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DARE REPORT ON ADJUSTMENTS

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CONTENTS

INTRODUCTION

As part of the Neurodiversity Employment Survey 2019, launched in partnership between the Centre for Research in Autism and Education (CRAE) at UCL and Autistica, we have been gathering data about the experiences of neurodivergent employees regarding the adjustments they have encountered in the workplace.

Adjustments are changes to the working environment and practice designed to make working accessible and allow people to work safely and productively. Adjustments can include modifications to the physical environment, processes of communication, social norms, company culture, job roles/responsibilities, and line-management.

This report describes the data gathered so far from responses to our public survey about adjustments. We are producing freely accessible interim reports, which will be periodically updated to ensure timely dissemination of findings for our participants and the wider autism and employment research field.

As such, these reports, reviewed by the DARE advisory board[i], are intended to provide summary insights of trends we are observing in the data and focus mostly on qualitative insights. For those interested in detailed scientific discussion of our research including analysis of the participant sample, methodology, statistical analyses and contribution of findings to existing academic literature, please check our website dareuk.org for further information.

TERMINOLOGY

Autistic people perceive and experience the world around them in unique ways. In this report, we use the term 'autism' to refer to everyone within the autism spectrum (including those with a diagnosis of Asperger syndrome or those who are labelled as 'high-functioning'). This reflects a shift away from dividing those on the autistic spectrum into separate categories in favour of using umbrella terms including 'autism' or 'autism spectrum disorder/condition'. Indeed, terms such 'high-functioning' or 'low-functioning' are often perceived to be unhelpful and even misleading labels that can prevent people from recognising individual strengths and needs.

We also use 'identity first' language, that is, we describe someone as an 'autistic person' rather saying a 'person with autism'. This is because it is the preferred term of autistic activists[ii] and many autistic people and their families[iii] and is less associated with stigma[iv].

We also use the term 'neurodiversity', which describes the range of different diagnoses and dispositions that may lead people to perceive and experience the world in different ways. We view autism as a natural part of human variation and neurodiversity. However, people may also have multiple diagnoses, including, for example, ADHD, or Tourette's and in our research, we therefore take a traits-based approach to understanding people – that is recognising their specific abilities, preferences, aptitudes, and experiences, rather than a labels-based approach that categorises individuals into "boxes" of typical behaviours. This approach is more nuanced and suited to identifying strengths and how to support them in neurodivergent individuals.

For more information about these terms, and our decision to use them, see the following resource: https://journals.sagepub.com/doi/full/10.1177/1362361315588200

The Neurodiversity Employment Survey was launched in May 2019. It was designed to elicit the employment experiences of neurodivergent people to date. The survey is ongoing and remains open to anyone, including people without a diagnosis. Participants can describe, in their own terms, the factors that are relevant to the way they perceive and experience the world around them.

The survey is structured around seven key topic areas:

- Experiences around diagnostic disclosure.
- Experiences around masking (or 'camouflaging', which is suppressing neurodivergent traits to fit in).
- Perceptions of organisational culture.
- Adjustments used in the workplace.
- Experiences of recruitment processes.
- Mental health.
- Priorities for future research on autism and employment.

Participants can choose which topic areas they would like to respond to once they have completed the sign-up process for the survey.

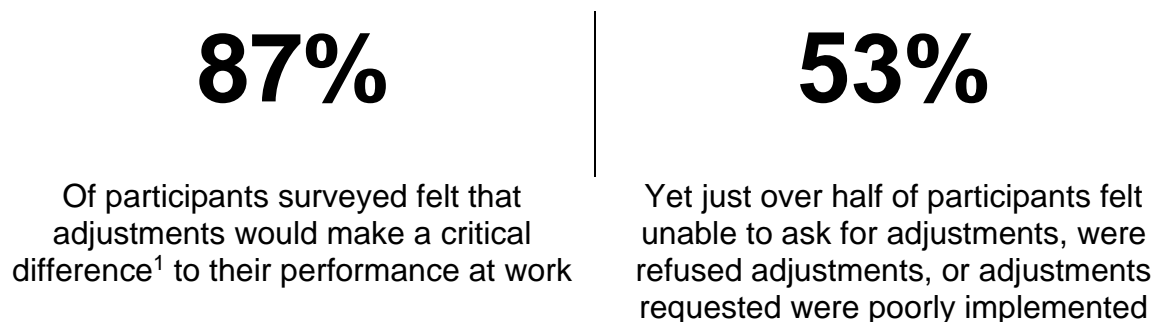If you would like to take part in the 2020 edition of the survey, please use the following link: **http://bit.ly/NEScrae2020**

SUMMARY FINDINGS

By September 2019, over 650 participants had taken part in the public version of the survey. The main survey had separate "modular" sections which were optional to take. The data reported here relates to neurodivergent participants who chose to complete questions on adjustments (n=206). Participants were asked questions about:

- The frequency of adjustments requested
- The type of adjustments requested
- The extent to which they could discuss adjustments with their employer
- Their perception of the value of adjustments on workplace performance

Participants were also asked questions about their experiences of adjustments, what they felt made them successful or unsuccessful, and what their perceptions were of organisational decision-making around implementing adjustments.

Figure 1: Adjustments impact

87%

Of participants surveyed felt that adjustments would make a critical difference[1] to their performance at work

53%

Yet just over half of participants felt unable to ask for adjustments, were refused adjustments, or adjustments requested were poorly implemented

Source: Neurodiversity Employment Survey 2019, CRAE. (n = 206).
[1] Impact rated as "very important" or "extremely important"

The data have highlighted three key themes:

1. Identification: Not knowing which adjustments might be helpful

Often neurodivergent job-seekers/employees would report that their managers were unaware of what adjustments could be implemented within the organisation they worked in. This could be due to:

- A lack of information about adjustments previously used within the organisation.

- A lack of understanding about different types of support needs and the respective strengths of different adjustments in addressing those needs.
- Placing the burden of responsibility of identifying adjustments upon neurodivergent individuals who themselves may lack the communication skills required to introspect or speak up about concerns.

2. Implementation: Challenges reported with implementing adjustments

In cases where adjustments could be identified, successful implementation faced a number of challenges including:

- Perceived stigma for requesting adjustments (e.g., being seen as a "trouble-maker");
- Making adjustments sustainable over time given potential changes in job role;
- Unclear organisational pathways (e.g., should the employee talk to the manager first or talk to Human Resources?), which were felt to be anxiety-provoking for neurodivergent employees; and
- Adjustments being refused, which was reported by participants for various reasons, including in cases where the line-manager explained the adjustment would impact other employees.

3. Consequences: Impacts on wellbeing and policy

Participants felt that managers and employees often differ as to whether an adjustment is seen as "reasonable", reflecting ambiguity and potential inconsistency in adherence to the Equality Act 2010. They further felt that these challenges impacted on:

- Employee wellbeing;
- Employee retention; and
- Legal processes where employees have been dismissed and reasonable adjustments have not been provided.

Data on employee wellbeing, mental health, and wider employment impacts have been gathered and will feature in forthcoming reports. In this report we address two

knowledge gaps outlined above: **Identification** of which adjustments are possible (through documenting the range of adjustments neurodivergent people have reported to have found useful, see Appendix), and the key considerations around successfully **implementing** such adjustments.

This report will continue to be expanded through further iterations as our data collection is ongoing. The main aim of the report is to provide timely dissemination of findings for our participants and the wider autism and employment research field. In doing so, it is hoped that the report can also help employees and their employers to identify and implement the adjustments that neurodivergent people need to flourish in the workplace.

KNOWLEDGE GAP 1: IDENTIFYING POSSIBLE ADJUSTMENTS

Figure 2: Neurodivergent experiences of adjustments in the workplace

34%	**44%**	**2%**
Over one third of participants reported that their request for adjustments had been successfully implemented	The most common type of adjustment requested related to processes of communication, reported by 44% of participants	Only 2% of participants reported that their employers had proactively supported seeking and implementing adjustments
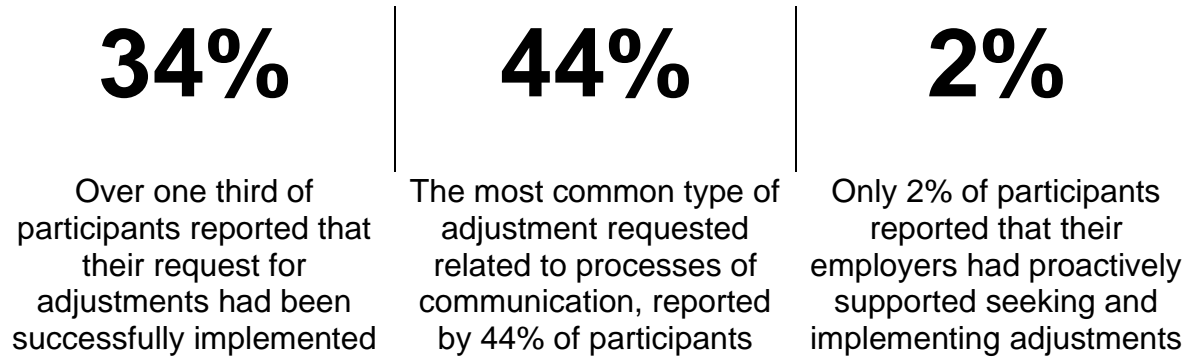
Source: Neurodiversity Employment Survey 2019, CRAE. (n = 206).

What adjustments are available or previously used?

Over half of participants surveyed reported significant difficulties in accessing adjustments. For neurodivergent participants, a lack of resources for identifying which adjustments are possible within an organisation was reported as a major barrier to successful employment. While some neurodivergent participants had an idea of what adjustments might work for them based on past experience, often the onus was on neurodivergent employees to speak up about their concerns. Neurodivergent participants reported that they were not always able to identify their own adjustments or recognise how they could be implemented in the workplace. In addition, hiring managers or line managers themselves may not be aware of which adjustments are possible, particularly if there is no centralised process for gathering this information and communicating it back to employees.

PARTICIPANT QUOTE

"[I] have not experienced being offered or given any adjustments, only disbelief that I had any genuine need."

In response to the challenge of how to identify possible adjustments, we have provided an anonymised list of reported adjustments from our survey in Appendix. This is a list that will continue to grow as we gather more data. This list can help to facilitate conversations between employees and their organisations through broadening the range of ideas about possible adjustments.

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We have categorised adjustments reported in participants' data into three types:

- Adjustments to job role and management processes (including communication)
- Adjustments to physical space and equipment
- Adjustments to social/cultural practices within the organisation

Which support needs can be addressed by workplace adjustments?

Adjustments support different aspects of employee performance at work and overall well-being. Improved identification of which specific needs an individual may have will play an important role in determining the success of adjustments. In our data thus far, participants' support needs fall into one of six areas:

- Physical mobility and access – adjustments that make workspaces and tasks accessible to people of all physical abilities.
- Social – adjustments that reduce difficulties in social situations that neurodivergent people may experience.
- Cognitive – adjustments that support the difficulties that neurodivergent people may have with processing times, memory and organisation skills.
- Sensory – adjustments that recognise the unique way in which neurodivergent people may perceive and experience different sensory stimuli in the workplace including sound, vision, touch, taste and smell.
- Mental health and wellbeing – adjustments that facilitate the mental health and wellbeing needs of neurodivergent employees.
- Skill and experience – adjustments that recognise the extent to which neurodivergent people may have been previously disadvantaged by the education system/prior work experiences. Such adjustments involve establishing a targeted structure for supporting the growth of skills and experience.

What are the intended outcomes of adjustments?

Adjustments also work towards different outcomes. For example, some adjustments are aimed at minimising distractions (e.g., using site blocker software to avoid distractions on computers, or noise cancelling headphones for those with extra-

sensitive hearing), while others are designed to enhance focus (e.g., a weekly plan and apps designed for managing tasks). Awareness of the intended outcomes that respective adjustments can achieve may help to increase the effectiveness of their implementation.

Another key challenge reported by participants is the process of transitioning from a familiar to a less familiar environment or set of routines. Transitions are commonplace during employment, including, for example into a new role, moving through promotion, through growth of the company, through changing one's responsibilities or leaving the workplace altogether. Adjustments can help to manage anxiety and provide structure when routines change. For example, weekly plans with managers can help to establish expectations and assist neurodivergent candidates by helping to organise and prioritise their workload.

Therefore, in identifying adjustments, it is also important to be aware of the different outcomes associated with adjustments. Figure 3 below provides a summary of factors associated with identifying adjustments within the workplace.

Figure 3: Summary of factors to consider when identifying adjustments

What adjustments are available?	**What are support needs?**	**What are intended outcomes of adjustments?**
• Physical environment and equipment • Job role and management processes • Social and cultural practice	• Physical mobility and access • Social • Mental health and wellbeing • Cognitive • Sensory • Skill / experience	• Remove barriers to access • Minimise discomfort / distraction • Enhance comfort / focus/ performance • Facilitate transitions (into work, through work, and across work-life balance)

KNOWLEDGE GAP 2: IMPLEMENTING EFFECTIVE ADJUSTMENTS

Figure 4: Ability to discuss adjustments with employer

30%	**37%**	**15%**
Just under one third of participants felt unable to discuss the need for adjustments within their organisation	Over one third of participants chose to discuss adjustments privately with someone they trust	Only 15% of participants reported that they were comfortable openly discussing adjustments within their organisation
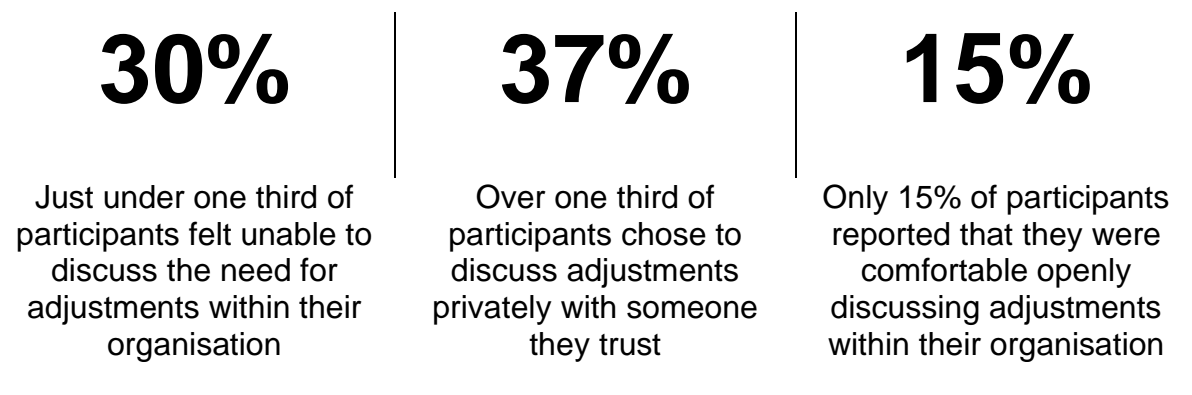
Source: Neurodiversity Employment Survey 2019, CRAE. (n = 206).

Successful implementation of adjustments was another key issue identified by participants. Implementation refers to embedding an adjustment within organisational practice so that the adjustment is sustainable over time and tailored to individual needs and working patterns. Successfully implementing an adjustment requires more than accurate identification of support needs, it also requires an iterative and continuous approach to evaluating effectiveness and understanding how to improve support. For example, individual differences mean that what works for one employee may not necessarily work for another. Likewise, an adjustment may be effective to begin with (e.g., wearing headphones in an environment where this is normalised) but may become challenging if there are changes in organisational context. In our data, factors associated with successful or unsuccessful implementation of adjustments focussed on two key areas: communication and management.

PARTICIPANT QUOTE

"I find that often people respond to [adjustment] requests positively but forget and fail to keep up the good work. I don't think this is ill will but probably because they are busy and thinking about other things which seem more pressing and/or fail to see what a difference it makes to the autistic person."

In the following sections we outline factors associated with communication and management before drawing these together into a visual framework for understanding adjustments.

Can pathways for requesting adjustments be simplified?

For neurodivergent employees, pathways for seeking adjustments can be challenging. According to the Equalities Act 2010, employers have a duty to provide reasonable adjustments if an employee has a disability. However, neurodivergent participants reported that they had difficulty in accessing adjustments because they did not always feel safe to disclose their diagnosis. Likewise, some participants also wanted adjustments but had self-diagnosed and did not feel that they were afforded the same level of protection by the Equalities Act 2010. Stigma also affected recruitment processes, where participants reported that they did not indicate on application materials about their diagnosis for fear of negative discrimination. Moreover, speaking up about adjustment needs can be challenging given the communication difficulties encountered by many neurodivergent people, which is why organisations need to be proactive in supporting ongoing dialogue with employees around adjustments.

Participants reported that it would be better if pathways to adjustments were simplified and involved a designated point of contact for raising questions about adjustments, exploring what is possible, and having adjustments implemented. The point of contact would ideally not be a line-manager, since this can cause anxiety about speaking about support needs, particularly if such needs are related to processes of line management itself. Similarly, if the point of contact is too far removed from the team, this can also mean that specific support needs within the immediate working environment might not be fully taken into consideration.

How to reduce anxieties associated with requesting adjustments?

As part of our study, we asked people about their anxieties associated with reporting adjustments. Our data highlight a range of factors, including those associated with manager personality traits (e.g., their empathy), resources (e.g., time and effort), organisational factors (e.g., productivity benefit) and factors related to the way the neurodivergent employee believes they are valued by their line-manager.

Figure 5: Factors neurodivergent employees felt are associated with manager decision-making towards an adjustment

Manager traits	Resources	Organisational factors	Employee factors
• Values • Knowledge of autism • Empathy • Desire to retain staff	• Cost • Convenience • Space • Time	• Brand image and team ethos • Effect on other staff • Productivity benefit • Equality policy	• Employee status (e.g level of seniority in company) • Perceived compliance of employee • Mental health

The data indicate a range of factors associated with requesting adjustments. In particular, requesting an adjustment was felt to be intrinsically linked with employee identity and perceptions of how the employee is perceived and valued by those around them. Therefore, manager traits, such as empathy and knowledge of autism featured highly on reported factors affecting decision-making around an adjustment. Likewise, the perceived status of the employee and their effect on team productivity are also commonly reported factors. These insights therefore highlight that there appear to be considerable anxieties associated with requesting an adjustment.

How will adjustments be sustainable?

Good communication also extends beyond the adjustment being initially implemented. Often neurodivergent employees reported that they had to advocate for adjustments after they had been implemented. For example, if an employee wanted to avoid unnecessary physical contact, systems needed to be put in place to ensure that new people remained informed about such preferences. Adjustments therefore need to be successfully embedded within organisational practice otherwise neurodivergent employees will repeatedly have to advocate for themselves which itself can detract from wellbeing. Establishing interaction protocols where both employee and employer can discuss and evaluate adjustments will help to ensure sustainability. Sustainability

also links with broader considerations related to management, which are outlined below.

What resources do adjustments require?

Adjustments may sometimes, but not always, require resources. For example, some organisations will be better placed than others to set up a quiet zone within an office to facilitate short breaks. Resource considerations commonly reported include:

- Time (from management and HR to identify and implement an adjustment)
- Effort (from management and HR to identify and implement an adjustment)
- Financial cost (e.g., if adjustment involves new equipment, or funds to invest in neurodiversity training)
- Space constraints (e.g., setting up a quiet room may not always be possible)

It should be noted, however, that most adjustments identified by participants (see Appendix) are low cost and easy to implement. This is particularly important because many participants reported that they felt they were denied adjustments due to resource concerns, with their own individual needs secondary to such concerns.

What variations in employment may affect adjustments?

Selecting adjustments that support job performance and well-being also requires consideration about the impact of changing contexts. Changing contexts can include factors such as:

- Changing responsibilities
- Management restructuring
- Changing work location
- Changing work personnel (both internal and external)
- Changing workload

For example, some participants reported that they actively resisted promotion from their current job role because they did not want a change of responsibility and routine. Likewise, employees reported that they would have benefitted from more realistic expectation-setting by the employers. For example, job adverts are sometimes vague

about ad-hoc tasks associated with job roles, meaning that employees are insufficiently prepared for changes associated with their core workload.

How can adjustments be tailored for individual needs?

Embedding adjustments within everyday practice can sometimes take time to become honed to individual needs and organisational practice. Moreover, many adjustments will need to be iteratively developed over time as people's needs change. This highlights the importance of good communication and organisational protocol for monitoring and following up on adjustments. Ideally, employees would benefit from being supported by adjustments as they start work, which necessitates a pre-employment discussion about what adjustment needs there may be. Follow-up discussions can be scheduled, or even integrated to probationary meetings, to periodically assess the effectiveness of adjustments and identify new adjustments as the employee becomes familiar with their day-to-day roles and responsibilities.
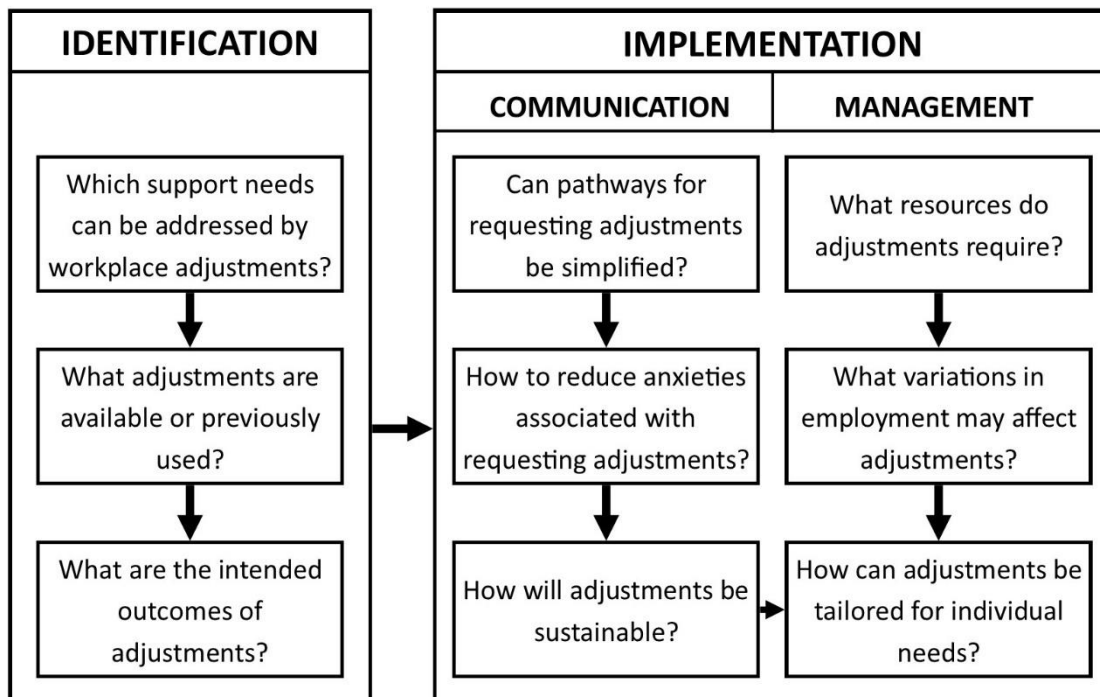
> **PARTICIPANT QUOTE**
>
> *"Frequent feedback, I now know, is vital for me. Effective, respected, experienced managers who genuinely believed in supporting and developing their teams helped me to work better […] it's not about being micro-managed (that's hell) it's about appropriate management."*

Often organisations do not have centralised knowledge about what adjustments have been used or embed this knowledge within a resource that line-managers can access. This framework (outlined below), as part of wider DARE's resources (https://dareuk.org/resources), can help to address some of the knowledge gaps.

DARE FRAMEWORK FOR ADJUSTMENTS

To summarise, our data have highlighted factors associated with implementing adjustments for neurodivergent employees. We have drawn these factors together into the following **9-question framework** to help organisations structure their approach to tailoring adjustments to individual needs and enable employees to flourish in the workplace.

DARE ADJUSTMENTS FRAMEWORK

IDENTIFICATION	IMPLEMENTATION	
	COMMUNICATION	**MANAGEMENT**
Which support needs can be addressed by workplace adjustments?	Can pathways for requesting adjustments be simplified?	What resources do adjustments require?
What adjustments are available or previously used?	How to reduce anxieties associated with requesting adjustments?	What variations in employment may affect adjustments?
What are the intended outcomes of adjustments?	How will adjustments be sustainable?	How can adjustments be tailored for individual needs?

APPENDIX: LIST OF ADJUSTMENTS

The following lists are designed to help facilitate discussions between neurodivergent employees and managers about what possible adjustments could be implemented. It details common types of adjustments reported in the DARE dataset. Adjustments and their suitability will vary from person to person, as well as workplace roles. Therefore, the adjustments listed below should be discussed on an individual basis in conjunction with the questions highlighted by the DARE Adjustments Framework above in order to identify what may work or not work.

Job role and management processes

- **Accurate job descriptions (e.g., not emphasising social presentation skills when not necessary, clarifying likelihood of taking on additional responsibilities)**
- **Advanced notice of changes**
- **Avoid role-play on training courses**
- **A culture of asking one question at a time**
- **Explicit communication (e.g., written instructions rather than verbal)**

- **Evolving job role based on strengths**
- **Extra breaks to prevent becoming overwhelmed**
- **Extra time meeting with managers**
- **Flexible deadlines**
- **Flexible work hours to avoid commuting in rush hour**
- **Frequent feedback**
- **Longer time to familiarise with new routines when there are changes**
- **Maintain consistent job roles, patterns and working partners where possible**
- **Minimise unnecessary away days**
- **Minimise unnecessary face-to face meetings**
- **Minimise face-to-face interaction where possible**
- **More time for tasks**
- **Online access to further information about sources of support for job role, mental health and wellbeing**
- **Option to work remotely where possible**
- **Process for having concerns recorded and taken seriously**
- **Realistic manager expectations**
- **Specifying clear action points in emails so that recipients understand what is being asked of them**
- **Trialling workspace before starting**
- **Using a mentor (external) to help manage challenges**
- **Using an internal advocate who can communicate on behalf of the employee**
- **Weekly plan with manager**
- **Widespread training on neurodiversity available to all employees**
- **Written communication preference over verbal communication**
- **Written questions for job interviews and circulated ahead of time**

Physical environment and equipment

- **Ability to adjust temperature where possible (e.g., through air conditioning, desk fan)**
- **Allocated desk (i.e., in otherwise hot-desking environment)**

- **Allocated parking space**
- **Avoid fluorescent strip lighting if possible**
- **Avoid open plan office if possible**
- **Blue screen filter for computer screen to see colours more easily**
- **Clear signage throughout building and designated quiet areas**
- **Communication devices (e.g., a slider on desk to indicate when working from home).**
- **Designated quiet space**
- **Ear defenders**
- **Ear plugs**
- **Ergonomic chair**
- **Ergonomic wrist-rest and keyboard**
- **Fast response to malfunctioning equipment (e.g., a flickering light above desk)**
- **Laptop stand (neck and back support)**
- **Maximise personal space where possible (e.g., spaced out seating in meetings)**
- **Noise-cancelling headphones**
- **Online accessible resources about getting up to speed in a new role**
- **Option to work away from doors (which slam shut) and busy pathways**
- **Repositioning of desk (e.g., in corner to avoid being startled)**
- **Secondary glazing (to provide sound protection) where possible**
- **Site blocker software to avoid internet distractions**
- **Small desk lamp (if main light too bright or not bright enough)**
- **Software to improve accessibility (e.g., screen reader)**
- **Tinted glasses (to minimise overpowering lights)**
- **Visual partitions of workspace (i.e., to minimise distraction and sound)**

Social and cultural practice

- **A team culture that is aware of sensory impacts (e.g., eating lunch away from desks due to potential sensory discomfort from smell)**
- **A team culture that encourages quieter lunchtime conversations**

- **Ability to explore other job roles within the organisation**
- **Access to senior mentoring**
- **A team culture that educates about negative language in the workplace (e.g., describing autism as a tragedy)**
- **A team culture that avoids unnecessary metaphorical and idiomatic language (which can be hard to interpret for autistic people)**
- **A team culture that respects preferences concerning physical contact (e.g., no handshakes)**
- **Being asked about one's preference for social events (e.g., whether to receive birthday cards, location for social dinner)**
- **Colleagues conscious about wearing strong perfumes**
- **Ensuring all team members understand and respect adjustments in absence of manager**
- **Flexibility regarding clothing choice if possible**
- **Handouts in advance of training/presentations (to follow what is being discussed verbally)**
- **A culture that respects keeping promises if they are made**
- **More patience and flexibility from colleagues regarding misunderstandings**
- **Offering the option to refuse taking on more work (since some employees find it very difficult to say no)**
- **Reduced overnight stays where possible**
- **Relaxed obligations to social commitments**
- **Specified hours for responding to emails**
- **Training staff on neurodiversity and specific needs**
- **Working near familiar and understanding colleagues**

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[i] The DARE Advisory Board consists of neurodivergent expertise and business expertise.

[ii] Sinclair, J. (1999). Why I dislike 'person-first' language. *Jim Sinclair's website*. Available at http://web.archive.org/web/20090210190652/http://web.syr.edu/~jisincla/person_first.htm

[iii] See 'Which terms should be used to describe autism? Perspectives from the UK autism community'

[iv] Gernsbacher, M.A. (2017). Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of child psychology and psychiatry, and allied disciplines, 58*(7), 859-861. doi:10.1111/jcpp.12706