

Transition to adulthood webinars: Care Act script

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Hello and welcome to Care Act session of the Autism and transition to adulthood webinars. These webinars are brought to you by the Greater Manchester Autism Consortium part of The National Autistic society.

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The aims of this session are:

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

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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

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What are the main points to be aware of?

- Anyone with a diagnosis of autism is eligible for an assessment
- There is 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

Autism is a substantial impairment so is covered by the care act, but in addition the Autism Act statutory guidance mentions that you have a specific right to an assessment. If you are told you can't have one because they don't have an autism team or that you can't have one because you're autistic and won't be eligible then that is not legal.

However, the right is only to an assessment, not a care package

National Eligibility criteria should mean there is less local variance and that you can carry assessments across. Unfortunately, this does not seem to be consistently happening, in fact it is often used as a gate-keeping tool and that is its main function for many councils.

Ask for an advocate at the point of referral. In most areas this is organised by the social worker, so don't wait for the first visit/ session, request one at the outset. It will avoid further delay

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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 they can pursue opportunities to realise their potential

This is worth noting as it reminds us what the statutory duties that the social care teams have towards you. It is worth including these words in any correspondence you have with them by letter or email.

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

- If your young person 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 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)
- It is not true that family members do not have a say in capacity or wellbeing/best interest related decisions. The law says they have an important role to play and should be involved wherever possible

Sometimes there can be dispute between you and professionals, or between your young person and professionals, about whether their wishes and choices are actually safe or in their best interests, and related to that, whether they have the 'mental capacity' to make that decision at that time.

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Mental Capacity assessment

2-stage test:

- 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 his decision (whether by talking, using sign language or any other means)

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

Put simply, a lot.

For more details see Chapter 10 of the Council for Disabled Children's free publication online. You will find a link to this in the useful links section at the end of this session.

<https://councilfordisabledchildren.org.uk/help-resources/resources/disabled-children-legal-handbook-3rd-edition>

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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 any one likely to be needing to transfer to adult social care
- Included in that is whether the person is **"likely"** to have care support needs
- And also that 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

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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.

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Assessing 'eligible need' under Care Act national eligibility criteria

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

- 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 **well being**

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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, recreational facilities or other services
- Carrying out caring responsibilities the adult has for a child
- Most assessments also cover managing finances and medication

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Defining the need for support

An adult is to be regarded as being **unable to achieve** an outcome if they:

- are unable to achieve it *without assistance* which includes prompting or supervision
- are able to achieve it *without* assistance which includes prompting or supervision but doing so causes the adult *significant pain, distress or anxiety*
- are 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; or
- are able to achieve it without assistance which includes prompting or supervision but *takes significantly longer* than would normally be expected.

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Outcomes for carers with support needs

- Carrying out any caring responsibilities the carer has for a child, young person or adult
- 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>

You do have a right to an assessment under the Care Act as a carer. Being unable to achieve similar outcomes to the person you care for is part of eligibility, as is defining these restrictions as having 'a significant impact' on your physical or mental wellbeing. If you are assessed to have eligible needs, you may get some support or a budget for extra help. Look at the NHS link and prepare well if you want to request an assessment in your own right.

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Exercise

Think about your family member and consider what difficulties they may have in relation to the Care Act outcomes

- 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, recreational facilities or services.
- Carrying out caring responsibilities the adult has for a child.
- Finance and medication

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You have had the assessment, congratulations you are eligible for support.
What next?

- Get a copy of the Care Plan in writing
- Direct payments/personal budget
- Consider the use of brokerage if you don't know where to start?
- Ask social care to commission the service
- <https://www.autism.org.uk/advice-and-guidance/topics/social-care/social-care-england/paying-for-social-care>

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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 you disagree with the assessment and in exact terms why and how you disagree
- You may be referred to other services for people who do not meet eligibility for short term input
- You may be "sign-posted" 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/by passed a system

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

<https://www.autism.org.uk/advice-and-guidance/topics/social-care/social-care-england/assessments-and-care-plans>

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In Summary

- It's complicated
- The professionals are still learning about the Care Act, so don't assume they know more than you.
- Question things/check it out for accuracy
- If you have a clear idea of how to meet a 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
- Follow 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 if you want to get better outcomes.

- Don't ever apologise for asking for things or be guilt tripped by being told "There are others in a worse position than you"
- It shouldn't be this hard, but it often is... Be kind to yourself and seek support from us and others

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On this page you will find useful links on the topic of Care Act assessments

<https://councilfordisabledchildren.org.uk/help-resources/resources/disabled-children-legal-handbook-3rd-edition>

<https://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-assessment.aspx>

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