

The Autism Alliance is a network of 16 autistic charities supporting thousands of adults and children affected by autism across the UK. We strive to support, raise awareness and increase understanding of Autism Spectrum Conditions throughout the UK to allow all affected by autism to lead productive and fulfilling lives.

The Autism Alliance have produced a guide, the Know your Rights Campaign so autistic people know their rights under the law and best practise as written in the Autism Act 2009, Care Act 2014 – the duty to promote well-being, Autism Strategy - 'Think Autism', the statutory guidance by the Department of Health in supporting the fulfilling of the Autism Strategy, The Equality Act 2010 – the duty to make reasonable adjustments. We have also produced a helpful guide for local authority statutory obligations.

We have now produced a guide to support all health and social care professionals whilst carrying out a care needs assessment, this is compliant with all of the above legislation.

This guide provides an overview of key elements to consider whilst undertaking a care needs assessment for autistic people/ND and references the law under the Autism Act 2009, the Care Act 2014 statutory guidance, Chapter 6: Assessment and Eligibility as well as other relevant legislation.

In order to carry out a care needs assessment, as set out in Regulation 5 of the Care and Support (Assessment) Regulations 2014 which requires a local authority to ensure that a person carrying out an assessment has the skills, knowledge and competence to carry out the assessment in question and is appropriately trained. Local Authorities must therefore ensure that assessors carrying out assessments of people with autism have the skills, knowledge, competence and training to carry out such assessments.

To help the adult with needs for care and support, or the carer, prepare for the assessment the local authority should provide in advance, and in an accessible format, the list of questions to be covered in the assessment. This will help the individual or carer prepare for their assessment and think through what their needs are and the outcomes they want to achieve.

1. Involvement in choice

- + The assessment should be person-centred throughout. Local authorities must find out the extent to which the person being assessed wishes to be involved in the assessment and should meet those wishes as far as is practicable to do so, as the person is best placed to understand the impact of their condition(s) on their outcomes and wellbeing.
(Care Act 2014 Statutory Guidance 6.35)
- + Putting the person at the heart of the assessment process is crucial to understanding the person's needs, outcomes and wellbeing, and delivering better care and support. The local authority must involve the person being assessed in the process as they are best placed to judge their own wellbeing. In the case of an adult with care and support needs, the local authority must also involve any carer the person has (which may be more than one carer), and in all cases, the authority must also involve any other person requested. The local authority should have processes in place, and suitably trained staff, to ensure their involvement of these parties, so that their perspective and experience supports a better understanding of the needs, outcomes and wellbeing.
(Care Act 2014 Statutory Guidance 6.30)
- + Understanding their own needs, the outcomes they want to achieve and the impact of their needs on their own wellbeing to allow them to effectively engage with the assessment process.
(Care Act 2014 Statutory Guidance 6.36)
- + Understand the basis on which decisions are reached.
(Care Act 2014 Statutory Guidance 6.36)
- + To support the person's involvement, the local authority should establish the individual's communication needs and seek to adapt the assessment process accordingly. In doing so local authorities must provide information about the assessment process in an accessible format.
(Care Act 2014 Statutory Guidance 6.37)
- + Where there is a concern about a person's capacity to make a specific decision, for example as a result of a mental impairment such as dementia, acquired brain injury or learning disabilities, then an assessment of capacity should be carried out under the Mental Capacity Act (MCA). Those who may lack capacity will need extra support to identify and communicate their needs and make subsequent decisions and may need an independent Mental Capacity Advocate. The more serious the needs, the more support people may need to identify their impact and the consequences. Professional, qualified staff, such as social workers, can advise and support assessors when they are carrying out an assessment with a person who may lack capacity.
(Care Act 2014 Statutory Guidance 6.32)

1. Involvement in choice (cont.)

- + At the point of contact, request or referral (including self-referral), local authorities must seek to ascertain whether an individual is able to be involved in their assessment and local authorities must therefore consider whether the individual has substantial difficulty in doing so. Local authorities must consider whether the adult would experience substantial difficulty in any of these 4 areas: understanding the information provided; retaining the information; using or weighing up the information as part of the process of being involved and communicating the person's views, wishes or feelings. Where a person has substantial difficulty in any 4 of these areas, then they need assistance. (*Care Act 2014 Statutory Guidance 6.33*)
- + Local authorities should also consider the impact of the assessment process itself on the individuals' condition(s). People may feel uncertain and worried about what an assessment involves and may find the process itself to be strenuous. Local authorities should therefore give consideration to the preferences of the individuals with regards to the timing, location and medium of the assessments. (*Care Act 2014 Statutory Guidance 6.40*)
- + The assessment should be designed to reflect the wishes of the person being assessed, taking into account their presenting need and their circumstances. An assessment process which benefits an individual in one instance may not necessarily be as effective for another. Local authorities should recognise this and in order to maintain a person-centred approach, local authorities must ensure that assessments are flexible to each individual case. (*Care Act 2014 Statutory Guidance 6.41*)

2. Reasonable adjustments

- + Devise, implement and promote reasonable adjustments to meet people's support needs to improve outcomes for people, including greater independence and participation
- + Appraise how limited communication and health literacy may reduce the ability of autistic people to convey health needs effectively to others
- + Promote methods of sharing knowledge of an autistic person's health and communication needs e.g. health/hospital/communication passports/books. Advise how they provide important information about a person's communication and care needs (including for autistic people who do not have a Learning Disability) and any potential hazards such as a risk of choking, known allergies and epilepsy
- + STOMP <https://www.vodg.org.uk/campaigns/stompcampaign/> and Positive and Proactive Care
- + Implement current guidelines and principles aimed at stopping the over-medication of people with a learning disability and/or autism
- + Work collaboratively across agencies and boundaries to improve inter-agency collaboration and communication, including best practice around named healthcare co-ordinators
- + Support and enable capacity building and partnership working to promote health equality and reasonable adjustments, challenging poor practice if appropriate
- + Implement appropriately and effectively, and communicate current legislation, policies and guidance relevant to autistic people accessing healthcare
- + Promote and apply the Accessible Information Standard for health and social care organisations including requirements for policy, procedures, human behaviour and where applicable, electronic systems. This includes the five-step process for:
 - i. Identification of needs
 - ii. Recording of needs
 - iii. Flagging of needs
 - iv. Sharing of needs
 - v. Meeting of needs
- + Actively promote sources of relevant local or national guidance, information and support
- + Nearly all people make small adjustments to fit in better or conform to social norms. However, autistic girls invest constant and elaborate effort to pass as 'normal' by modelling other women's behaviours and interests, literally meeting set expectations, and using set social scripts. Masking often then develops as a natural adaptation strategy to navigate reality. There is a price to masking such as exhaustion stress, low self-esteem and a deterioration in mental health.

2. Reasonable adjustments (cont.)

- + Additionally, many autistic people are well supported by families and/or autistic individuals without a learning disability may employ strategies which obscures their symptoms to the untrained eye. Large amounts of scaffolding often cover up the extent to which autism affects the individual. The constant effort required to maintain autism specific scaffolding may also break down due to negative life events, exhaustion or further rejection.
- + For example, Lynn reports that this masking enabled her to get a degree at Bristol University. However, following a failed PIP assessment, because the assessor was untrained and did not ask the correct questions, she lost the ability to self-manage. Despite being a bright university educated woman she is now failing in her interpersonal domain of functioning as she lacks social understanding and is no longer strong enough to constantly using 'learned' skills to pass which has resulting in high levels of anxiety.
- + By deep delving questions the assessor should be able to unmask the individual and/or reveal their unique autism profile without the scaffolding of support. For example, rather than asking do you have friends an assessor should ask: tell me about your teenage years? Have you always had friendships? Did your mother help you navigate these friendships?

3. Strengths of the Autistic Individual

- + At the same time as carrying out the assessment, the local authority must consider what else other than the provision of care and support might assist the person in meeting the outcomes they want to achieve. In considering what else might help, authorities should consider the persons own strengths and capabilities, and what support might be available from their wider support network or within the community to help. Strengths-based approaches might include co-production of services with people who are receiving care and support to foster mutual support networks. Encouraging people to use their gifts and strengths in a community setting could involve developing resident's groups and appropriate training to support people in developing their skills.
(Care Act 2014 Statutory Guidance 6.63)
- + Local authorities might also consider the ways a person's cultural and spiritual networks can support them in meeting needs and building strengths and explore this with the person. Any suggestion that support could be available from family and friends should be considered in light of their appropriateness, willingness and ability to provide any additional support and the impact of them doing so. It must be based on the agreement of the adult or carer in question.
(Care Act 2014 Statutory Guidance 6.64)

4. Autism

- + Autism's sensory issues can involve both hyper-sensitivities (over-responsiveness) and hypo-sensitivities (under-responsiveness) to a wide range of stimuli.

These can involve:

- + Sights
- + Sounds
- + Smells
- + Tastes
- + Touch
- + Balance
- + Body awareness (proprioception)

For example, many people on the spectrum are hyper-sensitive to bright lights or certain light wavelengths (e.g. from fluorescent lights). Many find certain sounds, smells and tastes overwhelming. Certain types of touch (light or deep) can feel extremely uncomfortable.

Hypo-sensitivities are likewise common. A low sensitivity to pain is a classic example. Another is under-responsiveness to the body signals that help control balance and physical coordination. This can result in clumsiness, which has long been associated with autism.

Awareness and accommodation can help ease related discomfort.

Remember each person with autism is unique, and this includes their personal sensitivities.

Examples of reasonable adjustments for hyper-sensitivities

- + Dimmed lights
- + Incandescent versus fluorescent lighting
- + Sunglasses or visor to block overhead fluorescent lighting
- + Ear plugs or headphones in noisy environments
- + Closed door or high-walled work areas to block distracting sights and sounds
- + Avoidance of strongly scented products (perfumes, air fresheners, soaps, etc.)
- + Food options that avoid personal aversions (e.g. intensely spicy, textured, cold, hot, etc.)
- + Clothing that accommodates personal sensitivities (e.g. too tight waistbands and/or scratchy fabric, seams and tags)
- + Request Visual supports for those who have difficulty processing spoken information
- + Sensory-stimulating toys (e.g. safe chewie's and fidgets)
- + Opportunities for rocking, swinging and other sensory stimulating activities
- + Strong tasting and/or textured foods, cold drinks, etc.
- + Firm touch (according to preference)
- + Weighted blankets
- + Fun opportunities to practice physical skills (catching, dancing, jumping, running, etc.)
- + Furniture arrangements that reduce chances of bumping into sharp or hard surface

5. Behavioural

- + Positive Behaviour Support
- + Skills for Care - A Positive and Proactive Workforce Guide will help adult social care commissioners and employers to make decisions when planning, purchasing or providing learning and development which will help your workforce to work in a positive and proactive way, and minimise the use of restrictive practices, when supporting people who display behaviours which challenge.
- + PBS training should reflect the PBS competency framework, which was developed by the PBS Academy in 2015.
- + Positive behaviour support is a behaviour management system used to understand what maintains an individual's challenging behaviour. People's inappropriate behaviours are difficult to change because they are functional; they serve a purpose for them. These behaviours are supported by reinforcement in the environment. PBS employs the principles of Functional Analysis and Person Centred Planning to create a hypothesis as to why a Challenging Behaviour is occurring, through changes to the Ecological and Programmatic environment around the person and focussing on skills acquisition to take the place of the Challenging Behaviour, changes to quality of life can occur and be maintained.

6. Medication

- + STOMP national initiative
- + Psychotropic medication to treat mental health
- + Psychotropic medication to manage behaviours
- + As required medications to manage acute distress/anxiety

7. Wellbeing Principals

Authorities must consider whether the adult is 'unable' to achieve 2 or more of the outcomes set out in the regulations and must also be aware that the regulations provide that 'being unable' to achieve an outcome includes any of the following circumstances, where the adult: (Care Act 2014 Statutory Guidance 6.105)

- + 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 attempt 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
- + 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.
- + The Eligibility Regulations set out a range of outcomes. Local authorities must consider whether the adult is unable to achieve 2 or more of these outcomes when making the eligibility determination. The following section of the guidance provides examples of how local authorities should consider each outcome set out in the Eligibility Regulations (which do not constitute an exhaustive list) when determining the adult's eligibility for care and support: (*Care Act 2014 Statutory Guidance 6.106*)
- + 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.
- + the adult's inability to achieve the outcomes above impacts on at least one of the areas of wellbeing (as described in Section 1 of the Act and chapter 1 of this guidance) in a significant way
- + In making this judgment, local authorities should look to understand the adult's needs in the context of what is important to him or her. Needs may affect different people differently, because what is important to the individual's wellbeing may not be the same in all cases. Circumstances which create a significant impact on the wellbeing of one individual may not have the same effect on another.

8. Family Approach

- + Intention of the whole family approach is for local authorities to take a holistic view of the person's needs and to identify how the adults needs for care and support impact on family members or others in their support network.
(Care Act 2014 Statutory Guidance 6.65)
- + During the assessment the local authority must consider the impact of the person's needs for care and support on family members or other people they authority may feel appropriate. This will require the authority to identify anyone who may be part of the person's wider network of care and support.
(Care Act 2014 Statutory Guidance 6.66)
- + The local authority must also identify any children who are involved in providing care. The authority may become aware that the child is carrying out a caring role through the assessment of the person needing care or their carer or informed through family members or a school. Identification of a young carer in the family should result in an offer of a needs assessment for the adult requiring care and support and, where appropriate, the local authority must consider whether the child or young carer should be referred for a young carer's assessment or a needs assessment under the Children Act 1989, or a young carer's assessment under section 63 of the Care Act. Local authorities should ensure that the adults' and children's care and support services work together to ensure the assessment is effective - for example by sharing expertise and linking processes.
(Care Act 2014 Statutory Guidance 6.68)

9. Training

- + Para 6.86 of the Care Act 2014 states "assessors undergo regular, up-to-date training on an ongoing basis. The training must be appropriate to the assessment, both the format of assessment and the condition(s) and circumstances of the person being assessed. They must also have the skills and knowledge to carry out an assessment of needs that relate to a specific condition or circumstances requiring expert insight, for example when assessing an individual who has autism, learning disabilities, mental health needs or dementia"
- + It is essential that the needs assessment is carried out to the highest quality. The assessment must identify the persons needs, outcomes and how these impact on their wellbeing; consider the person's strengths and capabilities; and consider what universal services might help the person improve their wellbeing. Local authorities must ensure that their staff have the required skills, knowledge and competence to undertake assessments and that this is maintained. This applies no matter how the assessment is carried out, including first contact, any assessment over the phone or online, or self-assessments where the person carrying out the assurance will need to have the appropriate training.
(Care Act 2014 Statutory Guidance 6.85)
- + Local authorities must ensure that assessors are appropriately trained and competent whenever they carry out an assessment. This means ensuring that assessors undergo regular, up-to-date training on an ongoing basis. The training must be appropriate to the assessment, both the format of the assessment and the condition(s) and circumstances of the person being assessed. They must also have the skills and knowledge to carry out an assessment of needs that relate to a specific condition or circumstances requiring expert insight, for example when assessing in individual who has autism, learning disabilities, mental health needs or dementia. This training must be maintained throughout their career. As part of maintaining their registration, social workers and occupational therapists are required to evidence the Continuing Professional Development.
(Care Act 2014 Statutory Guidance 6.86)
- + When assessing particularly complex or multiple needs, an assessor may require the support of an expert to carry out the assessment, to ensure that the person's needs are fully captured. Local authorities should consider whether additional relevant expertise is required on a case-by-case basis, taking into account the nature of the needs of the individual, and the skills of those carrying out the assessment. The local authority must ensure that the person is able to be involved as far as possible, for example by providing an interpreter where a person has a particular condition affecting communication - such as autism, blindness or deafness. See the Equality Act for necessary provisions around reasonable adjustments.
(Care Act 2014 Statutory Guidance 6.87)