

The National Autism Project's priorities for the Department of Health

The attached briefing outlines the key priorities for the Department of Health identified by the National Autism Project (NAP). It builds on the extensive work undertaken to produce NAP's report, *The Autism Dividend: Reaping the Rewards of Better Investment*. Our report shows that there are significant gaps in evidence about what interventions are most beneficial to autistic people, and cost effective to the country. It also demonstrated many of the challenges facing autistic people and their families and carers, and identified a number of critical recommendations for reform.

NAP's key asks

1. Improve the quality and scope of autism data

A lack of robust data collection around autism prevalence, health issues and staffing has a significant impact on the care and support given to autistic people and their families. NAP is calling for:

- The introduction of an anonymous National Primary Care Register for autism
- Robust local data collection of autistic populations (as required in the Autism Act) to enable councils and NHS commissioners to accurately plan the services needed
- The introduction of autism-specific indicators in NHS and social care accountability frameworks

2. Create an autism identity in NHS England

While many autistic people manage one or more health condition, there is a lack of a distinct identity for autism in the NHS. Too often it is bundled together under mental health or learning disability, leading to a lack of autism-appropriate services or support. NAP is calling for:

- An increase in the number of psychologists with specialist autism knowledge who understand the relationship between autism, anxiety and other mental health issues
- Recognition of the distinction between autism and learning disability, whilst acknowledging the potential overlap between the two conditions to ensure appropriate support and services are available

3. Better access to social care for autistic children and adults

There is growing evidence that autistic children and adults are being systematically excluded from the vital social care services they need. There are clear breaches of the Autism Act, the Care Act and poor implementation of the Transforming Care programme for autistic people. NAP is calling for:

- A review of children and adult social care eligibility and how it impacts autistic adults and children in practice
- Transition assessments for all autistic children moving to adult services
- A review of how the Transforming Care programme is affecting the numbers of autistic people in institutional care, especially those without a learning disability

4. Investment in autism research

NAP undertook an extensive literature review for its report, *The Autism Dividend*, and identified significant research gaps. This limits understanding of – and improvements to – all aspects of life for autistic people, including diagnosis, interventions, stigma and family support. NAP wants to see:

- Greater investment in autism research, specifically but not exclusively, focused on autistic adults and on practical support
- Future research to be designed with the full involvement of autistic people

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- Long-term follow-ups should be included where possible and the economic impacts of interventions should be included in study design

5. More effective training for professionals dealing with autistic people

More needs to be done to support and upskill professionals working and supporting autistic people. While helpful, generalist autism awareness courses do not provide the level of practical understanding required for meaningful impact. NAP wants to see:

- Autism training to be focused on the practical, realistic elements of living with autism, rather than the theoretical approach often taken
- Autistic people should be involved in the design, content and delivery of training

This list is ambitious and bold. However, the National Autism Project's work has found that a great deal more could and should be done to support autistic people as well as generate evidence to shape policy and improve practice. The failure to do so results in a UK economic impact of £32 billion per annum, yet the needs of autistic people remain unmet.



Briefing for Department of Health on the National Autism Project's priority areas for reform

Introduction

The National Autism Project (NAP) was established to map and analyse the evidence base for autism interventions and identify research gaps. It is a three-year initiative supported by the Shirley Foundation, and brings together a wide range of experts in the autism community. The project has also benefitted throughout from the advice of an Autistic Advisory Panel.

An extensive literature review to consider the effectiveness and cost-effectiveness of current autism interventions was undertaken by Professor Martin Knapp and his team at the London School of Economics. Alongside this, a series of workshops and meetings were held by the NAP team to inform the wider picture. The resulting report, [*The Autism Dividend: Reaping the rewards of better investment*](#), was launched in January 2017. It highlights the most urgent challenges facing autistic people today, as well as recommendations for reform and research priorities.

Over the course of the project, NAP has met with key stakeholders to discuss how the report's recommendations could be implemented. The content of these discussions and the report's recommendations have culminated in the identification of the five key areas, in the purview of the Department of Health, where improvements most urgently need to be made.

1. Data

The lack of autism data collected was consistently identified throughout our research as a key barrier to progress. The 2017/18 mandate for NHS England reiterates the expectation "to strive to reduce the health gap between people with mental health problems, learning disabilities and autism and the population as a whole". The NHS Digital Corporate Business Plan for 2016/2017 maps its activities to the DH Shared Delivery Plan and intends to collect "data and metrics on access to services, CCG level metrics" and "link to transformation plans that will be developed e.g. children and young people, whole system approach to mental health (with Ministry of Justice and the Home Office)". Despite these commitments, the Mental Health Services Data Set does not fully record autism, and the NHS Digital portal does not have health or social care indicators that mention autism. The absence of routine collection, monitoring and publication of data on autism, results in a number of serious consequences:

Autism diagnosis in GP records is frequently not included in referrals, leading to the absence of reasonable adjustments by the medical profession and a failure to track autism-specific data through the health and social care systems

- Introducing a single diagnostic code for autism in GP records would aid the collection of data for statistical purposes, and would enable/aid the task of separating out information on the autistic population from those people with mental health issues (MH) or learning disability (LD) in currently collected health data. This would however also include data on autistic people and any co-occurring conditions they might have such as MH issues or LD.

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We support the recommendation of an anonymous National Primary Care Register for autism.

Inadequate information on prevalence, health issues (e.g. trends in mortality and morbidity) and social care needs hampers the task of planning the commissioning of services

- Commissioners cannot know what type and intensity of autism-specific services are needed without data on autism in their local population across the lifespan, including autistic mortality, or what the overlap is with LD and MH issues.
- According to the Autism Act, local authorities and NHS bodies with commissioning responsibility should jointly be including the number of people with autism in their area as part of the Joint Strategic Needs Assessment process. Under the Self-Assessment framework only 66% report that they do this. Even so, there are concerns about the quality and consistency of this data and its use in planning services, specifically whether the large numbers of autistic adults not receiving social care services are being taken into account. It is unclear what data LAs or NHS bodies would have access to which could possibly allow them to monitor the actual total number of autistic people in their area (expected to be approximately 1% of their local population).
- Despite NICE recommendations, very few LAs have autism-specific social care teams. Public bodies still tend not to “see” the autistic population because they are subsumed into LD, MH or are not in either service (a group which is generally assumed to need no support).

There is inadequate (or non-existent) recording of autism data in accountability frameworks

- Autism-specific indicators should be created in the NHS Digital portal, the NHS Outcomes Framework and the ASC Outcomes Framework. All bodies should be required to have autism-specific protocols (e.g. in the Risk Management Assessment Framework or the quality standards/outcome metrics in the NHS standard contract for CCGs).

There is inadequate information to make decisions on research priorities, particularly on what services are useful, effective and cost effective (see section below on Research)

Discussion point:

In view of the huge social and economic impact of autism, and the inadequacy of current provision, how can the collection and use of autism-specific data be further supported within health and social care services?

2. An autism identity in NHS England

Inadequate data collection on autism has contributed to the failure to establish a distinct identity for autism in the NHS, a problem not shared with other conditions with comparable social and economic impact such as dementia, cancer and heart disease. The failure to accord a separate identity to autism results in it being inappropriately assigned to and therefore falling between two stools, mental health and learning disability. This was very clear in the lack of research on autism-specific interventions available for analysis as part of the Autism Dividend’s literature review.

Autism is associated with a disproportionate co-occurrence of mental health issues, in particular, anxiety, depression and suicidality, as well as other conditions such as epilepsy. As many as 80% of autistic people may be affected at some point in their lives.

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- Mental health issues experienced by autistic people are frequently due to the difficulties they encounter in understanding and adjusting to the neurotypical world.
- Mental health services seeking to treat the mental health issues experienced by autistic people commonly attribute this to being part of the autism ('diagnostic overshadowing'). On the other hand, mental health services which do try to treat mental health issues in autistic people often end up trying to 'fix' aspects of the person's autism instead of recognising that they are innate, and that the autistic person needs reasonable adjustments helping them towards "personal recovery".
- As an example, Improving Access to Psychological Therapies (IAPT) offers CBT as a therapy with reasonably good evidence for its effectiveness in some autistic people. But the level of knowledge of autism in IAPT practitioners is not sufficient for them to understand that the permanent stress of being autistic is what leads to anxiety and disability. They end up treating the latter two but fail to address the cause. Appropriate training of at least some practitioners to whom autistic people can be directed would certainly improve matters. But until autism has a separate identity this is not going to happen - The Five Year Forward View for Mental Health mentions autism in its introduction as a risk factor for mental health issues but is thereafter not considered and, as previously noted, the NHS Outcomes Framework has not a single autism-related indicator.

Conflation of autism and learning disability ignores the majority of autistic people who do not have a learning disability.

- About 1/3 of autistic people have a learning disability, although the range of estimates is very high. It is also estimated that about 1/3 of learning disabled people are autistic.
- Practitioners with experience of LD are more likely to accept that autism is a lifelong condition and that the aim is to improve quality of life and life chances, but failure to provide an autism identity inevitably leads to lack of appreciation of the specific autism needs.
- As an example, the Transforming Care programme (see also below) is about people with "learning disabilities and/or autism who have a mental illness or whose behaviour challenges services". The focus has been to decrease the numbers in acute treatment units but the proportion who are autistic and do not have an LD is rising (currently 16-17%). There are of course further questions about the reasons which caused them to display "challenging behaviour" in the first place. This trend is not compatible with the DH mandate to reduce health inequalities of autistic people.

Discussion point:

What is the DH doing to address the issue of an autism identity in NHS services?

3. Social Care

The challenges facing autistic people needing to access social care services impacts on many of the issues identified in *The Autism Dividend*. Here, we consider three aspects of social care: access, transitions and the Transforming Care programme.

Access to social care

The majority of autistic adults do not have access to social care

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- The requirement in the Autism Act that all adults receiving a diagnosis of ASD be informed of their rights to a social care assessment was intended to improve access to social care for autistic adults. However, the most recent figures from Local Authorities' Self-Assessment returns indicate that the number of autistic adults assessed as being eligible for social care is worryingly low compared with any reasonable estimate of prevalence and need.

Autistic children without LD are often excluded even from assessment for social care

- For accessing support from children's social care, autistic children are generally considered under the policy envelope of children with disabilities. Those being assessed for an Educational Health and Care (EHC) plan because they have Special Educational Needs should be receiving a social care assessment. However in practice access to children's social care in most local authority areas is restricted by diagnostic category and excludes children without LD even from assessment despite being open to legal challenge. This is a function of the extremely dated legal framework which actually governs what local authorities have to provide. The education and health aspects of an EHC do have statutory force.

Transition from children's to adult services

Despite the requirements of the Care Act (2014), transition assessments for access to adult social care are not being offered to all young people who may need care and support as adults.

- In practice such assessments tend to be limited to those attending special schools and/or receiving children's social care, meaning that many autistic young people are not actually offered an assessment for adult social care. Transition from children's to adult services is often a crucial stage for those with the most complex needs and behaviours which may challenge, where a badly-handled transition can set a young person on the pathway to inappropriate institutional care. The recent Lenahan review identified an urgent need to review the needs of young adults aged 18-25 currently in inpatient provision, which includes those with autism.

Transforming Care

The Transforming Care programme is struggling to make sustained progress in bringing down numbers in inappropriate institutional placements.

- The National Implementation Plan refers throughout to "people with a learning disability and/or autism", but never addresses the separate and specific needs of autistic people. In addition a recent NAO report identified several barriers to progress of the programme including lack of financial resources for community provision. Worryingly the entire focus of the report was on people with an LD.
- Approaches used in institutional care to address behaviours of concern may not take into account the environmental stress experienced by autistic people and place too much reliance on interventions such as Positive Behavioural Support for where there is limited evidence of effectiveness and about which some autistic people and their families have expressed strong concerns regarding ethics.

Care Quality Commission



Although the CQC is developing inspection indicators specific to autism there is evidence of wide-ranging concern on the part of those inspected that the CQC inspectors are under-trained and under-prepared to assess the care provided to autistic people.

Discussion points

- **How can the DH address the barriers to access that currently prevent autistic adults and children from receiving assessment and provision of social care to which they are entitled at key life stages including the transition from child to adult?**
- **How can the DH ensure that the specific needs of autistic people affected by the Transforming Care initiative are properly assessed and addressed?**
- **What influence can the DH have on the CQC inspection approach to care provided to autistic people?**

4. Research

The recommendations in our report, *The Autism Dividend*, were based in large part on an extensive literature search of priority areas and topics. These were selected with the advice of a team of external academic and other experts recruited to the project, including an Autistic Advisory Panel composed of autistic adults. From that work we can identify a number of clear research gaps. Those that are most relevant to policy areas for which the DH is responsible are:

- Ways to improve autism identification and diagnosis rates and processes, perhaps using telephone or other remote approaches at a time when health and care budgets are stretched. This should include exploring ways to encourage the use of *standardised* screening tools.
- Interventions that can help autistic people (particularly adolescents and young adults) to develop friendships and generally build social skills. Research should include investigation of the effects on parents or other carers.
- Cognitive behavioural therapy (CBT)-based interventions can help alleviate anxiety symptoms, but this approach is not appropriate or effective for everyone. Research is needed to get a better understanding of who is most likely to benefit. Research should also examine the benefits of CBT-based approaches when delivered by therapists with the right training to support autistic people (see our earlier comments about IAPT). Telehealth-based CBT also warrants closer examination.
- Few autistic people are in paid employment, and although employment support is primarily the responsibility of DWP, the health benefits of employment need to be recognised. Research should investigate the benefits of employment support, both in formal ways (such as through the Individual Placement and Support model, which can be delivered in NHS contexts) or by ensuring that employment is a recognised goal for many autistic people in contact with more general health and care services.
- How to improve access to healthcare for autistic people, especially high-functioning individuals who might be socially isolated and unemployed (given the higher risks of mental health issues).
- Interventions that improve awareness among key professionals of the risk of suicide among autistic people. Interventions to prevent suicide.
- Interventions that support the personalisation of care and support for autistic people, tailored to individual circumstances and strengths, responding to individual preferences, and creating better opportunities for people to take more control of their lives.



- Robust studies of assistive and related technologies: most evidence in this area comes from poorly designed small studies. Research is also needed on how best to provide infrastructural support for autistic children and adults in the use of new technologies.
- Interventions to tackle stigma and discrimination.
- Interventions to support parents and other carers, particularly where being a carer can have negative impacts on health, employment and wellbeing.

It should go without saying that any such research should be ethical, conducted to high scientific standards, and should be designed with the full involvement of autistic people. Long-term follow-ups should be included where possible. Economic impacts of interventions should be included in study design.

5. Training

Inadequate training of professionals coming into contact with autistic people is a major contributor to unsatisfactory practice. It contributes to late or incorrect diagnosis, inappropriate placing and education of autistic children in schools, difficulties in gaining access to social care, inappropriate social care, barriers to healthcare provision, and exclusion from employment.

Autism awareness courses are useful and necessary for those professionals dealing in general with the autistic community but are inadequate for those directly involved in meeting the needs of autistic people. More in depth knowledge of autism and training is needed for a proportion of professionals in every sector and at every level

- The recent House of Lords Select Committee report on the Long-Term Sustainability of the NHS was critical of workforce planning, education and training and called on Health Education England to take the lead on changing the culture of conservatism in health and social care training. The report also regretted that HEE has had its budget cut in real terms.
- What little training is available beyond “awareness” level for professionals focuses heavily on diagnostic criteria and theories of autism. The current Skills for Care Autism skills and knowledge list and the DH CPD curriculum guide for social workers working with autistic people guide and support that focus. However, whilst this is appropriate for professionals responsible for diagnostic screening, referral and diagnosis itself, much more practically-orientated content focussing on the day to day issues autistic people experience in actually living their daily lives is needed for those providing post-diagnostic services and support e.g. residential care staff, social care assessors, IAPT and psychology professionals.

Autistic people should be involved in the design, content and delivery of training

- DH should consult widely on the content of autism training in order to reflect faithfully the spectrum of needs of autistic people. The views of autistic people themselves are critically important to improving care and interventions

Discussion point:

What are the DH’s plans for improving training of professionals in key areas such as diagnosis, healthcare provision, and assessment for social care?



Department of Health and Social Care written response to the National Autism Project's findings

Background

On 20 July 2018, officials from the Department of Health and Social Care (DHSC) met with a delegation from the National Autism Project (NAP). NAP presented five key asks for the DHSC. These were discussed verbally at the meeting. DHSC committed to a written response to the NAP's key asks. This is detailed below.

The DHSC welcomes the report produced by the National Autism Project. The report provides an excellent depth of analysis, and the strength of support from the Shirley Foundation is acknowledged. The strong focus on evidence and cost-effectiveness is commended.

NAP's key ask 1: Improve the quality and scope of autism data

DHSC response

Robust, comparable data that is regularly collected and monitored helps to clarify the prevalence of autism, the requirements of services and enables partners across the health and care sector and beyond to focus their attention on priority areas for improvement.

The DHSC is working with partners to improve the tracking of referral to assessment time for autism diagnosis. Following a consultation in 2017, NHS Digital will be collecting and recording waiting time from referral for suspected autism to a first appointment. This data will be captured in the Mental Health Services Data Set from April 2018, with data available from 2019.

In August 2017, the NICE Indicator Advisory Committee recommended the inclusion of Autism in the menu of GP indicators. This would enable monitoring of the uptake of services and screening within general practice in the future and give a more accurate picture of service use for autistic adults. NICE and NHS England are currently exploring the possibility of including Autism in the GP Indicators data set.

DHSC has put in place a revised accountability and governance model for implementing the Autism Strategy in line with the Autism Act (2009). This revised model has clarified the key objectives and required actions and introduced revised governance processes that are expected to achieve greater traction and support delivery of the required outcomes.

Under this revised governance model, a number of task and finish groups (TFG) have been established. This includes the *Measuring, understanding and reporting the needs of people with autism* TFG. Led by the DHSC, this group's remit includes improving:

- GPs awareness of patient's condition (establishment of Autism Register in GP practices)
- Awareness of diagnosis waiting times and post diagnostic outcomes
- the use and interpretation of social care return data to support implementation of the autism strategy
- Research conducted into causes of life expectancy gap, and the best interventions to address these.

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The TFG is currently developing a work plan to fulfil the objectives outlined in the Strategy.

NAP's key ask 2: Create an autism identity in NHS England

DHSC response

DHSC has always been clear about the definition of autism in their publications and guidance. DHSC outlines the difference between autism and learning disability in their publications, and has funded awareness work and the development of training materials to reiterate this difference.

DHSC continues to engage with NHS England on the autism agenda, for example the 2016 board paper on autism diagnosis services, which was discussed by the Autism Programme Board in June 2016.

Under the new governance arrangements, a *Workforce Development* TFG has been established. This group will work to ensure that health and care staff, and staff in organisations with public facing responsibilities, who have a direct impact on and make decisions about the lives of adults with autism, have appropriate specialist knowledge of the condition.

NAP's key ask 3: Better access to social care for autistic children and adults

DHSC response

DHSC has reiterated within Statutory Guidance the need for social care assessments for autistic people who have care needs. DHSC has also recently funded the National Autistic Society to work with other autism charities to develop a good practice guide for local authority staff who undertake social care assessments for autistic people.

In 2016, the DHSC supported NHS England and the Association of Directors of Adults Social Services to undertake a series of visits to a sample of Clinical Commissioning Groups and local authorities to develop a better understanding of autism diagnostic pathways and to identify good practice. The DHSC will continue to identify best practice examples and to share this learning widely to ensure that autistic children and adults have appropriate access to social care.

NAP's key ask 4: investment in autism research

DHSC response

DHSC funds the National Institute for Health Research to carry out mental health research in relation to neurodevelopmental conditions.

Current projects include a £2.5 million, five year research theme on neurodevelopment conditions and a £2 million grant programme on improving outcomes by reducing mental health problems amongst autistic people. The National Institute strongly encourages researchers to apply for the funding available across its research programmes.

Under the new Strategy governance arrangements, the *Measuring, Understanding and Reporting needs of people with autism* TFG will work to ensure that research is conducted into causes of the life expectancy gap for people with autism, and the best interventions to address these.

NAP's key ask 5: More effective training for professionals dealing with autistic people

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DHSC response

Since the launch of the original Autism Strategy in 2010, DHSC has funded over £1 million of training materials produced by health, social care and third sector organisations.

Most lately, DHSC has funded the Royal College of General Practice's 2 year Autism Initiative and is currently engaged with similar work being planned by the Royal College of Psychiatrists.

Under the revised governance model for implementing the Autism Strategy, a Workforce Development Task and Finish Group has been established. The TFG is co-chaired by Health Education England and Skills for Care, to focus on the training of Health and care staff (and staff in organisations with public facing responsibilities), and may consider how best to provide training in autism diagnosis for clinicians in the NHS.