

Written evidence submitted by The National Autistic Society

Progress improving mental health services

The National Autistic Society is the UK's leading autism charity. Since we began 60 years ago, we have been pioneering new ways to support people and understand autism. Based on our experience, and with support from our members, donors and volunteers, we provide life-changing information and advice to millions of autistic people, their families and friends. We also support professionals, politicians and the public to better understand autism.

Autism is a lifelong disability that affects how a person communicates with and relates to other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that while there are certain difficulties that everyone on the autism spectrum shares, the condition affects them in different ways. Some autistic people are able to live relatively independent lives, while others will need a lifetime of specialist support. It affects more than one in 100 people in the UK.

The National Autistic Society campaigns for better services for autistic people across the country. We want to try and improve the availability and quality of mental health services for autistic people to prevent them from reaching crisis and/ or from being admitted as inpatients to mental health hospitals.

We highlighted many of the issues that autistic people and their families face through our Transforming Care campaign. We run the Autism inpatient mental health casework service (England) which offers advice and support to autistic people and the families of autistic people in England who have been detained in a mental health hospital or are at imminent risk of detention or re-detention.

This submission will address Department of Health and Social Care, NHS England and Health Education England ambitions to improve mental health services with a focus on the impact on autistic people. There are a number of milestones and aims that have not been met or risk not being met as well as multiple areas of mental health services that require improvement in order to achieve value for money.

Evidence on how far the Department of Health and Social Care, NHS England and Health Education England have met ambitions to increase access, capacity, workforce and funding for mental health services, and improve service standards

Despite a number of ambitions and strategies from the Department of Health and Social Care and NHS England to improve mental health services, a system that is unfit for providing good quality mental health care remains the reality for autistic people. These issues are longstanding and despite the fact that there have been multiple opportunities to effect change over many years, in many respects the situation remains unimproved. Ambitions from the NHS Long Term Plan¹, the Five Year Forward View for Mental Health² and Stepping forward to 2020/21, the mental health workforce plan for England³ include:

- tackling health inequalities,
- reducing inpatient provisions and avoidable admissions (including reducing inpatient provision for autistic people and people with a learning disability to less than half of 2015 levels by March 2023/24)
- improving access to and quality of community services
- supporting people to live healthily in their own communities
- eliminating out of area placements
- achieving a 24/7 community-based mental health crisis response
- Retaining the workforce needed to increase access to quality

¹ [NHS Long Term Plan v1.2 August 2019](#)

² [NHS England » The Five Year Forward View for Mental Health](#)

³ [Stepping forward to 2020/21 - The mental health workforce plan for england.pdf \(hee.nhs.uk\)](#)

Despite these aims, autistic people remain subject to health inequalities, unnecessary admission to inpatient units including out of area placements and have a lack of access to appropriate community support and crisis services. Workforce capacity issues like staff shortages and staff burnout continue to have significantly negative impacts on the care and treatment of autistic people.

Numbers of autistic people in mental health inpatient units

The NHS long term plan states that by March 2023/24, for every one million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit.⁴ Despite this, the latest monthly Assuring Transformation NHS Digital data⁵ shows that in February 2023 there were 2,045 autistic people and people with learning disabilities in inpatient mental health hospitals in England. 1,290 of these people are autistic. There are 200 under 18s in inpatient units that are autistic or have a learning disability, of these, 95% are autistic. As this rise is being primarily driven by admission of autistic patients, it is clear that more specific data collection is needed for autistic patients as well as reduction targets that are differentiated from learning disability figures.

The lack of appropriate community mental health care for autistic people means that some reach crisis-point and are admitted to mental health hospitals. This not only establishes a lack of success in achieving value for money, good quality community mental health services but also results in ongoing costs that are disproportionately high in comparison to the negligible or non-existent benefits. Mental health hospitals are not the right place for the vast majority of autistic people and often compound distress. Autistic people often spend many months, even years, in hospitals many miles from their families. Mental health treatment for autistic people in inpatient settings is often unhelpful and untherapeutic and the recent Safe and Wellbeing Reviews: Thematic Review⁶ found both inappropriate use of medication and that in particular autistic people experienced inconsistent and high levels of restraint, seclusion and segregation. This is a deprivation of liberty which poses serious human rights concerns and it continues to be extremely costly to provide long term inpatient care.

There has been some progress in moving people with a learning disability out of inpatient units but while in 2019 autistic people made up 54% of the number of autistic people and or people with a learning disability in hospital, now autistic people account for 63%.⁷ This suggests a clear need to differentiate between autistic people and people with a learning disability when considering the quality of access, capacity, workforce and funding for mental health services as well as outstanding needs. Data collection across the board should make sure to differentiate between autistic people without a learning disability and people with a learning disability.

According to NHS Assuring Transformation statistics there has been a notable rise in the numbers of autistic women and girls in mental health hospitals. In 2015 women made up 24% of autistic people and people with a learning disability in mental health hospitals, this has since risen to 31%¹⁰. This suggests that efforts to improve community mental health services have not been successful for this cohort and does not take into consideration specific risk factors and gaps in care for autistic girls and women. Ultimately, leaving them more prone to reaching crisis at which point mental health care becomes increasingly expensive.

The National Autistic Society's survey into the mental health experiences of autistic people⁸ reveals that often autistic people struggle to access support. 82% of autistic adults felt that it took too long to receive support. As well as this, risk factors for mental ill health in autistic people including late diagnosis and school exclusions, are not given due consideration by the current system. Part of achieving good quality mental health care for autistic people includes meeting objectives in the NHS Long Term Plan and beyond on autism and learning disability in order to mitigate inequalities that lead to mental health crises.

⁴ [NHS Long Term Plan v1.2 August 2019](#) p. 53

⁵ [Learning Disability Services Statistics - NHS Digital](#)

⁶ [NHS England » Safe and wellbeing reviews: thematic review and lessons learned](#)

⁷ [Learning disability services monthly statistics from Assuring Transformation dataset: Data tables - NHS Digital](#)

⁸ [NAS-Good-Practice-Guide-A4.pdf \(thirdlight.com\)](#)

Showing consideration to mental health risk factors, is particularly vital for those who are multiply marginalised including black autistic people, transgender autistic people and financially impoverished autistic people. Understanding intersections between race, gender, socioeconomic background, sexuality and additional disabilities is necessary to address the risks of mental ill health and additional barriers to care and support. For example, autistic people from minority ethnic communities or those with English as a second language may experience additional barriers to adequate mental health care because of an unfamiliarity with systems, lack of access to information, not speaking English, a lack of diversity in the workforce, cultural misunderstandings from professionals and a lack of policy to improve access and outcomes of mental health provision for autistic people from marginalised groups.

Further attention is needed on the experiences of autistic people from marginalised communities. As well as this the commissioning of mental health support services should be representative of the views and needs of autistic people from marginalised groups and increasing the number of professionals with an in depth understanding of good practice for marginalised communities should be considered a key tenet for good quality mental health services.

Better value for money could be achieved by making appropriate investments into community mental health care that mitigates the risk factors that lead to inpatient admission for all autistic people. Particularly those who are at a higher risk of developing a mental health condition due to additional protected characteristics.

Community care

According to the NHS long term plan by “2023/24, new models of care, underpinned by improved information sharing, will give 370,000 adults and older adults greater choice and control over their care, and support them to live well in their communities.”⁹ There is little doubt that the provision of good quality community care is key to good quality mental health services and is also financially more viable than inpatient care. However, at present there are a lack of community mental health services with adequate resources to provide specialist mental health treatment for autistic people.

Our APPGA report ‘The Autism Act:10 Years on’¹⁰ found that 71% of autistic people had mental health and/or social care needs that were unmet. As well as this, barriers go beyond access alone. The results of our 2020 mental health survey reveals that autistic people often feel that their behaviour is misinterpreted in mental health settings. Conversations with healthcare professionals highlighted that often professionals lack experience with supporting autistic people’s mental health and can lack confidence with autistic clients. This is a significant weakness given the high rates of mental ill health among autistic people.

Our mental health survey¹¹ also revealed that 94% of autistic adults experienced anxiety; almost six in ten said this affected their ability to get on with life. 2 in 5 had a current diagnosis of an anxiety disorder and almost half fell into the severe category based on the GAD-7. 83% experienced depression, half said this affected their ability to get on with life and almost 3 in 10 fell into the severe category based on the PHQ-9. These figures emphasise the need to consider the specific needs of autistic people when looking to achieve good quality and better value for money mental health services. The inappropriate and unadjusted nature of community mental health services for autistic people is a barrier to achieving this and can lead to the escalation of needs meaning that subsequent treatment is more expensive.

As well as this, for autistic people who are admitted to mental health hospitals, there are significant barriers to discharge. The NHS safe and wellbeing thematic review¹² reveals that 41% of the autistic people and people with a learning disability who were reviewed, did not need to be in hospital and could have their needs met in the community. Barriers to achieving discharge include delays, a lack of community services for patients to be discharged to, staff shortages and legal issues. Many did not have a clear discharge plan in place and often individuals and their families were not involved with discharge planning.

⁹ [NHS Long Term Plan v1.2 August 2019](#)

¹⁰ [nas_appga_report.pdf \(thirdlight.com\)](#)

¹¹ [NAS-Good-Practice-Guide-A4.pdf \(thirdlight.com\)](#)

¹² [NHS England » Safe and wellbeing reviews: thematic review and lessons learned](#)

A lack of community accommodation was amongst the most significant barriers to discharge. 19% of those reviewed were ready for discharge but couldn't be due to a lack of available community settings. There were significant regional variations, for example in the Southwest of England 53% of individuals did not need to be in hospital to receive the right care which is 12% higher than the average. Again, this suggests that ambitions around improving workforce capacity and the quality of community mental health provisions have been unsuccessful and investments insufficient for securing meaningful change.

Out of area placements

The Five Year Forward View for Mental Health programme¹³ aimed to eliminate inappropriate out of area placements for non-specialist acute care by 2021. However, the Safe and Wellbeing Thematic Review¹⁴ revealed that of those reviewed 57% of autistic people and people with a learning disability were in out-of-area hospitals away from their homes, families, friends and familiarity. Again, there was regional variation, for the Southwest of England 73% of individuals were in an out of area placement compared to an average of 57%. According to the NHS Digital Assuring Transformation dataset¹⁵ 27% of patients who are autistic or have a learning disability are in units 100kms or more away from their homes.

Commissioning

The CQC 2020 report 'Out of sight who cares'¹⁶ references significant flaws in commissioning. Namely, "it was not always clear whether commissioners had the oversight or knowledge required" to make effective commissioning decisions and "considerable amounts of money were being spent to support people in restricted environments in hospitals," which would often be "better spent on providing individual person-centred care in the community". To add to this, the March 22 progress report¹⁷ found that the majority of recommendations had not been met at all. This includes recommendations to:

- make sure that the right community services are commissioned.
- hold commissioners accountable therefore improving the value of care and treatment reviews
- make sure that people receive the right services in hospital

Safe and Wellbeing thematic review

The Safe and Wellbeing thematic review¹⁸ revealed a number of other concerns at odds with ambitions around capacity, workforce, funding and standards for mental health services. This included the following:

- Many patients were placed in inappropriate settings. Autistic people in particular experienced inconsistent and high levels of restraint, seclusion and segregation.
- Safeguarding referrals were not always made, incidents were not always reported and safeguarding plans were not always put in place.
- A lack of opportunities for social connection, physical activity and building skills for life outside of hospital.
- The availability and quality of professional advocacy was inconsistent and unclear for both professionals and patients.
- Care and treatment reviews were not always carried out in line with guidance or at all

¹³ [NHS England » The Five Year Forward View for Mental Health](#)

¹⁴ [NHS England » Safe and wellbeing reviews: thematic review and lessons learned](#)

¹⁵ [LD_AT_DataTables_Jan2023.xlsx \(live.com\)](#)

¹⁶ [Out of sight – who cares?: Restraint, segregation and seclusion review - Care Quality Commission \(cqc.org.uk\)](#)

¹⁷ [Restraint, segregation and seclusion review: Progress report \(March 2022\) - Care Quality Commission \(cqc.org.uk\)](#)

¹⁸ [NHS England » Safe and wellbeing reviews: thematic review and lessons learned](#)

Workforce issues were particularly prominent and had wide ranging negative impacts. Workforce limitations included both staff shortages and staff burnout. Many services were found to be reliant on agency or temporary staff and staff did not always have the right level of training. This is a particularly significant financial issue as not only do staff inconsistencies have negative implications for patients but “temporary staff, such as doctors and nurses supplied by agencies, cost on average 20% more than those from the NHS’s own ‘staff banks’ despite doing the exact same job”¹⁹.

Funding flows and lack of data

The RedQuadrant²⁰ analysis of funding flows associated with ‘Building the Right Support’²¹ reveals crucial limitations in the collation of data to understand funding flows, the cost effectiveness of community vs inpatient care and whether additional money that has been invested is sufficient and being used or directed to the best effect.

The hope was to be able to “access financial data which could give an insight into the money that had been released through the reduction in inpatient beds, and the money that had been invested in accommodation with care and support for individuals as well as developing community support, including preventative and crisis services. We hoped to be able to compare the costs of community services with inpatient care and the impact of investment in different services and at varying rates at a local, regional and national level.”²² However, and importantly the report acknowledges that the financial data that was shared in reality was far more limited than hoped for, making it impossible to provide an accurate picture.

There are at present perverse disincentives in the system that lead to autistic people and people with a learning disability being detained, often for months or years. However, the full extent of these disincentives and their link to community and wider allied services as well as overall performance and value for money, cannot be determined without access to full and complete data. The report acknowledges that “pooled budgets and joint commissioning arrangements significantly improve performance on achieving discharges for people.”²³ However, there is a lack of clear data on the numbers of ICBs and local authorities that have enacted the use of pooled budgets.

Since publication of the RedQuadrant report²⁴, there is no evidence to suggest that recommendations, including mandating collation of financial data have been progressed. However, without better mechanisms to capture financial data it is impossible to accurately report on the impact of NHS transformation funding, long term plan funding and other relevant investments.

The incompleteness of data extends beyond the financial implications mentioned above. Whilst Assuring Transformation data does provide key insights into the mental health treatment of autistic people and people with a learning disability, there are limitations to this. Analysis by NHS England of the MHSDS suggests that we may still be under-identifying autistic people in the cohort by a significant amount. We are also unable to determine an individual’s pathway through the mental health system and prior care and treatment that they may have received.

To better understand progress on ambitions to increase access, capacity, workforce and funding for mental health services, and improve service standards, collation of and access to data must be improved. Specifically, it is necessary to understand levels of community spend, community spend preadmission for those at risk, community spend post discharge, inpatient spend and crisis intervention service spend. These figures also need to be broken

¹⁹ [NHS England » NHS could free up £480m by limiting use of temporary staffing agencies](#)

²⁰

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1089371/RedQuadrant-DHSC-Building-the-Right-Support--An-analysis-of-funding-flows.pdf

²¹ [Building the right support for people with a learning disability and autistic people - GOV.UK \(www.gov.uk\)](#)

²²

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1089371/RedQuadrant-DHSC-Building-the-Right-Support--An-analysis-of-funding-flows.pdf

²³ [Building the Right Support: an analysis of funding flows - GOV.UK \(www.gov.uk\)](#)

²⁴ [Building the Right Support: an analysis of funding flows - GOV.UK \(www.gov.uk\)](#)

down and looked at separately for autistic people and people with a learning disability rather than combined. The work of and recommendations from the Building the Right Support Funding Flows Task & Finish group will be vital to improving standards of data collection.

There is also a lack of data collection and means by which to assess the suitability of mental health services for those belonging to multiple marginalised groups. We know that those marginalised due to their race²⁵, culture, socioeconomic status²⁶, gender or sexuality²⁷ are far more likely to experience adverse mental health effects. The same is true for autistic people. However, we firstly lack ways of identifying the impact of being from more than one of these marginalised groups and secondly lack quantitative ways of determining how adept mental health services are at providing suitable care for those who are multiply disadvantaged.

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²⁵ [RHO-Rapid-Review-Final-Report_v.7.pdf \(nhsrho.org\)](#)

²⁶ [From pandemic to cost of living crisis: low-income families in challenging times | JRF](#)

²⁷ [Help for mental health problems if you're LGBTQ - NHS \(www.nhs.uk\)](#)