



## The National Autism Project's priorities for the Department for Work and Pensions

The attached briefing outlines the key priorities for the Department of Work and Pensions identified by the National Autism Project (NAP). It builds on the extensive work undertaken to produce the 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 policy and research recommendations for reform.

### NAP's key asks

#### 1. Employment

The poor rate of employment amongst autistic people has been well publicised and at least partially understood. However, autistic people are still struggling to find and retain suitable employment. The publication of the *Work, health and disability: improving lives* Green Paper, although welcome, does not address issues directly faced by autistic people. The 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

#### *Comment from DWP*

*We want to deliver the awareness agenda principally through Disability Confident – Access to Work can fund specific awareness training for an employee's colleagues – although not general, speculative training for employers. We are training our staff for the needs of people on the autistic spectrum and have trained nearly 2,000 to date.*

#### 2. Benefits

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
- Exemption from repeated assessment to be offered to all autistic people
- Appropriate tests to assess benefit eligibility for autistic people across the spectrum

#### 3. 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



*Comment from DWP*

*We will look to include autistic customers in our forthcoming Access to Work research piece and also the recording of this group distinctly on the new Access to Work computer system replacement.*

#### **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

*Comment from DWP*

*DWP refers us to the Hidden Impairment National Group and their toolkit which they make available to Jobcentre Plus advisers.*

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 Work and Pensions 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 four key areas, within the purview of the Department of Work and Pensions, where improvements most urgently need be made.

### 1. Employment

The poor rate of employment of autistic people has been well publicised through the National Autistic Society's campaign on the "Autism Employment Gap". To meet the government's pledge to halve the disability employment gap by 2020 (i.e. by increasing employment of disabled people from 47% to 64%) would require a doubling of the number of autistic people in work. The issues are well understood: autistic people need support in applying and getting employment; and the work place environment, work colleagues and employers need to make reasonable adjustments in order to manage their expectations and to accept difference.

While autistic people will welcome the "Improving Lives" green paper, it needs to be pointed out that autism does not fit into the categories of disability or illness, or problems with mental health. The majority of autistic people do not have a learning disability and while many autistic people suffer from mental health conditions, this is frequently a consequence of the difficulty they experience living in the neurotypical world. The establishment of an "autism identity" in services for autistic people is one of the main priorities we are bringing to the attention of the Department of Health. The "autism identity" extends from accurate data collection, to the training of people who come into contact with autistic people across all sectors, and this is particularly pertinent to employment.

The majority of autistic people want to work. The productivity loss for every autistic person out of work is well over £20,000 per annum, and employment, for those for whom it is suited, can contribute to their quality of life, cognitive functioning, mental health and well being.



**Autistic people need support in getting employment and keeping employment but only 10% of autistic people receive it**

- Most autistic people seeking employment rely on pan-disability schemes that may not be well suited to their individual needs. There has been a trend to move away from “train and place” to “place and train” schemes that offer on-the-job training and support. These should consider the equally important task of adjusting the employment environment, both physical and in training the rest of the workforce.

**Employment schemes are effective in getting people into employment, and reduce overall costs**

- There is good evidence that employment support schemes are effective in helping autistic people get and retain employment. NICE concluded that employment support is cost-effective according to health and social care measures. However, new analysis by the National Autism Project looking further at productivity gains for autistic people and their carers, showed that Individual Placement Support is actually *cost-reducing*.
- There are several other good models of employment support e.g. Prospects, a scheme that was supported by the then Department for Education and Employment in collaboration with the National Autistic Society, guidelines from the Business Disability Forum and the Auticon business model for IT consultancy.
- Jobcentre Plus does not work for autistic people, the majority of whom rate their experiences as poor to very poor. This is largely attributed to lack of appropriate training of Jobcentre Plus staff to understand the communication and other needs of autistic people (see below, section 4).

**Employers are wary of employing autistic people**

- The majority of employers do not know where to get advice and support for the employment of autistic people.
- We agree with the National Autistic Society that the DWP should run a national autism-specific programme to promote employment. Such a scheme should involve a diverse range of autism-organisations and ensure sufficient representation of autistic people in its development. To take advantage of the cost-reduction identified by our report, this national programme should include investment in employment schemes, and could include financial inducements to encourage employers to hire autistic people.

**Discussion point:**

**What is the DWP doing to address the employment gap for autistic people?**

**2. Benefits**

**Autistic people should be exempted from repeated assessments for ESA/Universal credit and PIP**

- Assessments are hard, depressing, stressful and a communication nightmare for most autistic people. Constant reassessment is highly unhelpful for their chances of being able to work.
- The current proposed exemption from repeated assessments for those with lifelong conditions would apply to those in the ESA/Universal Credit support group (and not to PIP assessments), and to claimants “who have the most severe health conditions and disabilities. These are people with severe, lifelong, often progressive and incurable conditions, with minimally fluctuating care needs, who are unlikely to ever be able to move closer to the labour market and into work.” Assessments for exemption are likely to be undertaken by health professionals from the private sector with little or no autism knowledge to decide how “severe” a claimant’s autism is.



- Autism is lifelong and incurable but not progressive and most autistic people have minimally fluctuating care needs. Autistic people however, vary enormously in their fitness for work, and being in work does not equate to an autistic person being "better" and with no need for further support. Furthermore, "severity" is a difficult term to apply to autism and autistic people. Individuals may be high-functioning in terms of language or IQ but poorly competent in other activities and unable to navigate the neurotypical world without support. Low-functioning people may be assessed as such on the basis of language tests which are not a true reflection of their intelligence. As with Jobcentre Plus, assessment staff need appropriate training to understand the communication and other needs of autistic people and the challenges that they face daily.
- Exemption from repeated assessment should be offered to all autistic people and extended to PIP assessment on the grounds that they have a lifelong, stable condition.

#### **Changes to the rules on PIP mobility support unfairly disadvantage autistic people**

- The mobility part of PIP has recently been changed to add the words "For reasons other than psychological distress" to the descriptors about being unable to plan or follow a journey. The new arithmetic means that autistic people have to be completely housebound before qualifying for even the standard level of PIP support. This excludes many autistic people from qualifying for PIP mobility support and shows a profoundly disappointing lack of understanding of the sensory, social and communication difficulties that many autistic people face and which substantially affect their mobility, even those who may be in employment.

#### **Discussion point:**

**What will the DWP do to remove unfairness for autistic people from the current assessment process for ESA/Universal credit and PIP?**

### **3. 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 DWP is responsible are:

- The benefits of employment support. Research should investigate such benefits both in formal ways (such as through the Individual Placement and Support model) and by ensuring that employment is a recognised goal for many autistic people in contact with more general health and care services.
- 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 – including through Access to Work provision.
- Interventions to tackle stigma and discrimination, especially in the work environment.
- Interventions to support parents and other carers, particularly where being a carer can have negative impacts on health, employment and wellbeing.
- Making concerted efforts 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 people, whatever their intellectual ability.
- Research on outcomes for autistic people who are signed off from supported services or have support reduced.



#### 4. 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 assessing needs of autistic people. More in depth knowledge of autism and training is needed for all medical examiners and decision makers**

- Autistic people often have poor communication skills and the anxiety created by stressful activities such as assessments for employment or benefits can make these even worse. A toolkit from The Advocate's Gateway provides guidance on reasonable adjustments, and the questioning of autistic witnesses and defendants in the justice system. A similar guide for use by DWP is needed.

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

- DWP 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 the quality and accuracy of assessments.

**Discussion point:**

**We are aware that the Autism Alliance has been contracted by DWP to carry out training of Jobcentre Plus staff. What are the DWP's plans for providing autism-specific training for Decision Makers, and for those who carry out Work Capability and PIP Assessments, particularly from private sector providers?**