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# Autism in the workplace

Written for the TUC by Janine Booth



### **About the author**

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### **Introduction by the General Secretary**

Autism is a term covering a wide range of conditions that reflect neurological differences among people: the barriers placed in the way of workers who have an autistic condition may affect their lives at work. This first ever TUC guide to autism aims to inform trade union officers, representatives and members of the facts, and advise how to support members who are autistic to secure the adjustments they may need, and to which they are legally entitled. The author is an expert who is already successfully challenging unions and employers to understand neurological diversity and its consequences for neuroatypical workers and I hope that many unions will make use of this expertise to equip themselves to tackle the challenges and obstacles faced by ignorance and prejudice faced by workers who are autistic.

**Frances O'Grady**

TUC General Secretary *April 2014*

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## Section one

# The social versus medical model

There are different ways of understanding disability. The two main ones are:

- the social model
- the medical model

The trade union movement uses the social model of disability. This section explains the social model and how it applies to autism. The rest of this handbook uses the social model to understand autism in the workplace and trade union strategies for taking up this issue.

### **Social model of disability**

The social model looks at the barriers that our society puts in the way of disabled (in this case, autistic) people's participation, including both attitudes and practical barriers. It aims to remove unnecessary barriers which prevent disabled people accessing work and services and living independently.

The social model identifies the problems faced by disabled people as a consequence of external factors. For example, bright lighting in a workplace might cause distress to an autistic person who has sensory sensitivity to light.

The social model distinguishes between *impairment* and *disability*.

*Impairment* is described as a characteristic or long term trait which may or may not result from an injury or disease or condition. For example, a person on the autistic spectrum may have executive function impairment (explained in section two below).

*Disability* is the difficulty experienced by people with an impairment by society not taking sufficient measures to take account of their needs. For example, an individual is not prevented from carrying out a sudden change in working practices by being autistic, but by the employer not giving enough notice of and preparation for the change.

The social model identifies attitudes which may impede disabled people's participation and equality. There is prejudice and ignorance surrounding autism. There are also workplace practices, procedures, cultures, unwritten rules and communication forms which do not take account of people on the autistic spectrum.

## **The social versus medical model**

### **Medical model of disability**

The medical model presents the impairment as the cause of disabled people's disadvantage and exclusion. If an employer decides that a person cannot work for his/her company because s/he is autistic, rather than considering how to make the workplace suitable for an autistic person to work in, that employer is probably being influenced by the medical model of disability.

Unfortunately, the medical model dominates much political and legal decision-making.

### **The trade union response**

The trade union movement supports the social model of disability. In individual representation, collective bargaining, drawing up demands and campaigning for them, the most effective approach for trade unions to follow is to identify the factors in the workplace environment and working conditions that disable the autistic worker. Then, the union can identify and fight for the changes that would remove these factors.



## Section two

# What is autism?

### **Neurological diversity**

Autism is an example of *neurological diversity*, or *neurodiversity*. Humanity is a neurologically diverse species – people have different neurological make-up, different ‘brain wiring’. A population – whether that is a workforce, the people of a particular country, an age group, etc – is *neurologically diverse* or *neurodiverse*.

Autistic people are *neurologically atypical* or *neuroatypical*.

Other neurological conditions include dyslexia, dyspraxia, dyscalculia and attention deficit hyperactivity disorder (ADHD).

People without a neurological condition are referred to as *neurologically typical*, or *neurotypical* – or even ‘NT’!

### **Autism**

Firstly, it is worth noting that understanding of autism is growing, but is still limited. We have a lot further to go!

The National Autistic Society describes autism as ‘a lifelong developmental disability’. However, some autistic people find this definition quite negative.

A more neutral and descriptive definition might be: *Autistic Spectrum Conditions* are neurological developmental conditions. They occur when atypical (unusual) brain connections lead to atypical development. These differences in the way the brain functions lead to particular challenges and abilities and unusual development.

### **Autism is a spectrum**

Autism affects different people in different ways.

You may have heard terms such as Asperger syndrome, High functioning autism, Low functioning autism, Classic autism or PDD-NOS (Pervasive Development Disorder – Not Otherwise Specified). All are part of the autistic spectrum.

Some of these distinctions may be unhelpful. For example, a person labelled ‘low-functioning autistic’ may find that his/her skills and abilities are overlooked; while a person labelled ‘high-functioning autistic’ may find that his/her needs are overlooked. It is important that each person with autism is recognised as an individual.

## What is autism?

“The autistic spectrum covers a very wide range of people, and these people don’t always fit neatly into the available groupings. ... Essentially, the people in all the above groups are all a part of the autistic spectrum ... The personality and needs assessment of a person on the spectrum should be looked at on an individual basis, rather than on the basis of a label.” *Aspies For Freedom*

### What the manual says

The [Diagnostic and Statistical Manual of Mental Disorders](#) is the [American Psychiatric Association](#)’s classification and diagnostic tool, and provides a medical definition of autism. Its Fifth Edition, abbreviated as DSM-5, was published in 2013. Previous editions had listed ‘Asperger’s Disorder’ separately, but DSM-5 abandoned this practice, and includes a single definition of Autism Spectrum Disorder.

### Social communication

People on the autistic spectrum may communicate differently from typically-developing people. A minority do not speak.

### Social interaction

Typically-developing people learn through social interaction, from childhood.

People on the autistic spectrum may not do so, and may only learn social ‘rules’ by being taught, by themselves or others.

You can think of this as being similar to how people learn languages. Most people learn their first language by ‘picking it up’ from the people they live with. They may then learn another language by studying it, for example at school.

So, neurotypical people learn ‘social skills’ through social interaction, like you learned your first language. People on the autistic spectrum may not do so, and may have to study to learn ‘social skills’ – like you might have learned an additional language at school.

Many social ‘rules’ are not written down or explained – it is assumed that people will know them. But how is an autistic person supposed to know what s/he is supposed to say or do?

Eye contact may be uncomfortable or difficult for an autistic person.

“I can actually listen better if I don’t make eye contact. It’s an autism thing. Please be understanding.” Campaign T-shirt

A person with autism may find it difficult to ‘read’ emotions in people’s facial expressions.

A person with autism may find it difficult to ‘read’ social cues eg. when to speak; when to stop speaking; when a conversation is over; how close to stand to someone.

### **People with autism tend to think literally**

However, typically-developing people do not always speak literally. So from an autistic person’s view, neurotypical people can be hard to understand and seem very odd at times! NTs often:

- say things that they don’t mean (‘I’m going to kill her’)
- tell you to do things that they don’t want you to do (‘Pull your socks up’)
- ask questions but don’t want an answer (‘Why is he such a #\*#@#!?’)
- ask questions but don’t want an honest answer (‘How are you?’)
- answer a question with an answer to a different question (‘Are you having your meal break now?’ ‘I’ve got to finish this report.’)
- use figures of speech (‘You’ve got ants in your pants’)
- don’t say things they do mean (‘I’m not interested in this subject’)
- say things in an illogical order (‘It’s time for the shop to close – make an announcement’)
- laugh when there is no obvious joke (‘Terrible weather – ha ha ha!’)
- think you have said things that you haven’t (‘You’re saying I’m wrong’)
- say the opposite of what they mean (they call this sarcasm) (‘Yeah, right!’)
- expect you to figure this out!

### **Rules, routines and schedules**

People on the autistic spectrum tend to be comfortable when rules, routines and schedules are adhered to, and can become uncomfortable or distressed when they are broken, disrupted or changed.

### **Special interests**

“Many people with autism have intense special interests, often from a fairly young age. These can change over time or be lifelong, and can be anything from art or music, to trains or computers. Some people with autism may eventually be able to work or study in related areas. For others, it will remain a hobby.” National Autistic Society

It is notable that in our society, if an autistic person has a ‘special interest’ in, say, UFOs or train timetables, this may be seen as eccentric or as an unhealthy

## **What is autism?**

obsession – but that non-autistic people’s obsessions with boy bands or football teams are usually considered perfectly normal!

### **Executive function**

This is the set of abilities that enable people to translate motivation into action, to:

- START doing something
- CHANGE what they are doing
- STOP doing something once started
- manage time.

People with autism may have impaired executive function.

### **Motor function**

People with autism may have impaired motor function: balance; movement; co-ordination.

### **Sensory sensitivity**

People on the autistic spectrum may be intensely sensitive (hypersensitive) or under-sensitive (hyposensitive) to one or more sensory stimuli eg. heat, cold, sound, light, dark, textures, smells, pain.

### **Sensory overload**

For many autistic people, the constant bombardment of sound, light, colours, patterns, numbers, temperatures, textures, smells and feelings can become too much.

“My brain lets all this in ... It doesn’t seem to have a filter ... so I can take in and process loads of information ... and think about it constantly ... but it can overwhelm me.”

### **Distress**

It is little wonder that with all this going on – communication barriers, frustrations, misunderstandings, sensory sensitivity, sensory overload, unexpected changes, rules being broken, discrimination, prejudice – that many autistic people experience stress, anxiety, and sometimes, ‘meltdowns’.

### **Self-stimulatory behaviours (‘stimming’)**

Many autistic people engage in habitual, repetitive movements that provide comfort and/or stimulation eg. rocking, spinning, jumping, skipping.

## Section three

# Myths and facts

**Beware of stereotypes; they can overlook people's individuality, and lead to mocking and bullying.**

*'Autism is one of those trendy 'conditions' that everyone seems to have these days.'*

This is a commonly-heard view, but an inaccurate prejudice which undermines the very real experiences of people with autism and their friends and families.

*'Autism is just an excuse for bad or anti-social behaviour.'*

This is another commonly-heard view, but again, an inaccurate prejudice. 'Bad behaviour' can just be unusual or eccentric behaviour which may not harm anyone. Behaviour that does cause difficulties may be the product of distress, in a situation that does not take into account the needs of a person with autism eg. sensory overload, change to routines, unkind comments.

*'Autism is a disability.'*

Yes, autism is a disability, and people with autism are entitled to the support, protections, welfare benefits etc that disabled people should have.

However, many autistic people assert that autism is not just or always a disability, it is a *difference*, and that it has positive aspects that are often overlooked.

Using the social model of disability, we can see that society disables people with autism.

*'Autism is a learning disability.'*

Autism is not in itself a learning disability, but it can often be accompanied by learning disability. It is estimated that 60–70 per cent of people on the autism spectrum have a learning disability.

## Myths and facts

*‘Autism is a mental illness.’*

Autism is not in itself a mental illness. Autistic people may be more vulnerable to developing mental health problems, due to distress caused by social conflict, sensory overload, misunderstandings, discrimination and other factors.

*‘Autism is a tragedy.’*

Autism can certainly have a big impact on individuals and families, who can face great difficulty and distress. However, portraying autism as a ‘tragedy’ can have very negative consequences for autistic people.

“Negative media coverage and deliberate pity campaigning have created the public opinion that autism is a “tragedy”, and that people with autism have no hope of achieving anything.

“The majority of autism fundraising is currently generated using “pity” campaigning, suggesting that autism is tragedy, disease, or epidemic that needs to be stopped.

“This “tragedy” view of autism is extremely damaging to autistic people ... It causes employment discrimination, it worsens social isolation, and it leads some parents to give up on helping their children, in favour of holding onto a false hope of a cure.

“Autism isn’t a tragedy, or a side-effect of genius – it’s a difference to be valued.” Aspies For Freedom

*‘Autistic people are like that bloke in Rainman.’*

Dustin Hoffman’s character Raymond Babbit was based on Kim Peek, who was probably not autistic! He did have a neurological condition, and was a ‘savant’ (meaning that he could memorise and recall a remarkably large amount of information).

Some autistic people may be like Raymond, but autism is a spectrum, and many are not like him.

While some people on the autistic spectrum may have ‘special talents’ or unusual, striking abilities, it is unfair to expect all autistic people to be like this, or to treat their abilities like ‘party tricks’.

*‘Autistic people are of low intelligence.’*

No. Autism is a spectrum, and includes people across the range of intelligence.

*‘Autistic people are unable to empathise with others.’*

People on the autistic spectrum are often thought to be unable to empathise. However, it may be more accurate to say that autistic people empathise differently from the way that neurotypical people do. One theory is that autistic people lack ‘cognitive empathy’ (the ability to predict others’ intentions), but have ‘affective empathy’ (the ability to share others’ feelings) and ‘compassionate empathy’ (the desire to help others).

*‘Autism mainly affects boys and men.’*

Many more boys and men than girls and women are diagnosed as being on the autism spectrum.

However, these statistics may be skewed by diagnostics being geared towards autistic traits that show themselves more often in men/boys than in women/girls. Socially-constructed ideas about gender, and about what is ‘normal’ or ‘abnormal’ for boys and girls to do, may also influence who gets diagnosed with autism.

*‘Autistic people are weirdos with no social skills.’*

This is a judgemental view that labels and stigmatises people. It is based on a narrow view of ‘social skills’ centred on neurotypicality.

Dismissing people in this way can prevent them getting support with social interactions. This view detracts from employers’ and institutions’ responsibility to adapt to and engage with people with autism.

*‘Once you have met one person with autism, you know what autistic people are like.’*

Autism is a spectrum; autistic people are individual and differ from each other. Once you have met one person with autism, you ... have met one person with autism!

*‘Autism is caused by vaccinations and other chemicals.’*

The theory that the MMR vaccine caused autism has been discredited.

There have been similar theories concerning other vaccinations, lead, and other substances, but none has yet gained general scientific endorsement.

The fear caused by this theory led to many parents not having their children vaccinated, and eventually to higher rates of measles. In Swansea in 2012-13, a measles outbreak saw more than 1,200 people fall ill, 88 visit hospital and one

## Myths and facts

person die. It is a reflection on society's fear of autism that so many people were prepared to expose their children to this risk in order to 'avoid' autism.

*'Autism runs in families.'*

Scientists are still not certain of the cause of autism, but believe it may be an interaction of various factors, including genetic predisposition.

*'If there is no cure for autism yet, we should prioritise developing one.'*

There is no cure for autism.

Many people would welcome progress in alleviating the more distressing aspects of autism. But many of these could be alleviated by better support, services and understanding from society; an end to prejudice and discrimination; and an acceptance that humanity is neurologically diverse.

Many people with autism do not want to be cured, seeing their autism as a difference with positive aspects, and wanting support and inclusion not a cure.

Many autistic people are also concerned that the search for a cure is detracting from support and campaigning for social change.

*'There are medications, therapies and treatments for autism.'*

There are no medications to treat autism. People may use medications to treat conditions that may be associated with autism e.g. depression.

There are various therapies, treatments and support promoted to people with autism or their carers. Some are helpful, such as speech and language therapy, learning support assistants, housing support, specialised medical services, and employment support services. But there are others which many people feel are unproven or even harmful e.g. electro-convulsive therapy, aversive behavioural therapies, restraints, restriction of non-harmful stimming and even exorcism.



## Section four

# Autism is a trade union issue

Autism is an issue for trade unions, because:

- Most autistic people can work, including in ‘normal’ (whatever that may mean!) workplaces.
- Where adults with autism do not work, it is often because working conditions are unsuitable, and/or because they have had jobs but have not been able to continue with them because of issues such as bullying, discrimination or a lack of reasonable adjustments.
- Many trade union members have caring responsibility for autistic dependants.
- Parents of autistic kids (or carers of adult autistic dependants) are entitled to work – and may well need to.
- Autistic kids of school age will usually be attending school.
- Appropriate care for autistic children may well not mean isolation at home with a parent.
- Trade unions must speak up for autistic workers, but not because autistic workers cannot speak up for themselves.
- People with autism have various means of communication – some are more verbal than others.
- Trade unions are the bodies through which autistic and other workers can organise and speak up for themselves.
- Trade unions are working-class organisations, and the working class is neurologically diverse. Trade unions must unite all workers, and overcome division and discrimination.
- Understanding autism can help trade unions improve our own ways of working.

### **Autism, unemployment and under-employment**

There are about 332,600 people of working age in the UK with an autism spectrum disorder (ASD).

Only 15 per cent of adults with autism are in full-time employment; only 9 per cent are in part-time employments.

## Autism is a trade union issue

Fifty-one per cent of adults with autism in the UK have spent time with neither a job nor access to benefits, 10 per cent of those having been in this position for a decade or more.

Sixty-one per cent of those out of work say they want to work.

Seventy-nine per cent of those on Incapacity Benefit say they want to work.

Fifty-three per cent of adults with autism said they want help to find work, but only 10 per cent are getting the support.

Twenty-six per cent of graduates with autism are unemployed.

(above stats: National Autistic Society)

Only 11 per cent of carers who have children with autism work full-time, and 70 per cent say the lack of appropriate care facilities stops them working.

(Ambitious About Autism)

“Jack, 12, ran away from his school in Hertfordshire, broke into his own home and rang his mum to say that he was hungry. The school insisted that his mum take him home every lunchtime because it ‘cannot cope’ with him. Jack’s mother had to give up her job. A volunteer supporter is trying to get her some free specialist help so she can ‘take on the system’ and get Jack back to school.” The Observer magazine, 28 October 2007

## Section five

# How workplaces can create difficulties for autistic workers

Workplaces and employers make work difficult for autistic workers for the following reasons:

*Discrimination:* Treating the autistic worker differently from, less favourably than, others.

*Bullying by management,* including ridicule and physical/ verbal abuse.

*Lack of communication and support.*

Andrew Beck, who has Asperger's Syndrome and learning difficulties, had worked as a golf club green keeper since 1986. He had no problems at work until the appointment of a new head green keeper in 1999. His new boss:

- told him to wear highly visible clothing and a red cap to distinguish him from other staff and to alert golfers to his presence
- banned him from using a motorised vehicle and made him cart heavy equipment in a wheelbarrow
- gave Andrew duties which involved an unfair amount of heavy work, often without breaks of lighter work, in contrast to other green keepers.
- approached him from behind and violently knocked a rake out of his hands, then pushed him out of the way, using bad language.
- accused him of not pulling his weight and used a stream of obscenities.
- subjected Andrew to a cheap joke by giving him a child's game as his staff Christmas present.
- gave him a verbal warning because of alleged numerous instances of failing to carry out tasks.

The employer did not communicate with Andrew properly and he had no-one to talk about his anxieties. In 2007, Andrew resigned because of continuing pressure and its effect on his health. Andrew won an Employment Tribunal claim for constructive dismissal and disability discrimination, and was awarded £78,000.

## How workplaces can create difficulties for autistic workers

*Preventing an autistic worker from carrying out duties or using equipment when there is no valid reason to do so.*

“The first line manager to be informed of my Asperger’s reacted by recommending that I be excluded from presenting results at conferences, on the grounds that I didn’t give a ‘favourable impression’.”

Louise, formerly employed in the scientific civil service

*Rates of pay:* An employer might pay a worker less than the rate for the job, using the autism as a pretext or excuse.

*Exploitation:* An employer may think that s/he can ‘get away with’ treating an autistic employee badly.

Adam O’Dee, who has Asperger’s syndrome and dyslexia, worked as a chef at a hotel from February 2010, having been introduced by Remploy, which helps disabled people find work.

His boss paid him £95 per week – less than half the minimum wage – because he thought he could get away with it. He was not paid for working extra hours at weekends and busy times like Christmas.

The boss claimed that Adam had to be ‘carried and pampered’. He threatened to sack Adam for ‘taking too much off the end of a cucumber’; and threw frozen bread rolls around the kitchen after wrongly blaming him for not taking them out of the freezer.

Eventually, Adam resigned, complaining of harassment and victimisation. Adam won an Employment Tribunal claim for unfair dismissal, disability discrimination and breach of minimum wage law, and was awarded £40,000+.

*New work processes:* The imposition of new arrangements at work may cause difficulties for workers on the autistic spectrum.

“Following a change in working practices it became apparent that my [autistic] son could not cope with the increased demands and the conflicting requirements of the job role. Having changed from a ‘job and finish’ work pattern to one that involved prioritising, swapping and changing, he became very ill, depressed and stressed, resulting in a breakdown. Once he became ill, his duties were changed and his role altered, he was allocated a mentor and did a phased return to work.” Mother of an autistic postal worker

*Past experiences:* Working conditions in the past may have caused difficulties for the worker, perhaps especially when the law was weaker.

*Unemployment:* Autistic workers are more likely to have periods of unemployment, often due to losing or leaving a job because conditions are unsuitable.

*Self-confidence may be decreased by experiences of discrimination or bullying.*

*Performance management regimes may cause undue pressure and distress to autistic workers.*

*Working environment:* Autistic workers may need a ‘benign’ environment with fewer distressing factors.

“I was out of work for 15 months after I was dismissed in 1991, when there was no disability legislation requiring employers to make ‘reasonable adjustments’ to support my performance at work. I appealed against dismissal with the support of my trade union, but was downgraded as there was no Disability Discrimination Act to ensure that I was transferred to another job on the same grade. I had to wait till January 1994 to be re-employed within the Civil Service.

“I experienced bullying with performance again in 2004. My self-confidence since 1991 was destroyed and I felt deterred from striving for promotion. I felt ashamed of my condition and could never trust any manager or employer.

“Recently, I have been coming out in the open as a disabled person. My main area of weakness is a learning disability associated with new duties. I need more time than others to become accustomed to the technical duties.

“When I revealed my condition to my line manager in 2005, I asked to work in a benign environment with a supporting letter from my doctor. I was, then, made to feel that I was not being bullied. As a result, my performance improved.” Civil servant

*Managers being overly ‘bossy’ can distress autistic (and other) workers.*

*Disruption of routines.*

A worker with *undiagnosed autism* may not get support or adjustments.

*Contracting-out* enables third-party companies to insist that workers are removed, even sacked, just because they do not like the worker concerned.

“I represented a member who didn’t know he was on the spectrum. But he shows all the classic signs. He likes routine, and everything is black-and-white.

“He keeps getting into trouble at work primarily when people boss him about and ruin his routine. His last employers said they didn't know he needed help (even though it is clear that he does on first meeting him). I got them to use reasonable adjustment by moving him away from destructive personalities. But by then it was too late as the contractor wanted client removal. Upshot: I got him an extra 9 months pay and he has another job.” Kevin, RMT union representative

*Expecting people to abide by ‘social rules’ at work without ever specifying what they are.*

## How workplaces can create difficulties for autistic workers

*Problems with assessment and/or promotion processes.*

*Making judgements about a worker's social interaction based on neurotypical standards e.g. not hiring someone because s/he did not make eye contact during interview, assuming s/he was disinterested or dishonest.*

“Think how it feels that we, of all people, who have such powerfully single-minded vocations, and hunger more than most to fulfil our vocations, must everywhere seem to be prevented by those eagle-eyed gatekeepers, the networkers, the social police who will prevent us from accessing the resources we need because we fail an irrelevant eye-contact test, or the right-kind-of-smile-on-the-way-to-the-water-cooler test.” Judy Singer, Foreword to Jean Kearns Miller, “Women From Another Planet?”

*Stress or anxiety.*

*Colleagues or managers misunderstanding you.*

*Feeling ‘left out’ socially.*

*Conflict with colleagues or managers.*

*Misunderstanding rules, policies or instructions.*

*Difficulties organising your work.*

*Feeling that autistic positives/skills are not recognised.*

*Frustration with others’ poor organisation of work.*

*Timekeeping (either yours or others’).*

*Unexpected events or disruption of work schedule.*

“We had work meetings that would regularly start late – sometimes several hours after the scheduled time. I found it so distressing that by the time the meeting started, I was mentally exhausted and found it difficult to concentrate and keep my temper in the meeting. With a change in office personnel, meetings started on time and my working life got so much better!” Voluntary sector employee

*Irregular working hours.*

*Sickness/absence policies.*

*Dealing with diagnosis as an adult.*

*Sensory issues eg. noise, light, smell.*

Section six

# How workplaces can create difficulties for workers with autistic dependants

*Refusal of time off:* An employer may refuse a request for time off, for example a career break or a period of leave to adjust and make arrangements when a dependant is diagnosed with autism.

*Childcare:* Few employers provide workplace childcare; of those that do, few provide care suitable for autistic children.

*Career progression being held back.*

*Unkind comments or ‘jokes’:* by managers or workmates.

*Stress and isolation:* being (or thinking you are) the only person in this position.

“When my son was small, he had behavioural problems, and speech and language delay. Childcare was tricky. When he was four, he got his diagnosis of autism. I was working as a marketing manager for a children’s charity. I asked for six months unpaid leave to get myself together and sort out provisions to meet his needs. They refused, so I resigned.

“I spent 18 months taking him to appointments, getting a Statement, and settling him into school. I went back to full-time work when he was six. I had to take a step back in my career. I had to take time off for appointments, but my boss was fine about it.

“One colleague used to make jokes about people ‘being autistic’. One day when he made a joke I marched up to him and said to the office that if I heard one more ‘autism’ joke, I would punch the next person. Not a recommended way of approaching things, but nobody ever made that joke again ... All parents have a certain amount of stress, but it is hard to share when you are thinking about the “meltdown” that your kid had because they didn’t remember where they’d put their homework.” Former charity worker

*Need for regular working hours to ensure predictability for the child’s routine.*

*Stress affecting health and relationships.*

## How workplaces can create difficulties for workers with autistic dependants

*Lack of care/support by employer:* who may see the employee's caring responsibilities as a problem.

*Discrimination.*

*Rates of pay:* A low rate of pay will make it harder for a worker to exercise options like taking unpaid leave or working part-time.

*Business ethic:* The notion that a public service has to run as a business can lead to employers not providing support or adjustments if that is considered too expensive.

“I used to work on a railway station. I have a young son, Christy, who has several disabilities, including autism/Aspergers. I am a single mum, after the pressures of trying to balance work and parenting broke up my marriage to Christy's dad.

“I used to do late shifts, but a new manager told me I had to work shifts around a roster. This was very disruptive for Christy, who relies on a predictable daily routine. His behaviour became problematic, with more frequent 'meltdowns'. I had to take time off, and became ill due to stress. The company issued me with warnings for absence; my manager told me 'We are running a business, not a crèche'.

“Like many autistic kids, Christy did not sleep well, so I was losing sleep too. I had commendations for my work, but I felt that my employer considered me a problem not an asset. A manager said to me, 'You should consider what your priorities are', implying that I could not be both a railway worker and the mother of an autistic son. This manager suggested I go part-time, but I would not be able to live on a part-time wage.

“They stopped me doing work projects (eg. school visits, first aid) and stopped me doing a secondment and taking promotion three times. Eventually, I had no choice but to leave.

“I took my case to Employment Tribunal, but while my employer admitted some failings and was prepared to settle, their lawyers found a technicality and got my claim kicked out. I only got an apology.” Nikki, former railway worker

*Getting time off work to attend appointments.*

*Being allowed to leave work to deal with an emergency; lateness or absence due to emergencies.*

*Loss of income due to unpaid leave.*

“I did shiftwork. I had to take Saturdays off to take my son Joe to therapy. The law gave me the right to take this leave, but it is only an entitlement to unpaid leave, and my employer would not go further than this legal minimum.



So every time I was rostered to work on a Saturday, I lost a day's pay. It added up to quite a lot." John, railway worker

*Shift patterns or irregular working hours.*

## Section seven

# Making workplaces autism-friendly

Many employers assume that they do not need to make any changes until a worker identifies him/herself as autistic and requests adjustments (if they even think about the issue at all!). However, there are plenty of changes that an employer can implement to make the workplace more autism-friendly before an individual requests it. The advantages of doing this are:

- It will benefit workers who may not be aware that they are on the autism spectrum, who do not have a formal diagnosis, who do not feel ready to 'come out' and/or do not have the confidence to ask for changes.
- A workplace that is more autism-friendly is one that recognises neurological diversity, and is therefore a workplace that is better for all workers.
- It approaches the issue as a collective issue rather than an individual one – and collective action is what trade unions are all about!
- Having possible adjustments for individuals listed in a collective policy or agreement will make it easier for the individual to request and receive them when the need arises.

Whether or not there is an identified autistic employee in the workplace, the union may table to the employer demands for:

- a relaxation space in the workplace: e.g. a quiet room
- all changes to working practices to be negotiated with the union, and proper notice given before they are introduced
- reduction in sensory distraction/overload in the workplace: e.g. maximise natural light; enable easy control of light, temperature etc; reduce strong smells information about autism, and about support services, available so that all workers can access it
- the company's welfare and/or occupational health services to be equipped to provide assistance
- training for managers and others about autism, including recognising autistic positives and skills
- providing paid time off for trade union representatives to attend trade union training and events about autism
- all instructions and policies to be written and communicated clearly and accurately

- a variety of tools to assist personal work organisation, for example visual timetables, organiser apps
- that only objective criteria are used for assessment/promotion
- that work schedules are adhered to
- inclusion of autism in harassment and bullying policies, to minimise harassment and bullying of autistic workers and so that managers or employees who bully or discriminate against autistic workers are dealt with appropriately.

Reasonable adjustments for individual autistic workers might include:

- paid time off when needed
- fixed hours rather than variable shifts
- reducing specific sensory stimuli in the workplace, e.g. locating that individual's workstation in a quieter or less bright part of the office
- change of work location, for example to be nearer home, or nearer support facilities, or to a work location which is quieter or less over-stimulating
- extra breaks to enable relaxation
- providing a mentor
- individual support where schedules are unavoidably disrupted and when changes are introduced
- adjustment to the way in which assessments are carried out
- a clear routine and work schedule
- a personal workstation (rather than sharing a workstation or 'hot-desking') specific tools to aid work organisation, such as a visual timetable or organiser app
- relaxation of triggers for disciplinary action for matters such as sickness absence or mistakes arising from executive function impairment
- additional training time off for treatment/appointments, as part of a policy for disability leave
- re-allocating some work to colleagues, with their agreement.

Access To Work funding may be available for some of these measures. You can see more information about this here: <https://www.gov.uk/access-to-work/overview>.

## Section eight

# Nothing about autistic people without autistic people

The trade union movement supports the demand of the disabled people's movement: 'Nothing About Us Without Us'.

Many trade unions have structures for disabled members; if so, it may be useful to invite and welcome autistic members' involvement in these.

There are organisations of autistic people, and trade unionists may benefit from their expertise.

The UN Convention on the Rights of Persons with Disabilities, Article 4.3, states that 'In ... decision-making processes concerning issues relating to persons with disabilities, States Parties shall involve persons with disabilities, including children with disabilities, through their representative organisations.'

However, in March 2012, the Autistic Rights Movement UK (now Autistic-UK) complained that the government's National Autism Programme Board (APB) had been meeting since March 2010 with no involvement of autistic people's organisations.

"Successive British governments have failed to understand (or have wilfully refused to understand) the importance of Disabled People's Organisation (DPOs) – organisation of disabled people not organisations for disabled people."

ARM-UK (now Autistic-UK), March 2012

Medical professionals and some charities provide useful services and resources for people with autism and for those supporting them. However, while some may campaign in the interests of people with autism, this does not necessarily mean that they speak for people with autism.

Moreover, some charities have come into conflict with trade unions, and/or pursue policies which are at odds with those of trade unions. For example, in 2013/14, teaching unions NUT and NASUWT were in dispute with the National Autistic Society about terms and conditions for staff at its schools. The National Autistic Society sponsors several 'free schools', which teaching unions oppose.

## **Mind your language**

See the TUC briefing, *Words Can Never Hurt Me?*, for a detailed explanation of how choice of language can help or hinder our campaigning for disabled rights.

The language we use can reinforce negative stereotypes of autistic people, or it can challenge them. If a trade union uses terms that insult or demean people with autism, this will suggest to autistic workers (and workers with caring responsibility for people with autism) that the union does not understand or empathise with them, and that if they get involved in the union they may face prejudice.

In using the term 'disabled people', the TUC follows most of the British disability movement. In the USA, the term 'people with disabilities' is more common, and some British (and many Irish) disabled people follow this American usage. The TUC does not regard 'people with disabilities' as offensive.

In line with this, all the following are acceptable:

- people (workers, etc.) with autism
- people (workers, etc.) on the autistic (or autism) spectrum
- autistic people (workers, etc.)

## **Words to avoid**

Some terms definitely are offensive.

Trades unionists should know that words such as 'retarded', 'defective' and 'handicapped' are unacceptable. These words encourage people to think less of their fellow workers, and some of them convey hate or contempt.

Words and phrases which present people as victims or pitiable reinforce negative assumptions. It is not good to refer to autistic people as 'suffering' from autism.

Phrases like 'differently able' and 'physically challenged' can be patronising or sarcastic, not egalitarian, and are not recommended by the British disability movement.

Trades unionists should aim for a natural and relaxed style of speaking and writing which avoids giving unnecessary offence.

## Section nine

# Hate crime

In 2013, Labour MP Ian Mearns introduced a Ten-Minute Rule Bill to require the police to maintain a register of hate crimes committed against people with learning difficulties, learning disabilities and autism. During the early months of 2014, this Bill is progressing through its Parliamentary stages.

“Disability hate crime has no place in 21st century Britain but an alarming number of people living with autism in the UK have suffered bullying, exploitation and harassment. This has to stop.

“It is both shocking and sickening that people with autism become targets of crime because of their disability, but unfortunately due to the social difficulties people with autism experience it can leave them vulnerable to being taken advantage of by unscrupulous individuals.”

Sarah Lambert, Head of Policy at the National Autistic Society, in response to Ian Mearns’ Bill

“On 23rd June 2012, Steven Simpson, a gay autistic student, was verbally abused, stripped, and his body scrawled with offensive slogans. He was then doused in tanning oil and 20-year-old Jordan Sheard set fire to his crotch with a cigarette lighter. The flames engulfed his body, his attackers fleeing as neighbours tried desperately to extinguish the flames. Steven died the next day suffering 60 per cent burns.

“Steven was murdered because of his sexuality and disability. However, on 21st March 2013 at Sheffield Crown Court, Judge Roger Keen dismissed the crime as “good-natured horseplay” that had “gone too far” and sentenced Sheard to only three-and-a-half years in prison. Sheard’s lawyer described Steven’s killing as a “stupid prank that went wrong in a bad way”. We demand justice for Steven Simpson.

“We believe that the sentence given to Jordan Sheard does not reflect the serious nature of the hate crime committed.

“We call on the TUC to support campaigns to raise awareness of hate crime and the issues involved.

“We believe that due to his appalling comments Judge Keen is unfit to hear cases such as this. We demand that his description of this attack as “good natured horseplay” is legally overturned.”

Resolution passed by TUC Disabled Workers’ Conference 2013

## Section ten

# Autism and austerity

“We know that LAs [local authorities] have had their budgets slashed and are making cuts which are impacting on adults with autism and families living with autism. Families are being told that they will have to re-apply for Direct Payments and respite is being shaved and in some cases cut altogether. Provision to support families is also being removed.

“We are concerned that these cuts will make it even harder for children and adults to access provision. We are concerned that even more adults will continue to fall through the cracks, especially those without a generic learning disability and that the postcode lottery that we currently have will continue to spread.

“It is difficult to imagine that the Adult Autism Strategy Fulfilling and Rewarding Lives - Increasing Awareness and Understanding of Autism (England) and The Autism Strategy (Scotland) will be able to deliver what had been hoped by the autism community. It is difficult to imagine that new services for both children and adults will be commissioned while LAs and CCGs struggle to maintain the services that they are already delivering.

“The wider implications of the cuts that the voluntary sector will experience will result in higher volumes of families and adults contacting them for support and information. This will place a considerable burden on the voluntary sector who are already struggles in the face of cuts to their budgets from statutory bodies.

“Charity used to be the icing on the cake – now charity IS the cake.”

Act Now for Autism

### **Examples of cuts and campaigns**

Nottinghamshire’s Adults with Asperger’s Team is estimated to have supported at least 10 per cent of the adult population living with Asperger syndrome in the county. When Nottinghamshire County Council considered disbanding the team as part of its plans to make £154m cuts, campaigners organised lobbying and protests. The Council dropped the plan and continues to run the service.

In August 2013, concern was expressed that health cuts were leading to people with autism being left undiagnosed in some local authority areas in Scotland. NHS Grampian made cuts to its diagnosis service for local adults with autism; the National Autistic Society Scotland (NAS) said that was symptomatic of wider problems with diagnosis across Scotland.



Austerity-driven cuts to public services may also impact on people with autism – both workers and service users.

Statement by Autistic-UK on London Underground cuts, January 2014:

“London Underground has announced that it plans to close all its ticket offices and remove up to 1,000 staff from its stations. The company states that it is consulting on these plans, so we hope it takes notice of our objections.

“Autism is a neurological difference, and autistic people may experience difficulties with social and communication issues. Public transport, including London Underground, is essential to allowing autistic children and adults to access services and participate in society, but can be a difficult environment. It can trigger sensory overload and can cause extreme distress when there is unexpected disruption or an emergency. Moreover, we may find automated ticketing systems hard to use and – with only 15 per cent of autistic adults in full-time employment – can not necessarily access online payment methods.

“For these reasons, the presence of staffed ticket offices and adequate numbers of staff on stations is essential to enable autistic people’s access to London Underground. The plans announced by LUL will only serve to exclude autistic people and further our social isolation.

“We strongly urge London Underground Ltd to rethink.”

### **Work Capability Assessments**

In January 2014, the Court of Appeal upheld a ruling made the previous May which found that the process used to decide whether hundreds of thousands of people are eligible for Employment and Support Allowance (ESA) disadvantages people with autism, learning disabilities and mental health problems. The Court ruled that autistic people and others were disadvantaged by the process of gathering evidence for Work Capability Assessments.

### **In Europe**

“Amidst the recent budget cuts and austerity measures being implemented in many European countries, people with Autism are suffering significant cuts to the basic services they depend on for housing, health and education. How long can we go on cutting spending on the most vulnerable people in society? Can sacrificing human rights to save money possibly achieve positive outcomes?”

Nikki Sullings, Autism-Europe, 2011

Italy: 10 billion euro in funding cut in 2012–2013 from regional and local health and social services.

## Autism and austerity

Greece: 40 per cent cut to the state's financial contribution to non-government organisations and charities that provide essential services to people with Autism, including supported living centres, announced in 2011.

Evelyne Friedel, President, Autism-Europe President:

“We are seeing these funding cuts across many European countries.”

“Providing support to people with disabilities is a human right – the governments of Europe have confirmed that when they signed the Convention [United Nations Convention on the Rights of Persons with Disabilities, December 2010].

“It's not acceptable to put the rights of people with disabilities aside when financial difficulties arise.

“Governments and the European Union institutions must ensure that their commitments under the UNCRPD are fulfilled and that persons with Autism Spectrum Disorders benefit from the same opportunities as the rest of Europe's citizens.”

## Section eleven

# Autism in parliament

The All-Party Parliamentary Group on Autism (APPGA) is a formal cross-party backbench group of MPs and Peers who share an interest in autism and Asperger syndrome. It was set up in February 2000. Its role is to campaign in Parliament for greater awareness of autism and Asperger syndrome, and to lobby the Government for improved services for people with autism and Asperger syndrome, and their carers.

The official objective is:

“To raise awareness of issues affecting people with autism and Asperger syndrome, their families and carers; to raise Parliamentary awareness of autism; to campaign for changes to government policy to benefit people with autism and Asperger syndrome and improve diagnosis or, support for, people with autism and Asperger syndrome.”

The APPGA does not have any powers to introduce legislation, nor is it part of Government. But it provides a useful platform for important and topical issues around autism to be discussed and raised in Parliament.

Among its members, Labour MP John McDonnell MP has worked closely with trade unionists on the issue of autism.

## Section twelve

# A guide to the law

### **Definition of disability**

Under the Equality Act 2010, a person has a disability if s/he has a physical or mental impairment which has a substantial and long-term adverse effect on his/her ability to carry out normal day-to-day activities. Autism should qualify as a mental and/or physical impairment.

### **Unlawful discrimination**

The following actions by an employer are unlawful under the Equality Act 2010:

**Direct discrimination:** treating a disabled (for the purposes of this handbook, an autistic) person less favourably than other employees.

*e.g. if an employer gives a bonus to all workers other than the autistic worker.*

**Indirect discrimination:** applying a provision, criterion or practice that is discriminatory in relation to an employee's autism. ie. a provision that it does not apply to non-autistic employees, or which puts autistic employees at a particular disadvantage, and is not a proportionate means of achieving a legitimate aim.

*e.g. if a promotion application process includes a social skills test that is irrelevant to the job being applied for and disadvantages an autistic applicant.*

**Discrimination arising from disability:** treating an autistic employee unfavourably because of something arising in consequence of that employee's autism, and cannot show that the treatment is a proportionate means of achieving a legitimate aim.

*e.g. if an employer dismissed an autistic worker because s/he rocked on his/her chair at work, even though s/he performed adequately in his/her job.*

**Harassment:** engaging in unwanted conduct related to the worker's autism which had the effect of violating that person's dignity, or creating an intimidating, hostile, degrading, humiliating or offensive environment for the autistic worker.

*e.g. making 'jokes' about autism, or imitating an autistic worker in a derogatory fashion.*

The Equality Act 2010 also requires employers to consider and, where appropriate, implement reasonable adjustments: changes to the way things are

done in the workplace to remove any physical barriers or provide extra support to employees and applicants with disabilities (see Section 7, ‘Making workplaces autism-friendly’ for examples.) What is ‘reasonable’ will depend on all the circumstances of each individual case. Refusal to make reasonable adjustments is unlawful.

### **Emergency leave**

The Employment Rights Act 1996 provides for emergency leave. As an employee, you are entitled to take a ‘reasonable amount’ of time off during your working hours: to assist when a dependant falls ill, gives birth or is injured or assaulted; to make arrangements for the provision of care for an ill or injured dependant; in consequence of the death of a dependant; when your dependant’s care arrangements unexpectedly end or are disrupted; to deal with an incident involving your child at school (or other educational establishment).

You have to tell your employer why you are absent and for how long you expect to be absent, as soon as reasonably practicable.

The law provides a detailed definition of who counts as a ‘dependant’.

### **Flexible working**

Under the Flexible Working (Eligibility, Complaints and Remedies) Regulations 2002 and the Flexible Working (Procedural Requirements) Regulations 2002, an employee may apply (according to a prescribed procedure) to work flexibly in order to care for a child under 17, a disabled (for the purposes of this handbook, an autistic) child under 18 or certain dependant adults (this should include many autistic adults). You may apply for a change to hours, times or location of work.

As long as you have complied with the procedural requirements and are eligible to make the application, the employer must then follow a prescribed procedure to consider the request.

The employer may turn down a request for one or more prescribed business grounds.

### **Community care services**

Under the National Health Service and Community Care Act 1990 and some previous legislation, Local authorities and the NHS have a duty to provide services to disabled children and adults, to enable them to continue to live in the community.

Social services have a duty to provide services to a disabled adult who is ‘ordinarily resident’ in their local authority area.

## **A guide to the law**

It appears that autism, when diagnosed, must now be included within the legal definition – and that any difference in treatment by a local authority of persons with autism will have the potential to constitute unlawful discrimination.

Local authorities have a statutory duty to assess a person's needs for community care services.

The funding of domiciliary care services for people with autism is the responsibility of local authorities, with care delivered by social services.

### **Autism Act 2009**

The Autism Act 2009 requires the Government to produce a strategy to improve delivery of social care and health services for people with autism.

The Autism Act requires the implementation of a strategy which will lead to:

1. the provision of relevant services for the purposes of diagnosing autistic spectrum conditions in adults
2. the identification of adults with autism
3. the assessment of the needs of adults with autism for relevant services
4. planning in relation to the provision of relevant services to people with autism as they move from being children to adults
5. other planning in relation to the provision of relevant services to adults with autism
6. the training of staff who provide relevant services to adults with autism
7. local arrangements for leadership in relation to the provision of relevant services to adults with autism.

### **Fulfilling and rewarding lives – The strategy for adults with autism in England 2010**

In 2010, in response to the Autism Act 2009, the government published 'Fulfilling and rewarding lives: The Strategy for adults with autism in England (2010)'. This sets out the government's vision for autism services and five areas for action aimed at improving the lives of adults with autism:

- increasing awareness and understanding of autism
- developing a clear, consistent pathway for diagnosis of autism
- improving access for adults with autism to services and support
- helping adults with autism into work
- enabling local partners to develop relevant services.

The purpose of the strategy is to make existing policies and public services work better for adults with autism. The government also produced statutory

guidance to supplement the strategy. The guidance says it is vital that local authorities ensure that adults diagnosed with autism who may have community care needs are offered an assessment.

Section thirteen

# TUC Disabled Workers' Conference policy

The following motion was passed unanimously at 2013 Conference.

“We note that autism is a neurological spectrum condition. Our society - including our workplaces - causes various difficulties to people on the autistic spectrum (diagnosed or undiagnosed), and to people caring for autistic people. Problems include: bullying; imposed changes to work routines; sensory overload; and difficulty getting time off or fixed hours when needed.

“There have been appalling cases of discrimination against and mistreatment of autistic workers. Statistics suggest that just 15 per cent of adults on the autistic spectrum are in full-time employment – resulting from hostile employers and workplaces rather than inability to work.

“We further note the serious impact that government austerity cuts are having on provision for children and adults with autism.

“We resolve to challenge discrimination and negative portrayal of autistic people; educate and train trade unionists about autism; campaign for stronger anti-discrimination legislation; and work with appropriate representative organisations of autistic people.

“We welcome the ‘Autism In The Workplace’ training developed by RMT and WEA, and ask the TUC to support its expansion and accreditation.

“We ask the TUC to publish an ‘Autism In The Workplace’ handbook for trade union representatives.

“We resolve to campaign for autism-friendly workplaces, recognising that the measures involved will benefit all workers.”



## Section fourteen

# What your union can do

Be aware that your membership (nationally, in your region, branch, workplace, etc.) is neurologically diverse, even if no-one has identified themselves to you as being on the autistic spectrum or having another neurological condition. Your union's strength comes from uniting its members and mobilising the talents of all its members.

### **Defend your members**

Represent autistic members and members with caring responsibility for autistic dependants as effectively as possible.

“I represented a member – ironically, a social worker in a learning disability team, my team! She has three children, the oldest of whom is a young adult with a learning disability and autism who lives at home with my member, who is the main carer.

“The member was having problems getting the leave she needed for specific things, such as community dentist appointments, which are very stressful – even when the leave was recommended by the professionals who were supporting her.

“She was also experiencing problems with long-term flexible start times. Her daughter is picked up to go to college but times vary, and she needs to be at home until the bus arrives. This should not be a problem in our team at all.

“Trade union representation helped her a great deal, as when management saw she would challenge them and had support, they backed down.

“And our union has benefited too, as she is now chair of our Black and Minority Ethnic members' group!”

Lynne, UNISON rep in a London borough council

Organise and mobilise union members in support of workmates who are facing discrimination or unfair treatment at work.

## What your union can do

Mo works in a ticket office for a railway company, and has a young daughter who has autism. His daughter needs a very stable and predictable home routine, but Mo's roster meant that one week, he was doing early shifts, the next week late shifts, etc. His daughter was very distressed. He applied for 'flexible working' to have regular hours, but his manager was hostile. She grudgingly agreed to a short period of fixed hours, but undermined it from the start. A trade union representative accompanied him to all meetings and challenged the manager's attempts to put him back on the round-the-clock roster.

Union members organised a petition of his workmates supporting Mo's fixed-hours arrangement, which made the manager look rather silly when she claimed that his workmates had complained about it!

The case was reported to the union branch, and members would have been willing to take industrial action in support of Mo.

When the manager failed to follow the policy and tried to cancel the fixed-hours arrangement, the union appealed to a higher-level manager, and got Mo's hours restored to what he needed.

### Use collective bargaining

Demand that employer adopts an autism/neurodiversity policy.

### Organise!

Does your union cover organisations which provide services to autistic people (eg. in education, social care, local government, supported employment, the voluntary sector etc). If so, get those workplaces unionised!

Produce recruitment materials aimed at autistic workers and carers.

Use 'know your rights' guides to make workers confident about demanding their rights through collective union organisation.

### Communicate effectively

Ensure that union materials are clear and accurate.

Use a variety of formats – graphics, cartoons, videos etc. as well as words.

Do not allow union meetings to become dominated by jargon and cliquey banter.

### Fight the cuts

Defend autism services under attack from austerity cuts.

Ensure that protests are autism-friendly where possible. The major TUC marches in recent years have had a quiet section – and bear in mind that chants are probably more bearable (and more political!) than whistles and horns.

### **Nothing About Us Without Us**

Ensure that the union has representative structures for disabled members, that these structures and their activities are publicised, and that autistic members know that they are welcome to get involved.

Make contact with autistic people's organisations.

### **Make union events and meetings autism-friendly**

Meetings should have a clear agenda and run to time as far as possible.

Procedures should be clear, so that members know when and how to raise the issues that they want to raise.

Keep good order in the meeting.

Consider the physical venue that you use for union meetings, particularly regarding sensory issues. Choose a venue (or arrange the venue that you already use) to ensure: minimum background noise; adjustable light levels; away from strong smells, etc.

Consider the location of your meeting venue – can you help with transport if it is hard to access?

Offer help with childcare/carers' costs to enable members with autistic dependants to attend meetings.

### **Training**

Provide training for union reps about autism.

WEA London Region runs one-day briefings on Autism in the Workplace for trade union representatives. You can publicise these briefing days to reps in your union; and you can request that the course is run specifically for your union. For more information, contact Monica Gort [mgort@wea.org.uk](mailto:mgort@wea.org.uk) or Janine Booth, [j.booth@rmt.org.uk](mailto:j.booth@rmt.org.uk).

Make sure that all your union's training is autism-friendly.

WEA London Region is developing a training day for tutors to help you do this.

### **Promote understanding, tackle ignorance**

Display materials at work which promote greater understanding of autism.

Distribute this handbook to union reps and branches.

## **What your union can do**

Educate members about language, and challenge unkind or inappropriate comments at work and at union events.

Hold a discussion at your union branch meeting about autism; perhaps invite a speaker.

Section fifteen

## Useful websites

All Party Parliamentary Group on Autism

<http://www.appga.org.uk/>

Autism Europe

<http://www.autismeurope.org/>

Autism Hub (list of autism blogs)

<http://autism-hub.com/>

Autistic UK

<http://autisticuk.org/>

DANDA (Developmental Adult Neuro-Diversity Association)

<http://www.danda.org.uk/>

National Autistic Society

<http://www.autism.org.uk/>

## Section sixteen

# Glossary

### **Asperger syndrome**

An autism spectrum condition that affects the way a person communicates and relates to others. People with Asperger syndrome usually have fewer problems with language than those with other forms of autism, and may not have the accompanying learning disabilities often associated with autism.

### **Attention deficit hyperactivity disorder (ADHD)**

A developmental condition involving difficulties with attention, activity levels and impulsivity.

### **Autism / Autistic Spectrum Conditions (ASC) / Autistic Spectrum Disorders (ASD)**

Neurological developmental conditions which occur when atypical (unusual) brain connections lead to atypical development. These differences in the way the brain functions lead to particular challenges and abilities and unusual development.

### **Carers**

Family members, professionals or paraprofessionals who provide constant or regular care.

### **Dyscalculia**

A condition associated with significant difficulty with numbers and calculation.

### **Dyslexia**

A condition associated with significant difficulty with reading.

### **Dyspraxia**

Impairment of the organisation of movement with associated problems of language, perception and thought.

### **Echolalia**

Repeating back something said to you; many autistic people use echolalia.

### **Executive function**

The set of abilities used to plan complex cognitive tasks, to translate motivation into action.

### **Flexible working**

Changes to hours or location of work to suit a worker's caring responsibilities.

### **Hypersensitivity**

An unusually high or intense response to a particular stimulus eg. smell, texture, colour.

### **Hyposensitivity**

An unusually low response to a particular stimulus eg. light, pain, sound.

### **Neurological diversity / neurodiversity**

Difference in the neurological make-up, or 'brain wiring' of a population.

### **Neurologically Typical / Neurotypical / NT**

(A person) not having a neurological condition such as autism.

### **Non-verbal communication**

Communication through means other than words, for example facial expression, posture, gesture and body movement.

### **Reasonable adjustments**

Changes to working conditions – for example, equipment, duties, hours of work – to enable a person with a disability to carry out his/her job.

### **Savants**

Individuals who possess special talents, usually in the areas of music, mathematics, drawing or calendrical calculations.

### **Self stimulation / stimming**

Behaviours often used by people with autism to provide stimulation, assisting with calming, adding concentration or shutting out an overwhelming sound. Examples include rocking back and forth, skipping, vocalising or making repetitive noises, flapping hands or spinning round.

## **Glossary**

### **Spectrum**

Variation in the way a condition affects or shows itself in individuals with that condition. Autism is a spectrum condition, meaning that individuals have different traits, to different degrees.

### **Triad of impairments**

A theory of autism identifying impairments affecting social interaction, social communication and imagination.



## Section seventeen

# Appendix: an autism timeline

**1910:** Swiss psychiatrist Eugen Bleuler coined the term ‘autism’, derived from the Greek word *autós* (αὐτός, meaning self). Bleuler was researching the symptoms of schizophrenia and identified a ‘withdrawal’ present in some patients as autism.

**1943:** Austrian-American child psychiatrist Leo Kanner described autism as a distinct condition in his paper *Autistic disturbances of affective contact*. Kanner established ‘early infantile autism’ as a childhood psychiatric disorder, classified under schizophrenia.

**1944:** Austrian paediatrician Hans Asperger published *Autistic Psychopathy in Childhood*, based on studies of boys (his ‘little professors’), describing a ‘milder’, ‘higher-functioning’ condition later known as ‘Asperger syndrome’.

**1960s–1970s:** Research into treatments focused on medications such as LSD, electric shock and behaviour change techniques that often relied on pain and punishment.

**1962:** Founding of what was later called The National Autistic Society.

**1966:** A study in Middlesex estimated the rate of autism in children at 0.04 per cent – the most commonly cited figure until the 1980s.

**1967:** The International Statistical Classification of Diseases and Related Health Problems of the World Health Organisation classified autism as a form of schizophrenia.

**1971:** Psychologist Bruno Bettelheim promoted the ‘refrigerator mother’ theory, which holds that cold, unnurturing parents, especially mothers, are to blame for autism.

**1977:** American psychiatrist Susan Folstein and British psychiatrist Michael Rutter published a study of autistic twins in which they prove that autism has a genetic basis.

**1979:** British psychiatrists Lorna Wing and Judith Gould presented the idea of a ‘triad of impairments’ and an autism spectrum.

**1980:** The third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) included ‘infantile autism’ as a Pervasive Developmental Disorder – the first time autism appeared as a distinct disorder rather than linked to schizophrenia.

**1981:** Lorna Wing introduced the term Asperger Syndrome.

## **Appendix: an autism timeline**

**1987:** ‘Autistic disorder’ replaced ‘infantile autism’ in the diagnostic manual.

**1988:** The film *RainMan* raised public awareness of autism.

**1989:** Christopher Gillberg, a professor of child and adolescent psychiatry, published the first diagnostic criteria for Asperger syndrome. Michael Rutter, Ann LeCouteur and Catherine Lord published an assessment for autism, called the Autism Diagnostic Interview.

**1980s–1990s:** Behaviour therapy and controlled learning environments emerged as primary ‘treatments’ for many forms of autism. Other treatments included medical and dietary therapy.

**1994:** Asperger’s syndrome was added to DSM-IV as a progressive developmental disorder.

**1998:** Andrew Wakefield and others published a controversial study in the *Lancet* suggesting that the measles-mumps-rubella (MMR) vaccine causes autism. The research was later discredited.

**1999:** The Autism Research Centre (ARC) was set up at Cambridge University.

**2000:** The All-Party Parliamentary Group on Autism (APPGA) was launched.

**2007:** Scientists found genetic bases of autism spectrum disorders.

**2007:** The US Senate designated April as National Autism Awareness Month. The following year, the United Nations General Assembly declared 2 April as World Autism Awareness Day.

**2013:** Updated DSM-V controversially merged Asperger Syndrome under autism.





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