safeguarding process and these directly inform what happens.”*
2. Prevention – It is better to take action before harm occurs. *“I receive clear and simple information about what abuse is, how to recognise the signs and what I can do to seek help.”*
3. Proportionality – The least intrusive response appropriate to the risk presented. *“I am sure that the professionals will work in my interest, as I see them and they will only get involved as much as needed.”*
4. Protection – Support and representation for those in greatest need. *“I get help and support to report abuse and neglect. I get help so that I am able to take part in the safeguarding process to the extent to which I want.”*
5. Partnership – Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse. *“I know that staff treat any personal and sensitive information in confidence, only sharing what is helpful and necessary. I am confident that professionals will work together and with me to get the best result for me.”*
6. Accountability – Accountability and transparency in delivering safeguarding. *“I understand the role of everyone involved in my life and so do they.”*

The Act includes new duties for agencies to work more closely together and share information. Fears of sharing information must not stand in the way of protecting people – the Act contains a statutory duty to share when asked by the SAB.

Agencies that support adults at risk can prevent and detect harm but they must act swiftly and competently when abuse is suspected or reported. There must also be sufficient support, specialist expertise, independent advocacy and access to criminal justice within each area.

The advances in personalisation of social care go hand-in-hand with the new approach to safeguarding; empowering people to speak out, make informed choices, with support where necessary, and encouraging communities to look out for one another. The two concepts are also inseparable from quality of life and dignity.

The emphasis must be on sensible risk appraisal, not risk avoidance, which takes into account individuals' preferences, histories, circumstances and life-styles to achieve a proportionate tolerance of acceptable risks. In the words of Lord Justice Munby: *"What good is it making someone safer, if it merely makes them miserable?"*

Changes to adult safeguarding introduced by the Care Act

To ensure that people are set at the centre of all safeguarding processes the following changes have been set out in the Act and will come into force from April 2015.

Local Authorities have a duty to ensure the provision of Independent Advocacy within Safeguarding

The role of the independent advocate within safeguarding is explored in more detail in the next chapter.

Safeguarding Adults Boards will now be mandatory

The Act requires Local Authorities to set up a Safeguarding Adults Board (SAB) which must include membership from Local Authority, NHS and the Police

"What is a Safeguarding Adults Board" – Local Safeguarding Adults Boards are multi-agency boards that have been brought together by a local authority to ensure the Safeguarding of Vulnerable Adults that may be at risk. ([SCIE & Skills for Care](#))

At the very least, the boards must have significant senior membership from the local authority, the NHS and the police, to enable strategic decision making and the allocation of resources, but should also include representation from a wide range of external partners such as service providers and advocacy services.

The Act places 3 specific Duties on a SAB and its members: -

- Decide when a SAR is necessary, arrange for its conduct and if it so decides, to implement the findings. Where the SAB decides not to



implement an action from the findings it must state the reason for that decision in the Annual Report

- They must publish a strategic plan for each financial year that sets out main objectives of the SAB and its member actions. They must involve local people and the Local Healthwatch organisation in writing the plan
- They must publish an Annual Report detailing the activities of the SAB, Member Activity reports and the findings of any SAR.

It also introduces the requirement for organisations who are involved with Safeguarding Adults to have Designated Adult Safeguarding Managers.

The Act makes further recommendations about membership of SABs which are in addition to the statutory requirements and they include membership from the Fire Service, Care Providers, Voluntary Sector Support Organisations, Housing Providers, Probation Service and Criminal Justice System.

Safeguarding Adult Enquiries will be a statutory duty for Local Authorities

Where a local authority has reasonable cause to suspect that an adult has care or support needs or is at risk of neglect or abuse and is unable to protect themselves from neglect or abuse, it must make whatever enquiries it thinks necessary (or cause, by instructing, others, to make enquiries), to inform decisions about what actions should be taken and by whom

The objectives of an enquiry into abuse or neglect are: -

- To establish facts
- Find out what the individual's views and wishes are
- Gain consent where possible
- Assess the needs of the individual
- Make decisions about what actions should be taken with regard to the person or organisation responsible for the abuse or neglect

The Act requires that Local Authorities make enquiries or cause enquiries to be made when they think a vulnerable person is at risk of abuse (including financial abuse), harm or neglect in their local area (even if they are not currently providing any level of care or support for that individual).

A Safeguarding Enquiry can be raised following an alert made by the Individual, a Carer, a Support Provider, Care Manager or anyone who has a concern that

someone may be suffering from abuse or neglect.

Practice example

Monica is 30 and has a mild learning disability and significant communication difficulties. She has recently moved out of the family home into a flat with support staff because her parents are elderly and unable to look after her. The advocate that supported Monica through the move into her own flat is concerned that the staff are neglecting Monica's care needs: the flat is dirty and Monica seems as though she is not eating properly.

The advocate contacted the Local Authority to raise concerns. As a result the Local Authority began a Safeguarding Enquiry into the service provision.

There is no duty to make a safeguarding enquiry if the person is regarded as being able to keep him/her safe even if for all other purposes he/she is regarded as a vulnerable adult. An initial assessment of whether the individual can "look after" him or herself determines if an enquiry should be started.

The Act is also very specific about it being the duty of the local authority where the individual is residing at the time of the abuse or neglect that has the duty to make a safeguarding enquiry, regardless of where the individual usually lives. For example the individual may be in short term respite care, away on "holiday", in hospital or in residential care outside of the local authority area that is paying for the care and support package when the abuse or neglect occurs. In addition if a concern has been raised about a vulnerable individual, it isn't always the duty of the local authority to make a safeguarding enquiry.

Practice example

A neighbour contacted the local authority to say she is concerned that her neighbour, Mr Moore, is not able to look after himself properly. She has noticed he is limping, seems to have bruises on his face and arms and has lost a lot of weight in a short space of time. The social worker visits Mr Moore to find out if he needs any support to look after himself and keep safe but Mr Moore insists that "there is nothing wrong and I can very well look after myself thank you very much".

In this instance, because Mr Moore has said he doesn't need any help, the local authority does not have a duty to make enquiries into the nature of his care, support or living arrangements. However if the local authority believes that Mr Moore has deteriorating mental health or he doesn't seem to be aware of his



situation or it suspects he is being influenced or abused by a third party then it has a duty to make enquiries to ensure that it is in fact a lifestyle choice that he has made for himself.

A safeguarding enquiry is usually the part of the safeguarding process that happens because abuse or neglect is suspected and before any serious incident occurs so that measures can be put in place to prevent them happening.

However, a safeguarding enquiry may lead to an assessment of care and support need or a Safeguarding Adult Review (SAR) of an existing care or support plan. Or it may be that an enquiry begins and ends with just a conversation with the person who is the subject of an enquiry as in Mr Moore's example.

Safeguarding Adults Reviews (SAR) will be mandatory in certain circumstances

From April 2015 it will be mandatory for authorities to carry out a review of an individual's care and support where there is reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult where an adult has **died** and the SAB knows or suspects that the death resulted from abuse or neglect **OR** (again a review is mandatory) if the adult has not died, but the SAB knows or suspects that the adult has experienced serious abuse or neglect.

A Safeguarding Adult Review will usually take place as a result of information from a Safeguarding Enquiry where it has been shown that there is cause for concern. They are often the result of Safeguarding measures not working or where incidents of abuse, neglect or death have occurred as a result of a breakdown of support and care arrangements.

The purpose and objective of conducting a review is to make certain that the Safeguarding Adults Board is fully informed of what went wrong and to ensure that care professionals and service providers work better together to ensure the safeguarding of adults deemed to be at risk.

Safeguarding Adult Reviews will identify any lessons to be learnt, how they will be acted upon and what changes need to be made either to the care provision and/or service providers' operating procedures to prevent serious incidents from happening again. For example:-

Practice example

Mr Brodie has advanced dementia. He was receiving treatment for a Urinary Tract Infection and was being treated on a locked ward. An advocate had been appointed to support him through a Safeguarding Enquiry that had been raised by staff at the hospital after an incident where he had assaulted staff and patients.

While visiting him in hospital the advocate read in his care notes that he had assaulted several staff and patients. On one occasion an elderly patient who had been admitted with a head injury had, according to the hospital notes, been found lying on the ward floor and Mr Brodie had admitted to having hit and knocked him down following an altercation. On another occasion a fellow patient had attacked Mr Brodie and hospital security has been called. There were several other incidents recorded in the notes.

When the advocate questioned the ward staff it transpired that none of the incidents had been reported as safeguarding and no action was taken to minimise the chances of the same happening again.

Acting on information from the advocate, a Safeguarding Adult Review was instigated to look at practices on the ward. It found the ward had failed to act on safeguarding concerns and had failed to seek legal authorisation to deprive the man of his liberty. The review led to new training being implemented, changes to recording systems and more awareness of when to refer for a DoLS authorisation.

Safeguarding Adults Boards must arrange a Safeguarding Adult Review if an adult in its area dies as a result of neglect or abuse and it suspects the reason to be because agencies haven't worked effectively together to prevent it happening. Safeguarding Adult Reviews must also be arranged if an adult has not died but has suffered serious abuse or neglect which might have resulted in death or permanent harm.

Safeguarding Adult Boards may also call for Safeguarding Adult Reviews if they have concerns that agencies are not working together in the best way to ensure safeguarding of adults; where there seem to be practice issues with particular providers - if for example there seem to be many "incidents" occurring or where they have complex safeguarding cases where they need to make sure that practices are improved.



Providers, Agencies and Individuals have a duty to ensure that they provide Safeguarding Adults Boards with relevant information

The Act provides that any individual or organisation who has been involved with the individual who is the subject of the Board's functions, and who might have any information relevant to the function, **must** share any information related to eg. the enquiry or SAR with the SAB for use only in the Safeguarding Enquiry or SAR. This is to ensure that issues can be tackled quickly and prevent them happening again.

It must be remembered that advocates working under the Care Act must have consent from the person they are supporting before they share any information with the SAB. If the person is unable to consent to the advocate sharing information because of fluctuating capacity (or not having capacity), the advocate should only pass on information which:

- reflects the views, wishes and preferences of the person
- is in line with the advocacy provider's 'confidentiality' and 'safeguarding' policies
- is relevant

The guidance suggests that 'relevant information' is any information or data that applies to the actual safeguarding issue and that which can help towards the decision making process. Advocates must be mindful to be 'client led'⁹ as much as is practicably possible and work at all times to their organisations information sharing policy.

The council will have a duty to protect a person's property when they are in residential care or hospital

Where a Local Authority believes there may be risk of loss or damage to items of property belonging to a person admitted to residential care or hospital they have a duty to protect those items. In order to do that, the Local Authority must have obtained consent from the individual or a person who has authority to give consent on behalf of the person admitted to care before moving or making safe the property.

However, the Local Authority may act in the person's best interest if the individual is unable to give consent or if there is no other appropriate person authorised to give consent.

⁹ A Code of Practice for Advocates describes how advocates are client led within the principle of 'Putting People First': "*The advocacy scheme will ensure that the wishes and interests of the people they advocate for direct advocates' work.*"

Advocates may need to ensure that the Local Authority is complying with this duty and has permission to remove items, or is meeting their duty to protect items or acting in the person's "best interest" if there has been no-one appropriate to give consent.

Practice example

Mrs. Ward contacted the local authority as she hadn't seen her neighbour Elsie for two days which was unusual. Social Services gained access to the house and found Elsie lying in the bathroom after she had slipped and fallen. She was in pain, very confused about what had happened and seemed unsure of her name and circumstances.

Elsie was admitted into hospital where it was expected that she would need to remain for at least 4 weeks.

Because the area where Elsie lived had experienced a number of break-ins recently, Social Services identified that her flat would need to be made secure while she was in hospital. Unfortunately the keys could not be found and Elsie couldn't remember where they were. Her personal belongings such as handbag and purse were still in the flat.

As there was no one willing or appropriate to give consent for them to change the locks and remove her belongings, the Local Authority deemed it to be in Elsie's best interest for it to have the locks changed and remove her personal belongings to the hospital for safe keeping while she was in hospital.

Advocacy in action

The role of the Independent Advocate in Safeguarding is the same as their role within the key decision making processes of assessment, planning and review: namely to support qualifying adults who are the subjects of Safeguarding Enquiries or Safeguarding Adult Reviews to be as involved as much as possible in the process and to represent their own views, wishes and feelings.

The advocate will work with the individual to help him/her understand the safeguarding concerns (and ensure these have been carefully explained by the safeguarding board), what the safeguarding adult board suggests should happen as a result and then help the individual express his/her views about any decisions or protective measures.



Guidance also suggests that in addition to the key functions of helping a person to:

- Understand processes
- Understand rights
- Make decisions
- Communicate views, wishes and feelings
- Understand plans
- Challenge decisions
- Access records

...advocates supporting individuals through safeguarding processes will also assist a person to:

- Decide what outcomes/changes they want
- Understand the behaviour of others that are abusive/neglectful
- Understand which actions of their own may expose them to avoidable abuse or neglect
- Understand what advice and help they can expect from others (inc criminal justice system)
- Understand what parts of the process are completely or partially within their control
- Explain what help they want to avoid reoccurrence and also recover from their experiences

However, the advocate must remember to remain within the independent advocacy role and would only undertake these activities if led by the person. It is not the advocate's role to be part of any investigation.

Where the advocate is supporting a person who lacks the capacity to instruct their advocate or make decisions within the safeguarding process, the advocate would adopt a Non Instructed Advocacy approach. The advocate could:

- Use the person centred approach to gather information about the person, their views, preferences, outcomes and aspirations and how these could affect decisions to safeguard the person

- Use the Watching Brief approach to consider how suggested protective measures may impact upon the person.
- Use the Human Rights approach to ensure that the rights of the person (particularly protected under the Human Rights Act, Care Act and Mental Capacity Act) are being upheld and that decisions are taken in line with legislative frameworks

In all instances of using Non Instructed Advocacy, the advocate should submit a report presenting the information gathered, how it impacts on the decision, specific issues the safeguarding board should consider in their decision making, any parts of the MCA or Care Act which are relevant and any concerns the advocates wishes to raise.

Practice example

Jennie is an elderly lady living in her own home with her daughter Joan who attends to all of Jennie's personal needs.

Joan's mental health has recently deteriorated with the stress of looking after her mother – she feels she is becoming increasingly frustrated and angry with her mother, shouting at her and shaking her whenever she had issues with her incontinence. The neighbours were becoming increasingly concerned and had called the police reporting the shouting and screaming coming from Jennie's house.

At this time no real physical harm had come to Jennie but Joan had refused to accept that she needed any help with looking after her mother. However the police and the neighbours were concerned that one day Joan would actually harm her mother who was becoming increasingly frail.

The police contacted social services who immediately started a safeguarding enquiry to ensure not only the safety of Jennie but also to support Joan.

Social Services believed that Jennie was in a confused and distressed state, and was therefore unable to understand what was happening. An advocate was offered to support Jennie through the safeguarding enquiry process and to help her understand why the police and social services were involved. The advocate helped Jennie understand what social services were suggesting should happen.

The advocate explained to Jennie that Joan needed some help and that they were going to assess Jennie and Joan to see what needs the local authority



could support meeting which would relieve any stressful situations and ensure Jennie remained safe.

The advocate was able to find out from Jennie that she would be happy if someone came in to help with her personal needs as she felt that having to let her daughter do that for her was rather upsetting. Jennie also said that she wanted some time away from Joan as she didn't want to be a burden and quite liked it when they spent some time apart. Jennie also said she liked living with Joan and didn't want to live apart, and especially didn't want to go into a care home.

The outcome was that Jennie had a care plan that included care support each morning and evening and Joan received a carers support plan as well as help from the mental health team.

Practice example

Mr Hart was recovering from a stroke in a nursing home. As he began to recover he remained quite confused and difficult to understand. When he regained the ability to walk he started to wander outside the home. Carers were becoming concerned as it was a busy road which Mr Hart was not familiar with.

Although they did not want to restrict his freedom of movement they were concerned that he might come to harm if he continued to leave the building and eventually wander into the road. A safeguarding enquiry was initiated and an advocate appointed to support Mr Hart to express his concerns and views about the proposed measures to ensure he was protected from putting himself at risk outside of the home.

Discussing his care with the nursing staff and the GP, the advocate heard that although Mr Hart could be confused, when they talked about the potential risks that he was exposing himself to, he seemed to understand what he was doing. The advocate established that Mr Hart had always worked outdoors and been active and he at times felt constrained and uncomfortable in his room.

Following further discussion with Mr Hart and the care staff it became clear that he understood the risks involved and that his ability to walk and to get fresh air was important to his wellbeing. The advocate ensured the safeguarding adults board were aware that there were no concerns about Mr Hart's capacity and he was aware of the risks.

It was agreed that Mr Hart should be supported by care staff to leave the confines of the care home for walks around the grounds and a review of his support plan was initiated to identify how this could be facilitated.

Chapter 8: Challenging Decisions

Advocates can support people to challenge decisions, raise concerns, ask questions and put forward alternatives where the person is unhappy with the process or outcome.

The Care Act also expects advocates to independently challenge or raise concerns about how the local authority has acted, the decision which has been made or the outcome which is being proposed. Indeed, the Act *requires* advocates who are supporting a person who does not have capacity, or is not otherwise able, to challenge the decision on the person's behalf where the advocate believes the decision does not promote the individual's wellbeing. The ultimate goal of this representation is to secure a person's rights, promote the individual's well-being and ensure that their wishes are taken fully into account.

Challenging decisions involves a wide spectrum of actions including simple questioning, raising informal concerns, providing feedback, highlighting rights that are threatened, moving through to making formal complaints, accessing the Court of Protection or Administrative Court for judicial review, and submitting formal challenges to the decision.

*'Guidance to support advocates in challenging decisions or actions with or on behalf of individuals'*¹⁰ provides comprehensive guidance on the best routes to challenge decisions, the practical skills needed and the spectrum of methods to resolve issues.

If the person wishes to make a challenge

Advocates may support people who are unhappy about the process, decision or identified proposals and wish to challenge the local authority. Advocates can support their challenge by exploring what it is they specifically want to challenge and identifying their preferred outcome. Depending on what they want to happen the advocate could support them to refuse to agree to the proposals, complain, appeal, apply for Judicial Review or access the Court of Protection on their

¹⁰ Guidance to support advocates in challenging decisions or actions with or on behalf of individuals' VoiceAbility 2015



behalf.

Practice example

Kiran is 19 and has multiple disabilities. He is going through transition from children to adults services and is likely to move out of the family home. Prior to the assessment he discussed with the advocate his wishes to live near the town centre as he valued his independence. He told the advocate he felt free and happy when he was in an electric wheelchair and could move around the shopping centre by himself. Kiran only had a manual chair and wanted to purchase an electric wheelchair with his personal budget. The advocate support Kiran to express this during the assessment.

The draft care and support plan makes no reference to Kiran's need to feel 'free' and be independent which contributes to his definition of wellbeing. The plan also does not include Kiran's request to use his personal budget to purchase a new electric chair.

Kiran wants the advocate to help him to challenge this as he feels the suggestions he made during the assessment / planning process have been ignored and not even referred to in the care plan.

Where the independent advocate has concerns

The advocate may hold concerns as a result of witnessing or becoming aware of poor practices that need challenging. For instance:

- the advocate is concerned that during the assessment process the assessor does not appear to be taking seriously what the person expresses (ie they do not record what is being said).
- the draft plan does not reflect discussions held during assessment
- where contentious issues remain following assessment / review they have been overlooked or left unresolved
- there are safeguarding concerns that are not being taken seriously or acted upon

Where the advocate holds such concerns they should always, in the first instance, discuss these with the individual to ascertain if they would like to raise concerns or make a challenge. The circumstances of each individual's case will be different but the first stage, with the person's consent, should be to contact the local authority or provider as the issue may have arisen from a misunderstanding or error that could be quickly rectified.

When a person is deemed to lack capacity to make the required decision, the advocate must scrutinise the options and question plans on the person's behalf. If plans do not appear to meet all eligible needs or do not meet them in a way that fits with the person's wishes and feelings, or have not considered the least restrictive of people's lives, the advocate should challenge local authority decisions on well-informed grounds, where necessary. The advocate should immediately consider raising a formal concern when the advocate:

- has a reasonable belief there is (or could be) a violation of a person's human rights,
- is seriously concerned about the legality of the way the local authority is acting or has acted,
- is aware of a safeguarding concern,
- believes the issue(s) is so serious that there is no time to try an informal approach to resolution,
- believes using a formal method such as an injunction is necessary in order to delay a decision so that further discussion can take place.

Advocates must also challenge any decision where they believe it is inconsistent with the duty to promote the individual's wellbeing. The guidance says that the advocate must write a report outlining their concerns which the local authority must discuss with the advocate.

Practice example

George Crane is 45 years old, he has moderate learning difficulties and has a diagnosis that places him on the autistic spectrum. Until recently he had always lived with his parents in the rented three bedroomed house he had grown up in. His mother passed away leaving him on his own after he had spent the previous two years as her main carer. Prior to this Mr Crane had worked but he had given that up to care for his mother.

Mr Crane has a brother Bill who whilst supportive of Mr Crane, lives some way away to be of any immediate or practical help if Mr Crane is having a crisis. Mr Crane has shown signs of mental health issues including depression and self-harm and is monitored by his GP. Since his mother's death Mr Crane has been in receipt of 6 hours per week support – 2 direct 1:1 hours with a support worker and the rest as support at a day service, which Mr Crane does not really engage with.

Both Bill and the support worker believe that Mr Crane would fare better in a supported living environment rather than on his own in the house.

The local authority believes that Mr Crane would benefit from the support of a Care Act



Advocate during the assessment and planning for services to support him into the future as he has substantial difficulty understanding social care process and procedures.

Due to Mr Crane's autistic traits he is only able to concentrate on one issue at a time yet there are several interlinked things that need to be addressed. The advocate worked with Mr Crane to try and work out what were the most important things for him and the order they should work on them.

Very soon after the advocate was appointed, Mr Crane received a letter from the housing association. Whilst they acknowledged Mr Crane's housing need, they informed him he could not succeed to the tenancy and he would be under occupying. It was clear to the advocate that Mr Crane wished to live independently and did not agree with his brother or support worker.

The advocate explained to Mr Crane what the letter meant and that he would have to move. Mr Crane was quite enthusiastic and looked forward to a new start, but he wanted time to look for another property and asked the advocate to speak to the Housing Association. The advocate contacted the Housing Association who agreed to waive their normal procedures and allow Mr Crane extra time to view properties and complete the transfer and in so doing had his secured tenancy in his own right.

The advocate and Mr Crane then embarked on the next issue of planning with the local authority. They were reluctant to commit any more support hours without further psychiatric assessment as they said he did not meet the threshold for LD services. The mental health team also said Mr Crane did not meet their criteria for support.

The advocate felt little progress was taking place and decisions were being passed to and fro between the local authority and mental health services. Mr Crane agreed that the advocate should challenge their decision not to provide more support. Mr Crane did not feel he could put forward his case in front of other people as he was afraid he would not understand and would say something wrong or get too anxious and upset.

The advocate wrote a report emphasising the local authority had a duty to regard Mr Cranes wellbeing and raised concerns that the assessment process had not been completed correctly. The advocate also reminded the authority they had to have due regard for adjustments that needed to be considered under the Autism Act.

Challenging decisions and the Mental Capacity Act 2005

Sometimes, conflicts may arise which are about issues connected with care assessment and planning and the MCA. For example, disputes may arise about a best interests decision about a particular care plan or a safeguarding intervention. Very often disputes can be resolved through informal discussion and representations made by the person, the advocate or others. Sometimes the advocate may use their power to write a report to outline their concerns, or help the person in making a complaint. Reference to the Code will help advocates

explore with the authority and other parties whether the right approach has been taken.

If advocates believe that a person may be deprived of their liberty as a result of a care planning or safeguarding decision,¹¹ they should raise this with the individual and the local authority, to ensure that the appropriate safeguards are applied. If a dispute arises between the relevant person or their family and the authority about a person's mental capacity or best interests, and it concerns a serious welfare matter and it cannot be resolved by other means, then it should be referred to the Court of Protection by the authority as soon as possible.¹²

Failure to do so may result in a violation of the person's human rights, even if the authority was acting in good faith or in relation to a safeguarding matter.¹³ If these situations arise, advocates should help the person to understand their right to apply to the Court of Protection¹⁴, and remind the authority of their obligations to refer serious disputes to the court.

Writing a report

The Care Act requires that where the advocate wishes to raise serious concerns they must write a report for the local authority who in turn, should arrange a meeting with the advocate and provide a response in writing after the meeting has been held. It is sensible to address this to the Authority's statutory Monitoring Officer, usually the Head Lawyer, whose role is to keep a roving eye out for impending illegality or maladministration in the Authority, and who has an independent statutory duty to form a view about the stance set out in any such notification, and take steps to stop it if he or she agrees.

There is no standard format for the report referred to in the Care Act Guidance but a simple but rigorous format is often the most effective in presenting clear concerns and seeking resolutions. Advocates should:

¹¹ Deprivation of liberty is defined as situations where a person is subject to continuous supervision and control and is not free to leave. See *P v Cheshire West and Chester Council and another; P and Q v Surrey County Council* [2014] UKSC 19 and paragraphs 10.67 – 10.72 of the *Care and Support Statutory Guidance: Issued under the Care Act 2014*.

¹² *London Borough of Hillingdon v Neary & Anor* [2011] EWHC 1377 (COP), §22; §33

¹³ See, for example: *The Local Authority v Mrs D & Anor* [2013] EWHC B34 (CoP); *Milton Keynes Council v RR & Ors* [2014] EWCOP B19; *Somerset v MK (Deprivation of Liberty: Best Interests Decisions: Conduct of a Local Authority)* [2014] EWCOP B25.

¹⁴ Guidance for advocates and others on assisting the person to make the application has been commissioned by the Department of Health: Ruck Keene, A. (2014) *Guidance Note: Acting as a litigation friend in the Court of Protection*, 39 Essex St Chambers and University of Manchester.

<http://www.law.manchester.ac.uk/medialibrary/Main%20site/LAC/Acting-as-a-Litigation-Friend-in-the-Court-of-Protection-October-2014.pdf>



- clearly explain their concern and/or challenge
- provide supporting evidence
- use underpinning legislation wherever appropriate
- use direct quotes wherever possible;
- be objective and impersonal, use concise language;
- describe the impact that the decision being challenged will have on the person and their wellbeing;
- include any suggestions or ideas the person has to resolve the problem;
- upon completion, ensure the person is given enough opportunity and support to read through and approve.

Mr & Mrs Tudor

Mr & Mrs Tudor are both in their 80's. Mr Tudor has been living with dementia for 5 years and has been supported at home by his wife without any involvement from social services.

As part of their preparation for the possibility of declining health they had decided to have their bathroom changed into a wet room. Whilst this was being completed Mr Tudor tripped over a small lip in the floor and injured his leg in the fall resulting in a hospital admission. Medical staff who had never met Mr Tudor before told social services that it was not safe for Mr Tudor to return home and on discharge from hospital he was placed in a 'residential / nursing placement to 'convalesce'. Both Mr & Mrs Tudor asked when he could go home. The local authority social worker suggested that because of Mr Tudor's dementia he did not have insight into the risks of living at home and that he was to be assessed for his care needs being addressed in a residential placement.

A friend of Mrs Tudor informed her that as a carer she was also entitled to an assessment of her needs in supporting her husband. Mrs Tudor was so worried about what was going to happen to her husband she was unable to take in what her friend was telling her and in fact had no understanding of the social care system. Her friend contacted the local authority and explained this to them.

The local authority offered Mr & Mrs Tudor an advocate as they believed they both faced 'substantial difficulty' in understanding the assessment and care planning process. The advocate met with Mr & Mrs Tudor and established that their goals were the same namely for Mr Tudor to return home and there would be no conflict of interests in working with them both.

As Mr Tudor's mobility was still impaired the advocate worked with Mrs Tudor to arrive at a plan that would help her to support her husband – carers visiting to assist with transfers at crucial times of the day, a carer / or someone to be in the house with her husband for two hours twice a week to allow Mrs Tudor time for shopping and have a small break. The times of the day for visits by the carers were based on the frequency of interventions taking place in the care home but with the times amended to better suit

their family life.

Mr Tudor's attitude was more simplistic in that all he wanted was to be at home and whatever that required was fine with him, 'My wife will make sure I'm alright; I just want to be there with her.'

Following the assessment and meeting with Mr & Mrs Tudor and the advocate the local authority produced a care plan that focussed on Mr Tudor who was now deemed to lack the mental capacity to make a decision about his residence and treatment and therefore a best interests decision had been made to keep Mr Tudor in residential care.

The advocate shared their concerns with Mr & Mrs Tudor that the local authority was not complying with their duty to under the Care Act to promote wellbeing and could not see any evidence that the principles and processes of the Mental Capacity Act being adhered to: for instance there was no written assessment of mental capacity. The advocate prepared a report highlighting how the local authority's proposals had not taken into account many of the key principles and standards that the local authority must have regard to. The report highlighted the following rights and provisions introduced by the Care Act, which the advocate felt had been overlooked:

1. The importance of beginning with the assumption that the individual is best-placed to judge the individual's wellbeing.

The local authority should assume that the person themselves knows best and must listen to their own outcomes, goals and wellbeing. The care plan produced by the local authority made no reference to Mr Tudor's goals and own definition of wellbeing.

2. The individual's views, wishes, feelings and beliefs.

Both Mr & Mrs Tudor demonstrated and voiced a clear wish to remain together in their own home. The initial assessment had recorded this wish; however no further consideration had been explored and suggestions put forward by Mr & Mrs Tudor for personal carers had not been considered.

3. The importance of preventing or delaying the development of needs for care and support and the importance of reducing needs that already exist.

The care requested by Mr & Mrs Tudor was not unreasonable and likely to be more cost effective than for Mr Tudor to remain in care. The assessment and planning process should recognise that they had managed very well for the previous five years without any intervention and the care requested could allow them to maintain their independence.

4. The need to ensure that decisions are made having regard to all the individual's circumstances (and are not based only on their age or appearance, any condition they have, or any aspect of their behaviour which might lead others to make unjustified assumptions about wellbeing).

The medical staff had made assumptions about Mr & Mrs Tudor without knowing their



circumstances or their domestic capabilities and these assumptions had been perpetuated by the local authority without considering the impact that their decisions would have on the couple.

5. The need to protect people from abuse and neglect

The local authority had not demonstrated any grounds that indicated that Mr Tudor was at any more risk being in his own home than he was at risk from being in a care home placement.

Having prepared the report the advocate discussed it with Mr & Mrs Tudor before sending it in adding in their final comment that they required a speedy resolution as they feared that the longer he stayed in care Mr Tudor's health and wellbeing would deteriorate.

The local authority responded within 7 days with the proposal that they would allow Mr Tudor back home with the care package requested – for a trial period. Within two weeks Mr Tudor's state of mind stabilised he was less confused and was saying how happy he was to be home. His mobility improved significantly so much so that the carers' visits for personal were discontinued as he could weight bear. However the service provided to enable Mrs Tudor to shop and have some respite time for herself remained in place for which she was extremely grateful as it was such a relief to know she did not have to worry.

The financial burden on the local authority was considerably reduced. The advocate continued to support Mr and Mrs Tudor through period of reviews of the care package.

The complaints system

Prior to April 2016, if the person (or advocate) wishes to appeal a specific decision, or are unhappy with the service received from adult care services, they should consider using the complaints system.

Urgent cases

If someone has an urgent need for a social care service which has been refused or withdrawn, it is helpful to get legal advice about the best way to challenge this, in other words, whether to use the complaints process first, or whether it is possible to take immediate legal steps to access the service they need. If there is an urgent need for a service to be provided it is helpful to get community care legal advice.

Complaints procedures can be used before starting legal proceedings, however, it is important to understand there are time limits for bringing legal proceedings and using a complaints procedure does not extend the relevant time limit.

It is advisable to seek specialist advice if legal proceedings are being considered and the person wants to complain as well: often a complaint will not usually be investigated once legal proceedings have started.

Bringing a legal claim

If someone has an urgent need for a service or treatment now from a public body, and it is not possible to wait until the complaints procedure is followed, it may sometimes be possible to use a legal procedure called judicial review to challenge the lawfulness of the decision to refuse or fail to supply that service.

Time limits for this are short and a judicial review must be made promptly and at least within three months, so it is important to obtain advice from a community care solicitor as soon as possible

Making a complaint

Since April 2009 there has been a single complaints system for all health and adult social care services, and this is set out in the [Local Authority Social Services and National Health Service Complaints \(England\) Regulations 2009](#). The system covers complaints against Local Authorities, NHS hospitals, Clinical Commissioning Groups and independent providers. GP practices are included under Clinical Commissioning Groups. These are known as “responsible bodies”.

A person who has used health or social care services has the right to complain about their own experience. They might want to complain, for example, about delays, the quality of service, a refusal to provide a service, difficulties in accessing services or the way they have been treated. A complaint can be made by a person on behalf of the service user, who is known as a representative, if the service user:

- has asked the representative to act for them.
- is a child
- is unable to make the complaint themselves because of a physical incapacity or lack of capacity
- Has died

Advocates would only make a complaint on behalf of a person (without instruction) if the person lacked the capacity to make the complaint themselves and the advocate felt making a complaint would either be in their best interests or be necessary to protect their rights.



The complaints system

Normally the complaint needs to be made within 12 months of the matter(s) that are the subject of the complaint. This time limit does not apply if it can be shown that there were good reasons for not making the complaint earlier and it is still possible to investigate the complaint properly. For instance the consequences of the incident have become apparent outside of this timescale.

A complaint can be made verbally, in writing or electronically. Where the complaint is made verbally, the responsible body must make a written record of the complaint and provide a copy to the complainant.

Initially people can complain to the service provider, this may be a local authority, GP, dentist, hospital, pharmacist, optician, care provider or they can complain to the commissioner of that service, either through NHS England, or through the local Clinical Commissioning Group (CCG).

A complaint has to be acknowledged within 3 working days of receipt. The responsible body must offer to discuss with the complainant how the complaint is to be handled, and how long it will take to complete an investigation and provide a response. If the complainant does not wish to discuss this, the responsible body still has an obligation to reach a decision.

The responsible body must investigate the complaint as quickly and efficiently as possible and keep the complainant informed of progress. As soon as reasonably practicable after the end of the investigation, the responsible body must send the complainant a written response. This must include an explanation of how the complaint has been considered and the conclusions reached.

The responsible body must also confirm that it is satisfied that action needed has been taken or will be taken. It must tell the complainant of their right to take the complaint to the Health Service Ombudsman and/or the Local Government Ombudsman if they are not satisfied with the outcome.

The Equality Act 2010 applies to the way complaints procedures are organised. If somebody has a disability which makes it very difficult for that person to use the complaints procedure, then the responsible body has a duty to make reasonable adjustments to the procedures to assist that person access the complaints service.

Complaints about care and support

Local authorities and all registered providers of adult social care must make information available to the public on its own arrangements for dealing with

complaints and how further information about those arrangements may be obtained. Advocates should familiarise themselves with these local arrangements.

If a person has concerns about social care services which are provided or arranged by a local authority, there are formal complaints processes via which he or she can pursue those concerns. Complaints might be, for example, about the way in which a local authority has carried out an assessment or about the services someone receives in a care home, or their own home, where a local authority is funding, arranging or providing that care.

Where adult social care services are commissioned or arranged by a LA, a complaint may be made directly to the local authority either about the LA's function in the arrangement or commissioning of those services or care and support from a registered care provider. If the complaint is considered partly or wholly a social care provider complaint the local authority should, with the consent of the person, pass the details of the complaint to the relevant adult social care provider. After the local complaints process is complete, if a complainant is not satisfied with the response from the local authority or registered care provider, they are able to refer the case to the independent Local Government Ombudsman (LGO).

The regulations do not, however, apply more generally to providers of social care, unless the provider is (rarely) the LA itself. People who have made, and are paying for their own social care arrangements are not covered by the LA complaints procedure because that care is not being provided by, or arranged by, the LA. Self funders raise their concerns about their service with their care provider in the first instance (all providers are required as part of their registration requirements with the CQC to have a complaints procedure). Although if they are not satisfied with the response they receive, they also may ask the Local Government Ombudsman to investigate.

Complaints about care and support

Potential changes to social care appeals

At the time of writing (August 2015) the Department of Health are consulting on policy proposals for a new appeals process. This information is based on proposals contained within this consultation document and they are likely to change in response to the comments and views. Advocates should check the outcome of this consultation on whether and when system for appeals will be implemented (expected by the end of 2015).



Providing Independent Advocacy under the Care Act 2014

The policy proposals recognize that people have a right to appeal against a decision made by the local authority in certain circumstances (see below). It sets out that Appeals may be made by the person who the decision affects, their carer, friend or anyone who has the consent of the person (if they have capacity to consent), or who are doing so in their interest (if they lack capacity).

An appeal may also be made by an independent advocate. This may be an advocate appointed under the Care Act or instructed under the Mental Capacity Act, or any other independent advocate.

What can be appealed?

Current proposals allow people and their representatives to appeal any the following decisions where they disagree with the decision or how it was reached:

Area	What to appeal
Assessment (Section 9)	The local authority's decision as to the format of the needs or carer's assessment eg. should it be face-to-face compared with a phone assessment
Eligibility (Section 13)	A decision by the local authority as to whether the adult's needs are eligible for care and support or whether a carer's needs are eligible for support.
Care planning (Section 25)	The needs that the local authority is going to meet and how it is going to meet them
Direct Payments (Section 31)	Decisions by the local authority for direct payments to the adult or nominated/authorised person
Personal Budgets (Section 26)	The amount that the local authority deems is appropriate to meet eligible needs
Independent personal budgets and care accounts (Section 28)	The costs which count towards the cap for a person meeting their own needs
Deferred payment agreements (Section 34)	Decisions about how much local authorities allow people to defer
Transition for children to adult care and support (Section 58)	The local authority's decision to refuse a transition assessment to a child, young carer, or child's carer
Independent Advocacy Support (Section 67)	Decisions by the local authority as to whether a person should have an independent advocate

Before the system of appeals is introduced, advocates should support people to access the complaints system.

The Local Government Ombudsman

If the complaints procedure does not resolve a complaint about **social care services**, a complainant may ask the relevant Local Government Ombudsman to investigate. There are two Local Government Ombudsmen for different regions in England and one for Wales. The Ombudsmen are entirely independent of the Local Authority and of the Government.

The Ombudsman is not obliged to investigate every complaint referred to him or her and will not generally take on cases unless they have been through the Local Authority complaints procedure. He or she will not investigate a complaint which is the subject of legal proceedings.

The Ombudsman can investigate complaints that a council has not provided a service which it has a duty to provide, that there has been a failure in providing a service or that there has been maladministration connected with action taken by or on its behalf.

If the Ombudsman does find that something has gone wrong with a case then they can request that the council:

- Take action to put the matter right, including giving an apology
- Make a decision that should have been made before
- Improve its procedures so that similar problems do not happen again and
- Make payment for financial loss or for the inconvenience or worry caused.

Advocacy and complaints

Complaints advocacy is a specialist service, which supports people who are considering, or wishing to make a complaint about the health and care services they receive. In 2015, Healthwatch England proposed a set of standards to inform how complaints advocacy is delivered.¹⁵

Confusingly, there is a legal duty for local authorities to provide for NHS complaints advocacy in their area, but there is no corresponding duty for them to provide for social care complaints advocacy to be available. Many local

¹⁵ See [Independent Complaints Advocacy Standards to support the commissioning, delivery and monitoring of the service](#) Healthwatch England 2015



authorities recognise the benefit of independent advocacy for social care complaints and some provide non-statutory services locally. Individuals who receive care and support services – and advocacy support under the Care Act – may wish to complain about their care and/or treatment and can access specialist complaints advocacy provision. The Care Act does not affect the role of the specialist complaints advocate nor does it exclude Care Act Advocates from helping a person to submit a complaint.

Practice example

Sunil is detained under section 3 of the Mental Health Act and is receiving help for severe depression. He is about to be discharged with a package of support to help him live at home. An independent advocate has been offered to support Sunil as he experiences problems in remembering large amounts of information and does not have anyone available to help to participate through the assessment and care and support planning stages.

Sunil has explored with his advocate how an individual budget and direct payment could help him in his daily living. He is keen to use the budget to pay for activities and internet access in order to develop new interests and reengage in the community. He feels without this he will fall back into habits like heavy drinking that make his mental health problems worse.

His social worker has told Sunil that budgets are not to be used for this purpose and so he can't have one. Sunil asks his advocate (who is already working with him under the Care Act) to help him to complain. The advocate offers Sunil intensive support with his complaint, helping him to attend resolution meetings and fully understand his options.

Accessing the Court of Protection¹⁶

The Court of Protection is a specialist court, set up as part of the Mental Capacity Act (MCA), to deal with decision-making for adults who may lack capacity to make specific decisions. Generally, the court has a range of powers, including decisions about:

- whether a person has capacity to make a particular decision
- whether an action is in a person's best interests
- whether a person is being deprived of their liberty the validity of lasting and enduring powers of attorney the appointment of deputies.

¹⁶ Information taken from SCIE Guide 42 Good practice guidance on accessing the Court of Protection

Decisions about whether an application should be made to the Court of Protection must be informed by the MCA Code of Practice and case law. The Code of Practice confirms some of the situations when decisions must be taken to the Court of Protection which include:

- the proposed withholding or withdrawal of artificial nutrition and hydration (ANH) from a patient in a permanent vegetative state (PVS)
- cases where it is proposed that a person who lacks capacity to consent should donate an organ or bone marrow to another person
- the proposed non-therapeutic sterilisation of a person who lacks capacity to consent (for example, for contraceptive purposes)
- cases where there is a dispute about whether a particular treatment will be in a person's best interests.

The Code of Practice also provides details of situations when the Court of Protection should be accessed. This includes cases where:

- There is doubt about whether withholding or withdrawing life-sustaining treatment is in the patient's best interests
- There is a major disagreement regarding a serious decision, which cannot be settled in any other way; this includes where a person should live
- It is unclear whether proposed serious and/or invasive medical treatment is likely to be in the best interests of the person who lacks capacity to consent
- There is genuine doubt or disagreement about the existence, validity or applicability of an advance decision to refuse treatment
- A family carer or a solicitor asks for personal information about someone who lacks capacity to consent to that information being revealed
- Stopping or limiting contact with a named individual because of a risk of harm or abuse to a person lacking capacity to decide on the contact (the DH (2010) has said that Deprivation of Liberty Safeguards should not be used in non-contact cases other than as a short-term measure).

Practice example

Anna has dementia and lacks capacity to decide where to move following the closure of her current care home. There is dispute between the advocate and local authority about which option is in Anna's best interests.

The advocate who was instructed to represent and help Anna through the long term accommodation decision is concerned that the option proposed by the local authority will severely limit the opportunity for contact with the few people she does know and she counts as friends. Anna enjoys going out but the home proposed has poor access to public transport, shops and other facilities. They have visited the new home with Anna,



who displayed clear signs of not wanting to move there.

The local authority will not reconsider its decision. The advocate draws its attention to the Code of Practice and requests the local authority makes an application to the Court of Protection for a decision.

Anyone can seek permission to apply to the Court of Protection on behalf of someone who lacks capacity to make the application themselves. This includes: family members and friends professionals and paid carers advocates, including advocates. The MCA Code of Practice provides the following guidance to IMCAs:

'IMCAs may use complaints procedures as necessary to try to settle a disagreement – and they can pursue a complaint as far as the relevant ombudsman if needed. In particularly serious or urgent cases, an IMCA may seek permission to refer a case to the Court of Protection for a decision (10.37).'

The application can be submitted either in the name of the person submitting the application or in the name of the person to whom the decisions relate. If the latter applies, they will be making the application as a litigation friend.

Practice example

An advocate is appointed under the Care Act to support Seema, a woman with learning disabilities and mental health needs during a safeguarding (financial abuse) enquiry.

The local authority are concerned that Seema's brother has fraudulently taken several thousands of pounds. A mental capacity assessment was completed and the assessor concluded that she lacked capacity to make decisions for large amounts of money and recommended that there should be an application for a deputy to be appointed.

Seema was unhappy with this outcome and explored with the advocate her options in challenging the decision. The advocate explained they could request another assessment and/or push for the local authority to apply to the Court of Protection. The advocate and Seema subsequently challenged the assessment and requested a new assessment which found that she did have capacity.

The advocate raises this with the local authority who disagree with the new assessment. The advocate suggests that the local authority should make the application to the Court of Protection to make a decision on her capacity to manage her finances, particularly because she has a lot of money and this was not the first time she had been financially abused.

When judicial review may be an option

The Court of Protection can only make decisions that could be made by the person who lacks capacity themselves, for example whether they have capacity or what is in their best interests. If a person disagrees with a decision made by a local authority or CCG, an option for challenging such a decision is to apply for judicial review.

Judicial review is a form of court proceeding where a judge reviews the lawfulness of a decision or action made by a public body. In general terms, judicial review may be appropriate where the challenge is based on an allegation that the public body has taken an unlawful decision or action, and there is no adequate alternative remedy.

Applying for judicial review will usually only be considered if the disagreement cannot be resolved following a formal complaints procedure. Judicial review involves the court in deciding not whether the public body has made the 'right' or 'correct' decision, but whether the correct legal basis has been used in reaching it.

Chapter 9: Supported decision making

The Care Act guidance states that 'The modern care and support system should routinely enable supported decision making, where options and choices are presented simply and clearly'.¹⁷ Supported decision making means helping a person to understand and evaluate the different choices available to them, and recognising that a person has the right to make their own decisions, including making decisions that other people may regard as unwise. It places the person at the centre of making decisions about their life, and choosing how they want to be supported to make them.

The United Nations Convention on the Rights of Persons with Disabilities

Supporting people to make their own decisions is a key human rights value, enshrined in the United Nations Convention on the Rights of Persons with

¹⁷ Department of Health (2014) *Care and Support Statutory Guidance: Issued under the Care Act 2014*, London. Paragraph 10.4



Disabilities (CRPD).¹⁸ The CRPD is sometimes described as a 'new paradigm' of disability rights, which moves away from paternalistic welfare approaches and emphasises respecting 'individual autonomy including the freedom to make one's own choices'¹⁹ and non-discrimination²⁰.

Article 12 of the CRPD is the 'right to equal recognition before the law', and has four core elements:

- Disabled people are recognised as *persons* in law²¹;
- Ensuring that disabled people are not discriminated against in exercising their legal rights to make decisions²²;
- Ensuring that disabled people have access to the support they need in order to make legal decisions for themselves²³;
- Ensuring that people's rights, will and preferences are respected.²⁴

Article 12 of the CRPD challenges the existing system of substituted decision-making, including guardianship and 'best interests' decisions²⁵. Supported decision making is different to substituted decision making. Substituted decision making means other people making decisions in a person's best interests, or imposing decision makers on people against their will. Supported decision making means the person choosing how they want to be supported and making decisions for themselves. In situations where a person is not able to express a decision, the phrase supported decision making is sometimes used to mean

¹⁸ Article 12(3) CRPD states that 'States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity'.

¹⁹ Article 3(a) CRPD

²⁰ Article 5 CRPD

²¹ Article 12(2) CRPD. In some countries disabled people are not considered legal persons, and may for example be denied core rights as citizens such as a birth certificate or passport.

²² Article 12(2) states that 'States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.' 'Legal capacity' means recognition that one's decisions are legally binding, and it is different from 'mental capacity' which is about a person's perceived or actual ability to make decisions.

²³ Article 12(3) states that 'States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.'

²⁴ Article 12(4) states that measures relating to legal capacity must have appropriate safeguards to ensure that they 'respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.'

²⁵ Martin, W. (2014) 'Mental Capacity Law Discussion Paper: Consensus Emerges in Consultation Roundtables: The MCA is Not Compliant with the CRPD', 39 *Essex St Mental Capacity Law Newsletter*, August (Issue 49).

making the decision that is the best interpretation of the person's will and preferences.²⁶

The Mental Capacity Act 2005 (MCA) was drafted before the CRPD was adopted by the United Nations, and in some respects it sits in tension with the empowering approach of Article 12 CRPD.²⁷ Advocates' are obliged to work within the MCA framework under domestic law. Both the MCA and the Care Act contain important tools that can be used by advocates to promote the empowering ethos of the CRPD.

The CRPD pushes us to move toward a new framework where people are supported to be their own decision-makers. It recognises that loss of opportunities to make decisions and make mistakes can limit people's abilities to learn and develop as individuals. Taking decisions away from people can be distressing and even dangerous if people's voices are not heard, even if this is done with the best of intentions. The Care Act provisions for supported decision making take us closer towards the empowering ethos of the CRPD.

Supported decision making and independent living

Article 12 CRPD is closely linked to Article 19 CRPD – the right to independent living. Disabled people around the world have campaigned for independent living for decades, and for the first time in the CRPD it has been enshrined in international human rights law. The Care Act guidance states that independent living is a 'guiding principle of the Care Act' and that the Wellbeing Principle is intended to cover the key components of Article 19 CRPD.²⁸

Under the CRPD, independent living is about having **choice and control**, **equality** and **inclusion in the community**. It is *not* living without support, living alone or in a particular kind of service that calls itself supported or independent living. Nor is it about being required to learn 'independent living skills'. Article 19 CRPD is about disabled people having the same opportunities as others to choose where and with whom they live, and not being obliged to live in a

²⁶ Committee on the Rights of Persons with Disabilities (2014) *General comment No 1 (2014) Article 12: Equal recognition before the law*, (Adopted at the Eleventh session of the Committee, 31 March –11 April 2014, CRPD/C/GC/1) Geneva. §18bis

²⁷ Committee on the Rights of Persons with Disabilities (2014) *General comment No 1 (2014) Article 12: Equal recognition before the law*, (Adopted at the Eleventh session of the Committee, 31 March –11 April 2014, CRPD/C/GC/1) Geneva; Martin, W. (2014) 'Mental Capacity Law Discussion Paper: Consensus Emerges in Consultation Roundtables: The MCA is Not Compliant with the CRPD', *39 Essex St Mental Capacity Law Newsletter*, August (Issue 49).

²⁸ Department of Health (2014) *Care and Support Statutory Guidance: Issued under the Care Act 2014*, London. Paragraph 1.19



particular living arrangement against their will.²⁹ It means that states need to ensure that disabled people have access to appropriate services to support 'living in the community' and preventing isolation and segregation,³⁰ to make those choices meaningful. Because independent living is fundamentally about **choice and control**, it is important that people have access to the support they need to make decisions about where they live, who they live with and what support they receive. This is why supported decision making is essential for independent living.

Supported decision making and the social model of disability

The CRPD is based on the social model of disability. This means that disability is regarded as the outcome of an interaction between physical, mental, intellectual or sensory 'impairments' and various barriers which hinder people's full and equal participation in society.³¹ The social model of disability emphasises addressing environmental and social barriers, such as accessibility measures, supports, and tackling discriminatory attitudes, rather than treating disability as solely an individual or medical phenomenon.

In the context of decision making, the social model of disability means focussing on what changes can be made to people's environments, and what supports they need, to help them make decisions – rather than focussing on individual deficits in decision making skills. It also means addressing discriminatory attitudes which hold disabled people to higher standards of decision making than others, or are treated as unable to make decisions because they may communicate or make decisions in unusual ways.

Approaches to supported decision making around the world

There is no 'one size fits all' model for supported decision making. Supported decision making is something that most people use in their everyday lives, even if they do not call it that. Few of us make important or difficult decisions without consulting with trusted others to find out more information or weigh up the pros and cons of different options. Powerful people like politicians are surrounded by 'armies of advisors' to help them make decisions!³²

²⁹ Article 19(a) CRPD states: 'Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement'.

³⁰ Article 19(b)-(c) CRPD

³¹ Article 1 CRPD

³² Schulze, M. (2014) 'Plenary Presentations: Supported decision-making: for prime ministers only?', *Journal of Applied Research in Intellectual Disabilities*, 27(4), 289-290.

Around the world, many different supported decision making approaches are being developed to help disabled people reclaim their rights to decide. All of these systems emphasise building a relationship of trust between the supported individual and those supporting them, and helping people to make decisions that reflect their personal wishes, preferences and values. These models have been used by people with a wide range of disabilities, including learning disabilities and autism, brain injuries, mental health problems and dementia. Many have been developed by grassroots organisations of disabled people, mental health service users and their families.

Canada has been at the forefront of developing models of supported decision making which recognise the role of family and friends. In British Columbia, a person can appoint a legal 'representative' whose role it is to support them to make decisions and to represent their 'expressed wishes' in legal transactions, so far as they are known.³³ Some kinds of representation agreements can be made even by people with very limited decision making abilities – so long as they are able to communicate a desire to have support or representation in making decisions, can express approval or disapproval of others and have a relationship with the representative characterized by trust.³⁴

Other states in Canada have 'support agreements', that enable people to nominate supporters whose role it is to help them access the information they need to make decisions, to understand that information, communicate decisions to others and ensure that they are implemented.³⁵ There are plans to adopt similar laws in Ireland and Australia.³⁶

In South Australia, informal supported decision making agreements allow a person to nominate a trusted person as a supporter and draw up a contract saying how they want to be supported. For example, they might specify 'Remind me to look forward and think of the future' or '[Listen] to me first and try and understand'.³⁷

³³ Nidus Personal Planning Resource Centre and Registry (2009) *Experiences of adults living with Fetal Alcohol Syndrome Spectrum Disorder and their personal supporters in making and using a Representation Agreement*, Vancouver, B.C; Nidus Personal Planning Resource Centre and Registry (2009) *A Study of Personal Planning in British Columbia*, Vancouver, B.C.

³⁴ Representation Agreement Act (British Columbia) 1996

³⁵ James, K. and Watts, L. (2014) *Understanding the lived experience of supported decision-making in Canada*, Law Commission of Ontario.

³⁶ Assisted Decision-Making (Capacity) Bill 2013 (Ireland); Victorian Law Reform Commission (2012) *Guardianship Final Report 24*, Melbourne, Australia; Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws: Final Report*, (ALRC Report 124) Sydney.

³⁷ Office of the Public Advocate (2011) *Developing a Model of Practice for Supported Decision Making: Background information to assist the facilitation of agreements.*, South



Circles of support offer group input to help a person make decisions and achieve their goals. Circles of support have also been used around the world as an informal model of supported decision making. Sharing support with a group can draw from a wider range of skills, help share responsibility and promote positive risk taking.³⁸

Not everybody has family and friends to rely upon for support in making decisions, or wants them to take on that role. In Sweden, mental health service users developed a 'Personal Ombudsmen' (PO) service. POs are professionals that work entirely on their client's commission. Sometimes this means simply talking through existential matters if that is what is important to the client, but if the person asks them to they might also provide help in navigating services such as housing or healthcare. The PO scheme has been so successful in reducing mental health crises it has actually saved public authorities money, and has been rolled out to many other countries.³⁹

Each of these models of supported decision making has three things in common:

1. The person chooses who they want to support them and how - support is not imposed;
2. The support is characterised by a relationship of trust - which may take a long time to establish for professionals;
3. Support is about helping a person to understand and evaluate the options and express what they want. It is not about imposing other people's views of their best interests on a person.

Supported decision making is about much more than helping people to make one off decisions, or providing support during a mental capacity assessment. It is about a holistic system of support that places the person at the centre of decision making. Models of supported decision making around the world have helped people to avoid entry into 'guardianship', where third parties make decisions for the person, and have helped them to gain control over their lives.

Australia; Wallace, M. (2012) *Evaluation of the Supported Decision Making Project*, South Australia: Office of the Public Advocate.

³⁸ Advocacy for Inclusion (2012) *Supported Decision Making, Legal Capacity and Guardianship: Implementing Article 12 of the Convention on the Rights of Persons with Disabilities in the Australian Capital Territory*, Canberra City, Australia; Broome, S., Dellot, B., Lindley, E., Norris, E., Rowson, J., Soopramanien, D. and Truch, E. (2012) *Improving decision-making in the care and support of older people*, York: Joseph Rowntree Foundation; Inclusion International (2014) *Independent but not Alone: A Global Report on the Right to Decide*, London.

³⁹ Engman, T., Manning, F. and Ekecrantz, L. S. (2008) *A New Profession is Born – Personligt ombud, PO*, Socialstyrelsen, Fhebe Hjälms.

Supported decision making by advocates under the Care Act

Advocates play an important role in supported decision making under the Care Act. Local authorities must make a referral to an advocate where a person would have 'substantial difficulty' in understanding, using or weighing or retaining information about assessment, care planning or safeguarding, or communicating their views, wishes or feelings, where there is nobody else in that person's life who would be an appropriate person to represent and support the person and facilitate their involvement.⁴⁰

Advocates under the Care Act have a duty to support people in making decisions and communicating their wishes and feelings. They must assist the individual in:

- understanding functions such as assessment and care planning;
- communicating the individual's views, wishes or feelings;
- understanding how the individual's care and support needs could be met by the authority or otherwise;
- making decisions in respect of care and support arrangements;
- understanding the authority's duties in care assessment, planning and review and the individual's rights and obligations.⁴¹

This role ties into provisions in the Mental Capacity Act, which says that people should not be regarded as unable to make a decision unless 'unless all practicable steps to help him to do so have been taken without success'⁴² and that an explanation of the relevant information is given to the person in a way that is appropriate to his circumstances.⁴³ Chapter 3 of the MCA Code of Practice gives suggestions of how a person can be helped to make a decision for themselves. Supported decision making from advocates and appropriate persons may help people to demonstrate that they have the mental capacity to make decisions about their care for themselves.

In some cases the provision of supported decision making by advocates and others will not be enough to convince others that a person has the mental capacity to make a decision. Nevertheless, this support can still be very important in helping a person to clarify what they would like to happen and express their wishes, preferences, values and feelings. Advocates can then use this information to help ensure that best interests decision makers take the person's wishes and feelings, values and beliefs into account when making best

⁴⁰ s67 and s68 Care Act

⁴¹ Regulation 5(5)(a)-(b) of The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014

⁴² s1(3) MCA

⁴³ s3(2) MCA



interests decisions.⁴⁴ They can also help to ensure that the person is as involved in the decision making as possible.⁴⁵ It is important to recognise that the advocacy role under the Care Act is not about helping to determine the person's 'best interests', it is about helping the person to make decisions for themselves as far as possible, and helping them to express and advocate for what they themselves want.

Common dilemmas and difficulties in supported decision making

Supported decision making presents an opportunity to have a powerful and positive impact upon a person's life, however it also sometimes presents supporters and others with dilemmas and difficulties.

Challenging prejudice and low expectations

One of the biggest challenges encountered by both those making and those supporting decisions may be the attitudes of other people. Sometimes people may be reluctant to believe that people with certain kinds of disabilities, or people who have never been given opportunities, can really make decisions for themselves.⁴⁶ Sometimes third parties may not understand that the role of supporters is to help the person make and express their own decision, not to impose decisions on a person. Advocates may need to clearly explain their role to others, and help to challenge low expectations about the decision making abilities of those they are supporting.

Reflecting on the 'protection imperative'

Advocates themselves may find it difficult to help support a person in making decisions that they regard as unwise or risky. Providing support in these circumstances can be difficult, and they will need supervision and support from their colleagues and managers to work within a positive risk taking framework⁴⁷ and to understand any legal duties they have.

Supervision and peer support can also help advocates reflect on the 'protection imperative' felt by many professionals – even including judges⁴⁸ - where the

⁴⁴ s4(6) MCA

⁴⁵ s4(4) MCA

⁴⁶ James, K. and Watts, L. (2014) *Understanding the lived experience of supported decision-making in Canada*, Law Commission of Ontario.

⁴⁷ Department of Health (2007) *Independence, choice and risk: a guide to best practice in supported decision making*, London.

⁴⁸ *CC v KK and STCC* [2012] EWHC 2136 (COP), §25

desire to protect a person against perceived risks may cloud professional judgment.

Undue influence and conflicts of interest

In some circumstances advocates may be supporting people whom they believe are under the undue influence of others. Advocates may be involved because it is believed that people in a person's personal life are not 'appropriate' to support and involve the individual in care assessments and planning. These situations can be very tricky, especially as other people may feel threatened by the advocate's role, and may be upset if people make different decisions to those they want them to make. Advocates need to work sensitively within these situations so as not to inflame tensions and to respect what may still be an important relationship to the person. However, they must be clear that their first duty is to help support and involve the individual and help them to express their own wishes, not those of other people.

Advocates may also have to help a person to navigate various conflicts of interest in those surrounding a person. For example, those providing care may have conflicts of interest relating to resources – advocates may have to help a person understand their rights and entitlements under the Care Act and to challenge decisions about resource allocations or service provision where appropriate. Family members may also sometimes have conflicts of interest, perhaps connected with a person's finances or their own personal preferences for that person's care and living arrangements. And advocates should also be aware that they themselves may have conflicts of interest, for example in terms of the time and resources they can devote to helping a particular client or wishing to remain on good terms with professionals or commissioners of advocacy services. Good supervision and honest and thoughtful reflection will be essential for navigating these risks.

People who are unable to express a clear decision, even with support

In some situations people may not be able to understand the relevant information or communicate a decision, no matter how much support advocates are able to provide. For example, a person with a severe communication impairment may struggle to understand complex care planning decisions or communicate their wishes and preferences clearly. Advocates should always strive to the best of their abilities to support decisions – including through involving others who may be able to help improve a person's ability to communicate, retain, evaluate and understand information – but this may not always be possible. The phrase



‘supported decision making’ usually – although not always⁴⁹ - applies to situations where a person is able to express a decision with support. However, in situations where a person cannot clearly express a decision, it has been used to mean practices which try to implement the best interpretation of a person’s will and preferences.⁵⁰

In such situations, the Care Act duties to ‘involve’ a person in assessment⁵¹ and care planning⁵² still apply. In this context, the role of the advocate will be to help determine and represent the person’s wishes, preferences, feelings and beliefs as far as they can be ascertained. Advocates may also need to make representations to promote the person’s welfare if they are unable to do so for themselves, including challenging decisions.

Non-instructed advocacy is very important in these situations. However, where advocates are acting on their own initiative, or are representing what they believe are a person’s wishes but they cannot be certain, they should make this clear to decision makers. It is important to be clear that the wishes, feelings, values and beliefs of the individual are distinct from those of the supporter, however well intentioned.

⁴⁹ Committee on the Rights of Persons with Disabilities (2014) *General comment No 1 (2014) Article 12: Equal recognition before the law*, (Adopted at the Eleventh session of the Committee, 31 March –11 April 2014, CRPD/C/GC/1) Geneva.

⁵⁰ Committee on the Rights of Persons with Disabilities (2014) *General comment No 1 (2014) Article 12: Equal recognition before the law*, (Adopted at the Eleventh session of the Committee, 31 March –11 April 2014, CRPD/C/GC/1) Geneva. §18bis

⁵¹ s9(5) Care Act 2014

⁵² s25(3)(a) Care Act 2014

Chapter 10: The Care Act 2014 and the Mental Capacity Act 2005

The Mental Capacity Act (MCA) protects and promotes the rights of people where someone is unable to make a decision because of the way their mind or brain is affected, for instance by illness or disability or other condition that negates their ability to cope with the building blocks of cognitive functioning. The lack of capacity may be temporary - for instance due to an accident, being under anaesthetic or mental illness or may be long term such as advanced dementia or severe learning difficulties.

All staff assessing care and support needs, and undertaking care planning and reviews must apply the MCA if they are working with people who have been assessed as lacking capacity. Advocates will similarly need to understand its main provisions in order to assure themselves that the local authority have applied the MCA correctly when making decisions within assessment, care and support planning, review or safeguarding processes, on behalf of people who are unable to do so. The Social Care Institute for Excellence (SCIE) has a useful resource⁵³ which sets out the basics of the MCA and includes sections on the role of the Independent Mental capacity Advocate.

MCA underpinning principles

Underpinning the MCA are five principles which should inform every action people take when using the MCA to make decisions on behalf of a person without capacity. They are:

1. A person must be assumed to have capacity unless it is established that they lack capacity
2. A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success

This means people must seek to communicate in a way that invests a person with capacity – and organise practicable assistance where it could help.

3. Just because an individual makes what might be seen by others as an objectively unwise decision they should not be treated as lacking capacity to make that decision

⁵³ <http://www.scie.org.uk/publications/mca/index.asp>



The first three principles must be considered before there can be any consideration as to lack of capacity.

4. An act done or a decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests
5. Before the act is done, or decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

In other words, it does not have to be the least restrictive option if there is a good legal reason for it not being.

From the point of view of the independent advocate, the starting point is that a person has capacity if one is not sure that s/he does not. The essence of lacking capacity is that a person is incapable of understanding the consequences of information or a decision – as opposed merely to be having substantial difficulty. This might be in relation to the exercise of choice, or whether to accept a service. However, even if a person lacks capacity, their wishes and feelings are vital to the role of the advocate.

Has the person planned for their incapacity?

Where a person has been assessed as lacking capacity, the independent advocate must first establish whether a person has a Court of Protection financial deputy or a person with an Enduring Power or a registered financial **Lasting** Power of Attorney acting on their behalf. In relation to decisions that may have financial implications for the individual, their views are determinative; that is what those instruments confer – but the authority only goes as far as managing the money or property; and if there is an advocate appointed under the Care Act it must be because of some perceived concern about any such person.

It is also possible that a person has a valid and applicable Advance Decision to Refuse Treatment which might affect the care proposed. Finally they may have made a health and welfare LPA or have a deputy appointed in which case it is possible (depending on the terms of the LPA) that an attorney has lawful authority to make decisions. Again, if an advocate has been appointed, it would be on account of some concern about the bona fides of any such authorised person; and it must be remembered that holders of roles can be removed by the Court of Protection if they are not regarded as acting in the person's best interests.

This task should already have been undertaken by the local authority but the advocate should check and establish who the relevant people are.

Independent Mental Capacity Advocates (IMCAs)

The MCA introduced Independent Mental Capacity Advocates (IMCAs). Under the MCA, when people meet the IMCA criteria, local authorities and the NHS have a **duty** to instruct an IMCA for changes in accommodation and serious medical treatment decisions. For care reviews and adult protection procedures, local authorities and the NHS have **powers** to appoint an IMCA (where they consider it beneficial).

IMCAs are independent and work for advocacy providers who are not part of a local authority or the NHS. The MCA requires 'decision-specific' assessments of capacity. The IMCA will stop being involved in a case once the decision has been finalised and they are aware that the proposed action has been carried out. They will not be able to provide on-going advocacy support to the person. If it is felt that a person needs advocacy support after the IMCA has withdrawn, it may be necessary to make a referral to a local advocacy organisation.

The right to an IMCA applies to decisions about State funded long-term accommodation moves to or from a hospital or care home or a move between such accommodations (and serious medical treatment decisions) and Deprivation of Liberty Safeguards decisions, regardless of the funder of the placement. An IMCA safeguards the rights of people who:

- are facing a decision about a State funded long-term move into registered accommodation;
- lack capacity to make a specified decision at the time it needs to be made;
- **and**
- have nobody else who is willing and able to represent them or be consulted in the process of working out their best interests, other than paid staff.

An IMCA cannot be involved if a person has capacity (or the proposed long-term change in accommodation is a requirement under the Mental Health Act 1983).

Overlap between advocacy under the MCA and Care Act

There are similarities with the Mental Capacity Act (MCA), however the duty to provide independent advocacy under the Care Act is broader and applies to a wider set of circumstances. The Care Act provides independent advocacy support to qualifying people:

- who *have* capacity, but who have substantial difficulty in being involved in the key care and support processes, as well as those who lack capacity



Providing Independent Advocacy under the Care Act 2014

- in relation to their assessment and/or care and support planning regardless of whether a change of accommodation is being considered
- in relation to the review of a care and/or support plan (as a duty not a power)
- in relation to safeguarding processes (though IMCAs may be involved if the authority has exercised its discretionary power under the MCA to support the alleged perpetrator)
- who are carers, who themselves have substantial difficulty in engaging, whether or not they have capacity
- for whom there is someone who is appropriate to consult for the purpose of best interests decisions under the MCA, but who is not able and/or willing to facilitate the person's involvement in the local authority processes.

The statutory guidance stipulates the role of an independent advocate under the Care Act as being less about informing best interests decisions, and more about actively supporting the person to make the decision for themselves and participate in care planning, and then representing their interests when this is required. The regulations are framed in terms of helping a person to understand and exercise their rights, and also challenging decisions where necessary.

There are likely to be people who qualify for independent advocacy under the Care Act but not an Independent Mental Capacity Advocate (IMCA). However, most of the people who qualify for discretionary independent advocacy under the Mental Capacity Act 2005, in relation to care review and safeguarding, will also qualify for independent advocacy under the Care Act. Both the Care Act and the MCA recognise the same areas of difficulty but the test with the MCA is whether the person 'lacks capacity' to make specific decisions whereas the Care Act right is for those having substantial difficulty in being involved in key local authority processes.

To enable the person to receive seamless advocacy and not to have to repeat their story to different advocates, the same person could provide support as an independent advocate in both roles, if trained, qualified and with the appropriate skills to do both. However, under whichever legislation the advocate providing support is acting, they should meet the appropriate requirements for an independent advocate under that legislation.

The local authority must meet its duties in relation to working with an IMCA provided under the MCA as well as those in relation to an independent advocate under the Care Act when the independent advocate is acting in both roles.

In both Care Act and IMCA roles, independent advocates:

- support and represent people
- primarily work with people who do not have anyone appropriate to support and represent them
- require a similar skills set
- must adhere to similar regulations about appointment and training
- will need to be well known and accessible
- may challenge local authority decisions (and local authorities are under a duty to consider representations made by independent advocates in both types of roles).

Overlap between the principles of the Care Act 2014 and the Mental Capacity Act 2005

References to the Mental Capacity Act 2005 (MCA) core concepts of mental capacity and best interests can be found throughout the Care Act 2014. The principles of the Care Act have a strong affinity to the principles of the MCA: for example, under the Care Act, local authorities must begin with ‘the assumption that the individual is best-placed to judge questions of their own well-being’⁵⁴, just as under the MCA they must assume that a person has mental capacity unless it is shown otherwise.⁵⁵ Both Acts also emphasise the importance of:

- the individual’s views, wishes, feelings and beliefs;⁵⁶
- not jumping to conclusions about a person based on their age, appearance, any condition they have or an aspect of their behaviour which might lead others to make unjustified assumptions about them;⁵⁷
- the individual participating as fully as possible in decisions which are about them;⁵⁸
- involving others in helping a person to make decisions for themselves, or in making decisions which affect them;⁵⁹
- minimising restrictions on a person’s rights or freedom of action.⁶⁰

During the course of assessment and care planning, questions of mental capacity and best interests may arise for a variety of different reasons. For example, authorities may need to assess a person’s mental capacity to refuse a needs

⁵⁴ s1(3)(a) CA

⁵⁵ s1(2) MCA

⁵⁶ s1(3)(b) CA 2014; s4 MCA

⁵⁷ s1(3)(d) CA 2014; s2(3) and s4(1) MCA 2005

⁵⁸ s1(3)(e), s9(5)(a) s25(3)(a) CA 2014; s4(4) MCA 2005

⁵⁹ s9(5)(b) and s25(3)(b) CA 2014; s1(3) and s4(7) MCA 2005

⁶⁰ s1(3)(h) CA 2014; s1(6) MCA 2005



assessment⁶¹ or to involving others in care planning⁶² or reviews⁶³, their ability to make financial decisions around paying for care⁶⁴, or requesting direct payments⁶⁵.

Mental capacity issues can also often arise during safeguarding. This means that advocates may be involved in supporting people whose mental capacity is being assessed, or about whom best interests decisions may be made, in relation to local authority functions under the Care Act. Advocates can play an important role in ensuring that people are appropriately supported and represented during this process, and helping them to understand and assert their rights.

Advocates' general duties relating to the Mental Capacity Act 2005

Advocates must help individuals to understand their rights, and the local authorities' duties, in relation to the Care Act.⁶⁶ Where issues around mental capacity and best interests arise in connection with care planning and assessment, advocates may also need to help a person to understand their rights and the authority's duties in relation to the MCA.

Advocates have a general duty to 'make such representations as are necessary' to secure a person's rights in relation to the Care Act.⁶⁷ Where assessment and care planning raises questions of mental capacity or best interests, this duty to make representations may extend to securing a person's rights under the MCA. For example, advocates may consider it appropriate to remind authorities of the key principles of the MCA.

Like other professionals, advocates are legally obliged to have regard to the MCA Codes of Practice – including the Code of Practice on the deprivation of liberty safeguards (DoLS).⁶⁸ If the advocate becomes aware during the care planning

⁶¹ s11(3) CA 2014

⁶² s25(3)(c) CA 2014

⁶³ s27(2)(b)(iii) CA 2014

⁶⁴ s18(4) CA 2014

⁶⁵ s32 CA 2014

⁶⁶ s5(5)(b) of The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014

⁶⁷ s5(5)(c) of The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014

⁶⁸ s42(4) MCA 2005. These can be downloaded from the following websites:

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>
and

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085476

stage that arrangements may result in a DOL, they must alert the local authority (and managing authority) to apply for an authorisation.

Advocates' duties relating to supported decision making

The Care Act guidance states that 'The modern care and support system should routinely enable supported decision making, where options and choices are presented simply and clearly'.⁶⁹ Supported decision making means helping a person to understand and evaluate the different choices available to them, and recognising that a person has the right to make their own decisions, including making decisions that other people may regard as unwise.

Supporting people to make their own decisions is a key human rights value, enshrined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD).⁷⁰ The CRPD emphasises ensuring that a person's rights, will and preferences are respected⁷¹ and respecting 'individual autonomy including the freedom to make one's own choices'⁷². Around the world, many different supported decision making approaches are being developed – all of these systems emphasise building a relationship of trust between the supported individual and those supporting them, and helping people to make decisions that reflect their personal wishes, preferences and values.⁷³

Advocates play an important role in supported decision making. They must assist the individual in —

- understanding functions such as assessment and care planning;
- communicating the individual's views, wishes or feelings;
- understanding how the individual's care and support needs could be met by the authority or otherwise;
- making decisions in respect of care and support arrangements;

⁶⁹ Department of Health (2014) *Care and Support Statutory Guidance: Issued under the Care Act 2014*, London. Paragraph 10.4

⁷⁰ Article 12(3) CRPD states that 'States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity'.

⁷¹ Article 12(4) CRPD states that measures relating to the exercise of legal capacity must 'respect the rights, will and preferences of the person' and be 'free of conflict of interest and undue influence'.

⁷² Article 3(a) CRPD

⁷³ The European Union has developed a website, explaining the human rights background to supported decision making and describing different models of support: <http://www.right-to-decide.eu/>



- understanding the authority's duties in care assessment, planning and review and the individual's rights and obligations⁷⁴

This role ties into provisions in the MCA regarding support, which are discussed in more detail below.⁷⁵ Chapter 3 of the MCA Code of Practice gives suggestions of how a person can be helped to make a decision for themselves.

Advocates' roles in relation to the key principles of the Mental Capacity Act 2005

The presumption of mental capacity

Although advocacy referrals are made where a person experiences substantial difficulty understanding, retaining, using or weighing information or communicating with others,⁷⁶ this does not mean that the person automatically lacks mental capacity. They may be able to make some or all decisions about their care with appropriate support. In some situations it may be appropriate for advocates to remind the authority of the presumption of capacity under the MCA.⁷⁷

A lack of mental capacity can only be established following an assessment of a person's ability to make a specific decision, or decisions. A person lacks mental capacity if they are unable to understand, retain, or use or weight the information relevant to the decision, or to communicate their decision,⁷⁸ because of an impairment or disturbance in the functioning of the mind or brain.⁷⁹ People need to understand information about the decision's reasonably foreseeable consequences⁸⁰, but not all of its peripheral details.⁸¹

Assessors should not jump to conclusions about a person's capacity on the basis of a person's age, appearance, a condition they have or an aspect of their behaviour which might lead others to make unjustified assumptions.⁸²

⁷⁴ Regulation 5(5)(a)-(b) of The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014

⁷⁵ s1(3) MCA and s3(2) MCA

⁷⁶ s67(4) and s68(3) CA 2014. See also regulation 3 of The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014 and paragraphs 7.10-7.15 of the *Care and Support Statutory Guidance: Issued under the Care Act 2014*.

⁷⁷ s1(3) MCA

⁷⁸ s3 MCA

⁷⁹ s2(1) MCA

⁸⁰ s3 MCA

⁸¹ *LBL v RYJ & Anor* [2010] EWCOP 2665, §24

⁸² s2(3) MCA

The support principle

Under the MCA, a person should not be assessed as lacking the mental capacity to make a decision ‘unless all practicable steps to help him to do so have been taken without success’⁸³, and information about the decision has been given to the person in a way that is appropriate to his circumstances⁸⁴. In the case *CC v KK and STCC*, Mr Justice Baker said that when a person’s mental capacity is being assessed to make decisions about where they will live and how they would be supported, assessors must not start with a ‘blank canvas’ but should give full details of the care package that would be available to the person for each of the different options; he defined the care package as one which would provide all **practicable** support, although that would have to be explored by an Administrative Court judge, if there was a dispute as to whether what had been offered was lawful in relation to duties regarding sufficient personal budgets.⁸⁵

Ultimately, under the MCA, responsibility for ensuring that appropriate support is provided to help a person make a decision falls to whoever is responsible for assessing their mental capacity. Where assessments concern care planning, this will usually be the local authority. However, this can tie into supported decision making and advocacy functions under the Care Act. The MCA Code of Practice states that mental capacity assessors should consider whether others can help support a person’s communication⁸⁶ or otherwise help or support the person to make choices or express a view⁸⁷. Thus mental capacity assessors may involve the advocate themselves, or other people, in ensuring that a person has been given all practicable help to make the decision for themselves.

Advocates may also make representations if they have concerns about a mental capacity assessment which relates to a Care Act function; for example if they feel that a person has not been supported to make decisions in the most appropriate way, or if they feel that a person has not been given all the relevant information to make an informed decision.

Space for unwise decisions

The MCA states that ‘A person is not to be treated as unable to make a decision merely because he makes an unwise decision.’⁸⁸ However, sometimes mental

⁸³ s1(3) MCA

⁸⁴ s3(2) MCA

⁸⁵ *CC v KK and STCC* [2012] EWHC 2136 (COP), §68

⁸⁶ MCA Code of Practice, p29 and paragraph 3.10

⁸⁷ MCA Code of Practice, p30 and paragraph 3.10

⁸⁸ s1(4) MCA



capacity assessors are influenced by the outcome of a person's decision.⁸⁹ The courts have cautioned about situations where assessors 'may feel drawn towards an outcome that is more protective of the adult' and thus 'fail to carry out an assessment of capacity that is detached and objective', and may not take account of different individuals giving different weight to different factors.⁹⁰ Being prepared to tolerate a risk is not the same as not understanding, using or weighing it. Advocates may make representations if they have concerns in this regard.

Best interests decisions

If, following assessment, it is concluded that a person lacks the mental capacity to make a particular decision about their care, others may make decisions in their best interests and be protected from legal redress if they have abided by the Act and Code.⁹¹ This will usually be the local authority.⁹² Advocates may play a key role in representing a person and ensuring they are involved in best interests decision making but do not make the decision.

Best interests decision makers must 'so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible' in best interests decisions affecting them.⁹³ Decision makers must, so far as they are reasonably ascertainable, consider the person's past and present wishes and feelings, any beliefs and values that would be likely to influence the person's decision or other factors they would be likely to consider if

⁸⁹ P Willner, J Bridle, V Price, S Dymond, and G Lewis, (2013) 'What do NHS staff learn from training on the Mental Capacity Act (2005)?' (2013) 18 *Legal and Criminological Psychology* 83, 91; Emmett, C., Poole, M., Bond, J. and Hughes, J. C. (2012) 'Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards', *International Journal of Law and Psychiatry*, 36(1), 73-82; Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T. and Heslop, P. (2012) *Making Best Interests Decisions: People and Processes*, (Norah Fry Research Centre, University of Bradford Dementia Group and the Mental Health Foundation).

⁹⁰ *CC v KK and STCC* [2012] EWHC 2136 (COP), §25, §65; see also *PH v A Local Authority and Z Ltd* [2011] EWHC 1704 (Fam), §16 and *A Local Authority v TZ* [2013] EWHC 2322 (COP), §36.

⁹¹ s1(5) MCA

⁹² In some cases, the person may have a deputy appointed by the Court of Protection or have made a Lasting Power of Attorney giving named persons authority to make decisions about their health and welfare. It is important to distinguish deputies and attorneys with authority to make decisions about property and affairs (which are relatively common) from those with authority to make decision about health and welfare (which are comparatively rare).

⁹³ s4(4) MCA

they were able to do so. They must also consider any written statement made by them when they had mental capacity.⁹⁴

Best interests decision makers must, if it is practicable and appropriate, consult with others about their views of the person's best interests and the person's wishes, feelings, values and beliefs. These include anybody named by the person as somebody to be consulted, anyone engaged in caring for the person or interested in his or her welfare.⁹⁵ The Supreme Court has described the purpose of this process as to help consider matters from the person's own point of view.⁹⁶

Advocates under the Care Act may be involved in helping the person understand the best interests decision making process,⁹⁷ and to participate in making best interests decisions relating to the person's care. This is closely linked to the duty under the Care Act to involve a person in assessment and care planning.⁹⁸ Advocates should communicate the person's views, wishes and feelings⁹⁹ to best interests decision makers, including where a person may be unable to communicate these themselves, insofar as the advocate can ascertain them.¹⁰⁰

Except in the limited circumstances outlined above,¹⁰¹ advocates are not expected to come to a view on the person's best interests. Their role is limited to supporting, involving and representing the person's views, wishes and feelings during the best interests decision making process where this relates to Care Act functions.

Advocates may make representations where necessary to secure an individual's rights. For example, if a person is unhappy about a best interests decision regarding their care, advocates may remind decision makers that just as the well-being principle that underpins the Care Act includes emotional well-being as well as physical,¹⁰² judges have asked in relation to the MCA 'What good is it making

⁹⁴ s4(6) MCA

⁹⁵ s4(7) MCA

⁹⁶ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, §45

⁹⁷ Regulation 5(5)(a)(i) of The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014

⁹⁸ s9(5)(a) and s25(3)(a) CA 2014

⁹⁹ Regulation 5(5)(a)(ii) of The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014

¹⁰⁰ Regulation 5(7) of The Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014

¹⁰¹ Concerning consulting with others and taking copies of relevant records.

¹⁰² s1(2)(b) CA 2014



someone safer if it merely makes them miserable?'¹⁰³ They may also remind decision makers of the CA and MCA duty to consider the least restrictive option before making any other decision.¹⁰⁴

Practice example

Hannah has multiple sclerosis, and lived until recently with her partner, Peter, who had been her primary carer. However, Hannah and Peter have recently separated, and, concerned about her, Hannah's GP suggested that Hannah look into some care support. Hannah is not that keen on the idea of strangers in her house, but does agree to a visit from a social worker to discuss her options.

The social worker visits Hannah on her own, and during the visit, becomes concerned about Hannah's mental capacity; she has difficulty answering questions, and seems quite confused and doesn't really seem to understand why the social worker is there. The social worker considers that Hannah needs help to understand the process around her care assessment, and also considers that Hannah lacks the mental capacity to make the decisions around her care herself due to her lack of understanding of what was going on in the meeting. In the absence of anyone else who is really close enough to Hannah to perform the role, an advocate under the Care Act is appointed to help Hannah's understanding of what is going on.

The advocate meets several times with Hannah to help her understand the process of the care assessment and what is going on. The advocate finds that she generally understands the relevant information quite well, but things have to be explained carefully and slowly. She discovers that Hannah's reluctance to have care workers is due to the intimate nature of the personal care with which she requires assistance.

The advocate begins to doubt the finding that Hannah lacks capacity, and thinks that assumptions were made before all practicable steps were taken to help Hannah understand what was going on. The advocate finds over the course of two further meetings with Hannah that, on days where she is tired or in pain, her confusion levels are higher, and that difficult questions must be broken down into very short, simple questions, or even left to another day.

The advocate speaks to the social worker about her experience with Hannah,

¹⁰³ *Re MM (An Adult)* [2007] EWHC 2003 (Fam), §120; see also *Re M (Best Interests: Deprivation of Liberty) (Rev 1)* [2013] EWHC 3456 (COP) and *Westminster City Council v Sykes* [2014] EWHC B9 (COP)

¹⁰⁴ s1(2)(h) CA 2014; s1(6) MCA

explaining that she feels that she may not lack capacity, provided that the conversation is had when Hannah is not too tired or confused. The advocate reminds the social worker that capacity should be presumed, and that all practicable steps must be taken to assist someone before finding they lack capacity. She points out that this includes assessing capacity when the individual is at their 'best', at a time when and place where they are comfortable. Based on the information that the advocate gives him, the social worker agrees that the capacity test could be redone. Hannah's capacity is reassessed, and the local authority revises their capacity decision. The advocate continues to be involved on the basis Hannah faces still substantial difficulty in communication.

Practice example

Bob lives alone at home, but he is in bad health; he has dementia and also experiences shortness of breath and heart problems. He is on an end-of-life care pathway, and has 3 visits a day from carers, along with one visit from a hospice nurse. Bob has been adamant that he does not want to die in hospital or in a care home, and has a sign to that effect both above his bed, and also in his living room. Bob's niece and neighbour are both very concerned about him, and have tried to suggest numerous times that he consider moving to a residential home. However, Bob is very clear that he wishes to stay in his own home.

The local authority become involved and Bob's care plan is reviewed. At this point, Bob is considered to have capacity, but struggles with understanding the process. He does not want his niece or neighbour to act as his representative, so Bob is offered an independent advocate. A few weeks later, Bob has a mild heart attack, and is taken to hospital for treatment following a 999 call by his niece. A decision regarding Bob's care and residency needs to be made, but he has become much more confused. A second capacity assessment is conducted, and he is assessed to now lack capacity. A best interests meeting is convened to discuss what should happen to Bob's care. Bob is invited to attend with his advocate to represent his views.

Bob's advocate argues that his wishes and feelings have been made very clear throughout his time on the end-of-life care pathway, and while he had capacity: he does not want to die in hospital, he wants to go home. She argues for this strongly throughout the best interests assessment, pointing out that as well as the principles within the Mental Capacity Act regarding best interests, the Care Act also puts emphasis on the establishing the person's own definition of their 'well being' so far as that is agreed by the assessor.

As a result, it is agreed that Bob will return home, with his care package still in place. He passes away as he wished, three weeks later, in his own bed.



Chapter 11: The Children and Families Act (2014) and the Care Act (2014)

The Children and Families Act gives greater protection to vulnerable children, better support for children whose parents are separating, a new system to help children with special educational needs and disabilities, and help for parents to balance work and family life.

The Act also ensures vital changes to the adoption system can be put into practice, meaning more children who need loving homes are placed faster. Reforms for children in care include giving them the choice to stay with their foster families until their 21st birthday.

The Act includes a number of new measures to protect the welfare of children, including:

- changes to the law to give children in care the choice to stay with their foster families until they turn 21
- a new legal duty on schools to support children at school with medical conditions,
- making young carers' and parent carers' rights to support from councils, much clearer
- reforms to children's residential care to make sure homes are safe and secure, and to improve the quality of care vulnerable children receive
- a requirement on all state-funded schools - including academies - to provide free school lunches on request for all pupils in reception, year 1 and year 2
- amendments to the law to protect children in cars from the dangers of second-hand smoke

The Act will also help people to better balance their work and home life with the following measures:

- from April 2015, mothers, fathers and adopters can opt to share parental leave around their child's birth or placement. This gives families more choice over taking leave in the first year – dads' and mothers' partners can take up to a year, or parents can take several months at the same time
- from 1 October 2014, prospective fathers' or a mother's partner can take time off to attend up to 2 antenatal appointments
- adoption leave and pay will reflect entitlements available to birth parents from April 2015 - no qualifying period for leave; enhanced pay to 90% of salary for the first 6 weeks; and time off to attend introductory



appointments. Intended parents in surrogacy and 'foster to adopt' arrangements will also qualify for adoption leave and pay

- extending the right to request flexible working to all employees from 30 June 2014
- replacing the current statutory procedure, through which employers consider flexible working requests, with a duty on employers to consider with requests in a 'reasonable' manner

There is a distinct liaison between the Acts in relation to young people and transition into adulthood. Children's services will continue to be provided under the Children Act, but adult services do not have to start at the point of 18 – for instance the Care Act gives rights to children to be assessed for adult services before adulthood and for young carers to receive a Care Act assessment and support plan before the child is 18.

Similarities between the Children and Families Act 2014 and the Care Act 2014

There are a number of similarities between the Acts and shared goals:

Emphasis on person centre planning

Both Acts have created a dialogue for positive interaction with services in terms of assessment, planning and delivery with an emphasis on person centred planning.

The contributions made by those who care for the young person are more valued than before, but it is to be noted that this is a contribution and whilst consideration should be given, in terms of advocacy, it is essential the young person's views are expressed and are at the centre of the decision making processes.

The emphasis now moves from parent carers having the greater influence to the young person taking control with suitable support in place.

Practice example

Jamie is 20 and as a result of a serious motorbike accident, has complex needs. Jamie, prior to his accident had lived independently. He has, via his advocate indicated that he wishes to live away from his mother Danielle as he says he feels 'suffocated' by her caring which he says is slowing down his climb back to independence.

Jamie wishes to use a Personal Budget to fund his independence. Jamie has been given a range of information by his advocate around what is available to

him under the local offer. Having been supported to examine the offer and decide what he would like to spend his budget on and asks his advocate to support him to share his choices.

Danielle is initially not happy with Jamie's choice but after some discussion agrees to support his move.

Jamie chooses an adapted apartment close to Danielle where he can have Personal Assistants to support his daily needs. In addition, Jamie chooses to join the local wheelchair basketball team and hopes to play competitively.

A plan is drawn up which supports Jamie and his mother to begin the process of moving on and also allows Jamie to find suitable PA's that he will be happy to spend time with.

Wellbeing

Wellbeing is a theme which also cuts across the Acts and is a duty to which both acts must demonstrate.

Section 25 of the Children and Families Act requires local authorities must ensure educational and training provision is integrated with health and social care provision where this promotes the well-being of children or young people in their area with SEN or a disability or improves the quality of special educational provision.

Joined up services

Both Acts promote the ethos of joined up thinking in relation to Education, Health and Social Care, aiming for the best outcomes possible for not only the young person but also those who care for them.

Support for carers

Carers under these provisions are better protected within the Acts as they strive to ensure that the care which they provide to the young person is not detrimental to them. Therefore where there are carers involved in the planning of a young person's care, there may be situations where carers' advocates will work alongside young people's advocates to ensure that each are represented and heard.



Within the context of the Acts, the views of those who are involved in the care of the person in the centre of the assessment are to be considered with an emphasis on inclusion.

Access to information

Information Advice and Support are at the heart of both Acts ensuring that information is accessible when choices are being made. The support given by advocates is not to influence but to enable the process for those who have substantial difficulty to achieve positive outcomes as a result.

Practice example

Polly is 19 and lives with her father Sid 68. Polly's mother Hyacinth died recently after a short illness, which has caused Polly who was born with Down Syndrome to develop emotional distress to the nature and degree that a review of her care plan has been requested.

Polly had a very close relationship with her mother whom she loved to spend time with in the garden as both had a passion for flowers. Sid, who is a taxi driver, had by his own admission, been very much a secondary carer, is struggling to come to terms with the death of his beloved wife and his new found primary carer responsibilities.

Polly wants to remain in the house that she grew up in and says that she knows that her Mum wants her to stay there. Sid is unsure of most things at this point and unclear as to whether he can actually look after Polly's needs adequately.

Fraught with concerns, Sid has asked for an advocate to support him in the review of Polly's care needs. Similarly, Polly has raised her concerns that her father will not want to care for her and has also agreed to see an advocate. The local authority asked for separate advocates to meet with Sid and Polly.

Early in the process it became apparent there were distinct similarities around Polly's wishes and those of Sid:

- *For Sid, Polly represented the only person who was part of Hyacinth and that coupled with his love and desire to protect his daughter made him feel that he wanted to build on his tenuous and distant relationship with Polly. His fear was that he didn't know if he was capable and whether Polly would accept his inadequacies.*
- *For Polly, the distance that she felt from her father made her feel unloved and unsure as to whether her father would reject her and put her into a*

residential setting. Polly wanted to go to a centre where she could learn more about flowers and learn how to cook as her mother before becoming ill had done all the cooking, so that she could cook for herself and Sid. As most of her time had been spent with her mother, Polly expressed feelings of loneliness and isolation having not made friends as her mother had been her sole companion.

Both advocates expressed the wishes of their respective clients and together with Polly's Social Worker support Sid and Polly to draw up a joint care and support plan that enabled them both to receive support for their bereavement.

There was also a phased plan of support provided by social carers with input from Sid for Polly which would slowly decrease to a point whereby Sid could provide care for Polly and continue to drive his taxi even though he would lessen his hours on the road to ensure that he could be home for her.

A centre where Polly could build on her love of flowers and where she could achieve a certificate in horticulture and where she could engage with some cookery classes was found. It was also felt that Polly could explore friendships in this environment.

How the Children and Families Act 2014 may affect advocates working under the Care Act

Ensuring access to assessments

It is essential to note that under the Care Act there is a duty to carry out both child's carer's and a young carer's needs assessments where there is 'likely need' if there is an indication that support will be required post 18 and when the assessment would be of 'significant benefit'

When working as an advocate, it may be necessary to challenge the local authority where they have decided that there is no 'significant benefit' – it must provide written reasons to facilitate this.

Practice example

Rosario who is almost 17, has been caring for his mother Esmeralda who has Multiple Sclerosis. For the last 2 years Rosario has received help with caring for his mother from the local authority in the form of respite hours which have enabled him to attend the local college where he is able to develop his social network.



He has just received a letter from the Local Authority which informed him that the support will be withdrawn when he is 18. The reason given is that his mother has been 'stable' for the last 18 months. The letter also contains information about local and national voluntary service provision in the borough but Rosario feels they would not be able to meet his need.

Rosario is also concerned that in the last 3 months Esmeralda has shown signs of deterioration and is awaiting test results to establish the cause.

As a result of the deterioration in his mother's health coupled with his feelings of hopelessness, Rosario contacts the local disability rights organisation and requests that an advocate supports him to challenge the decision.

An advocate working under the Care Act, meets with Rosario and discusses his range of options and explores methods of conveying his thoughts and wishes to the local authority.

Having gathered the necessary information, the advocate helps Rosario to challenge the decision in writing citing that Esmeralda's health has deteriorated and that there is significant benefit to a carer's assessment being carried out.

As part of this assessment, Rosario has asked that he wants to further his education and apply to study at a local university subject to his A level results.

The local authority agree to meet with Rosario, his advocate and with his mother also in attendance.

On the day of the meeting, Rosario, with the support of his advocate explains his current situation, outlining what has changed and what support he now requires in order to have a reasonable quality of life and to ensure that his caring does not impact on his own aspirations.

It is agreed for his support hours to be slightly increased and that after the results of his academic studies and his acceptance into university, his hours and support plan will be reviewed.

Considering joint budgets

Assessed needs may be met through joint budgets and the commissioning of services across health, education, care, employment and housing as appropriate.

Bringing together these partners and their respective budgets, could mean that young people, and in particular those who fall within the area of transition will

have greater opportunities as budgets are pooled to have more positive outcomes with more joined up funding budgetary plans. Where the young person has assessed needs which can be met through combined services, the advocate should check the lead professional responsible for developing the care and support plan has worked with the relevant partners and considered a joint budget.

Practice example

Antonia is 16 and has severe Attention Deficit Hyperactivity Disorder (ADHD) and a learning disability. Throughout her school education she received a Statement of Education Need that outlined how the ADHD and learning disability impacted on her and what support she needed to get the best out of her education. She is currently moving from Children's Services to Adult Services and as such is in Transition.

Antonia is subject to the overlap between what she can receive under the Children and Families Act and the Care Act. In view of the requirement under both Acts to create positive outcomes for those who are eligible for care, there is scope (depending on what outcomes Antonia, her mother Lucinda, father Luigi and those who are involved in her care are interested in) to combine both Children and Families and Care budgets.

Antonia desperately wants both to study part time and work part time as her goal is to pursue a career in acting. There is an acting class for young people with a disability in a neighbouring town and there are also a number of employment opportunities that Antonia wishes to pursue.

As Antonia can often become easily distracted and feels uncomfortable in meetings when a number of people are present, she has asked an advocate to attend and help her to represent her views and wishes.

As education is a key focus for the Children's and Families Act and employment under the Care Act the multi-agency joint needs assessment meeting created an environment where both budgets were combined to create an opportunity for Antonia to receive the support required in order explore a meaningful outcome in her life.

Consulting with young carers

Under the Care Act, young carers' wishes are to be taken into consideration when assessments and reviews are being conducted in respect of the person for whom they provide care.



In all aspects of working with children, young people and young carers, additional time may need to be factored in to ensure that they have the opportunity and the environment to fully engage with the assessment process and to share their views.

Working with children and young people

Advocates appointed under the Care Act may be working with children and young people for the first time. Whilst the advocacy role is exactly the same as if working with an adult (to support their involvement to make choices and decisions), the advocate may consider how the following issues can impact upon their relationship:

- Children and young people often experience time differently from adults. Advocates may be familiar with supporting adults who think in weeks and months: children often see the future much more immediately and plan in days and weeks. It can be useful to develop and find ways in which to create a 'timeline' so that children and young people can, to varying degrees of capacity, understand and can engage with the process.
- Transition in anyone's life can be filled with difficult decisions that require a degree of knowledge in order to determine the choices made. Young people, particularly in the transitional phase of their lives are effectively leaving the support of their parents or carers and experimenting with varying levels of independence as they become adults.

Both the Children and Families Act 2014 and the Care Act 2014 also require young people and their parents to be fully involved making decisions about their care and support. This includes decisions about the most appropriate time to make the transition to adult services. The EHC plan or any transition plan should set out how this will happen, who is involved and what support will be provided to make sure the transition is as seamless as possible. Parents and carers may be used to making decisions on the young person's behalf and may be reluctant to give up this responsibility. Advocates supporting a young person under the Care Act will need to be sensitive to this and resist pressures placed on them by parents and carers who may want to know what the advocate is doing and what the young person is saying when they do not have the young person's consent to share such information..

- Young carers can often exhibit an inability to separate themselves from their caring role and see themselves as an individual with the right to express their wishes. Careful, empowering support is required when

working with young carers as they struggle to perceive their own needs in relation to the person that they care for.

- Young carers often suffer with low self esteem and self worth. Their confidence is sometimes eroded as a result of limited social interaction as their care giving can interrupt this area of their lives.



Chapter 12: The Mental Health 2007 and the Care Act 2014

Advocates will offer support to people who may experience mild or significant mental health issues that can impact on their ability to make decisions and choices. The impact of their mental health condition may mean they experience problems in the way they think, feel and/or behave. They may be de-motivated, agitated, restless, anxious, fearful and unable to cope with everyday life. They might hear voices, have an impaired ability to concentrate, have difficulty assessing, retaining information and have difficulty making decisions.

People with serious mental health issues often feel stigmatised. They can feel disbelieved, discounted and discriminated against. They may have a diagnosis which they may feel is more like a label such as schizophrenia, bipolar disorder (manic depression), depression, an anxiety disorder, panic attacks and phobias, obsessive compulsive disorder, an eating disorder, post-traumatic stress disorder (PTSD) or a personality disorder.

Advocates therefore need to offer a sensitive and compassionate response that meets the needs of people with mental health problems undergoing assessment, care and support planning, review and safeguarding processes.

The Mental Health Act 1983 and 2007

The purpose of the Mental Health Act is to protect and safeguard people and provide treatment and care to those people who are diagnosed with a defined mental illness.

The Mental Health Act 1983 sets out when a person can be admitted, detained and treated in hospital - including when this is against the person's wishes.

As the Mental Health Act requires the enforcement of medication regimes and restricts people's liberty, safeguards were introduced to protect the individual patient. Each detained patient has a right to appeal their detention, to apply for a second opinion and for the guiding principles (see below) to be applied to them. Since 2007 most detained patients also have a right to an IMHA – an Independent Mental Health Advocate (see below).

Guiding principles

The guiding principles are a framework of important values that need to be balanced in particular situations when decisions are being made about individuals

under the Mental Health Act. The principles are a shared vision of best practice. They are designed to inform decisions not determine them.

The five overarching principles are:

Least restrictive option and maximising independence

Where it is possible to treat a patient safely and lawfully without detaining them under the Act, the patient should not be detained. Wherever possible a patient's independence should be encouraged and supported with a focus on promoting recovery wherever possible.

Empowerment and involvement

Patients should be fully involved in decisions about care, support and treatment. The views of families, carers and others, if appropriate, should be fully considered when taking decisions. Where decisions are taken which are contradictory to views expressed, professionals should explain the reasons for this.

Respect and dignity

Patients, their families and carers should be treated with respect and dignity and listened to by professionals.

Purpose and effectiveness

Decisions about care and treatment should be appropriate to the patient, with clear therapeutic aims, promote recovery and should be performed to current national guidelines and/or current, available best practice guidelines.

Efficiency and equity

Providers, commissioners and other relevant organisations should work together to ensure that the quality of commissioning and provision of mental healthcare services are of high quality and are given equal priority to physical health and social care services. All relevant services should work together to facilitate timely, safe and supportive discharge from detention.

Discharge from hospital

When a patient is discharged from hospital, they should receive support to help them readjust to life in the community. However many people find they receive varying degrees of support. Difficulties can arise when the decision to discharge a person is made with little or no planning or even when the patient is on leave



from the hospital. The point of discharge, like the point of admission can be a difficult time for the person having to adjust to life again outside the hospital environment. Consequently, patients may find themselves in vulnerable situations.

Anyone who may have a need for community care services is entitled to a social care assessment when they are discharged from hospital from under a s2 or a s131 admission to mental hospital, to establish what services they might need. Some patients will be discharged with Section 117 after-care, which imposes a duty on health and social services **jointly** to provide aftercare services to certain patients who have been detained under the Mental Health Act for as long as the patient requires the services. This after-care should be planned within the framework of the Care Programme Approach after a thorough assessment in discussion with the individual patient.

Section 117 states that aftercare services must be provided to patients who have been detained in hospital:

- for treatment under Section 3
- under a hospital order pursuant to Section 37 (with or without a restriction order)
- following transfer from prison under Section 47 or 48

This also includes patients on authorised leave (s17) from hospital and patients who were previously detained under Section 3 but who stayed in hospital informally after discharge from section.

It also includes people who are living in the community subject to a community treatment order and restricted patients who have been conditionally discharged.

Section 117 **does not apply** to:

- patients detained in hospital for assessment under Section 2
- patients detained in an emergency under Section 4
- patients detained while already in hospital under Section 5(2)
- patients who were not detained under any section (informal or voluntary patients).

Guardianship

This is a social care led regime for enabling patients to receive care outside of hospital when that care cannot be provided without the use of limited compulsory powers. The Guardian, usually the Local Authority, has three specific powers:

- to decide where the patient will live
- to require the patient to attend for treatment, work, education, or training
- to demand that medical professional has access to the patient where they live

Guardianship requires an assessment under the MHA and clarity about the agreed arrangements and responsibilities. It should be accompanied by a comprehensive care plan. Guardianship does not give anyone the right to treat the patient without their permission or to consent on their behalf but it has been held to extend reasonable implied powers to the guardian similar to Best Interests powers under the MCA, subject to challenge for unreasonableness or a breach of human rights.

Leave of Absence (Section 17)

This Section (of the Mental Health Act) allows for a patient to be temporarily absent from hospital. It is granted for short term absences, usually up to 7 days where further in-patient treatment is considered necessary.

Supervised Community Treatment – SCT (Section 17A)

This Section is suitable when there is no reason to believe that the patient will need further treatment as a detained in-patient for the time being. It is intended to help patients maintain stable mental health outside of hospital and promote recovery. It allows for a patient to be recalled to hospital as a result of a relapse or a change in the patient's circumstances usually involving increased risk of harm to the health and safety of the patient or other people.

Deprivation of Liberty while under Guardianship, on leave or on SCT

Patients who lack capacity to consent to the arrangements required for their care of treatment, may occasionally need to be detained in a care home for further care or treatment for their mental disorder or physical health problem in circumstances where recall to hospital is not considered necessary. In these cases, the procedures for the Deprivation of Liberty safeguards in the Mental Capacity Act (MCA) 2005 should be followed. Guardianship does not convey a right to deprive a person of their liberty without safeguards or other legal authority.

Patients on an SCT or leave of absence who lack capacity to consent to the arrangements for their treatment and care and who need to be detained in hospital for further treatment, will be recalled under the Mental Health Act rather than using the MCA Deprivation on Liberty safeguards.



Independent Mental Health Advocate (IMHA)

Patients are eligible for support from an IMHA if they are:

- detained under the Act (even if they are currently on leave of absence from hospital)
- conditionally discharged restricted patients
- subject to guardianship; or
- supervised community treatment (SCT) patients

Some “informal patients” (not detained) are eligible if they are:

- are being considered for a treatment to which section 57 applies: or
- under 18 and being considered for electro-convulsive therapy or any other treatment to which section 58A applies

The IMHA role

The role of the IMHA is to engage with the qualifying patient to ensure:

- the views and wishes of the person are heard and taken seriously
- the detained person understands their rights and the rights others have in relation to them and any powers or restrictions applied to them
- the person understands the basis on which they are detained and which parts of the Act apply to them
- the person is able to access information
- the person understands the treatment they are receiving and the reasons for that treatment and the options for alternative treatment
- the person understands the legal authority for providing that treatment and the safeguards and other requirements under the Act that apply to that treatment
- the person is supported through ward rounds, care planning meetings, Managers’ Hearings
- the person is supported through the appeal process including at Tribunals
- communication between the patient and the clinical team is appropriate and effective
- the person is assisted to access appropriate legal representation
- that the person is supported in a range of other ways to ensure they can participate in the decisions that are made about their care and treatment

Aftercare and the Care Programme Approach (CPA)

The Care Programme Approach or CPA is a way in which mental healthcare is planned and delivered. It means that a person should be allocated a care coordinator, have multi-disciplinary care planning and review meetings and a written care plan. Not all patients will receive mental healthcare under the CPA. Even if mental healthcare is not provided under the CPA, patients should have their aftercare needs assessed if they are likely to need services to support them in the community when they are discharged from hospital.

Aftercare should be planned with the patient, their family and carers (if appropriate), as well as professionals, looking at both health and social care needs. The type of aftercare required will depend on the circumstances of the individual and health and social services are entitled to consider their resources when assessing needs. The care plan should be reviewed at regular intervals.

IMHA and Advocacy under the Care Act

An advocate appointed under the Care Act, if not also qualified to be an IMHA themselves, may find themselves working alongside an IMHA or may need to refer their client to an IMHA. Commissioners may also plan services so that IMHA, IMCA and advocacy under the Care Act are jointly commissioned so that service users just need to make one approach to the advocacy provider. Whilst this provides a seamless service for service users, it does require the advocate to be clear about their statutory role and which legislation frames their role.

Section 117 of the MHA places a duty on the NHS and Local Authority to provide aftercare and this will usually involve a joint assessment (often under the Care Programme Approach) including an assessment of the person's care and support needs, a care and support or support plan and subsequent review (which may reach a decision that a person is no longer in need of aftercare). Those people who do not retain a right to an IMHA, whose care and support needs are being assessed, planned or reviewed should be considered for an advocate under the Care Act, if they have substantial difficulty in being involved and if there is no appropriate person to support their involvement.

Practice example

Theo has an acquired brain injury and has been detained under s3 of the Mental Health Act for approximately 12 mths. Theo's mental health deteriorated following the death of his mother and he was admitted into hospital after he was found very distressed walking along a motorway.



The mental health team are now looking at discharging him and are assessing his mental health needs under s17 of the Mental Health Act. The Local Authority are also involved in assessing his care needs which include:

- *Housing: Where he will live, what support he will need?*
- *Rehabilitation: Does he need a package of rehabilitation support?*
- *Personal Care: Can Theo undertake personal care or will he need support to do this?*
- *Accessibility: What accessibility needs does Theo have?*
- *Communication Aids: How does Theo communicate and does he require aids to assist him?*

Theo previously lived at home with his mother, but this is no longer an option. Theo does not have any other family members and has been assessed as lacking the capacity to decide where he can live. His social worker has identified a specialist residential placement in his local area which could potentially meet his needs.

Theo is eligible to receive support from an Independent Mental Health Advocate (IMHA), an Independent Mental Capacity Advocate (IMCA) and an advocate available under the Care Act.

An IMHA would be available to support Theo only for the duration of his detention (or if he is moved to a Community Treatment Order). An IMHA could support Theo understand his rights under the Mental Health Act and understand the care and treatment he is receiving.

An IMCA would be instructed to support and represent Theo within the long term accommodation move as he is unbefriended and lacks the capacity to decide where to live. The primary role of the IMCA is to gather information about Theo's wishes, preferences and interests for the Decision Maker to consider as they make the final decision as to where Theo should live. The IMCA is likely to meet with Theo, consult with people who know Theo and write a report which reflects what is important to Theo and the types of things the decision should reflect. The IMCA will also check to see the decision is made in line with the Mental Capacity Act (that is that the principles and Best Interest checklist have been followed). If the IMCA is concerned that the decision maker has not followed the Mental Capacity Act they would raise concerns and possibly challenge the decision.

An advocate working under the Care Act would also be appointed as Theo faces substantial difficulty in engaging within the initial assessment and subsequent care and support planning. Their role would be to help Theo be involved in and understand the assessment and care and support planning process – or to use non instructed advocacy to gather information to inform these processes. They would become involved much earlier in the process than the IMCA... but later than the IMHA, and their role would have a different focus.

The Care Act Guidance suggests it is desirable (but not a requirement) for the same advocate to provide the different roles to minimise the number of people involved in a person's life and to prevent any negative consequences of the person having to repeatedly retell their story.



Appendix:

Resources

Action for Advocacy (2006) [Quality Standards for Advocacy Schemes](#).

Advocacy Quality Performance Mark (2014) [Advocacy Code of Practice](#).

Assist Advocacy Services in Staffordshire (no date). [The Watching Brief: Working with advocates using Non-Instructed Advocacy](#)

Bauer A, Dixon J, Wistow G & Knapp M (2013) [Investing in Advocacy for Parents with Learning Disabilities: What is the Economic Argument?](#)

Brown G, Standen N, Khilji B (2013) Dementia Advocacy in a Time of Austerity, Coventry University, Coventry.

Change UR Mind *Transitions Advocacy Project* Available at <http://www.changeurmind.org.uk/projects/8/transitions-advocacy-project>

Dementia Advocacy Network and Advocacy Plus (2012) [Taking Their Side: Fighting Their Corner 16 Stories Demonstrating the Difference Independent Advocacy Makes to the Lives of People with Dementia](#), DAN, London.

Department for Constitutional Affairs (2007) [Mental Capacity Act 2005 Code of Practice](#). London: The Stationery Office.

Department of Health: Mental Health Act Code of Practice 2015

Empowerment Matters: Making financial decisions: [Guidance for assessing, supporting and empowering specific decision making](#).

Equality and Human Rights Commission (2010) Research Report 67 [Advocacy in social care for groups protected under equality legislation](#).

Equalities National Council (2012) [Stop, Look and Listen: A Manifesto for Change and Inclusion of Black and Minority Ethnic Disabled People, Their Carers and Families](#). A BME user-led Disabled People Organisation, committed to developing advocacy services and community programmes.

Franklin A, Knight A (2011) [Someone on our Side: Advocacy for Disabled Children and Young People](#).

Horton C (2009) [Creating a Stronger Information, Advice and Advocacy System for Older People](#), Joseph Rowntree Foundation Solutions, York.

IRISS (2013) [Advocacy: Models and Effectiveness](#) The Institute for Research and Innovation in Social Services (IRISS).

Lawton A (2009) [Personalisation and Learning Disabilities: A Review of Evidence on Advocacy and its Practice for People with Learning Disabilities and High Support Needs](#).

Macadam A, Watts R and Greig R. (2013) [The Impact of Advocacy for People who Use Social Care Services](#). NDTi/ NIHR School for Social Care Research Scoping Review.

Rethink Mental Illness (2013) [Advocacy](#).

Royal College of Psychiatrists (2012), [Independent Advocacy for People with Mental Disorder](#), Royal College of Psychiatrists, London.

Ruck Keene, A. (2014) Guidance Note: Acting as a litigation friend in the Court of Protection, 39 Essex St Chambers and University of Manchester

Social Care Institute of Excellence (2010). [SCIE Guide 31](#): Good practice guidance for the commissioning and monitoring of Independent Mental Capacity Advocate services. *SCIE have a [resource page for IMCAs](#).*

Social Care Institute of Excellence (2009). [At a glance 12](#): Personalisation briefing: Implications for advocacy workers.

Social Care Institute of Excellence (2010). SCIE Guide 42 Good practice guidance on accessing the Court of Protection

Townsley R, Marriott A and Ward L (2009) [Access to Independent Advocacy: An Evidence Review](#). Office for Disability Issues.

Newbigging K et al (2012) [The Right to be Heard: Review of Independent Mental Health Advocate \(IMHA\) Services in England](#), University of Central Lancashire.

Voiceability (2015) [Guidance to support advocates in challenging decisions or actions with or on behalf of individuals](#)

Supported decision making information and resources

Circles of Support (UK): www.circlesnetwork.org.uk



Providing Independent Advocacy under the Care Act 2014

European Union *Choices* website: www.right-to-decide.eu

Helen Sanderson Associates: <http://www.helensandersonassociates.co.uk/>

In Control: <http://www.in-control.org.uk/>

Inclusion International *Right to Decide* campaign: <http://inclusion-international.org/the-right-to-decide/>

Jenny Hatch Justice Project (USA): <http://jennyhatchproject.info/>

National Resource Center for Supported Decision-Making
<http://supporteddecisionmaking.org>

Supported decision making resources from the Office of the Public Advocate in South Australia: www.opa.sa.gov.au/resources/supported_decision_making

Think Local Act Personal <http://www.thinklocalactpersonal.org.uk/>