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**Autism and LD Policy**

**[Date of Issue]**

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CONTENTS

[1. Introduction 3](#_Toc147931393)

[2. Policy Statement 3](#_Toc147931394)

[3. Scope 4](#_Toc147931395)

[4. Definition 5](#_Toc147931396)

[5. Procedures 5](#_Toc147931397)

[6. Extra Steps 9](#_Toc147931398)

[7. Company-wide Principles of Care Management 9](#_Toc147931399)

[8. COVID-19 10](#_Toc147931400)

[9. Monitoring 11](#_Toc147931401)

[10. Related Policies 11](#_Toc147931402)

[11. Legislation and Guidance 11](#_Toc147931403)

[12. Additional Legislation for Scotland, Northern Ireland and Wales 11](#_Toc147931404)

[13. Summary of Review 12](#_Toc147931405)

# Introduction

Considered to be primarily a genetic health condition, recent research indicates that there are approximately 450,000 adults living with autism in the UK, which is, on average, 1.1% of the population. The proportion of the national population who have been diagnosed with learning disabilities as well as autism is between 7 and 20%.

Autism in adults is frequently hard to diagnose owing to the wide range of anxiety and behavioural issues that co-exist with the condition. A further barrier to diagnosis is that autism is a ‘spectrum’ condition; individuals’ abilities and disabilities can fluctuate enormously as a result of several other factors, for example living conditions, external stimuli (visual, aural, noise), stress tolerance and the calibre of health and social care support systems currently available.

The NHS also states that there can be key differences in how autism presents in men and women, in that autistic women may be harder to identify because they can cope better in social situations and are able to mask their anxiety more successfully.

# Policy Statement

[Company Name] are committed to ensuring that all adults with autism and any associated behaviours in our care, either with or without a formal diagnosis, are able to live fulfilling and rewarding lives. Such associated conditions can include learning disabilities, complex needs and challenging behaviours.

[Company Name] are committed to providing person-centred, individually tailored multi-disciplinary services and support to autistic adults, based on bespoke care plans carefully discussed and agreed with the service user and their partners, carers and/or families.

**[Delete as appropriate]** As part of our person-centred approach, we encourage and facilitate the acquisition of social and domestic skills, access to local community clubs and leisure facilities, promote and support lifelong learning opportunities and even arrange travel and work experience for our clients, if appropriate.

As an integral part of the process of creating this policy, prevailing legislation and national guidance has been considered. Additionally, extensive national research has been carried out on the needs of autistic adults, as well as considering regional data and information. At all times in this policy formulation, we have remained mindful of the government’s latest stated vision:

*All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.*

*Source:* [*Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy:*](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf)

# Scope

[Company Name] have identified the following six specific objectives as the basis for improving the service and support we provide to our autistic adult clients, where applicable:

1. To help autistic adults access good quality health and social care services support
2. To ensure autistic adults to live in good quality housing that meets all of their needs
3. To help autistic adults feel like a part of their community and to be acknowledged, understood, accepted and respected by everyone with whom they come into contact
4. To support and facilitate autistic adults in finding and keeping employment
5. To support partners, family, carers and/or friends looking after adults with autism
6. To reduce and improve autistic adults’ interaction with the English Criminal Justice System (CJS)

This framework and its designated procedures (which are expanded upon later in this document) apply to all frontline health and social care professionals caring for, or who are in contact with, our adult clients with, whether formally or informally diagnosed, autism spectrum disorder and its associated conditions.

Our overarching objective for devising this policy is to ensure that the experience of care for adults with autism is as positive, consistent and effective as possible.

The Registered Manager is responsible for supporting staff in their compliance with this policy and ensuring that the content remains current and in line with the standards for best practice.

# Definition

For the purposes of this policy, these are the criteria we will use to identify and assess service users with autism, directly in line with the NHS’s defined chief characteristics, challenges and complications of this condition:

* finding it hard to understand what others are thinking or feeling
* getting anxious about social situations
* difficulties in making friends, preferring to remain alone
* sticking to exactly the same routine every day, at the same time, and getting upset if any changes to this routine are required
* coming across as rude, dismissive or not interested in other people, without meaning to
* not being able to express personal feelings to other people
* taking language literally (e.g., not understanding figures of speech, such as ‘it’s raining cats and dogs’)
* not understanding sarcasm or irony
* avoiding eye contact
* not understanding social rules (e.g., talking over other people and/or being perceived as ‘rude’ or ‘disrespectful’ in conventional terms)
* not understanding the concept of respecting personal space around other people
* noticing little details, patterns, smells and sounds that other people do not necessarily see
* having a consistent and very keen interest in very specific subjects or activities
* undertaking painstakingly precise planning ahead of any outing or activity.

Where we are caring for adults with undiagnosed autism, we will take the appropriate steps to arrange the necessary assessments leading to the creation of a formal care pathway that is to be shared with the service user and carers, friends and family, as well as with all members of the wider health and social care multi-disciplinary team sharing in their care.

# Procedures

**Helping autistic adult’s access good quality health and social care services support**

We will achieve this by:

* Working in partnership with the service user’s wider multidisciplinary health and social care team, ensuring as much continuity as possible with individual service provider personnel to help create a comfortable friendly relationship based on trust and familiarity.
* Helping to foster each client’s sense of autonomy by encouraging their active participation in discussions around the selection of options for their ongoing care and support
* Checking that further follow-up information about the services and interventions chosen is available in an appropriate, accessible language or format, for example different visual or easy read, verbal and aural media, or in different colours and font formatting
* Always remaining mindful that the service user might benefit from being signposted to a trained advocate

**Ensuring autistic adults live in good quality housing that meets all of their needs**

We will achieve this by:

* Understanding the exact nature of the care levels required for each individual. These can vary from a couple of hours at home daily, to 24/7 arrangements either on a long term, respite or temporary basis. We will also ensure that our client’s preferences and opinions, and those recommended by their partners, families and/or carers, are also taken into account.
* Carefully assessing the level of support and nature of any specific residential requirements or adaptations based on each individual’s situation and diagnosis, always conscious that every adult living with autism is affected in very different ways.
* Helping all our service users with the financial and logistical aspects of setting up and maintaining their care and housing support arrangements, including sourcing advice on claiming allowances.
* Ensuring that the home setting, in whatever form this might take, design and décor consists of low-arousal, neutral colours, no garish patterns, reduced fluorescent lighting and optimum natural sunlight, advising the introduction blackout curtains or use of tinted where appropriate and/or the use of earplugs in the case of potential aural disturbance.

**Helping autistic adults to feel like a part of their community and to be acknowledged, understood, accepted and respected by everyone with whom they come into contact**

We will achieve this by:

* Maintaining an understanding of the nature, development and course of autism and how it impacts on personal, social, educational and occupational functioning
* Remaining aware of the impact on and interaction with other coexisting mental and physical disorders and their management on both psychological and somatic levels
* Ensuring that adults with autism are easily identifiable (e.g., by wearing appropriate identification) so that encounters with other people they do not know are made easier and more comfortable for all concerned

**Assisting autistic adults to find and keep work**

We will achieve this by:

* Comprehensively understanding the potential practical/psychological capabilities and limitations of each client considering such a move, and accurately assessing whether they are confident and robust enough to seek and sustain the demands of employment before helping them to take their first steps. At all times we will ensure we carefully identify exactly the right balance between supporting independent living and fulfilling our duty of care responsibilities
* If deemed appropriate, and after various methods of exploration and investigation into individual circumstances, encouraging clients to undertake part time classes in life skills, time management and other employability training, including online tuition options. Part of this scoping process might include researching local college prospectus and exploring possibly sourcing experienced volunteer or professional mentors to help write CVs and prepare people for interviews.
* Signposting service users to national support groups, such as #WorkWithMe—a growing community of businesses committed to thinking and acting differently about recruiting people with autism and/or a learning disability.

**Supporting partners, family, carers and/or friends in looking after adults with autism**

We will achieve this by:

* Offering regular advice and information to everyone directly concerned and connected with our clients. For example, in the form of hints and tips on how to interact most effectively and comfortably with adults with autism, not only in terms of the language to use but general demeanour, such as remaining positive, patient, interested, respectful, empathetic and non-judgmental.
* Advising of coping strategies to help everyone plan, prepare and remain calm in times of stress, distress or challenging behaviour, such as episodes of flapping, rocking and twirling (which autistic people often demonstrate at times of stress). Additionally, suggesting recommendations for lifestyle changes that might alleviate daily stress, confusion or anxiety
* Providing information around promoting calmness and wellbeing, such as taking regular exercise and making healthier diet choices, taking into account any hyper and or hypo sensory activities and, if necessary, referring service users to an appropriate GP or dietician.
* [Delete as appropriate] Raising wider communities’ skills and knowledge, awareness and understanding in relation to autism. To this end, we seek to partner with local volunteer, charity and other support services to develop and enhance relevant resources. We will also pro-actively support, sponsor and attend local social and fundraising events, as well as national and global specific campaigns including International Autism Awareness Week. Additionally, our social media campaigns are designed to provide as much education and information as possible about autism to the general public.

**Reducing and improving autistic adults’ interaction with the English Criminal Justice System (CJS)**

By way of background, we would advise that, according to the NAS, “*Autistic adults are more likely to be witnesses or victims of crime than be offenders*”.

Confusion often arises because autistic adults, owing to difficulties with social communication, social interaction and social imagination, may be misinterpreted or misunderstood by members of the public and/or police officers arriving at a scene where an event has been reported. This could be further exacerbated by the fact that some autistic adults may have sensory difficulties and co-ordination problems so their actions may appear odd and can sometimes draw unnecessary attention.

Should they ever have cause to interact with any facet of the English CJS we are committed to offering all support required by:

* Ensuring our service users carry an Autism Alert identity card with personal details, details of their condition and contact to advise in case of emergency.
* Making sure each individual understands the importance of identifying themselves as being on the autistic spectrum as early as possible in any conversation with the police or CJS.
* Taking proactive steps to stay updated with the latest parliamentary statutory guidance on issues concerning autistic adults whenever they come into contact with the CJS, for example the provision of trained intermediaries and other special measures.

# Extra Steps

In conjunction with our work towards meeting our chief six policy objectives, we will concurrently align with best practice in the field, take account of new directives and take proactive steps to:

* **[delete as appropriate]** become active members of our local Autistic Adults Partnership Board
* **[delete as appropriate]** acquire/maintain formal National Autistic Society (NAS) Autism Friendly accreditation
* respond quickly and appropriately as and when new good practice recommendations are issued by the NAS, the Autism Alliance and the Social Care Institute for Excellence (SCIE), in addition to adhering to the statutory guidance issued regularly by the government in conjunction and the National Institute for Clinical Excellence (NICE).

# Company-wide Principles of Care Management

In order to meet our six stated policy and extra steps objectives, we will, at all times, ensure that all our staff working with adults with autism:

* work in partnership with adults with autism and, where appropriate, their families, partners and/or carers
* offer support and care in a respectful manner
* take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care
* clearly communicate the role and function of each member of staff to the people they are caring for
* address service users with the name/title they prefer
* explain in layman’s terms any clinical language used, always checking that the adult with autism always understands what is being said in literal terms
* always factor in communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and take steps to provide communication aids or independent interpreters (ideally with someone who does not have a personal relationship with the adult with autism)
* make a proactive effort to stay fully briefed on recognised local and national sources (organisations and websites) of legislation, practical guidance and general information and/or support around adults with autism
* encourage adults with autism to participate in self-help or support groups or access one-to-one support and provide support so that they can attend meetings and engage in the activities
* stay aware of the need to make adjustments and adaptations to the amount of personal space given (currently recommended by the NAS to be at least an arm's length)
* recognise issues around individual sexuality, including transgender issues, and implications around the need for adults with autism to develop personal and sexual relationships.

# COVID-19

Autistic adults are part of a cohort of the community considered to be at a generally higher risk of respiratory illnesses, which makes them particularly vulnerable to developing complications should they contract COVID-19. Additionally, those autistic adults living with very specific health conditions may be clinically defined as ‘extremely vulnerable’.

NHS England have been directly contacting people living with these conditions to provide further advice. The government has issued two new advisory documents in light of the current pandemic situation, aimed at carers of people with learning disabilities and adults with autism (staff are responsible for reading and ensuring their understanding of these documents in relation to the care of adults with autism and this policy):

* guidance for care staff supporting adults with learning disabilities and autistic adults: <https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults/coronavirus-covid-19-guidance-for-care-staff-supporting-adults-with-learning-disabilities-and-autistic-adults>
* guidance on shielding and protecting the clinically extremely vulnerable: <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

# Monitoring

The effectiveness of this policy will be monitored through routine auditing and the investigation of any associated adverse incidents.

# Related Policies

* Person-Centred Care Policy
* Incident Management Policy
* Mental Capacity Act and DoLS Policy
* Restraint Policy

# Legislation and Guidance

**Relevant Legislation**

* The Autism Act, 2009
* The ‘Fulfilling and rewarding lives’ strategy, 2010
* The Care Act, 2014

**Guidance**

* ‘Think Autism’ guidance, 2014
* The ‘Transforming Care’ programme, 2015
* NICE Guidance [CG142] - Autism spectrum disorder in adults: diagnosis and management [Overview | Autism spectrum disorder in adults: diagnosis and management | Guidance | NICE](https://www.nice.org.uk/guidance/cg142)

# Additional Legislation for Scotland, Northern Ireland and Wales

‘Autism and overview of UK policy and services’ covers statutory regulations and guidance that apply outside of the UK: [Autism – overview of policy and services - House of Commons Library (parliament.uk)](https://commonslibrary.parliament.uk/research-briefings/cbp-7172/)

# Summary of Review

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| --- | --- |
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