

Written evidence submitted by the National Autistic Society (ATW226)

1. Summary

- 1.1. Approximately 1 in 100 people have autism, but only 15% of people with autism are in full time employment. Furthermore, 43% of people with autism say they have left or lost a job because of their condition. Recently published research estimated that 42% of the £29 billion cost associated with adults with autism in the UK is from lost employment.
- 1.2. Access to Work (AtW) provides essential support for people with autism to access, and stay in, work. Unfortunately, the accessibility and effectiveness of Access to Work (AtW) for people with autism is being compromised for a number of reasons: the lack of training for advisors and decision-makers, the assessment method which relies on asking hypothetical questions and the rigid application process.

2. Introduction

- 2.1. The National Autistic Society (NAS) is the UK's leading charity for people affected by autism. We have around 20,000 members and 100 branches, who are at the heart of what we do. We provide a wide range of advice, information, and specialist services to 100,000 people each year, including in relation to accessing and maintaining employment.
- 2.2. Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Some specific difficulties can impact on employment. These can include: challenges around verbal and non-verbal communication; coping with change and the need for routine; and understanding other people's behaviour. However, it must be emphasised that autism is a spectrum condition, which means that while all people with autism share certain difficulties, their condition will affect them in individual ways. Approximately 1 in 100 people in the UK has autism.¹
- 2.3. Our research indicates that:
 - Just 15% of adults with autism are in full-time employment and only 9% in part-time employment.²
 - Unemployment rates for graduates with autism is 26% by far the highest rate of any disability group.³
 - 61% of those people not in work wanted a job. 79% of people in receipt of Incapacity Benefit said they wanted to work.⁴
 - 43% of adults with autism stated that they had left or lost a job because of their condition⁵
- 2.4. The NAS's specialist employment training and consultancy service supports employees and their employers throughout the UK. In 2013-14 the NAS trained over 1,000 people on

¹ Baird G, et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*, 368, 210-215.

² NAS, I Exist, 2008

³ AGCAS Disability Task Group What happens next? A report on the first destinations of 2009/2010 disabled graduates. Sheffield: AGCAS, 2010; 2011

⁴ NAS, Don't Write Me Off, 2009

⁵ NAS, The way we are: autism in 2012, 2012

understanding people with autism in the workplace and supported over 100 different organisations.

2.5. Following a joint workshop held in March 2014, the DWP has committed to producing an employment action plan, which will include ensuring Access to Work advisors receive training in awareness of autism and increased promotion of how the scheme can support people with autism.⁶ We understand that the plan is going through internal DWP process and will be made available to stakeholders in due course.

3. AtW and people with autism

3.1. Although AtW is providing funding to successfully support many people with autism, we regularly receive feedback that people with autism have had extremely difficult experiences when they have applied for AtW funding. Problems specifically relate to the inflexible application process and lack of awareness from advisors.

3.2. There are multiple factors limiting the effectiveness of AtW for people with autism and these are set out below. They include the lack of staff awareness of the difficulties people with autism may face in the workplace and the inaccessible application process. The application process is rigid and applications are made primarily by telephone, which many people with autism find extremely difficult or avoid. The application process also relies on an individual's ability to answer ambiguous, hypothetical questions, something many people with autism are unable to do.

Training for advisers and decision makers

3.3. In order to understand the employment support needs of people with autism, the assessor or decision maker will need a good understanding of the condition, specifically in relation to employment. Unless the advisor making the decision or the assessor has clear knowledge and understanding of autism including how to adapt communication when assessing someone with autism and the likely impacts of the condition in the workplace, it is unlikely that they will be able to comprehensively and fairly assess someone with autism. People with autism have a 'spiky profile' of skills and achievements, so an applicant may be extremely competent on the phone, may be extremely intelligent and may be in a high-achieving role, but still need high levels of support with communication and interaction, structuring work or dealing with anxiety.

3.4. Each AtW application we have supported people to make has had drastically different results depending on the advisor they person speaks to. AtW advisors who have a good knowledge of autism are able to understand the specific difficulties people with autism face in employment and the often unique reasonable adjustments they require. However those that do not understand autism are not able to make the appropriate recommendations. We have been contacted on multiple occasions for support when people with autism are finding it challenging to communicate their difficulties to AtW. This has included complaints that AtW advisers have told applicants with autism that they and their manager have a simple communication problem and they should speak to their manager about it, highlighting a very serious lack of awareness.

3.5. The NAS has previously offered to deliver free training sessions for AtW advisers, however this offer has not been taken up and no reason was given.

⁶ HM Government, Think Autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update, 2014 (The employment action plan should apply across the UK.)

Application process

- 3.6. AtW requires that the individual with a disability makes the application for funding directly. The application process relies on an individual ability to effectively communicate their difficulties in the workplace over the phone and to be able to interpret and answer a series of questions, including hypothetical questions. Using the telephone to speak to a new and previously unknown person often causes high levels of anxiety for people with autism. Many may work in roles where a 'reasonable adjustment' for them is that they communicate with external contacts via email instead of using the phone. Although alternative methods of application are available, the AtW website does not make these other options clear and easy to access. The NAS have encountered many people who have avoided applying for support as they were anxious about the application process.
- 3.7. As autism predominantly affects a person's communication and social interaction skills, it is important the adviser taking the call to discuss an application understands how to interact with the applicant with autism effectively. If communication methods are not adapted, the adviser will not get a clear understanding of the individual's workplace situation.
- 3.8. Autism impacts on a person's ability to think hypothetically and to imagine a situation that has not yet happened. Many questions asked during the application process rely on a person's ability to imagine what support they might find useful in the workplace. For a lot of people with autism these types of questions would be extremely difficult to answer and they may not be able to offer suggestions of possible solutions to their workplace problems.
- 3.9. The application process then requires an individual to sign a form sent to their home address and the return it to AtW. Many people with autism find it difficult to manage information about work in the wrong context, meaning if they receive information to their home address relating to work concerns it may lead to anxiety or avoidance. Many people also have difficulty with 'executive function' the part of the brain that is responsible for planning, prioritisation and organisation. If someone loses the form, forgets the form or does not return the form they will not get this support. Many people with autism do not have support at home, so are not supported to sign the form and return it. People not signing the form and returning it has led to significant delays in getting support in place.

Case study

David has worked for the same company for over 10 years and was having difficulty interpreting the information given to him by his employer and in understanding the social expectations within the workplace. David was at risk of losing his job and decided to apply for AtW funding for workplace support. With support from a member of staff from the NAS, David called AtW and gave permission for the NAS member of staff to speak on his behalf, recognising that some of the questions he was going to be asked may be challenging.

Following a long period of time without hearing from AtW, the NAS advisor contacted them to check on the status of David's application. They advised that they had called David following his initial application and he had told them that that his current work situation was fine. The application had been stopped. David finds unexpected change difficult, the call from AtW was not scheduled with David previously and he was not given the opportunity to prepare for the questions he was asked. David then had to begin the application process again; this delayed his support starting and had a significant impact on his performance at work and his anxiety levels.

Involvement of managers

- 3.10. The common difficulties within the workplace for people with autism is a lack of clear instruction and feedback from managers and/or colleagues. Raising awareness within the employee's team and particularly with their manager is crucial to the success of the individual's employment.
- 3.11. It is common for people with autism to not always be aware of their own difficulties in the workplace due to not correctly interpreting or not being provided with accurate feedback. Often the manager can offer valuable insight into what support the individual needs in the workplace. Currently the manager has little to no part in setting up the support for their employee, despite them often being the best placed person to advise AtW on their employee's needs.
- 3.12. As the person with the disability is the only person who is able to apply for AtW funding, currently the manager can not apply directly for support from AtW. The NAS has been contacted by a number of managers who want to receive support as they are struggling to manage their employee with autism, however their employee does not feel they need support and refuses to make the application for funding.

AtW Agreement

- 3.13. AtW agreements are currently sent directly to the employee, it is then up to the employee to share this with their employer. If the service provider and the employer does not know what has been agreed it is difficult to ensure that they are implementing the correct support as outlined in the agreement. People with autism often need clear guidelines and instructions, they may not be able to use their initiative to share documents with other relevant parties.

Expiration of funding

- 3.14. When funding has expired, or reached its limit the service provider is not notified of this directly. As stated in above people with autism need clear instructions to share information with relevant parties.
- 3.15. Issues have occurred in the past where providers have exceeded the amount of support hours given to the employee as they were not informed that the funding had reached capacity.

Claim worker forms

- 3.16. Currently the claim form system requires the manager and the employee to sign the claim form at the end of each month to confirm each mentoring support session occurred. This can be challenging if a manager is not always present. AtW does not accept scanned copies. When there is a problem with a claim form such as it being filled in incorrectly, this form is sent back to the individual at their home address.
- 3.17. Receiving a returned claim form has caused high levels of anxiety for many people with autism that the NAS have worked with, as they are not sure what to do with it and whether it means their support will stop. It is also common for people to not notify anyone that they have received this, which can lead to a backlog of forms needing amendments (see 4.9).

Case Study

John has been receiving workplace support provided by NAS for 1 hour every two weeks over a period of years. John had an Access to Work form relating to support received in January returned to him at home. There was a covering letter with the form but it was not clear what the problem was other than that the amount claimed was incorrect. The letter also made reference to the fact that if this happened more than twice, the claim would not be paid. John was upset and confused by this letter, he was unsettled by this incident and became anxious that he had done something wrong and that his support would be stopped.

Work based learning

- 3.18. AtW currently funds job coach support for supported internships, however does not fund specialist workplace assessments or awareness training for colleagues or managers of people on these internships. For people with autism, awareness training for colleagues can be the adjustment that enables them to succeed in the workplace.
- 3.19. AtW does not currently fund support for all work based learning schemes. Research shows that 43% of people with autism have left or lost a job because of their condition, support in any type of employment is crucial for the person to succeed.

ATW contracted providers

- 3.20. AtW commission work to contracted providers. The support offered by these providers sometimes appears to be tailored to meet the needs of people with physical disabilities and not those with hidden disabilities such as autism. Not all providers appear to have the in depth knowledge and experience of the unique challenges people with autism can face during employment.
- 3.21. Expert guidance, such as the NICE guidelines, recommend a personalised approach to employment support for adults with autism.⁷ Autism is a complex condition and without the correct background and experience it is difficult to understand the individual's needs and recommend the appropriate adjustments.
- 3.22. Many providers do not appear to be aware of the importance of raising awareness within the employee's team, often focussing on physical adaptations as reasonable adjustments. For most providers, their standard practice involves speaking only to the individual and they do not involve the employer in the assessment of needs. Many people with autism are not able to independently communicate their difficulties, meaning the assessment may not be a true representation of their needs.
- 3.23. We have received feedback from people with autism that some of the providers are not meeting their needs. Currently there does not appear to be a system in place to quality assure the support offered by these providers. As autism predominantly effects a person's communication skills, it can be difficult for some people to voice their concerns if the service they are receiving is not up to standard.

⁷ NICE Clinical Guidelines 142: Autism: recognition, referral, diagnosis and management of adults on the autism Spectrum, 2012

3.24. Recommendations

Knowledge and skill of Access to Work staff

- Autism-specific training should be provided to AtW advisers and assessors and all decision-makers within the AtW process on the issues faced by adults with autism. The NAS would provide this free of charge, if necessary.

Improving the quality of support and expanding access

- A quality assurance system should be implemented to ensure AtW providers are offering support to the highest standard. This should be based on feedback from employees and employers.
- AtW should be extended to provide specialist adjustments (e.g. autism awareness training for colleagues) to support students on work based learning programmes.

Improving the application process and management of ongoing paperwork

- The recently announced review of AtW should include consultation with individuals, employers and employment support providers to address the multiple administrative and operational issues they face. This should include addressing the recommendations below.
- AtW should develop:
 - A clear and easily accessible alternative to telephone applications; and
 - An online application and awards process, where documentation is emailed to customers, and timesheets can be completed online and authorised by the employer and employee.
- If a postal system continues, then letters and documents should be sent to the individual at their work address unless they specifically request otherwise.
- For people with autism, involvement of the individual's manager as appropriate throughout the application process and on an ongoing basis.
- AtW should send a copy of the agreement to all relevant parties, including the employer, the employee and the service provider.
- A clear, formal review process should be implemented for when funding comes to an end. The service provider should be included in this.
- The support provider should be notified of any returned claim forms and reasons for their return, as it is the provider who has completed the form and is claiming the funding.
- Service providers should have a named contact at AtW for any administrative or financial queries.

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