

THE AUTISM AGENDA



For too long autistic people have had to live with limited or no satisfactory care and support. The Autism Act (2009) in England and similar initiatives in N.Ireland, Scotland and Wales have failed to address this issue to a meaningful extent and the economic cost of autism to the UK has not changed in the last decade.

The National Autism Project set out to evaluate the effectiveness and cost-effectiveness of care, support and service design for autistic people and was surprised at the lack of good quality evidence on which to base decisions. We attribute this to the shamefully poor funding of autism research.

Autism is a lifelong condition that affects how people perceive the world and interact with others but poor understanding and appreciation of autism by service providers leads to inappropriate or inadequate decisions on meeting needs.

Autistic people often feel that being autistic is part of their identity but too often, interventions are designed to address deficits as they are perceived by non-autistic people, and fail to take account of autistic people's own perspectives on what a good autistic life is like.



There are an estimated **700,000** autistic people in the UK¹



Autism causes **difficulties with social communication and interactions** as well as a restricted and repetitive range of behaviours, activities and interests²



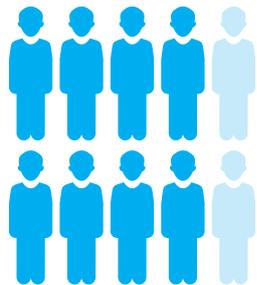
Many autistic people have **sensory-processing difficulties** that can heighten their anxiety and stress³



Approximately one third of autistic people have **learning or intellectual disabilities**⁴



Autistic people have a **high incidence of epilepsy**⁵



80% of autistic people, at some point in their lives, have **mental health problems** such as anxiety and depression⁶

The National Autism Project (NAP) is a three-year project that was established in 2015 to analyse the evidence base for autism interventions and identify research gaps. It is committed to addressing the needs of autistic people through greater investment in research and better practice.

Supported by The Shirley Foundation, the project brought together a wide range of experts including autistic people, resulting in a major research study, *The Autism Dividend: reaping the rewards of better investment*, which is widely regarded as the most comprehensive and far reaching review of the field that has been undertaken to date.

In our final months, we want to ensure that our work acts as a springboard for action on the policy and research recommendations of the report.

WHAT DO WE WANT TO SEE?

Our research highlighted the many barriers that autistic people face and the significant gaps in evidence about the best ways to offer support. To begin to address these challenges, NAP has made the following recommendations:

ENSURE TIMELY IDENTIFICATION AND DIAGNOSIS

Autistic people deserve timely identification and assessment but currently, a large number of autistic adults remain undiagnosed while autistic children and young people may be diagnosed too late to prevent the incidence of educational, social and healthcare problems. Without an initial diagnosis individuals have difficulty accessing suitably specialised care and support. Autism is typically diagnosed around the age of five, a situation which has not changed for a decade. Delay in identification and diagnosis is unjustifiable and must now be addressed.

PROVIDE EVIDENCE-SUPPORTED INTERVENTIONS

Autistic people should have access to evidence-supported interventions. Use of interventions which are not backed with evidence can not only be harmful for the individual but also costly. NAP's research showed that there is too little high-quality evidence on the effectiveness of autism interventions, particularly those used with autistic adults. Government departments should promote evidence-based interventions to support better decision making about care, support and commissioning of services.

MAKE THE ECONOMIC CASE FOR INTERVENTION

Interventions must make economic sense. Inaction or inappropriate intervention could prove to be costlier in the long-term. Autism costs the UK approximately £32 billion per year in treatment, lost earnings, care and support for children and adults – more than heart disease and cancer combined. Government departments must take responsibility for promoting cost-effective practice that delivers good outcomes that better support autistic people and their families.

REMOVE BARRIERS TO SOCIAL CARE ACCESS

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, the Children and Families Act, and poor implementation of the Transforming Care programme for autistic people. A review of the actual provision of social care for autistic children and adults throughout the country is urgently needed.

TACKLE ENVIRONMENT AND OTHER STRESSORS

The nature of autism means that autistic people are more at risk of stress from external demands. 98% of autistic adults have said that stress is a significant issue for them.⁷ Autistic people must be supported to tackle environmental stressors they encounter in their daily lives, and schools, workplaces and community settings should better understand how to make the right reasonable adjustments.

FIGHT STIGMA AND DISCRIMINATION

Very few autistic people or their families feel that the general public understands autism. This is also true of many professionals who work with autistic people, meaning they often fail to provide appropriate care and support. Misconceptions can lead to autistic people feeling isolated and alone, and autistic people too often face abuse and bullying. A national autism anti-stigma campaign is needed to raise awareness and understanding. Autistic children also often face discrimination in school. Children with Special Educational Needs (SEN), including autism, are far more likely to be excluded and constitute over half of all permanent exclusions – a situation that is wholly unjust and must be addressed.

ENSURE BETTER TRANSITIONS

There needs to be better awareness of the stress that transitions from one phase of life to another can cause autistic people. Transitions can be hazardous for many autistic children and unsuccessful transitions can be the trigger for long standing mental health problems. Transitions into employment can be particularly challenging. Many autistic people have very valuable skills that can be applied in the workplace, yet only 16% are in full-time work.⁶

COORDINATE ACTION ACROSS SECTORS

Autism affects every aspect of an individual's life. As a result, autistic people have needs that require support across different systems. Cross-departmental working – both at a national and a local level – is key to ensuring autistic people are fully supported.

BUILD BETTER INFORMATION SYSTEMS

There is an alarming lack of robust data collection around autism prevalence and services. This has a significant impact on the care and support given to autistic people and their families as without data, there are no means to benchmark the performance of services or local strategies. Robust local data collection of autistic populations is required to enable councils and NHS commissioners to accurately plan the services autistic people need.

INVEST IN RESEARCH

At present, just £4 million is spent each year on autism research – equating to £6 per autistic person per year.⁴ This compares with £220 for each cancer patient and £110 for each person living with dementia. The most significant gap in research is in understanding the effectiveness of interventions for autistic adults. Given the fact that 10% of the overall cost of autism arises in childhood and 90% in adulthood,⁵ this is a major oversight and one which must be addressed to deliver better outcomes for autistic people in a more cost-effective way.

To find out more about NAP and The Autism Dividend report, please go to www.nationalautismproject.org.uk or contact info@nationalautismproject.org.uk for more information.