

Care Act 2014 and Autism

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Aims of this session

- Know your main rights and entitlements
- Know when and where to ask for help
- Understand the “goalposts” for eligibility under the Care Act for adults with autism and their carers
- Understand how to register your disagreements
- Start to understand how the Mental Capacity Act might interact

What is a Care Act Assessment?

- A social care assessment under the Care Act 2014 regarding any need for adult social care support
- Replaced “community care assessments” under the NHS and Community Care Act 1990

What are the main points to be aware of?

- Anyone with a diagnosis of autism is eligible for an assessment
- There are national eligibility criteria
- You have a **right** to request someone who knows about autism, as there is a statutory duty to train social care staff
- If there is an argument about which social care team should do the assessment, tell them that is their job to figure out; it's not your problem!
- You have a right to request an advocate who will act on behalf of the autistic person. This needs to be requested at the outset as it won't happen automatically

What are the main principles of the Care Act?

That care and support:

- is **clearer** and **fairer**
- promotes people's **wellbeing**
- enables people to **prevent and delay** the need for care and support, and carers to maintain their caring role
- puts **people in control** of their lives so that they can pursue opportunities to realise their potential

A note about the Care Act and the Mental Capacity Act...

- If your son or daughter has significant difficulty in making or communicating their decisions, or if there could be debate about their wishes being safe or in their 'best interests', you need to find out more about the Mental Capacity Act (2005)
- In such cases, it might be more important to ensure that an independent advocate is on board from the start of the assessment process
- A person can only be deemed to 'lack capacity' to make a certain decision at a certain time (e.g. about managing their money, or their health care)
- The law says families and carers have an important role to play and should be involved wherever possible
- People have the right to make 'unwise decisions'

Mental Capacity assessment – 2 stage test

The legal mental capacity test asks these questions:

- 1) Does the person have an impairment or disturbance of the functioning of the mind or brain?
- 2) Is the person able:
 - to understand the information relevant to the decision?
 - to retain that information?
 - to use or weigh that information as part of the process of making the decision?
 - to communicate their decision (whether by talking, using sign language or any other means)?

Back to the Care Act: What does it say about transition?

Put simply, lots!

For more details, see Chapter 10 of this brilliant free publication online:

<https://councilfordisabledchildren.org.uk/help-resources/resources/disabled-children-legal-handbook-2nd-edition>

Back to the Care Act:

What does it say about transition? (2)

In summary, the Care Act says:

- Local Authorities have a legal duty to assess and prepare care plans for anyone likely to be needing transfer to adult social care
- Included in that is whether the person is “**likely**” to have care support needs
- And also whether the assessment will be of “**significant benefit**”
- If the LA refuses, they have to say why
- Assessment should include a section on whether the carer is willing and able to care for the young person after 18
- If your child has not been in receipt of social care as a child, you will need to request a Care Act assessment yourself

“You are going to have to manage a medium term project (a bit like restoring a building). You will need to get various experts to work together; you will need them to agree to work to deadlines and then ensure that they keep to these deadlines. You will need to keep records and to remind the experts of what needs to be done in each phase and by when. If the experts give explanations which you find unconvincing, you may need to challenge these. You will also need to be clear on ‘costs’. Generally, councils and NHS bodies must meet the needs of a disabled young person or adult: needs are fundamental and costs are secondary. Vague statements about ‘funding panels’ or ‘cost caps’ should be challenged and always clarified in writing.”

– Camilla Parker, ***Transition To Adulthood: A Guide for Parents***, Cerebra, 2014.

Assessing 'eligible need' under Care Act national eligibility criteria

An adult with care needs will qualify for support if their needs assessment shows that:

- The need for support is due to a physical or mental impairment (includes autism) or an illness.
- The person is unable to achieve two or more of the specified care outcomes.
- This has a significant impact on the person's wellbeing.

What does the assessment cover? (outcomes for adults with support needs)

- Managing and maintaining nutrition
- Maintaining personal hygiene
- Managing toileting needs
- Being appropriately clothed
- Being able to make use of the adult's home safely
- Maintaining a habitable environment
- Developing and maintaining family and other relationships
- Accessing and engaging in work, training or voluntary activities
- Making use of necessary facilities or services in the community, including public transport and recreational facilities or services
- Carrying out caring responsibilities the adult has for a child
- Most assessments also cover finance and medication

Defining the need for support

An adult is to be regarded as being **unable to achieve** an outcome if s/he:

- is unable to achieve it *without assistance* (which includes prompting or supervision)
- is able to achieve it without assistance (which includes prompting or supervision), but doing so causes the adult *significant pain, distress or anxiety*
- is able to achieve it without assistance (which includes prompting or supervision), but doing so endangers or is likely to *endanger the health or safety* of the adult, or of others
- is able to achieve it without assistance (which includes prompting or supervision), but it *takes significantly longer* than would normally be

Outcomes for carers with support needs

- Carrying out any caring responsibilities the carer has for a child
- Providing care to other persons for whom the carer provides care
- Maintaining a habitable home environment in the carer's home, whether or not this is also the home of the adult needing care
- Managing and maintaining nutrition
- Developing and maintaining family or other personal relationships
- Engaging in work, training, education or volunteering
- Making use of necessary facilities or services in the local community, including recreational facilities or services
- Engaging in recreational activities
- **'Significant impact on wellbeing'** rules apply to carers: <https://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-assessment.aspx>

Exercise

Think about your family member and consider what difficulties they may have in relation to the Care Act outcomes (sometimes called domains):

- Managing and maintaining nutrition
- Maintaining personal hygiene
- Managing toileting needs
- Being appropriately clothed
- Being able to make use of the adult's home safely
- Maintaining a habitable environment
- Developing and maintaining family and other relationships
- Accessing and engaging in work, training or voluntary activities
- Making use of necessary facilities or services in the community, including public transport and recreational facilities or services
- Carrying out any caring responsibilities that the adult has for a child
- Finance and medication

Congratulations! You have been assessed and found eligible for support.
What next?

- Your Care Plan – get a copy in writing
- Direct payments/personal budget:
<http://www.autism.org.uk/directpayments>
- Consider the use of brokerage if you don't know where to start
- Ask social care to commission the service
- Working out the budget includes assessing whether your young person can afford to contribute to their care

Your adult/young adult is found not to meet eligibility criteria. What next?

- Ask for a reason in writing, as well as copies of the assessment and Care Plan
- If you think the assessment is incorrect, then send a something in writing to say that you disagree with the assessment and, in exact terms, why and how
- You may be referred to other services for people who do not meet eligibility for short-term input
- You may be “signposted” to other services/groups
- Speak to us about options
- Use the complaints system if you feel they should have met eligibility – however, this will only help if the LA have failed to follow the law or bypassed a system

<https://www.disabilityrightsuk.org/complaining-about-local-authority-decisions>

<http://www.autism.org.uk/get-involved/media-centre/position-statements/adult-services-england2.aspx>

In summary...

- It's complicated!
- The professionals are still learning about the Care Act. It's only been implemented for 2 years; that is not long, so don't assume they know much more than you.
- Question stuff/check it for accuracy.
- If you have a clear idea of how to meet need (even if it's slightly unorthodox), mention it during the assessment! You will often have much more creative and innovative solutions than the social care department.
- Chase things up in writing, and keep a record of all contact.
- Don't be afraid to be the "parent from hell" in terms of tenacity if that is needed – but that said, bridge building is always better than bulldozing and in my view you get better outcomes this way.
- Don't ever apologise for asking for stuff or be guilt-tripped by the old "There are others in a worse position than you" chestnut.
- It shouldn't be this hard, but it often is... Be kind to yourself and seek support from us and others.