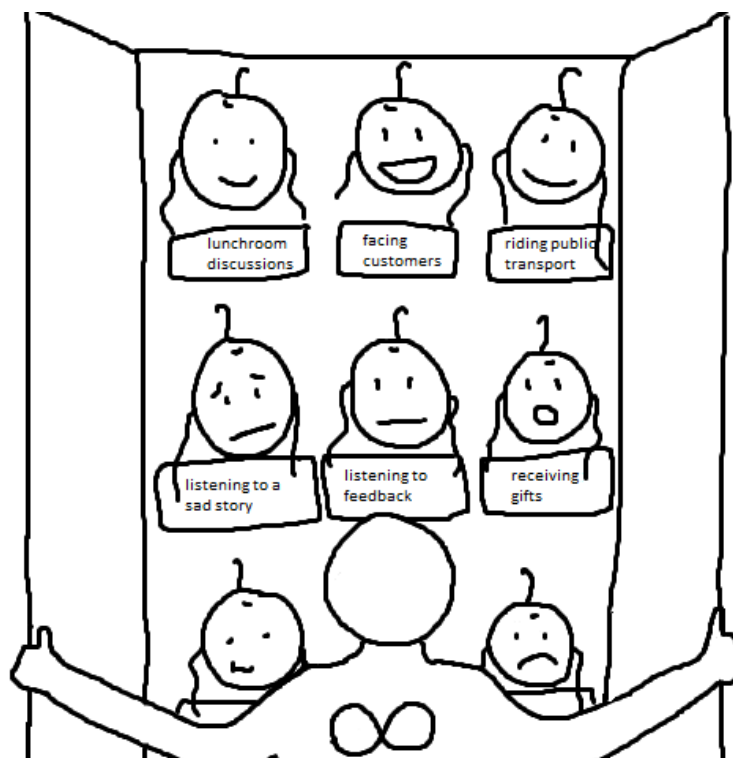


A message from Autistic colleagues on the crepuscule of Autism Awareness Month

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Cover art:

here is thing

An Anonymous Colleague, 2023

Foreword

Hi Yammer,

I'm posting on behalf of a group of #ActuallyAutistic staff members from across the agency.

We'd like to talk a little bit about Autistic advocacy, Autism 'Awareness' and how the Autistic community prefers to be talked about and represented, as well as what autism actually is and how best to work with and support your autistic colleagues.

We were drawn together through interactions on Yammer throughout Autism Acceptance month and inspired to write a post that was representative of how we felt. This document was written with contributions from 13 different people working in the same live document at the same time, before being edited by a single person. We did not want to not positively identify any specific author. In general, references to *I* are regarding an author's individual experience, and references to *we* are regarding a common or shared experience.

First of all, we want to make it clear we're not attacking anyone's acknowledgements that have been made so far this month. We know that it was done in good faith, and that the information out there can be conflicting or of poor quality. What we're hoping to do here is clear up some misconceptions and provide resources for people to refer to going forward. We'd really like to see Autistic voices consulted in the planning of these kinds of events and initiatives.

The Autistic community overwhelmingly prefers identify first language (IFL), e.g. 'autistic person', over person first language (PFL), e.g. 'person with autism', for an array of reasons. It mostly boils down to the fact that our autism can't be separated from us; it is a core part of who we are and how to relate to the world. There are other non-autistic voices that more numerous and have platforms that allow them to speak louder than us, who prefer PFL. They do not speak for us. They speak over us.

The Autistic community also broadly sees Autism Speaks, a leading organisation for Autism Awareness Month, and it's associated organisations as hate groups who are primarily pushing for a 'cure' for autism. Efforts to 'cure' autism and other 'early intervention' therapies (primarily ABA and those derived from it) are akin to so-called 'sexuality conversion therapy'. They are traumatic and harmful. Autistic communities also strongly prefer #AutismAcceptance over 'awareness', and the #RedInstead campaign over Autism Speaks' 'Light It Up Blue'. Similarly, a gold infinity symbol (echoing the rainbow infinity symbol for the wider neurodiversity movement) is preferred over the Autism Speaks blue puzzle piece symbology.

What is Autism?

Consider a radar chart

It's simultaneously hard to explain, and easy to explain. It's a spectrum of behaviours and traits that are clinically rated as "deficits" in comparison with the average neurotypical person.

Terminology note: *Neurotypical* describes someone whose brain developed and functions in a way considered standard or typical. Generally speaking, they don't have anything that could be diagnosed per the DSM5. *Allistic* means anyone who is not autistic. For example, someone diagnosed ADHD is allistic, but is not neurotypical.

The DSM5 defines the diagnostic criteria for Autism Spectrum Disorder ([Reference 299.00 \(F84.0\)](#)). It's quite a difficult and dense read, so you might have more joy reading from a companion piece such as this: [Decoding autism in the DSM-5 | Embrace Autism \(embrace-autism.com\)](#). Embrace Autism summarises the diagnosis criteria as follows:

- Category A: Autistic social communication and social interaction
- Category B: Repetitive patterns of behaviours (stimming, sameness, special interests, and sensory sensitivities)
- Criterion C: Symptoms must be present since childhood
- Criterion D: Degree to which autism affects daily functioning
- Criterion E: Traits not better explained by intellectual disability

We can try to explain this in a different way that you might be familiar with.

Have you ever heard of a talent tree or character sheet? They exist in character role playing games such as *Dungeons And Dragons*, or BioWare's *Mass Effect* or Bethesda's *The Elder Scrolls*. In these games, you play a character with a set of ability categories and as you progress through the game you can improve your skill level in these categories. A neurotypical person at around the mid-game will have an even trait tree, with equal skill level across all traits. An autistic character at around the mid-game will have some stacked traits and some empty traits. Perhaps something like this:



Actually, no, nevermind. This example is too niche. Sorry, fellow nerds.

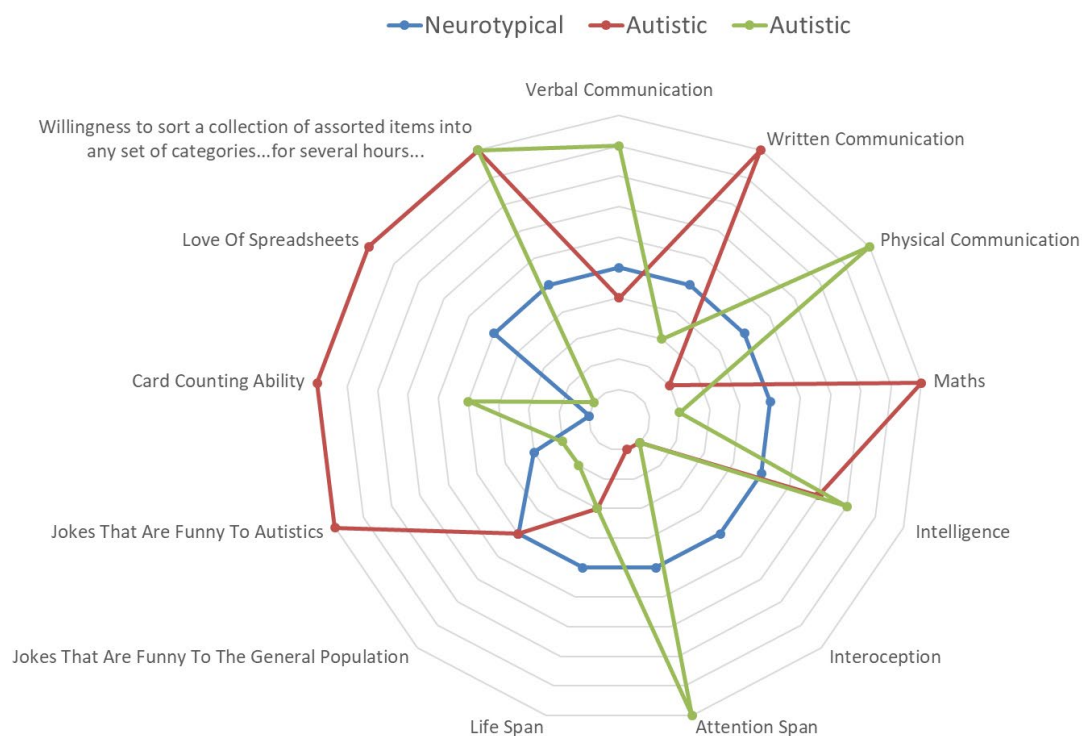
Instead, let's consider a radar chart where each axis is a skill or trait.

If we put the average neurotypical person on the chart, they plot something resembling a perfectly average circle. They're reasonably good at everything, and about as good at any one thing as any other thing. In our demonstration graph the average neurotypical is rated 5 on all but two axis. The differences between neurotypical people will be the *size* of the average circle but not the shape, i.e. all axis rate at 3, or all at 7.

If we put an autistic person on the same graph, their shape will be anything but a circle. Some traits will be highly rated, while others will be poor and entirely impossible to improve or adjust.

If we then put a different autistic person on the same graph, again they will not be near the average circle, but they will also not necessarily be at all like the other autistic.

An Unscientific Demonstration Of A Radar Chart Comparing The Neurotypical Average with Two Different Autistics



Caption: I was unable to find an adequate anonymous example of a radar graph, so we created our own for the purposes of this demonstration. The naming of the categories is one of those jokes that is funny to autistics.

This is what we mean when we say that it is a spectrum. We will each present in a different way, and by definition we will all be radically different when compared to the general population.

If you'd like to have a go at creating your own radar chart, you can complete *The Aspie Quiz*:
<https://embrace-autism.com/autism-tests/>

Note: The Aspie Quiz is community [created by an elder autistic](#) so please refer to the section later in this piece regarding the terminology 'Aspie.' This quiz is not recognised for formal diagnosis in Australia but you do get a cute radar graph at the end. The **RAADS-R** test is scientifically backed and can be used in evidence for a diagnosis in Australia when completed with a psychology professional. It is available at the same link.

We should also say, before you do any of these tests, **beware** (yes, this is an Autism Awareness pun)! You might just find something out about yourself that you were not expecting. **Do not seek if you do not wish to find.** If you do, and you wanted to reach out, you would be most welcome!

Communication and the Double Empathy Theory

Autism is clinically defined by social communication deficits. In autistic brains, the **amygdala** has been found to perform an entirely different function. There is research to suggest this is linked to the difference in social interactions; the so-called 'double empathy theory' where autistics and allistics will struggle to communicate effectively with each other, while communicating perfectly well with their fellow autistics or allistics respectively; [Autistic peer-to-peer information transfer is highly effective \(sagepub.com\)](#). So, how can we overcome this?

Autistic people and allistic people would both benefit from using clear and unambiguous communication methods.

The problem is that, being autistic, we are already doing this. We tend to use plain communication styles every day but unfortunately we're often misconstrued as being blunt or rude because of it. We really need you to use plain and accurate English, and avoid using unknown or abstract metaphors, phrases, and jargon - unless they're accompanied by a plain explanation. In short; **Say what you mean** instead of requiring the autistic recipient to read between the lines. The opposite is also true; **don't read between the lines** when receiving communication from an autistic person or you may end up manufacturing a message that doesn't exist.

It's also important to recognise that, just like allistic people can have an off day and struggle with their focus or generally not do as well in their day to day tasks, the same is true for autistic people. Just because someone usually has really strong verbal communication doesn't mean they'll always be able to find the right words, or any words at all. And because a lot of things that can be stressors to autistic people aren't obvious to allistics, it's not always clear to others why we might be having an off day. Maybe the tag in the back of their shirt has been rubbing on their neck all day and they're just at their absolute limit. Maybe the air conditioning is really loud. Don't expect an autistic person to always be at the same level.

The differences in the amygdala are now thought to be direct physical evidence of autism - though more research is required. That might sound familiar to some of you; the amygdala was actually referenced in *Empowering Excellence*. Some of the human resources and leadership strategies noted that they were informed by how the amygdala works within the human brain. I think you can see where I am going with this but to satisfy my own advice I will be clear: these strategies are not going to work as well, or at all, with your autistic colleagues.

Barriers and Outcomes - Part 1

How does being autistic affect your life?

We collectively have significantly worse life outcomes and face many barriers to success. [The Senate's Select Committee on Autism](#) tabled a report on 25 March 2022 which included the following points:

- autistic people have a life expectancy 20–36 years shorter than the general population
- the mortality rate in autistic people is two times higher than the general population
- 75% of autistic people do not complete education beyond year 12, compared to 36% of the general population
- the unemployment rate for autistic people is almost eight times the rate of people without disability

- 50–70% of autistic people experience co-existing mental health conditions, and are between five and eleven times more likely to die by suicide

The entire report is worth reading.

These barriers are not always obvious, even to programs which are designed to be accepting. For example, the agency's yearly grad program has a disability affirmative action pathway but has an entry requirement of a Bachelor qualification, and the ██████ program recommends that applicants have a degree to be competitive. 31.2% of Australians have completed a Bachelor qualification or higher, but just 8.1% of Autistic Australians have done the same. The barrier here appears to be the entry requirement, but it is also the unseen follow-on effects of the negative social experience during schooling that is known to push autistics away from even completing high school, never mind enrolling in and completing any higher education.

School education

3.22 The most recent Australian Bureau of Statistics (ABS) data shows that, in 2018, the proportion of autistic students whose highest level of educational attainment was Year 10 or below was more than double that of those without disability. The proportion was similar for those whose highest attainment was Year 11 or 12 (Table 3.1).

Table 3.1: Highest level of education attainment by disability status (per cent)

	No disability	All disability	Autism spectrum disorders
Year 10 or below	15.4	34.9	32.4
Year 11 or 12	21.7	14.7	43.2
Advanced diploma, diploma or certificate III/IV	28.1	29.4	17.9
Bachelor degree or higher	31.2	16.1	8.1

Source: Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings (2018)

Diagnosis Troubles

Does everyone who's autistic have a piece of paper to show for it?

No, we are not all formally diagnosed. It's worth noting statistics like those above often miss a lot of autistic people. For starters, autism is heavily underdiagnosed in women and girls, people of colour, and other minority groups. Historically, the diagnostic materials have been centred around the presentation of Autism in the white American boy. This is still true even today, and the adult formal diagnosis process heavily relies on reports from the subject's childhood (i.e. parental interviews, child medical records, school reports, etc).

For those not diagnosed as a child, there is a typical pathway of misdiagnosis from depression, to ADHD in men or to BPD in women, and finally to Autism once a holistic assessment is made including childhood reports. The process for a formal adult autism diagnosis typically takes 2-3 years from the first time Autism is identified as a possibility, and it costs several thousand dollars in total. After a decade of misdiagnosis and mistreatment, I finally landed with a regular psychologist who spent a year building a case for my autism assessment. After that, I was waitlisted for 16 months before getting my final assessment appointment. That final appointment alone cost \$1200.00 upfront.

Autistics have a shared experience of this difference to the general population, the shared diagnosis, and the shared root causes of this difference. We see these differences in ourselves and notice the sameness. It has been documented that people with a certain neurotype are more drawn to one

another within a social setting due to their core understanding of the world with shared experiences. Some of us (actually, just me) call this phenomenon the **neuroscope**, but the term hasn't quite caught on yet. Some people consider this another kind of informal diagnosis: community-diagnosis. Others consider it a good way to make friends with like-minded people.



*"Gretchen, stop trying to make **neuroscope** happen. It's not going to happen."*

A lot of autistic people choose to remain self-diagnosed or informally diagnosed. There are many legitimate logistical reasons for this, including the fact that an autism diagnosis as an adult can cost hundreds or even thousands of dollars and many people will have to travel to find a doctor who will do the assessment (last I checked, nobody does adult autism assessments in Canberra!). On top of that, for a lot of people who have made it to adulthood, a diagnosis would quite possibly put up more barriers than it would remove.

Many countries, [including Australia](#), won't allow you to immigrate if you have an autism diagnosis unless there are extreme circumstances or ministerial intervention. There are immigration law clauses about 'not placing undue strain on healthcare systems' and the like. Many jurisdictions will limit your autonomy when it comes to healthcare, especially gender and transition related care, limit your ability to adopt or foster children, and in many cases a diagnosis is counted against a parent in a custody battle.

Undiagnosed and informally diagnosed people are worth thinking about for a few reasons. Broadly speaking, there are a lot of autistic people who slip through the gaps of these kinds of statistics, because they only count diagnosed autistics. On a more personal level, especially if you're in a management role, it's important to recognise that even if someone doesn't have a formal autism diagnosis, they may still be autistic and as much as is possible that should be accounted for and accommodated. Requiring formal diagnosis paperwork for even the most basic accommodations makes a lot of workplaces a trade-off between being overwhelmed and uncomfortable for 8 hours a day, or risking huge parts of your life plans and goals with a formal diagnosis.

I, and other self-diagnosed autistics I know, get by with our comorbid diagnoses of anxiety disorder or ADHD, or other conditions. This can allow for at least some of the accommodations we need, without a lot of the undue restrictions that are created with a formal autism diagnosis. Be mindful of these kinds of things, and remember that the world on paper and the life of the person in front of you tell same story from different perspectives and for different needs - so please be flexible.

What does autism look like?

Autism in the media

There are a number of depictions of autism in the media, and most of them are negatively viewed by autistics. Films like *Rain Man* had a massive impact on the general understanding of what autism is, and what it looks like. We're not all like Rain Man at all.

Sure, [I can count cards too](#), but that's not the point.

In fact, the impact of *Rain Man* was so profound, it prompted a revisionist view of the earlier released *Forrest Gump* and [many now argue that Forrest is autistic](#) due to the similar characterisation, despite this not being stated in the film.

There are other examples. Sheldon from *The Big Bang Theory* is plainly characterised as autistic but they have avoided stating that he is autistic because he is played for laughs. It would be impossible in the modern age for a studio to create a show hinged around laughing at the autistic friend – so they do it in every way other than name instead.

There is a reality TV show called *Love On The Spectrum* which features real life autistic people in a speed dating setting. While the people are real, the editing and scripting again plays into these stereotypes, resulting in a show which infantilises us rather than humanises us.

Most media which include autistic people make their plot interaction hinge on the fact that they are autistic. We don't really want that.

But it's not all bad. There are characters who are not played as autistic or specifically identified as autistic, who behave and/or experience their worlds in ways that are relatable to autistic people. Captain Holt in *Brooklyn 99*. The book version of Willy Wonka. The Doctor from *Doctor Who*. Most incarnations of Peter Parker/Spider-man. Every adaptation of Sherlock Holmes. Brains from *Thunderbirds*. These characters show us the ideal. They show us a glimpse of an autistic person who is not externally defined by being autistic. They're just another character who happens to be autistic and no one makes a big deal about it. It also helps that they are successful in their roles in the plot.

Both Spock and Data from *Star Trek* get a special mention. They present a different aspect to autism in the media. In an autistic context, both exhibit the familiar trope of a [disability superpower](#) by being capable of complex mathematics and logic in an instant (just like all autistic people, right!?), but with the sci-fi twist being half Human/half Vulcan or being an android (instead of being autistic). They are plainly and openly characterised as being *other*. This sci-fi twist allows a certain element of suspension of disbelief from the audience who are comfortable that the key ensemble heroes in the story will ultimately be fine by the time next week's episode comes along. Their story arcs play through many familiar autistic experiences: knowing you are different due to being an alien/android (autistic), seeking to become human (pass as non-autistic), pushing back against their differences and seeking to be as far opposite of human (hyper autistic) as possible, navigating the apparent lack of emotions and communication issues (double empathy theory). Ultimately though, they find comfort in who they are, and the acceptance and friendship of their peers and colleagues.

The allistic view

Then there's the real life experiences of allistics. Most people's limited experiences with autism is through children, as autistic adults tend to drop off the social radar. Refer to the Senate report above: most of us don't work, don't socialise, and otherwise don't participate in allistic society, so the average allistic adult really doesn't have many experiences with adult autistics. You've either seen a portrayal of us in the media, or you might have an autistic family member, a cousin, nephew, or a friend's child.

Too many times have we told people of our diagnosis and been met with immediate dismissal. "You can't be autistic. My little nephew Timmy has autism [sic] and you're nothing like him!" Good! I sure hope I'm nothing like your nephew Timmy, considering that he's a 10 year old and I'm a few decades older.

Another response we often get is "You must be high functioning then." Well, that's not really how it works. The spectrum isn't a line from more autism to less autism and functioning labels are often used to deny people either agency or support depending on how 'functioning' they're perceived by others to be. It is closer to the radar chart as described above.

When other people judge our capacities, skills, abilities, and reasonable adjustment requests based on their limited and wildly incorrect idea of what autism is or isn't, it harms us greatly.

So...what does autism *actually* look like?

Well...I personally wear a basic Connor suit, shirts from Tarocash, and usually complete the look with my R.M.s. On weekends I wear jeans and a t-shirt.



Steal His Look!

Long Hair: \$0

Specsavers Sunglasses: 2 for \$199

Connor Suit Jacket and Pants: \$99

Target Merino Wool Jumper: \$49

Big W T-shirt: \$7

Oporto's Bondi Burger, Chips, and Coca-Cola: \$18

R.M. Williams Boots: \$500

8 Person Elevator Accessory: \$68,000

The point is, we look just like anyone else, and we don't look like anything in particular. However, we do often have some common behaviours that can be spotted: inability to sit still, fidgeting and other tics, a really great sense of humour, and we're generally collectively poor at maintaining eye contact. Try as we might to mask, we are easy to spot and you already know what to look for, even if you don't consciously know what you're looking for. Statistically speaking, most neurotypicals can tell who is autistic within 30 seconds of meeting, and will immediately form a negative perception of the autistic person *which never changes*: [Neurotypical Peers are Less Willing to Interact with Those with Autism based on Thin Slice Judgments - PMC \(nih.gov\)](#)

This is sometimes attributed to the *Uncanny Valley Effect*: a neurotypical person will immediately notice that the autistic person is different. They may not specifically think 'that person is autistic', but they will likely think 'that person is weird'. Whatever that sense is, call it the **neuroscope**, or anything else, it certainly made a lot of us stick out in our school years. There is a globally common experience of bullying and social exclusion of autistic children. Again, this is noted in the Senate report.

A lot of people are autistic and don't realise that this is the explanation for their experiences, or don't want to disclose it in a work environment for fear of the prejudice and barriers we often face. Whether or not you can tell, we are all around you, and we're just trying to live our lives. We do our best to make our way in a world that is often hostile (bright lights, loud sounds, unexpected changes in routine). What we're asking is for you to help us clear away some of those barriers, so everyone can work together better.

Barriers and Outcomes - Part 2

Masking

Autistic people don't exist in a vacuum, we must exist in a world of allistics where we must face significant barriers and hostile environmental stimuli, as well as the social barriers that exist when we don't address these stimuli in the expected normal way. The closer we can act like the average circle on the aforementioned radar chart, the more likely we are to successfully navigate the social world. This act is called **masking**. Masking is an exhausting and conscious effort. The worst thing about masking is that it doesn't address the barriers or hostile stimuli at all. The amygdala is one of the parts of the human brain that has responsible for the fight or flight response in humans. Autistics overstimulate our already deficient amygdala, all day, every day, just by existing. When we are masking we are also working over-time to fight back against the fight or flight response that has been triggered by an external stimulus or barrier.

This capacity to mask and process stimuli can also be explained using Spoon Theory. [Explaining Spoon Theory For Autism \(freshered.com\)](https://www.freshered.com/explaining-spoon-theory-for-autism)

Meltdown

When we exceed our ability to fight back against that fight or flight response, well, we experience it. This is called a **meltdown**. It doesn't appear like the typical fight or flight response though. The (negative) stereotype of an autistic meltdown that we all know (and despise) is that of the primary school child screaming as loud as they can while making snow angels in the dust on the floor of aisle 9 in your local supermarket. This is not what most autistic meltdowns look like.

Most autistic people experience a meltdown as an immobilisation. Many of us become non-verbal or experience auditory processing difficulties. Many of us become unable to concentrate and instead escape into a day-dream-like state. I personally find that I lose the ability to physically move with any haste. It feels a bit like trying to run under water but instead of pushing against the external pressure of the water I am pulling against some internal tension in my muscles. Meltdowns are caused by overstimulation so it can often be counter-productive to approach a person in autistic meltdown, even if you think you will be helping. All you are doing is adding yet another stimulus that can't be processed. There is no way to end a meltdown other than to reduce or eliminate the stimuli.

If you watched the previously linked casino scene from *Rain Man* in detail, you will see the immense stress that Ray experiences in the overstimulating environment. The cinematography, sound design, and acting, give a brief but reasonably good insight of an immobilising meltdown. Keep in mind, though, that this is just one example.

Burnout

There's another state that you may have heard of, that of **burnout**. Autistic burnout is different to the regular burnout that anyone (even autistics) can experience from being over worked and under rested, and different again to a depression episode that anyone (even autistics) may experience. Autistic burnout is perhaps best described as a state of extended mild meltdown. Burnouts can occur for a few days, or for months. There is no way to tell. Burnouts are generally triggered after an extreme state of stimulation which may have resulted in a meltdown, or an extended period of heightened stimulation that may have even been (at least, initially) manageable and therefore not resulted in a meltdown. This has exhausted our efforts and reduced our ongoing tolerance for stimuli. An autistic in burnout will often appear tired, worn out, easily agitated, introverted, or with a negatively affected attention span.

What barriers exist for autistics in the workplace?

- Attention and stimulus processing capacity - this ties into the earlier discussed amygdala and meltdown. The office workspace can be a very overwhelming place, particularly in terms of lighting and auditory processing. One of the issues is that we don't necessarily have the ability to control where what we spend our processing capacity on: The fridge in the office kitchen might be too loud, the buzz from the lights might be too loud, the sunrise or sunset coming through the window might be too bright, the temperature in the room might be too much in either direction, the person on the phone just over there might be too loud, people might be walking by you all day which catches your eye constantly. All of these stimuli are competing for our attention, in addition to the actual work itself. When we are overwhelmed and unable to process all of these stimuli at once, we don't generally get to choose which stimuli we will focus on and which we can block out. This leads to meltdown situations
- Communication - as mentioned in detail previously in this piece. Clear communication is key!
- Interoception - [the ability to sense your own body](#)
 - Temperature regulation - particularly in an office space where there are significant variations in ambient temperature across the floor
 - Gastrointestinal regulation - the absence of feeling hungry or thirsty can result in poor break management (you might work right through a break without realising it is lunch time), and poor energy regulation by not eating enough to sustain the physical energy required for the day
 - Touch regulation - this could be that the tag on your work shirt is in such a position that it causes prolonged distress
- Executive Function - it's easy to see this as 'task management' skill issue, but it's much more than that. Generally, the autistic task management thought process is quite accomplished, and it often comes to fundamentally different conclusions than the neurotypical thought process. It is the lack of control over the task management process in and around a workplace that can result in distress, and forcing a particular method that contradicts the executive function process will result in a meltdown
 - For example: I might have the perfect routine for getting up, getting ready, travelling to work, parking, attending work, getting lunch from the corner store, finishing work, travelling home from work, organising dinner, and getting ready for sleep. This routine has been established through careful and deliberate planning - good executive function. Now, imagine the stress you feel if there's an unexpected traffic jam, it's a minor issue and you'll just be 10 minutes late for work. No worries, right? Sorry, that's not how it works. What has actually happened is that, suddenly, your entire day's plan is broken because the next step in the process doesn't occur as expected, which means the next step in the process is also not going to occur as expected, and so on. In the autistic brain, that seemingly minor change can cause a distress that triggers in our amygdala into overdrive. It's enough to cause a meltdown
- Social interactions
 - Autistic eye-contact is variable – some of us may be able to maintain eye contact while someone else is talking to us, but when it's our turn to speak we can't keep the eye contact *and* focus on what we're talking about at the same time, so we tend to look away. This is another stimulus processing capacity barrier
 - We often struggle to make and maintain friendships, primarily due to the communication issues and the inherent negative thin slice judgements made by neurotypicals that were discussed earlier
- Workplace culture
 - Terms like 'growth mindset' really don't help. That's something which is incompatible with the autistic experience. For many of us, particularly people who received their formal

diagnosis as an adult, we have already spent a lifetime attempting to change ourselves into something resembling neurotypicality with no success - the task is fundamentally impossible. This is where we see the worst outcomes of the double empathy problem

- There is a glass ceiling that exists for all people with disabilities. While the words of hierarchy organisations across the country may say that disabilities are accepted, the actions across the board clearly do not demonstrate this. The statistics speak for themselves. The ceiling doesn't exist because of an actual capability issue, but a perceived capability issue and thin slice judgements

The 'Neurodiversity at Work 2023; Demand, Supply and a Gap Analysis' by the [Neurodiversity in Business Report Commission](#) had the following findings:

- <30% respondents had formal workplace adjustments in place
- Helpfulness of adjustments – top 10:
 - Having a flexible schedule
 - WFH [Work From Home]
 - Having a private space to work in when required
 - Dual screen or reading stand
 - Being able to change or modify noise levels
 - Being able to adapt work rules, policies or procedures
 - Change the intensity of lighting
 - Taking frequent work breaks
 - Coaching to support with organisational issues
 - Make changes to workplace arrangements
- Barriers to disclosure - worry about stigma and discrimination from management and colleagues, and that there were no supportive or knowledgeable staff
- Lack of representation at senior levels due to the way both entry and middle management roles are often reliant on being a good all-rounder in terms of strong administrative skills, self-organisation and compliance – this is contradicted as markers of success at senior management levels depending on creativity and innovative thinking, skills ND employees are reported to have
- There is a reported 'neurodivergent glass ceiling' that starts in early management
- Most important influences on the intention to leave are support by your manager, psychological safety, and career satisfaction
- Challenges to the implementation of adjustments - managers are often not convinced that adjustments help, are reluctant to try any adjustments, and others cite perceptions of unfairness to the team; reasonable adjustments should not be considered a privilege and should be relational, not transactional

In terms of overcoming or eliminating these barriers in a workplace, the approach must be different. Barriers for autistic people are unlike the often highly-visible barriers experienced by people with mobility disabilities that can be eliminated by adding ramps, wide doors, and hand rails to benefit everyone from cane/walker users to wheelchair users.

Each individual autistic person will be susceptible to particular stimuli and have a different processing capacity. There is no one size fits all solution to address or eliminate the barriers because we experience them in such a wide variety of ways. However, there is an overall approach that is known to work: allow the autistic person control over their environment. In a workplace context, this often means seeking a work from home adjustment. We have almost complete control over the stimuli in our own homes, without impacting others.

Research indicates that there are four key leadership behaviours or characteristics that are important for those leading individuals with ASD:

- providing clear and direct communication
- knowing about ASD
- providing individualized consideration
- creating a work environment accepting of neurodiversity

Further reading: [What We Know About Employers' Perspectives on Successfully Integrating Adults with Autism Spectrum Disorders in the Workplace \(researchgate.net\)](https://www.researchgate.net/publication/331111111)

IFL vs PFL

Why do you prefer 'autistic person' instead of 'person with autism'?

The use of Person First Language (PFL) or Identity First Language (IFL) is often unfairly considered a hot topic because when people think about this, they think about all kinds of disabilities and all kinds of people and attempt to assign us a homogenous collective stance. Collectively we might be called "people with disabilities" or "disabled people" depending on the context. The agency and [REDACTED] at large uses PFL when referring to the non-specific cohort of minority groups – and we don't have a problem with that. The problem with this approach is that we are not a homogenous group and this doesn't translate when referring to specific cohorts.

"Person with autism" comes from a place where autism is something bad; a disease to be cured, a wound to be healed. It is dehumanising because of how the language attempts to separate us from our fundamental and unchanging state of being.

The origins of PFL and Autism

The historical usage of PFL stems from the work of the Nazi Doctor Hans Asperger, using the alternate diagnosis title of 'Asperger's Syndrome'. Due to the phrasing, this can only be referred to in person first styles; it's a language limitation. You can't say 'that person *is* Asperger's'; you can only say 'that person *has* Asperger's'.

His work differentiated autistics in to two groups. Those judged as a utility for Nazi society were labelled under the Asperger's Syndrome banner and put to work. Those who were judged of no use to the Nazi society did not survive. There remain some fringe groups who prey on vulnerable autistics under the banner of 'Aspie Supremacy.' This is, unfortunately, exactly the fascist dog-whistle that it sounds like.

It took three generations but we were finally able to gain widespread support to cease using Asperger's Syndrome as a formal diagnosis title in 2013.

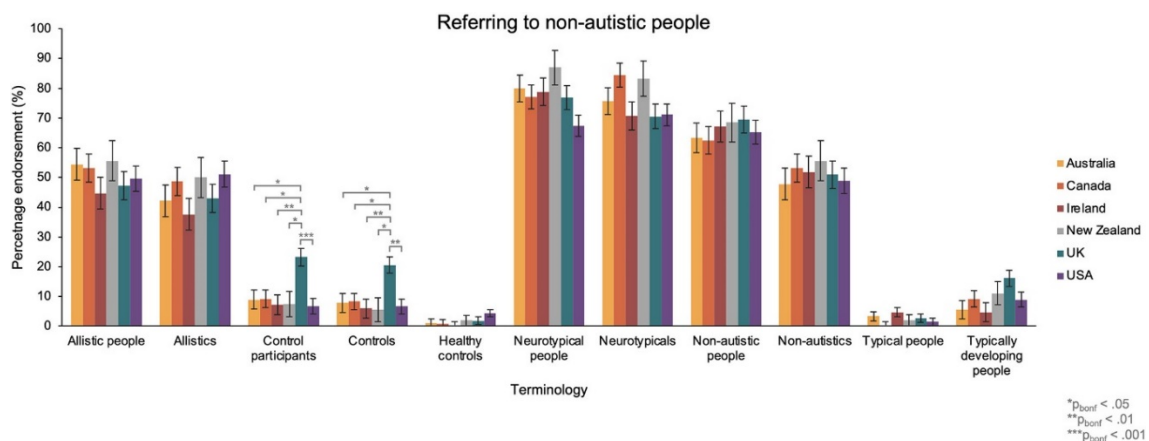
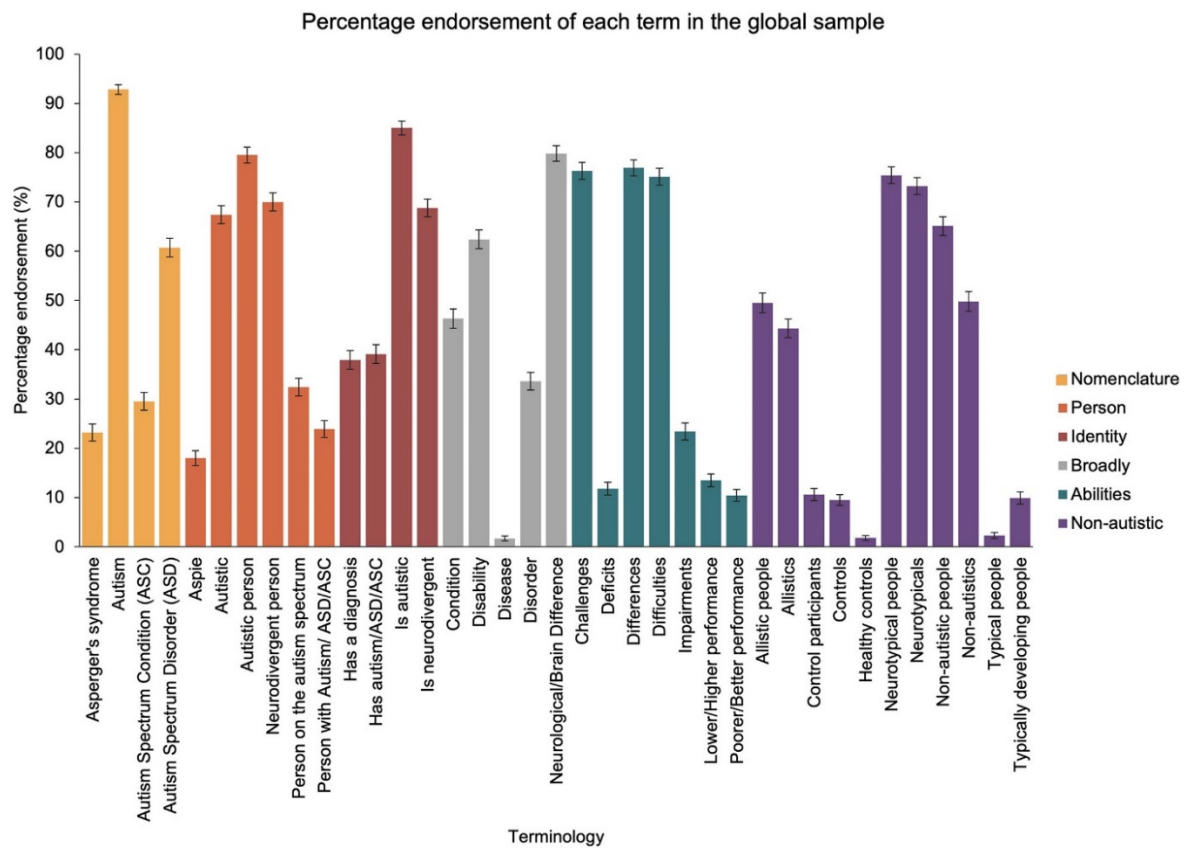
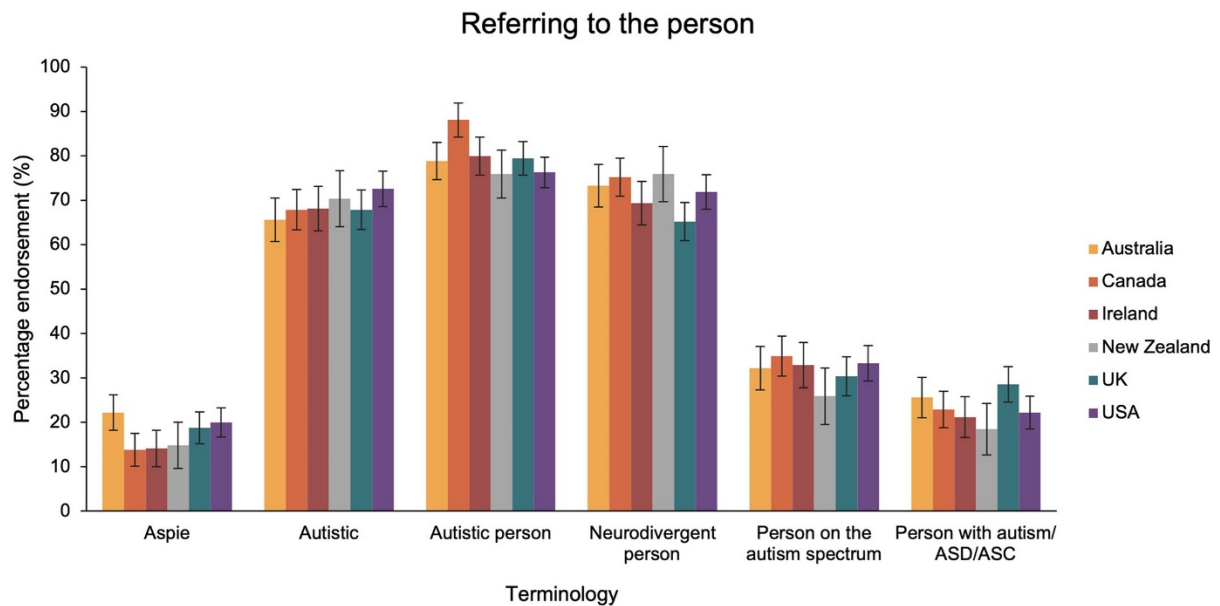
What is the consensus?

The use of PFL in the context of Autism stems from the initial and long standing belief that we need to be fixed.

We don't.

Autism is inseparable from me, I don't have autism. I am autistic. It is me. I wouldn't be who I am if all my autistic qualities were taken away. There is nothing to fix. IFL acknowledges that we have worth not just as people but as autistic people.

It has consistently been shown across multiple global studies that over 80% of native English speaking autistics prefer IFL.



See [Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation - Keating - 2023 - Autism Research - Wiley Online Library](#) and [Preferences for identity-first versus person-first language in a US sample of autism stakeholders \(sagepub.com\)](#).

It's worth noting that age, native language, and culture, can play a role in this. For example, the elder Dutch prefer PFL while the younger Dutch prefer IFL; ['Autistic person' or 'person with autism'? Person-first language preference in Dutch adults with autism and parents PMC \(nih.gov\)](#). Some older people still refer to their diagnosis as Asperger's rather than autism, including using the colloquial PFL variant term Aspie ('an Aspie', not 'person with Aspie'), though its use is decreasing. We have the opportunity to study this generational change as it progresses.

There are other considerations too: [Avoiding Ableist Language: Suggestions for Autism Researchers | Autism in Adulthood \(liebertpub.com\)](#)

There appears to be a blanket policy that the agency has to use PFL regarding the various diversity cohorts, [particularly with disability inclusive language]. However, there are exceptions. The agency already uses IFL for some specific groups [such as the LGBTQ+ community]. 'The language we use reflects the way we think about people. We all have the responsibility to be aware of the effect our verbal and written language has on others.'

We agree. There's no reason that we can't use IFL for autistic people too.

[This piece is quite long. Are you going to wrap it up soon?](#)

If you got this far, thank you for sticking with it. We had a lot to say.

We are proud to work at an agency that is open to being adaptable to the needs of its workforce as it changes over time, and is actively trying to provide opportunities for autistics to participate. Most of us have recommended the various pathways to employment to our autistic friends outside of the agency. This place is already doing a lot of good - but this doesn't mean we can stop here. We can keep improving. We'd like to see the agency progress by taking steps away from *Autism Awareness* and towards *Autism Acceptance*. What could this look like?

- Regular communication with senior leadership, including the I&D team, and eventually open representation in both [executive] and HR roles
 - As mentioned earlier, we'd almost prefer that they were just another [executive] who happens to be autistic. It helps so much when we can see successful outcomes for other autistics
- Promoting and applying autism recruitment programs and strategies openly, not just targeting and limiting these towards the autistic stereotypes of data and computer science roles
- Continued efforts toward a neurodiversity-friendly employee lifecycle at the agency, including workplace adjustments becoming standard in employee-employer relationships, and minimising or eliminating the many barriers we face
- Use of identity-first language as a default position when referring to autism and autistic people

In the end it doesn't really matter who is and isn't autistic. The important thing is to continue working to create a workplace where true understanding and acceptance informs the decisions and interactions you have with your colleagues: a person centred approach. This is not just for the benefit of autistics with formal or informal diagnosis, or other people with disabilities. Everyone will gain from this, even our customers.

Thank you