



Neurodiversity

in the Transport and Travel Industry

An exploratory study of knowledge and attitude towards neurodiversity, and perceptions of support and the management of employees with dyslexia, dyspraxia, dyscalculia, ADD/ADHD and Asperger syndrome

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tssa

The logo for tssa (Transport and Travel Skills Association) features the lowercase letters 'tssa' in a bold, red, sans-serif font. Below the text is a red, wavy horizontal line that tapers at both ends, resembling a stylized wave or a swoosh.

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Foreword

Dyslexia and other neurodiverse conditions such as dyspraxia, dyscalculia, ADD/ADHD and Asperger syndrome are found in workplaces across the travel and transport industry. Neurodiverse conditions are, in most cases, a protected characteristic under the Equality Act 2010. From booking offices to train despatch to call centres to engineering departments, if unrecognised and unsupported, neurodiverse conditions can have a serious impact on individuals' working lives and their access to learning, development and progression opportunities.

Since 2010 the TSSA has developed a series of related projects to tackle these non-traditional union issues with the support of TUC and Union Modernisation Funding. In 2010 the "Lost for Words" project broke new ground in talking about dyslexia in the travel and transport industry. From 2011, with support from both unionlearn and the Union Learning Fund, we broadened the scope of the project to include some of the conditions that often co-occur with dyslexia.

After much discussion, the term neurodiversity was adopted as a campaigning response to challenge the still common medicalisation and stigma associated with neurodiverse conditions, and to celebrate the strengths that are often found alongside the difficulties. As a union we are campaigning to change social attitudes and to dismantle the barriers to equality that exist in the structures and processes of organisations. We believe that neurodiversity should be a part of every employer's equality and diversity strategy, and we want each and every TSSA workplace to become more inclusive, accepting and welcoming of human difference of every kind.

This research was commissioned to enable us to find out more about what TSSA members and non-union members in the travel and

transport industry know, think and feel about neurodiversity – and how we as a union should respond. Our response to the findings in this report is to develop the capacity of our members, reps and ULRs to promote understanding of neurodiversity in their workplaces and to influence their employers to adopt positive policies, procedures and practices. We want our neurodiverse members to feel confident that they will encounter understanding, support, and access to opportunities at every stage of their working lives.

The team who conducted this research are from the Centre for Work and Wellbeing at Heriot-Watt University – Dr James Richards, Dr Kate Sang and Professor Abigail Marks. This team was chosen because they demonstrated a rigorous academic approach to conducting the research, along with an understanding of the collective aims of the trade union movement and the commitment to social justice that drives our work. It has been a productive collaboration and we thank them warmly for their commitment and hard work. We would also like to thank the Government for the financial support to make this research possible. Finally, thanks to all the people who contributed to the focus groups – current TSSA members and those who may join us in future.

We hope that you find this report interesting and enlightening. Most of all, we hope that whether you are a union member, a rep, or an HR manager, you take action on the recommendations that have been made, to improve the working lives and access to learning, development and promotion opportunities for the many people with neurodiverse conditions working in travel and transport today.

Susannah Gill

Neurodiversity
Organiser

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Executive summary

This study explored neurodiversity within the transport industry workforce, in particular, salaried workers. Neurodiversity is taken to be an umbrella term which covers dyslexia, dyspraxia, dyscalculia, ADHD/ADD and Asperger's syndrome. Specific objectives of the study were:

- To explore knowledge of neurodiverse conditions.
- To understand attitudes towards the notion of neurodiversity.
- To determine the perceived levels of support and the perceived quality of management of employees with a neurodiverse condition.

A two-stage research approach was used in order to explore neurodiversity in the transport and travel industry:

- Seven focus groups were conducted to assess baseline levels of knowledge, understanding and attitudes towards neurodiversity.
- Twenty three telephone interviews were conducted with transport and travel employees who either have a neurodiverse condition or who manage someone with a neurodiverse condition in the workplace.

Key findings from the study are:

- Knowledge of singular neurodiverse conditions, for example dyslexia, was significantly more common than knowledge of the wider range of conditions associated with neurodiversity. Knowledge on neurodiversity was typically acquired from non-employer-related sources of information.
- Neurodiversity was an unfamiliar term for most people. Once explained most people felt it was a positive term as it emphasised

diversity, rather than disability, disadvantage, negative difference, etc. However a minority of people with a neurodiverse condition believed the term to be unhelpful because it over-generalised a wide range of conditions.

- Perceptions of support available for the employee with a neurodiverse condition and the manager who manages an employee with a neurodiverse condition differed, typically in a negative way, from official availability of such support. For example, people reported that organisations offered occupational health support, but this was not always relevant in terms of supporting an employee with a neurodiverse condition.
- Perceptions of how well employees with neurodiverse conditions are supported in the workplace were quite mixed, with perceptions more negative than positive. Issues raised included the impact of cut backs and performance management initiatives, problems associated with disclosure, poor and good employment practice, as well as the positive role that trade unions can play in support practices.

The following recommendations are made on the basis of the main findings:

- The development of specific and industry wide policies and procedures to cater for the unique support needs of employees with neurodiverse conditions.
- The provisions of resources to raise awareness and provide a permanent supply of information related to support for employees with a neurodiverse condition and managers who manage an employee with a neurodiverse condition.
- The development of specialised line manager training in order to provide vital support for employees with a neurodiverse condition.

Glossary of terms

ADD/ADHD:

A group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness. Attention deficit disorder (ADD) is a sub-type of ADHD. Common symptoms of ADHD include: a short attention span, restlessness or constant fidgeting, being easily distracted¹.

Asperger syndrome

A form of autism, which is a lifelong disability that affects how a person makes sense of the world, processes information and relates to other people. Asperger syndrome is mostly a 'hidden disability'. This means that you can't tell that someone has the condition from their outward appearance. People with the condition have difficulties in three main areas: social communication, social interaction and social imagination².

Dyscalculia

A condition that affects the ability to acquire arithmetical skills. Dyscalculic learners may have difficulty understanding simple number concepts, lack an intuitive grasp of numbers, and have problems learning number facts and procedures³.

¹ NHS Choices

² The National Autistic Society

³ Department for Education and Science

Dyslexia

Dyslexia is a specific learning difficulty and most commonly characterised by difficulties with the acquisition of reading, spelling and writing skills. Dyslexic people often have auditory processing difficulties, poor organisational skills, poor physical co-ordination and directional confusion. The majority of dyslexic people have poor short-term memory that causes an inability to retain sequences of numbers and words, and instructions to carry out simple tasks⁴.

Dyspraxia

A condition that affects movement and co-ordination. People with dyspraxia may appear physically awkward and have difficulties with writing, typing, learning to drive a car and self-care tasks. They may also have difficulties with organisation and planning skills⁵.

⁴ Dyslexia Scotland

⁵ NHS Direct Wales

1 Introduction

1.1 Aim and context of the study

The broad aim of the study is explore neurodiversity in a distinct industrial sector. More specific aims include exploring knowledge of neurodiverse conditions, attitudes towards the notion of neurodiversity, perceived levels of support and management of employees with a neurodiverse condition. The context of the study is the transport and travel industry, where trade union memberships remain high by national standards and collective bargaining coverage is about or around 100 per cent¹. The study is focused on ‘white-collar’ employees, such as, administrative, managerial, professional and technical workers, who are employed by a wide-range of both public and private organisations that operate in British transport and travel industry.

1.2 Defining neurodiversity

While the conditions typically viewed to make up the ‘umbrella’ term of neurodiversity – dyslexia, dyspraxia, dyscalculia, ADD/ADHD, Asperger syndrome – have been widely recognised by medical clinicians for many decades, the idea of neurodiversity is little more than a decade old. However, advocates of the term neurodiverse reject the long held view that neurodiverse conditions are mental disorders of a neurological origin, thus being a problem of the individual,

¹ Arrowsmith, J. and Adam, D. (2008), *Representativeness of the European Social Partner Organisations: Railways Sector – United Kingdom*. Available at: www.eurofound.europa.eu/eiro/studies/tn0710037s/uk0710039q.htm

and instead call for the conditions cited above to be seen more as ‘alternative forms of natural difference’². Indeed, it is suggested that a person with a neurodiverse condition is simply ‘brain different’³. The main task, as such, is not to find a cure for people with a neurodiverse condition; it is more about challenging the often negative and ill-perceived perceptions of the wider public towards people with neurodiverse conditions⁴. In the context of this research, this equates to employers and colleagues developing more positive, understanding and flexible attitudes to employees with neurodiverse conditions. At the very least, it is to better acknowledge that neurodiverse conditions are very real and life-long impairments, despite not being detectable from outward appearances, and are therefore recognised under the Equality Act 2010.

1.3 Prevalence of neurodiverse conditions

There is some debate about the prevalence of neurodiverse conditions in the wider population. Key problems here, for example, include varying commitment and resources set aside for diagnosing dyslexia, as well as determining a cut-off point between, for example, what could be considered as a mild case of dyslexia and what could be considered a severe case of dyslexia. Further problems include the individual may receive a diagnosis for more than one neurodiverse

² Armstrong, T. (2010), *Neurodiversity: Discovering the Extraordinary Gifts of Autism, ADHD, Dyslexia and Other Brain Differences*, Philadelphia, PA: Perseus, p. 8.

³ Hendrickx, S. (2010), *The Adolescent and Adult Neuro-diversity Handbook: Asperger Syndrome, ADHD, Dyslexia and Dyspraxia and Related Conditions*, Gateshead: JKP, p. 15.

⁴ Babineau, S. (2012), *Neuro-diversity Works: A Study of Employees with ADHD, Asperger’s Syndrome and PTSD*, North Charleston, SC: CreativeSpace.

condition. As such, it is reasonable to suggest that official accounts based on measuring the prevalence of neurodiverse conditions should be treated as reflecting the minimum prevalence of such conditions. Statistical accounts of neurodiverse conditions, however, suggest the prevalence of dyslexia is estimated to be between 2 to 15 per cent⁵, dyspraxia between 4 and 6 per cent⁶, dyscalculia between 1 and 7 per cent⁵, ADD/ADHD 0.3 per cent⁷, Asperger syndrome 0.7 per cent⁸. While the prevalence of neurodiverse conditions varies somewhat it is quite reasonable to suggest that when taken together as a whole, neurodiverse employees represent a group larger than most protected groups covered by the Equality Act 2010.

1.4 Employment and neurodiverse conditions

There is a growing, yet quite limited research-related interest in the employment-related experiences of employees with a neurodiverse condition. However, space does not allow anything but a brief overview of such research. On the whole it is reasonable to note that neurodiverse employees experience a range of difficulties both in securing and maintaining competitive employment, with the difficulties appearing to relate to a lack of awareness of such

⁵ Parliamentary Office of Science and Technology (2004), *Postnote: Dyslexia and Dyscalculia*, Number 226, July. Available at: www.parliament.uk/briefing-papers/POST-PN-226.pdf

⁶ Penso, D.E (1999), *Keyboarding Skills for Children with Disabilities*, London: Whurr.

⁷ NICE (2006; 2012), *Methylphenidate, Atomoxetine and Dexamfetamine for the Treatment of Attention Deficit Hyperactivity Disorder in Children and Adolescents*. Available at: www.nice.org.uk/TA98.

⁸ Ehlers, S. and Gillberg, C. (1993), 'The Epidemiology of Asperger syndrome: A Total Population Study', *Journal of Child Psychology and Psychiatry*, 34 (8), pp. 1327–1350.

conditions amongst managers and colleagues, and a lack of support for employees with such conditions. For example, research suggests dyslexic employees tend to be fundamentally disorganised with this being a threat to continued or progression in employment⁹. Further, employees with Asperger syndrome may be unfairly labelled as arrogant as well as face workplace teasing¹⁰. Support is also an issue with only 10 per cent of adults with Asperger syndrome receiving specialist help at the interview stage and around 20 per cent when in employment¹¹.

1.5 Summary

This section has set out the broad terms of reference and the broader context of the study ahead. Details of the research methodology and method of recruiting research participants is described and discussed in Appendix One. The next section is based on a presentation of the main findings from the fieldwork and offers a rich and exploratory account of Neurodiversity in the transport and travel industry.

⁹ Fitzgibbon, G. and O'Connor, B. (2002), *Adult Dyslexia: A Guide for the Workplace*, Chichester: Wiley.

¹⁰ Attwood, T. (2007), *The Complete Guide to Asperger's Syndrome*, London: JKP.

¹¹ Beardon, L. and Edmonds, G. (2007), *ASpect Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*. Available at: www.aspectaction.org.uk/ASPECT%20Consultancy%20report.pdf

Case study one

Managing a neurodiverse employee in the workplace

Mia was diagnosed with dyslexia about nine years ago. She had been struggling in her role at work and went to see her GP as she was finding the situation upsetting. Her GP referred her for tests and she received a formal diagnosis. At the point of diagnosis Mia was made to feel inadequate by her line manager when she disclosed her condition.

This lack of confidence has permeated the rest of her working life and she has not disclosed her dyslexia to an employer since. She stated that 'my problem is constantly feeling like I have a lot more to prove so I have to go above and beyond what's required of me in my roles. To prove myself, this constant feeling in me of having to prove myself'.

Mia doesn't ask for further responsibility or seek promotion in case she 'gets found out'. Mia's perceives the male dominated working environment as causing further barriers in her working life as the sexist banter makes her even less keen to reveal her dyslexia. Mia is seeking alternative work and is desperate to find a job where she feels able to disclose her dyslexia and receive support and opportunities for progression.

2 Main findings

2.1 Sources of knowledge on neurodiversity

It was evident in the context of both the focus groups and interviews that the research participants knew far more about the particular neurodiverse condition that affected them directly or indirectly when compared to the wider range of neurodiverse conditions. As expected, for example, individuals with Asperger syndrome claimed to know far more about Asperger syndrome in comparison to their knowledge of dyslexia, dyspraxia, dyscalculia or ADD/ADHD. This was even the case with participants who had managed an employee with a neurodiverse condition. In other words, where research participants with line management reported experience of managing an employee with a neurodiverse condition it was restricted to a rare occurrence of managing an employee with dyslexia or Asperger syndrome.

Two sources of information appeared common across the focus group participants. The first common source of knowledge and understanding of neurodiverse conditions came from being a person with a neurodiverse condition or knowing/managing/being responsible for someone with a neurodiverse condition. A second common source of information on neurodiverse conditions involved popular media, such as the Internet (web-sites and social networking platforms), daily newspapers and television programmes. As expected, participants with a neurodiverse condition reported seeking and receiving direct information from specialist support agencies, such as the National Autistic Society and the Dyslexia Foundation. Participants with a family or friend with a neurodiverse condition reported accessing such information from books written by lay experts and pamphlets provided by healthcare professionals. Despite a sizeable proportion of

participants claiming current or previous line management experience, only a small minority reported receiving information on neurodiversity via employer run equality training courses.

“Only a small minority reported receiving information on neurodiversity via employer run equality training courses.”

While it was not within the remit of the research to test the accuracy of understanding of neurodiverse conditions, although it was evident that the potential for misleading or incomplete information about neurodiversity to emerge from such sources was quite probable, it did become quite clear that the onus for seeking information on neurodiverse conditions lay very much with the individual employee. Further, given that the onus appears to be on the individual to seek information about neurodiverse conditions, and that the vast majority of that information is sourced from outside the employer organisation, such information is likely to stay with the individual, as well as being largely inaccessible to others who may need to know or want to know more about neurodiverse conditions in employment-related situations.

2.2 Attitudes towards the notion of neurodiversity

Attitudes to the notion of neurodiversity were explored at both stages of the research. While the findings from the focus groups and interviews suggest there was not a complete and positive consensus surrounding the notion of neurodiversity, it became evident that the majority expressed favourable sentiments towards the term.

When recruiting research participants the term neurodiversity was used, yet in both recruitment drives neurodiversity was further detailed by reference to its umbrella conditions. Attitudes to the notion of neurodiversity were explored at both stages of the research. While the findings from the focus groups and interviews suggest there was not a complete and positive consensus surrounding the notion of neurodiversity, it became evident that the majority expressed favourable sentiments towards the term.

In the case of the focus groups, views towards the notion of neurodiversity were on the whole positive, although this may be related in some way to the fact that none of the focus group participants claimed to have heard the term before. A repeated reason why the idea of neurodiversity was viewed positively relates to how the conditions associated with neurodiversity overlap in many ways. The following focus group excerpts reflect this widely held view.

I haven't heard it, until you started using it. My wife has made a career out of being a mum of someone with learning disabilities. She works in SEN [Special Educational Needs] in local authority. Never heard her use the term. It does seem good. From experience with my son, you couldn't put him into one of the subdivisions that are written in front of us. You could put him in all of them, to different extents. It does seem a good term to use... *(focus group seven, London)*.

I have never heard of the term... Something general covers all areas and may put you in a better position. If you have got as far as you have, you have obviously got tools to overcome your difficulties. I never knew anything about it. It needs to be publicised. Push the name out. Government needs to lead *(focus group six, London)*.

The positive attitude was also evident in the case of one-to-one interviews:

I think it's a good idea because you can then put all that into an area. That's fair enough... *(employee with dyslexia)*.

Yeah, I think it sums up very, very well, the problems that people have. And it doesn't say it in a negative way at all. You know, I think neurodiversity is a very positive name. It's what I'd like to see or be referred to, actually *(employee with Asperger syndrome)*.

I think it pretty much describes itself in terms of, you know... I'm a deep believer that people are wired in different ways *(employee with dyslexia)*.

However, cautionary views concerning the notion of neurodiversity did emerge in the focus group setting:

I don't find it helpful. To use the term 'neurodiversity' is rather a generalised term for quite a lot of issues... *(focus group seven, London)*.

I don't want to be labelled [ADD/ADHD or Neurodiverse)... I just want to be a human being, and get on with my life and be normal, which is the hard part to deal with in life *(focus group five, London)*.

As expected, during interviews even more divergent views emerged. Indeed, here it is important to note that the disapproving views of neurodiversity were expressed by employees with a neurodiverse condition:

It's from the anti-cure movement and there are all sorts of silly words springing up on a timely scale; 'neurodiversity' is one of them (*employee with Asperger syndrome*).

What I imagine neurodiversity to mean is learning difficulties and I personally would understand the term learning difficulties. I think the term 'neurodiversity' would pretty much go over my head... if I weren't someone with a learning difficulty I don't think I would sort of make a correlation between the two things, if that makes sense (*employee with dyslexia*).

It would appear that the notion of neurodiversity appears to have been received by the research participants in a largely positive way. However, caution must also be taken because the notion of neurodiversity may be viewed by those who have a neurodiverse condition as a new means for others to attach convenient labels to them. Neurodiverse employees may also prefer to be referred to in another way or not referred to at all in this manner.

2.3 Perceptions of workplace support for employees with a neurodiverse condition

2.3.1 Actual workplace support for employees with a neurodiverse condition

Accounts of what workplace support is actually available for employees with a neurodiverse condition should be premised on the basis that not all employees require nor seek support for their neurodiverse condition. Indeed, several research participants reported the use of effective compensatory mechanisms that negated against the need to seek such support. Such strategies, however, may have also lowered

awareness of what support could be available for the employee with a neurodiverse condition.

Despite such scenarios, knowledge of a wide range of support mechanisms for employees with neurodiverse conditions was discussed in the focus group and interviews. Such mechanisms include adjustments related to working practices (e.g. voice recognition software for Dyslexics, or a preference to communicate via email for employees with Asperger syndrome), individual risk assessments, HRM inclusion policies and occupational health facilities.

However, accounts of attempting to access such support differed somewhat from simply listing off what is officially made available by employers. For example, access to such support is often through line management, yet many research participants questioned the people management skills of the typical line manager in the transport and travel industry:

[Company X] have largely outsourced the people management process to the line manager, who knows nothing about people management (*focus group six, London*).

I have asked my managers to link with Prospects [employment support provided by the National Autistic Society] who come in and help. It is like talking to brick wall at times. They can't take it in, they don't know how to deal with the information they have been given (*focus group one, London*).

Line managers who attended the focus groups also bemoan an apparent lack of support in order to augment formal and specialised support for employees with a neurodiverse condition:

We initially send [employee with problems related to neurodiverse conditions] to Occupational Health to get their assessment... After that, no idea what support I get. I get little anyway. This is because we are not familiar with these things across the company (*focus group four, York*).

One line manager interviewed reported her strategy to having team members with dyslexia. After attending a company provided workshop on dyslexia, the line manager noted that the problems outlined may apply to two members of her team. The line manager encouraged these team members to attend the workshop and to collaboratively identify methods of adapting the workplace to their needs. In addition, the line manager said she was concerned at the level of harassment her dyslexic team members were subject to, in the form of jokes. As a result, the line manager was in the process of sending all her team members on a dyslexia awareness workshop.

How such support is publicised was also an issue deeply criticised in the focus groups:

The problem is not that these resources aren't there, people are just not aware of them. There is Occupational Health as well, so there is a rich inter-land of expertise. Whether it is accessed is an issue. You have to be aware it is there to access it (*focus group seven, London*).

Generally, the findings suggest there to be a gap between the official line of the employer in relation to support for employees with neurodiverse conditions and the reality of the practice.

2.3.2 Ideal workplace support for employees with a neurodiverse condition

Research participants were also given the opportunity to consider, within reason, what would be an ideal way in which to support employees with a neurodiverse condition. Ideal support, for most, comes in the form of trade union input:

If I could choose, I would choose a union rep. Logically, that is where I think my first point of call would be (*focus group seven, London*).

Several believed specialised external support organisations would be ideal in such situations, but this was as much to do with 'neutrality' as it was to do with expertise:

Prospects were good for me, and the National Autistic Society. The fact that someone was prepared to come and talk to my employers and who was independent to the PMAs [People Management Advice manager], who are not independent... Prospects advised on a neutral basis (*focus group one, London*).

Ideal support, for some, however, is a holistic approach involving the individual, the line manager, the employer, as well as colleagues:

You want the person [with a neurodiverse condition] to know how they do things best, you want the manager to be aware, like about physical things at home. Then, you want colleagues to understand you are not getting special treatment. You want the company to be able to provide funding or resources. You don't want about five people helping; it's the support network. Would be nice if they listened to what you need, not just their ideas of what you need... (*focus group four, York*).

One interviewee, a middle manager with dyslexia, suggested that when an employee discloses a neurodiverse condition at selection, the employer should work with the person to adapt the workplace appropriately. This employee's experience as a person with a neurodiverse condition was that he had to actively seek support and was subject to bureaucracy that was difficult for him to complete with his dyslexia. As such, in this particular situation, the ideal would be that the employer should be more anticipatory of the needs of employees with dyslexia and other neurodiverse conditions.

Views concerning idealistic forms of support appear to be quite modest, that is, approaching such issues with the input of staff representation, external advice and impartiality, considering how inclusion of neurodiverse employees in the workplace to be principally seen as a collaborative effort, as well as the employer being more anticipatory and less reactionary in terms of providing necessary support. In terms of what this appears to translate into in relation to company policy and procedure includes first and foremost recognising that support for the neurodiverse employee should include the right to be represented and supported by a trade union official and/or an external specialist in such situations. Policy and practice should also put far less onus on the employee to be the arranger and architect of such support.

2.4 Perceptions of the management of neurodiversity in the workplace

2.4.1 The climate for managing neurodiversity in the workplace

Given the wider current economic difficulties and the many changes that have occurred in the transport and travel industry over the past few decades, reports of a changing climate for managing people with neurodiverse employees, was expected. How such changes are viewed and where the changes are most felt, however, is where this part of the exploration was concentrated. Where the climate for inclusion was raised during focus groups it tended to focus on two distinct issues, the first being financial cut backs:

It is also having the resources in the organisation, be it an employee or a union, to assist with that. I know within [Company Z], with the last cuts, we lost the Quality & Inclusion department people. That is sending the wrong message (*focus group one, London*).

You had medically restricted places... The latest staff cuts have now meant that there are less positions for such people... (*focus group one, London*).

However, the pressure placed on support for employees with a neurodiverse condition appears to be further problematised by recent performance management initiatives:

The sad fact is there is no humanity index in managers' KPIs (key performance indicators). You have to bring them to the table as a human being yourself (*focus group two, London*).

[Line managers] have great pressures. That's the problem; it's down to time management. So much pressure and demands. May be the managers are scared to say no to their senior managers and face getting sacked six months down the line (*focus group two, London*).

I think performance management has become much more intense, being pushed to produce more and more. This brings out these issues. It creates them (*focus group seven, London*).

Such factors may be unavoidable in contemporary organisations, yet it appears that cut backs and performance management initiatives are likely to have some effect on the employment prospects of employees with a neurodiverse condition. For example, transport workers on the underground stations – they said that since the cut backs everyone on duty has to be able to do every task. As such, people with dyscalculia may struggle with handling cash or people with Asperger syndrome may find customer service difficult. Further, there appears to be problems concerning safety critical roles.

2.4.2 Disclosing a neurodiverse condition

As expected, research participants expressed mixed views on whether or not, or how and when, an employee should disclose a neurodiverse condition to an employer from the transport and travel industry. In one sense many focus group participants initially expressed how disclosure is probably the right thing to do, as the following excerpt demonstrates:

There is an issue if you are having problems, or if you could do better at work by discussing you have a situation that could impact on the way you work, by disclosing you can come to a solution that makes things better, then that is a good reason for disclosure (*focus group seven, London*).

However, focus group discussions typically led to such sentiments being challenged and over-ruled by the majority of other research participants, particularly by individuals with a neurodiverse condition. The basis of such disagreements related to difficulties associated with disclosure:

My observation is it seems like we [dyslexics] are in a bit of a 'chicken and egg' situation, where people who are diagnosed with a condition don't want to disclose it, and I think I would be the same myself. If you don't need to know, I won't tell you. On the other side, people can't help unless they know. I don't know how you solve that. I would be exactly the same myself. 'It's my business; you don't need to know that' (*focus group three, London*).

Disclosure was also seen as problematic in terms of how the individual expected to be treated by the employer once this information was in the hands of, for example, a line manager:

People will be worried about how they will be treated. Potential for promotion, losing their job (*focus group four, York*).

The problem with some people is trust. If they recognise the individual that they want to give the information to is supportive, they are more likely to give it. If they are not, they won't reveal, unfortunately, and muddle through. This doesn't always work (*focus group four, York*).

During interviews further angles emerged in terms of disclosing a neurodiverse condition to the employer. In the following example the employee believes it best to only disclose once in the job:

No, no, generally, I don't disclose in interviews because sometimes, I'm like... is it something that you should disclose or not...? I disclose when I get to see my manager and say that's what I am (*employee with dyspraxia*).

It also became evident in interviews that a reluctance to disclose could also arise out of experiences going back to a time when intolerance for, or ignorance of, neurodiverse conditions was widespread:

It's just, sort of, growing up when I did, with dyslexia was quite difficult, so everything I've ever learnt tells me not to disclose it (*employee with dyslexia*).

Based on such accounts, it would seem that disclosing a neurodiverse condition is a problematic issue in the transport and travel industry. Trust in the employment relationship is clearly a factor in the reluctance to disclose, although that is not to suggest this issue is insurmountable. Pre-work experiences also appear to affect individual decisions on whether to disclose a neurodiverse condition or not.

“People will be worried about how they will be treated. Potential for promotion, losing their job.”

2.4.3 Perceptions of poor practice

Reports of perceived poor practice cropped up many times during the focus groups and the interviews. However, the nature of poor practice varied somewhat. A common issue raised in both focus groups and interviews surrounds the role of line management in such situations. Difficulties include perceptions of inadequate training and the lack of time to sort out any difficulties that may arise from neurodiverse conditions in the workplace:

At work, it is very difficult, as the line managers just don't have a clue how to deal with [Asperger syndrome], and how to best use me (*focus group one, London*).

I found with my own manager, I had to do the driving, the searching. They should be willing to have a look. I had to do everything. I got remote access in the end, but it was very painful for me to get it (*focus group two, London*).

Most very good managers have no time on their hands [to manage neurodiverse employees] (*focus group three, London*).

Evidence also emerged of arbitrary treatment of employees with a neurodiverse condition:

I got sacked for [having dyslexia] once. That was unpleasant. I wrote the word 'innovation' down wrong. A client laughed, and I got the sack. That was the end of it (*focus group three, London*).

A training deficit was also a regular theme. Several focus groups participants felt that awareness of neurodiverse conditions was poor amongst colleagues:

Most of the people in my team only know jokes about dyslexia which they heard on the playground 25 years ago (*focus group one, London*).

Some also felt that employer budgets concerning training on such issues had been in long term decline:

Do you think we invest enough [on training managers to better manage employees with neurodiverse conditions]? I look at how much is invested in training now compared to 20 years ago; there is a total difference now. I don't think we invest enough (*focus group two, London*).

In general, there was widespread concern that not enough time and resources were set aside for managing neurodiverse employees in the workplace.

2.4.4 Perceptions of good practice

When asked about what worked well in terms of supporting an employee with a neurodiverse condition in workplace it was evident that a good line manager was central to this process. For example, a level of empathy and understanding appear key in such situations:

My line manager. He knows about [Asperger syndrome] and his son has it. He has empathy and I trust him. If my manager didn't have these things, I don't know how I would cope or how hard it would be (*employee with Asperger syndrome*).

Line managers can also play a significant part in developing strategies to help neurodiverse employees stay on task:

One lad, who is easily distracted, was walking around the office talking to everyone, rather than doing his job. [The office manager] could see what was going on and asked if she could have a chat with him. She got him a clock and said 'you must do half an hour's work; then you can go and have a chat for 15 minutes'. [People with Asperger syndrome] are very literal. That clocked helped a lot... Okay, he'll never be as efficient as someone without the condition, but his efficiency got to 80 per cent just by recognising what the situation was, and how to work around it (*focus group four, York*).

Similarly, effective line management appears to also involve making informal adjustments to allow the employee with a neurodiverse condition to remain productive over a full-time shift:

My line manager lets me have some time looking at the Internet because I find it hard to stay concentrated at times... I still have to get my work done, but yeah, I get some kind of leniency... but I don't know if that's technically a reasonable adjustment (*employee with Asperger syndrome*).

More generally though, employees with a neurodiverse condition appear happy when they are satisfied that their line manager has done his or her best in such situations:

My line manager. They have all been good; they say they will help as much as they can. That is all I ask for. They can't move mountains across the company (*focus group six, London*).

It would appear that the line manager can make a significant difference in terms of providing a range of practical, emotional and informal support for the employee with a neurodiverse condition.

2.4.5 Role of trade unions

It was reported several times during the focus groups that effective management of neurodiversity in the workplace could not be sustained without the input of the trade union. Such sentiments relate to the prevention of problems arising in the first place:

There is not a lot a [person with a neurodiverse condition] can do, but one of the key positives that unions can do is address wider issues that one person may not want to bring up themselves. That is a key union role (*focus group three, London*).

That is what I would see [trade unions] doing. They are in the position. Unions could say they want neurodiversity recognised. They could say they want line managers within your company down to Band Four to understand what that means (*focus group six, London*).

However, the role of trade unions also extends to practical support when an employee faces some form of performance issue related to a neurodiverse condition:

Yes, talking to your line manager is what we are told to do, but I don't currently have a great opinion of mine. I think I will find out who my union rep is. They are defenders of equality (*focus group seven, London*).

From the point of view of the employee, a union rep or a colleague would be the first person you would go to. They are the people you trust. You may not trust your line manager to deal with your situation in the right way (*focus group two, London*).

However, some participants felt that the best intentions of the trade union may not be enough if the employer does not support the stance taken by the trade union on neurodiversity:

I think it is about partnerships. If the union becomes specialised in working with neurodiverse people, they can say we can help you get the best out of your employees, who have great skills, but they might find it hard [to convince] managers (*focus group five, London*).

The evidence suggests there is an appetite for trade unions to be involved in terms of proactive and reactive strategies related to managing neurodiversity issues in the transport and travel industry. The involvement appears to be on the basis of pressurising employers to recognise neurodiversity, and to be there for advice and when things go wrong.

“A union rep or a colleague would be the first person you would go to. They are the people you trust.”

2.5 Summary

The overall picture appears to be mixed, in that there is evidence of reasonable attention given to such issues by employers in this industry, yet there is perhaps greater evidence to suggest more needs to be done in terms of making more effective plans and adjustments in terms of managing employees with a neurodiverse condition. The final section of this report concentrates on making recommendations on key issues to emerge from the main findings.

Case study two

Trevor was diagnosed with Asperger Syndrome ten years ago after listening to the suspicions voiced by his then mother-in-law. He had spent over a decade being employed in roles that he wasn't satisfied by and didn't feel as if he was performing well at work. As a result of organisational restructuring, Trevor was offered a job that was not wanted by other employees and if he was not willing to take this role Trevor would have been made redundant.

For Trevor this was an incredible opportunity, it was his dream job. In his own words, 'probably the reason I didn't pursue that before was probably because of my limitations, that I knew I had to jump certain heights; I'd be asked to talk... I could deal with people or not. Probably I would have to go back to studying. I mean it's complete change yet I didn't have to move from where I already work.'

Trevor worked in an environment where he felt able to be open about his condition. Not only is he working in his ideal job, he was offered flexible working arrangements which allowed him not to travel in peak times as this made him feel uncomfortable.

3 Recommendations

The main findings suggest employers who operate in the transport and travel industry should consider the following when planning to manage employees with a neurodiverse condition.

3.1 Formulating/re-formulating specific policy and practice on neurodiversity

Good general policy and practice on neurodiversity in the workplace should begin with the formulation of a specific policy and practice surrounding such issues. This is because neurodiverse conditions are not self-evident in the employee and therefore employees with a neurodiverse condition are likely to require specialised consideration and workplace support. Such policy and practice should be designed in the spirit of the employer anticipating the employment of people with a neurodiverse condition, rather than on the basis of being reactive or responsive to such issues.

Such a document should be developed through the usual procedures and involve the usual organisational personnel, such as HRM and occupational health, yet should also involve consulting employees who have a range of neurodiverse conditions, external support organisations specialising in neurodiverse conditions, line managers with experience of managing employees with a neurodiverse condition, and trade union representatives who have had training or experience of supporting employees with neurodiverse conditions in the workplace.

Particular attention should be given to the impact of cut backs and performance management initiatives on support-related planning, seeking awareness (possibly going beyond the transport and travel industry) of best practice on managing disclosure, developing support

based on employee-centred planning and the inclusion of informal support methods where practical, training to support the employee with a neurodiverse condition, as well clearly defining who should be responsible for the day-to-day management of the employee with a neurodiverse condition. Given the relatively low prevalence of neurodiverse conditions and given that employers across the transport industry currently face a wide-range of challenges and constraints, it would make sense, both practically and financially, to develop such policy and practice on an industry wide basis.

3.2 Awareness raising and information on neurodiversity

The findings suggest more needs to be done in terms raising awareness of neurodiverse conditions in the transport and travel industry. Awareness raising, however, should be aimed at all employees working in the transport and travel industry. Awareness raising should involve at the very least a range of publicity events across the transport and travel industry. Ideally, awareness raising should extend to training events for all employees surrounding such issues. To compliment awareness raising drives, information linked to support for employees with a neurodiverse condition and support for managers who manage employees with a neurodiverse condition, should be made permanently available, such as through a web-site or company Intranet system.

3.3 Line manager training on neurodiversity

It was evident in the findings that the line manager can make an important difference between a successful employment and an unsuccessful employment experience for an employee with a neurodiverse condition. Wherever possible, the training of line managers should involve the input of line managers who have demonstrated an ability to effectively manage at least one employee with a neurodiverse condition. Further, and similar to the point raised

through recommendation one on general policy and practice, line manager training should be formulated via consulting those best placed to advise on what works for the employee with a neurodiverse condition.

Appendix One

Research methods and recruitment details

Research methods

A two-stage approach was used in order to gain a relatively broad and in-depth understanding of neurodiversity issues in the transport and travel industry. The first stage, a means to assess baseline understandings of neurodiversity in the workplace, involved the use of focus groups. Focus groups were used at the first stage because this particular research approach allows the researcher to examine the ways in which people with one another construe the general topics in which the researcher is interested¹. The focus groups were fully transcribed. The data was subsequently coded and analysed according to the main themes of the research – e.g. knowledge and attitude towards neurodiversity and perceived support and management of employees with neurodiversity in the workplace.

The second stage of the research involved semi-structured interviews conducted over the telephone. At this stage the aim was to acquire more individualistic, varied and in-depth perspectives and experiences of neurodiversity issues in the workplace. Indeed, semi-structured interviews are ideal in such situations because this approach is said to allow a more accurate and clear picture of a person's position or

¹ Bryman, A. and Bell, E. (2011), *Business Research Methods*, 3rd edition, Oxford: Oxford University Press.

behaviour to emerge². The decision to interview transport and travel industry employees via telephone represented a pragmatic rather than an ideal choice. The choice here related very much to the time and costs associated with interviewing people over a very wide geographic area³. Interviews were fully transcribed and also coded and analysed on the same basis as the focus groups. However, the analysis of the interviews focused more on identifying critical incidences and data from the interviews was intended to be used more as a way of illuminating good and not so good practice surrounding the management of employees with a neurodiverse condition.

Recruitment details

A range of strategies were considered in order to recruit participants to take part in the first stage of the study. Participants were recruited through a geographical sample of TSSA's membership. Emails and reminder emails were sent to more than 4,000 TSSA members in the south east of England and York area detailing the study and the research method. TSSA membership was not a precondition to take part in the focus groups and recipients of the recruitment emails were encouraged to pass on the details of the research to friends and colleagues in the transport and travel industry, regardless of trade union membership. No financial inducements were used other than to compensate travel expenses. In total seven focus groups were arranged (six in London and one in York) involving forty-four employees from the transport and travel industry (further details of the focus group

² Ghauri, P. and Gronhaug, K. (2009), *Research Methods in Business Studies*, 4th edition, London: Prentice Hall.

³ Cameron, C. and Price, D. (2009) *Business Research Methods: A Practical Approach*, London: CIPD.

participants can be found in Appendix Two). The focus groups were held in August and September 2012 and each lasted between sixty and eighty minutes. The eventual sample, as expected, was largely self-selecting, in that the majority reported having a neurodiverse condition, had a relative or friend with a neurodiverse condition, had managed or represented an employee with a neurodiverse condition, or had some training on neurodiverse conditions. Only three focus group participants reported no such experiences. All participants were given advance details of the nature of the study, informed of the right to withdraw from the study at any point in the proceedings, as well as being given details of how the data from the focus groups would be stored and eventually used.

Recruiting for and conduct related to the interviews largely followed a similar path to the focus groups. However, one difference was that no geographic limitations were imposed at this stage of the study and recruitment emails were therefore sent to all TSSA members who had provided TSSA with an email address, for contact purposes. In total twenty-three interviews took place as a result of the second recruitment drive. Seven out of the twenty-three interviewees had also taken part in the focus groups. The interviews took place in October 2012 and lasted between twenty-five and fifty minutes. Details of the jobs of employees taking part in both focus groups and interviews can be viewed by consulting Appendix Three. Out of the sample of twenty-three, seventeen reported having a neurodiverse condition and six reported managing or overseeing a work placement for an employee with a neurodiverse condition. The interview sample included ten employees with dyslexia, five employees with Asperger syndrome, one employee with dyspraxia and one employee with ADD/ADHD. Several participants reported a second neurodiverse condition, but in most cases this had not been formally diagnosed.

Summary

The methodology was designed to explore a range of issues related to neurodiversity in the workplace. While the approach represents in one sense a small proportion of all those employed in the transport and travel industry, the strength of the approach is in terms of exploring such issues through those most affected by such issues, as well as the use of research methods that allow a frank and deep exploration of personal views and experiences concerning neurodiversity in the workplace.

Appendix Two

Details of focus groups and focus group research participants

Number of focus groups	7
Total number of research participants	44
Average participants per focus group	6.3
Average age of participant	48.5
Trade union membership	90.9
Percentage male	79.5
Percentage female	20.5
Average length in current job	8.1
Has neurodiverse condition	27.3
Works with someone with neurodiverse condition	29.5
Has neurodiverse condition and works with someone with neurodiverse condition	9.1

Appendix Three

Example job titles of research participants

Architect

Business Manager

Case Officer

Commercial Analyst

Consultant Engineer

Contract Manager

Delivery Planner

Employee Communication
Executive

Engineering Data Analyst

Highways Interface Advisor

HSE Manager

Information Analyst

Lead Operations Specialist

Liabilities Negotiator

Performance and Assurance
Engineer

Principle Delivery Planner

Programme Engineer
Manager

Project Manager

Research and Data Analyst

Research and Insight
Manager

Route Control Manager

Safety Management System
Specialist

Safety Manager

Safety Specialist

Senior Assets Engineer

Senior Track Principles
Engineer

Service Centre Administrator

Signalling Bids Engineer

Station Assistant
Multifunctional

Station Supervisor

Support Engineer

Team Leader (Ticket Office)

TSSA Helpdesk number

020 73872101

Dyslexia and Dyscalculia

Dyslexia Action

www.dyslexiaaction.org.uk

Dyspraxia

Dyspraxia foundation

www.dyspraxiafoundation.org.uk

ADD/ADHD

AA-DD UK

<http://aadduk.org>

Asperger syndrome

National Autistic Society

www.autism.org.uk

Neurodiversity

tssa