



## The National Autism Project's priorities for the Department for Education

The attached briefing outlines the key priorities for the Department for Education 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. Evidence-supported interventions

There is currently an absence of clear guidance on effective and cost-effective provision for autistic pupils in schools. This often leads to disputes between parents, schools and local authorities. More needs to be done to enable access to evidence-supported interventions. NAP wants to see:

- Educational institutions 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

#### 2. Exclusions

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
- 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

#### 3. Assessment of SEN

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. NAP wants to see:

- Councils understanding that academic ability does not mean that a child does not have SEN or need an EHCP.
- EHCPs and learning plans recognising the particular difficulties faced by autistic children and including reasonable adjustments to the school environment.

#### 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 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



#### **5. More effective training for professionals dealing with autistic people**

More needs to be done to support and up-skill 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 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 the Department for Education 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 five key areas, within the purview of the Department for Education, where improvements most urgently need be made.

### **1. Evidence-supported interventions in education**

Parents, schools and local authorities are bombarded with information about a huge range of interventions whose effects vary from good to non-existent to harmful. The trend to shift the balance of risk and responsibility from the state to the individual can in principle be beneficial in that it encourages efforts to personalise interventions, but unfortunately the evidence base on which to make such decisions is limited as shown, for example, by our report and the excellent summary of interventions produced by Research Autism. Even so, NICE has already identified a range of still commonly promoted and marketed interventions which are at best pointless (e.g. homeopathy), and at worst harmful (e.g. vaccination avoidance, chelation therapy). This leaves a large number of seemingly "respectable" educational and other interventions for which the evidence of benefit may be exaggerated, perhaps for commercial reasons, and whose cost-effectiveness is demonstrably poor.

#### **The fragmentation of the educational landscape into local authority, academy, free and private schools hampers efforts to instil use of evidence-supported and cost-effective educational practice**

- Commercial and other vested interests are adept at marketing non-evidence based and/or costly practice to parents. Many schools encourage this either passively or actively depending on their circumstances. A mainstream state school with a small proportion of autistic children and little or no specialist autism expertise available in the authority may welcome the intervention of commercial entities especially when the additional costs are paid for from local authority funds. Academies and free schools are more at liberty than state schools to make their own choices on interventions and special schools may offer a particular intervention as their USP.



- An example is ABA (Applied Behavioural Analysis), commonly used in mainstream schools where individual autistic children are supported in class and at home by 1:1 ABA tutors. Many of these tutors are excellent and their commitment is often beyond criticism. Nevertheless ABA is expensive and frequently promoted as the only proven effective intervention, a view which is not supported by the evidence and gains it many critics, who support more personalised and eclectic approaches. It is particularly unpopular in some sectors of the autistic community for being controlling and succeeding only in making autistic children appear more neurotypical. The evidence from our report is that ABA is at best no more effective than other less intensive interventions, and is therefore without doubt not cost-effective.
- To deal with this general issue, all educational institutions should be provided with information on evidence-supported and cost-effective educational practice for autistic pupils. Additionally, the Department for Education should regulate use of commercial entities.
- Parents should be provided with clearer information on the interventions available and the level of evidence supporting them and to help decision-making, evidence supported interventions should receive a quality mark. Where evidence is underdeveloped, interventions could be supported on the understanding that they will be rigorously evaluated at the earliest opportunity.

**In the absence of clear and authoritative guidance on effective and cost-effective provision, parents, schools and local authorities are frequently involved in disputes. Even autism provision rated outstanding by Ofsted is repeatedly challenged in tribunals by parents seeking alternative provision**

- The education of neurotypical children is equally not predicated on a strong base of evidence-supported practice, but there is an accepted body of practice-based evidence that has stood the test of time. This is not yet the state of affairs in the education of autistic children. In contrast to the education of neurotypical children, even ASD-specific state provision that has already been judged as outstanding by Ofsted is repeatedly called to justify its quality at tribunals in which parents maintain that such provision is not suitable for their children.
- Parents frequently succeed at tribunals in gaining expensive provision for their children and they can hardly be blamed for seeking what they believe is the best. To overcome this, local authorities should make the evidence-based case for less costly provision of at least equal quality i.e. an autism-trained teaching assistant in mainstream, placement in a specialist autism unit within mainstream, or a special school, depending on the needs of the child. Each tribunal case lost impacts financially on the education of other children.
- Reliance on external providers is not only more expensive but does not increase the knowledge base of the school.

**Discussion point:**

**What is the DfE doing to foster evidence-supported and cost-effective educational practice for autistic children?**

## 2. Exclusions

Although exclusion rates are claimed to be falling, it is certainly a very gradual process. Children with SEN are far more likely to be excluded and constitute over half of all permanent exclusions. Children who have autism as their primary SEN make up around 9% of all those with SEN but it is not possible to get reliable figures on the exclusion rate of this group relative to other pupils with SEN or to all pupils. As we have pointed out to the Department of Health, data collection on autism is one of the most pressing needs.

**Autistic children excluded from school may spend extended periods out of education, or in unsuitable placements where staff lack adequate knowledge of autism.**

- Reasonable adjustments should be made for autistic children to reduce the number of avoidable exclusions and the impact this can have on working parents.
- Programmes to 'educate the educator' should be conducted to help improve the understanding of autism and behaviours that could be displayed by autistic children.
- Mainstream schools should be able to provide a programme of education for children at risk of permanent exclusion through additional funding.
- Autistic children are subject to informal (illegal) exclusions, but also to bullying. This is massively under-reported as the child may accept this as normal, and may become school-phobic as a result.
- Parents may react to the distress of their child by removing them from school for extended periods.

### Discussion point:

**What is the DfE doing to collect better data on autistic children being excluded from school, to reduce the incidence of exclusion of children with SEN and to ensure that autistic children also benefit from this reduction?**

## 3. Assessment of SEN

**While NAP accepts that not all autistic children may need an Education, Health and Care Plan (EHCP), many are being refused on the grounds of their academic ability.**

- This is a very common and widespread problem at the moment. Councils are routinely refusing requests for EHCPs for autistic children on the grounds that the child is academically able and therefore (in their reasoning) does not have SEN or at least does not need an EHCP. These actions are unfair, they betray a lack of understanding of autism and are, moreover, unlawful. In many cases, parents accept such decisions because they lack the knowledge or emotional and financial resources to fight them.

**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.**

- EHCPs have changed the language of SEN from "needs" to "outcomes", but there is still a culture that concentrates on "normalising" the child's behaviour. By their very nature, EHCPs start from a base line assessment that sets out what deficits the child has, and as a result, the "outcomes"



are almost always heavily focussed on changing the child to address these. EHCPs, along with Individualised Education Plans (IEPs) should also include reasonable adjustments that schools should make to support the child's education.

- Targets requiring eye contact, severely restricting stimming, requiring autistic children to emulate neurotypical social behaviour or "to improve his social interactions with his peers" are commonplace. In contrast, adult person-centred care plans set out the adaptations to the environment and support from people around them, which a disabled adult needs in order to live the life they want. Furthermore, EHCPs and IEPs for children with physical disabilities focus on adapting the environment to meet the needs of the child. It is hard to see why there should be this difference in approach especially as there are good examples of schools that do include IEP targets for adaptation of the environment, but this is not widespread.

**Discussion point:**

**What is the DfE doing to ensure that autistic children are not unfairly excluded from EHC Ps, and that these, and IEPs, better reflect the particular problems that autistic children face in school?**

#### **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 DfE is responsible are:

- The use of schools as the basis for collecting evidence on effectiveness and cost-effectiveness. An example is the collaboration between the UCL Centre for Research in Autism and Education and the Pan London Autism Schools Network (PLASN).
- Manualisation of educational interventions in schools as the prerequisite for data collection and comparative studies on outcomes. Variability in implementation of an intervention from one school or institution to another plagues assessment of effectiveness and comparison of interventions. It should be stressed that manualisation does not prevent the development of individualised programmes, adapted for each child's needs. In the absence of any expectation of setting up "educational trials" along the lines of multi-centre clinical trials, manualisation is the only way of ensuring some degree of consistency so that outcomes can be measured and compared.
- Addressing the need for high quality, ideally long-term studies of educational interventions. Such studies as have been performed are frequently of small size, of short duration and compare outcome with treatment as usual or waiting list controls rather than with other interventions. Many studies have been undertaken outside the UK and their relevance is therefore an unknown quantity.
- Further standardisation of outcomes of interventions is needed to allow comparison of one study with another. Outcomes are often biased towards the interests of the investigator or to increase the likelihood of success by selective choice of outcome parameters. Concerted efforts must be made to ensure that research on autism is co-produced with autistic people, in order that the outcomes reflect the true needs of the autistic community and serve all autistic children, whatever their intellectual ability.
- Research is needed to understand and help children transition from one phase of education to another (e.g. primary/secondary, secondary/FE) and leaving education, and to establish support



systems that bridge both sides. Transitions are hazardous steps for many autistic children and unsuccessful transitions can be the trigger for long standing mental health problems.

## 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 children. More in depth knowledge of autism and training is needed for a proportion of professionals in every sector and at every level**

- The core teacher-training curriculum will now specifically include autism as part of its SEN training. The Autism Education Trust (AET), supported by the DfE, is a major provider of training for existing school staff, which is delivered via commissioned “hubs”. Most of these “hubs” are local authority in-house SEN training teams (who may or may not have specialist autism knowledge themselves). AET training should be made compulsory in the teacher-training curriculum.
- We believe that AET training has only reached around 25% of school staff so far.
- There is no statutory requirement which would mandate autism training for existing school staff, not even SENCOs, and when schools are struggling with budget cuts, training which is not a legal requirement is unlikely to be a priority. More generally the fragmentation of education sector governance (due to the academies and free schools programmes detaching schools from local authorities) has meant something of a free-for-all in relation to staff training and it is now largely up to schools themselves to access and fund suitable training. There is little co-ordinated or strategic thinking and schools understandably tend to prioritise the things they get 'measured' on by Ofsted and via SATs/league tables. This means in effect that autism is included with other SEN and schools can claim to have provided SEN training without addressing autism to any significant extent.
- A long-standing problem, especially in mainstream schools, is that support for an autistic child (and indeed SEN in general) is often provided by funding a teaching assistant (TA). The TA is then 'attached at the hip' to the pupil and, in widespread though poor practice, is seen by the class teacher as 'responsible' for that pupil. The TAs concerned are low wage employees with limited skills and training, and despite their best efforts, there is convincing research showing that this isolates the autistic child from more highly skilled class teachers, impairs the development of the child's socialisation and actually inhibits rather than helps their progress.

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

- DfE should consult widely on the content of autism training in order to reflect faithfully the spectrum of needs of autistic children. The views of both parents of autistic children **and** autistic adults are critically important to improving the education of autistic children. Autistic adults are uniquely able to offer insights into current provision from an 'insider' perspective, which is often excluded from current training in schools.

### **Discussion point:**





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**What is the DfE doing to improve the quality and uptake of autism training in schools and to ensure that autistic children are always educated by suitably trained staff?**