



The National Autism Project's priorities for the Northern Ireland Executive Departments

The attached briefing outlines the key priorities for the NI Executive Departments identified by the National Autism Project (NAP) UK. 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.

The Scottish Autism Strategy, the Autism Act (NI), the Autism Act (England), the all Wales Autism Strategy and the current Autism Bill in Wales provide unique opportunities for a convergence of policy and provision for autistic people into which the findings of the National Autism Project can provide important input.

Within the context of the NI Autism Strategy (mandated by the Autism Act (NI) 2011, and led by the Department of Health), NAP submits the following 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 mandated by the Autism Act (NI) 2011) to enable NI Executive Departments to accurately plan the services needed
- The introduction of autism-specific indicators in health and social care accountability frameworks

2. Implement evidence-supported interventions and practice

There is currently an absence of clear guidance on effective and cost-effective provision for autistic pupils in schools and individuals within our communities. This often leads to disputes between parents, schools and the Education Authority which can spread further to involve the Health and Social Care Sector and beyond. More needs to be done to enable access to evidence-supported interventions. NAP wants to see:

- Health and Educational institutions and services providing comprehensive information on evidence-supported educational practice for autistic pupils
- Rigorous evaluation of interventions. Where evidence is underdeveloped, interventions could be supported on the understanding that they will be evaluated at the earliest opportunity.

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 (NI) 2011 reflected in poor implementation of the Transforming Care programme for autistic people. NAP is calling for:

- A review of child and adult social care eligibility and how it impacts autistic children and adults in practice
- Transition assessments for all autistic children moving to adult services



3. Create an autism identity

While many autistic people manage one or more health conditions, there is a lack of a distinct identity for autism in the NHS, Education and other departments. 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.

There is need for greater recognition and implementation of the specific ASD strategies vitally required to meet the learning support needs of autistic pupils within the SEN Code of Practice. Children with Special Educational Needs (SEN) are far more likely to be excluded and constitute over half of all permanent exclusions. In order to enable autistic pupils to stay in school NAP wants to see:

- Reasonable adjustments (for autistic pupils at school to reduce the number of avoidable exclusions) as required by the Autism Act (NI) 2011.
- Programmes to help improve the understanding of autism and behaviours that could be displayed by children on the spectrum to be delivered to all teachers in schools.

In England, many autistic children are being refused EHCPs on the grounds of their academic ability. In addition, EHCPs and Individualised Education Plans (IEPs) place too much emphasis on remediating the perceived deficits of the child and too little on considering how support and the external environment can be tailored to meet the child's needs. Setting this in a Northern Ireland context NAP wants to see:

- An Education Authority (EA) policy directive understanding that academic ability does not mean that a child does not have SEN or need an EHCP (IEP in Northern Ireland).
- IEPs recognising the particular difficulties faced by autistic children and including reasonable adjustments to the school environment.

4. 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
- Recognised independent formal accreditation of all ASD workforce courses and trainers through an approved accreditation independent centre or agency rather than the current common practice of awarding agency-specific certificates of attendance that have no external currency. Independent accreditation feeds more effectively into professional and career development plans.

The current assessments for ESA/Universal credit and PIP can be particularly difficult for autistic people. Autism is lifelong. Most people have care needs which are quite stable. NAP wants to see:

- Training for assessment staff to understand the needs of autistic people across the spectrum alongside exemption from repeated assessment to be offered to all autistic people with more appropriate tests to assess benefit eligibility for autistic people across the spectrum



The particularly poor rate of employment amongst autistic people is well proven but not addressed strategically. NAP wants to see:

- More information for employers on how to make reasonable adjustments for employees with autism
- Relevant training for employers across all sectors on the needs of autistic people
- Training for Jobcentre Plus staff to understand the communication needs of autistic people
- A national autism specific programme to highlight and promote the positive impact of autistic people in the workplace

The challenges for autistic individuals within the Criminal Justice System (CJS) are increasingly being recognised and training of key staff is crucial if any strategic identification (red flags) policy is to be effective in targeting appropriate interventions.

5. 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
- Long-term follow-ups should be included where possible and the economic impacts of interventions should be included in study design

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.