

Royal College of Nursing – Written Evidence (AAC0333)

This response will focus on healthcare needs of autistic people. This content is largely taken from our November 2024 position statement on 'the health inequalities autistic people face in accessing health and social care services and the potential role of the nursing workforce in addressing these', which was developed in response to a 2023 Congress resolution.

RCN SUBMISSION 1. Introduction

- 1.1. With a membership of over half a million registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.
- 1.2. The RCN's primary concern in relation to access to healthcare is that inappropriate placement of autistic people can cause harm and deprive people of their human rights. There needs to be appropriate and sufficient support for autistic people, and understanding of autistic needs across health and social care. This issue was debated and a resolution passed at our 2023 RCN Congress. This year, identification and support for neurodivergent individual was debated and passed.

2. Question 11 – pathways for identification and support

- 2.1. The RCN is concerned about the unmet need, and waiting times, for individuals of all ages seeking assessment and support. This was raised at our RCN Congress in May 2025, and will become an active focus for us.
- 2.2. The implementation of timely assessment, including potential screening for those presenting with commonly co-occurring conditions, should be addressed in relevant guidance and commissioning processes, and included as a specific, funded commitment and plan within the forthcoming Ten Year Plan for the NHS in England, as part of the shift from sickness to prevention.
- 2.3. Clear accountability for government, commissioning bodies and providers for the provision of assessment and care for autism should be set out in legislation, due to the stark inequalities and exclusion of autistic individuals from this basic provision.

2.4. Health Visitors and School Nurses (specialist registered nurse roles) are well placed to identify when families, including undiagnosed adults, may be experiencing mental health challenges common with autism. Since 2009, the number of Qualified School Nurses has decreased by 24% and the number of Health Visitors has decreased by 30%.¹

2.5. A greater emphasis on knowledge of autism would help prevent diagnostic overshadowing within mental health pathways.

3. Question 12 – how can the government improve assessment, diagnosis and postdiagnostic support for autistic people

3.1. The NHS England Long Term Plan (2019) provided further commitment and incentive to reduce the health inequalities autistic people experience through initiatives to improve the quality of autism assessment pathways, access to physical healthcare, and improvements in mental health treatment and support. These are underpinned by a focus on [https://www.england.nhs.uk/long-read/autistic-peoples-healthcareinformation-strategy-for-england/](https://www.england.nhs.uk/long-read/autistic-peoples-healthcare-information-strategy-for-england/) enhancing autism data, research and evidencebase, enabling local decision-making essential for appropriately funded, high-quality service development and workforce planning.² There is an established autism core competencies framing in place for informing autism support at all levels.³

¹ [NHS Workforce Statistics - November 2024 \(Including selected provisional statistics for December 2024\) - NHS England Digital](#)

²² [NHS England » Autistic people's healthcare information strategy for England](#)

³³ [Supporting autistic people and/or people with a learning disability | Skills for Health](#)

3.2. There is a lack of clarity and accountability with regard to the assessment of support needs, and provision for this, upon diagnosis. While these steps are set out in NICE Guidance, the implementation, funding and reporting mechanisms for these are not in place.

3.3. For too many people, a diagnosis does not result in the identification of support needs, or assessment for common co-occurring conditions. Many autistic people struggle to live independently, and may be heavily reliant on relatives and partners, which can also leave them vulnerable to abuse. The lack of post-diagnostic support is possibly related to the fact the nature and intensity of the support needed varies from individual to individual, requiring a high level of integration and oversight between services. While this might not seem necessary for autistic individuals

without apparent learning disability, there is potential for a wide range of unmet needs to result in poor health and wider life outcomes.

4. Question 13 – access to healthcare

- 4.1. Based on current evidence, comorbidity of physical health conditions occurs more commonly in autistic people. A cross-sectional study found that the health needs of autistic people are often poorly met. This study outlined that one in three autistic adults reported they were unable to access primary healthcare due to factors including a lack of understanding of autism, communication differences, and sensory issues.¹ This is despite a legal requirement for services to provide reasonable adjustments to support accessibility. While there is a Learning Disability register for annual health checks, there is no equivalent for autism, and this should therefore be introduced.²
- 4.2. RCN Members have reported that mandatory training and core professional training often contains minimal autism-related content, and autism-related content is not specified in the NMC Future Nurse Standards. Members of the nursing workforce may personally choose to progress their professional development to obtain competencies in autism to meet the needs of autistic people in their care. However, this continuing professional development is not standardised across the UK.
- 4.3. The nursing workforce must have appropriate autism training and understanding relevant to their role. This includes the availability of further autism specialist training where needed, including post-registration training and Continuing Professional Development. Nurses should utilise the professional frameworks for autism competencies for their country to align with their role and identify which competencies are needed and at what level, with a minimum expectation of Tier 2/autism informed.
- 4.4. Since 2017, NHS England Assuring Transformation data has shown a steady increase in the number of autistic people admitted to mental health inpatient care. In 2023, the number of autistic people admitted to mental health inpatient settings in England exceeded admissions for people with a learning disability for the first time.³⁴
- 4.5. Studies have shown that more than six in ten autistic people have considered suicide, and more than three in ten autistic people have

¹ [Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study](#) | BMJ Open

² [Our 2030 Goals: Health Checks](#) | Autistica

³ [Learning Disability Services Statistics - NHS England Digital](#)

⁴ [Suicide - Autism research](#) | Autistica | Autistica

attempted suicide.⁷ For autistic young people, struggles with fitting into school, social media, and identity are among the reasons given for the increased use of mental health services, both community and inpatient services.⁵ Research findings clearly demonstrate that young autistic people might be particularly disadvantaged as a result of the mental health challenges that confront them – through difficulties evaluating their own mental health and the many obstacles they face when trying to access mental health support (especially the lack of autism-specific and person-centred support from key professionals).

- 4.6. Despite the increase in diagnosed autism prevalence and subsequent research output, there is a disconnect between what is researched and the evidence base needed to guide clinical practice. More clinical research is needed to test the efficacy and costeffectiveness of interventions and service models for improving outcomes for autistic people accessing health and social care services, including how existing treatments and interventions can be adapted to meet the needs of autistic individuals.

5. Question 14 – problems with access to community support

- 5.1. The RCN remains concerned that the Mental Health Act is being used to detain individuals with autism and/or learning disabilities due to a lack of appropriate alternative services, primarily within community settings. Mental health inpatient settings are not appropriate to meet the needs of these groups, and the environment is likely to contribute significantly to mental distress. This has been exacerbated by successive cuts to local government budgets and a lack of long-term planning for social care services.
- 5.2. There will continue to be a very small number of people with autism and/or learning disability who will require an inpatient admission. For people who need to access care in alternative settings, there must be a robust social care solution to provide the appropriate care. The RCN is concerned that without an appropriate legal framework contained in the Mental Health Act, or within other applicable legislation, this presents a safeguarding risk to protect the rights of individuals and to enable hospitals or other care providers to act legally. The planned reforms could create a gap in provision which risks how people with learning disabilities are cared for.

6. Question 15 - problems with the quality of healthcare and support

⁵ 'Something needs to change': Mental health experiences of young autistic adults in England - Laura Crane, Fern Adams, Georgia Harper, Jack Welch, Elizabeth Pellicano, 2019

6.1. There is insufficient research into what models of support and care can best support quality of life, and optimal health outcomes, for autistic individuals. More research relating to effective health and social care support for autistic people is needed, and nurses have a key role to play in informing and undertaking this research.

6.2. Utilising the nursing workforce to lead, undertake and deliver research across the NHS will promote continually improving healthcare. Research and use of the evidence it generates enables us to address some of the most important and exciting challenges, including advancing our future workforce. More specifically, utilising the nursing workforce to deliver clinical intervention trials supporting autistic people across the NHS would have the benefit of improving clinical practice. It would also contribute to developing new knowledge on meeting the needs of autistic people across our services.

6.3. Workforce modelling is required for each region and country to describe the autism skills needed in the nursing workforce, and wider health and care services. Health and Social Care commissioning bodies and health and social care providers across all sectors should carry out robust workforce planning in line with the RCN's Nursing Workforce Standards, describing the strategy for a nursing workforce who have appropriate and sufficient knowledge and skills to meet the needs of autistic people.

6.4. The RCN remains concerned by the steady stream of press reports published in recent years of autistic children, young people and adults receiving sub-standard care across health and care services in England.⁶ A BBC investigation of 51 Prevention of Death Notices (a third of which were in relation to children) found that coroners have raised the following as issues to be addressed to prevent premature mortality:

- A lack of trained staff with an understanding of autism
- Failure to treat autism and mental health problems as two separate conditions
- Shortage of specialised accommodation
- Lack of a health professional to co-ordinate a young person's care - as recommended in NICE guidelines
- Late diagnosis of autism

2nd June 2025

⁶ [Young autistic people still dying despite coroner warnings over care - BBC News](#)

