

Produced by and for Autistic people

The Spectrum

Edition **112** October 2022



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National
Autistic
Society

The Spectrum

The Spectrum is run by and for autistic adults (although some parents subscribe on behalf of their under-sixteens). The magazine is owned and run by the National Autistic Society, and aims to connect autistic people through their letters and articles and to share information so that they can lead more independent lives.

Please note that *the Spectrum* receives many letters each quarter so it is not possible to respond to every one, nor for every contribution to be printed. Discussions on editorial choices will not be entered into. The magazine protects the identity of contributors by not printing full names unless the writer asks for their full name to be used.

The Spectrum is available at

www.autism.org.uk/theSpectrum

or by paying a subscription. To subscribe you, we need your postal address. Please subscribe online or contact the Goth for a subscription form. All contact details are below. Organisations requiring multiple copies: please get in touch.

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This magazine was founded as *Asperger United* in 1993 by Pamela Yates and Patricia Howlin, in association with the Maudsley Hospital, and Mark Bebbington and Judy Lynch of the National Autistic Society.

This was in response to a recognised dearth of services for people with Asperger syndrome and the potential for self-help and networking as a means of support for this group.

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds, John Joyce and the current editor, the Goth.

Pamela Yates provided support and advice to the editors until the publication was handed over to the National Autistic Society in 2000.

The name *Asperger United* was chosen by the group of original readers as the most "appropriate name" for the publication. This was suggested by Anna Kaczynski. The name *the Spectrum* was suggested by dozens of people and chosen in an online poll in 2018.

Please send all correspondence and subscription requests to:

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and follow the link to the submissions form.

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Please note that the views expressed in *the Spectrum* are not necessarily those of the editor, the National Autistic Society or those involved in the publication of the magazine.

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The Spectrum is available in **large print** on A3 sheets (double the size of this page). If you need large print, please let us know using the email address or postal address above.

Contributions for the next issue should reach *the Spectrum* by **3 November 2022**

Welcome to the October edition of *the Spectrum*.

On the cover is the winner of the art competition, with the runners-up on page 11. Also on page 11 are three short descriptions of the art written by the artists.

As well as all the art entries, there was a very good number of pieces on the subject of freedom, so clearly another inspiring topic. Dreaming up another such topic, I fear, is beyond me, but I will see when you send me your

thoughts on art and creativity, as well as your art and written creations.

As ever, this is only a suggestion, and I will enjoy your writing on any topic, along with your art and photography.

I shall be very much looking forward to the postbag.

Yours,

the Editor

the freedom edition – suggestion for next issue, page 10

Contents

Winner of the art competitioncover
Shining time station celebration
 by Jordan

Freedom4-5
 feature by Tom

Freedom and Shakespeare..... 5
 featured poem by J A Mickleburgh

Hello stranger 6
 article by Pauline Ehlert

Apples and oranges – article by Michael 6

Freedom 7
 article by Nick

“You’ve become more autistic since your diagnosis”... 8
 article by August Grace

ND Pride – poem by Shan Lena..... 8

Autism and melodrama 9
 article by C A Thompson

Letters to the Editor..... 10
 one about privacy from Mr Chakotay and
 one about stress from Paigetheoracle

Runners-up to the National Autistic11
 Society’s art competition
Identity anti-crisis by Luci and
Disconnection by Tyrone

My experience 12-14
 article by Sarah

PDA: a Preventable Delicate Activity..... 14-15
 article by Richard Woods

Bridal make-up artist 16-17
 article by Eleanor Norman

Virulon SL26 18
 story by Alexandra Stobiecka

The rules of *the Spectrum* 19

A bit different..... back cover
 poem by Tom

Freedom

by Tom

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Where I am now in my psychological development, after my diagnosis more than a decade ago, is that through therapy I'm starting to unlock a lot of emotions I thought I'd dealt with, but as it turns out really just pushed away. That's good, since the only way to deal with emotions is to go through them. When you try to push them away like I did, or try to distract yourself with all kinds of obsessive or addictive behaviours, they only grow stronger.

Something small (or large) happens and through association an old memory presents itself with the same emotional intensity of the moment I'm remembering. That's a sign that I didn't process the emotions from that moment. I'm fairly sure of that because I have other memories that have intense emotions associated with them, like the time leading up to my diagnosis, or the death of my father, which I don't relive with such intensity whenever I'm reminded of them now. That tells me that I did process those emotions.

So it's not everything that comes flooding back, but enough to make me remember with some intensity how uncertain and scared I felt as a boy. The objective of my therapy, which is reaching its conclusion with this process, is to develop within me a sort of parent, a benevolent grown up who can take that uncertain, scared, hard-working boy by the hand and guide him through all those big, scary emotions, preferably while maintaining some semblance of daily functioning.

Right now, however I frequently feel like my thirteen-year-old self: scared to death about things I know aren't actually that scary. I really thought I'd put much of that behind me.

Something else I notice is how easily I project

my feelings outwards; especially anger, which usually serves to camouflage fear or another emotion (since anger always covers some other emotion). Politics is always an easy thing to get worked up about, of course, but at times it's overwhelming me how angry I get at the people I disagree with and how much fear that masks.

Besides that there is a very real fear of what will happen to me — being socially and economically vulnerable — should the worst come to pass and democracy fall to be replaced by some kind of (right wing, as it stands now) dictatorship. I can hardly believe I write this, but it seems distinctly possible right now. I never gravitate towards extreme ends of the political spectrum, nor am I susceptible to the myriad conspiracy theories that are so much more visible these days.

I do, however, recognise many of the mechanics behind these phenomena, because I use that for my own psychological management. The basics are this: the more scared you become the less physically capable of rational thought you become. This is literally physical: brain research has shown that the areas containing the higher brain functions basically shut down when you get scared enough. Eventually, you enter the freeze-flight-fight response that accompanies extreme fear. In evolutionary terms that's understandable since it rather hurts your survival chances when you stop to ponder the fur of the sabre tooth tiger hurtling towards you instead of just jumping out of the way. For myself, such extreme and irrational thoughts serve as a signal that I — although I might not entirely be aware of it at the time — am experiencing extreme emotion and that, thus, all the thoughts that whirl through my mind are not “real”. The emotion I feel is very real, but the thoughts aren't. That more or

feature (continued) and a second feature

less frees me to leave those thoughts be and reminds me that the cause of my emotion isn't some fiendish thing outside me, but my own psychology (often my susceptibility to overstimulation). That helps me to (gradually, my emotions are quite intense) break free of these emotions and realise that since the cause is inside me, I have some control over it, even if it doesn't feel that way immediately. I don't mean that the emotions disappear, but it helps me realise that they are part of me instead of something I need to fight.

Much of this same process seems to me to occur in others, particularly those on the more extreme (right wing, authoritarian) end of the spectrum. Much as I can lose myself in blaming anything and everything around me for what's bothering me at that moment, I see others do much the same blaming foreigners, muslims, Europe, and so on. Where people with autism like us are intimately familiar with fear and have learned to function (to a degree) while experiencing fear or anxiety, people without autism (or any other affliction that induces similar amounts of anxiety) find it much harder to break free of their anxiety-induced thought processes. What seems to me to exacerbate this now is on the one hand the echo chamber effect of social media that reinforces (and even promotes) every extreme idea, on the other that years of neoliberalism and deregulation have left a lot of people so (psychologically) vulnerable and without a safety net that they are easily pushed into extreme levels of anxiety.

In any case, the central paradox that I recognise playing out in society and within myself is that the more I lose myself in my fear-induced anger, the more I want to restrict this, that and particularly the other. A bit like a tinpot dictator. Whenever I manage to let go of that, I realise again that what I'm really doing is restricting myself. I find the most freedom when I manage to let go of trying to restrict the freedom of others, because then I can let go of restricting myself and feel empathy towards myself.

Freedom and Shakespeare

by J A Mickleburgh

© J A Mickleburgh 2022

The world says we should all live and be free,
that no person should have their life prescribed.
Now, I don't know if I believe that, me.
It sounds like our celestial maker lied.

We live and learn in some rich man's schema.
But no one sees that this is not the best
And if you break free you'll be dubbed "dreamer".
Their every action will become a test.

But you can, and you should break free,
be authentic to yourself
be unapologetically you

for jokes won't land,
things won't go as planned,
other people's intentions you won't understand.

But we're all expected to try.
To fit in to the world that isn't made for us.
The world that can be scary for us.
The world that doesn't seem to welcome us.

But as always, we bow to what we're told.
Suppress ourselves so we don't break the mould.

Hello Stranger

by **Pauline Ehlert**

© Pauline Ehlert 2022

Tell me, what do you see when you look at me?

You might see a face, a body, maybe even a person. But who is she? Is she somebody who means business, somebody you want to be friends with? Somebody you would trust to be your lawyer or your child's teacher? Maybe I remind you of somebody else you know, maybe even of yourself. Would you want to talk to me? If you had to ask somebody for directions, would it be me? Do you think I'm smart, funny, charismatic? Do you think I'm a good person? Will you remember me?

I don't necessarily care about what strangers think of me, but in a way, I really do. Because when I look into the mirror, I don't know what I see. I see somebody, but is she the same person you see? And is she even real, if I'm the only one who sees her? She looks right into my soul. She wants to be known, seen, understood. She wants to be loved too. Sometimes I think she must be really lonely, all alone in that glass prison of hers. No way of knowing what else is out there. Sometimes I catch a glimpse of her in the window of a shop on my way home, but she seems different then. It almost seems

like she knows we're not alone there, like she's aware that she's very close to being seen by other people too. She looks more guarded then, closed off. Sometimes I wonder why she looks uneasy around other people if she's lonely, but then I remember that not being alone is a very different thing than not being lonely. And if I'm the only one who sees her the way she wants to be seen, being around other people means confronting that maybe a lot of what I see in her comes from me and not from her. In a way she is in the same predicament as I am. Just wondering what all these strangers see when they look at her. Hoping they see her but at the same time scared they see her too clearly. She's just as scared of being known and not wanted as she is of never being known at all. When the two of us meet we have a silent understanding. We try to really see each other, to have at least each other to truly know. If we can never know how much of us is our own and how much is just one projecting herself onto the other, we can at least promise to be curious to find out more about each other.

Goodbye Stranger,

I'll see you in the mirror sometime.

Apples and oranges

by **Michael**

I found myself in a situation a few weeks ago where I was asked to describe how my feelings of being overstimulated are different to what a neurotypical person felt.

I used the sensation of being too hot and it physically and emotionally overwhelms me. They responded with "well, I hate being too hot too and it makes me uncomfortable."

I could only try to describe it within the limits of my own experience. I don't, and can't know how you feel.

I can only assume that my reaction is beyond the normal based on how other people comment or act in reaction to my distress (I'm being "dramatic", "rude", "selfish", "ignorant" and so on).

How am I meant to describe a feeling? I can only use the words that approximate what I have learned other people view my experience as. I get angry. I get overwhelmed, I get anxious.

It's like being asked to describe a colour.

Freedom

by Nick

Freedom is such a precious concept at present given the terrible situation in Ukraine. We are so lucky here as I have the freedom to travel, to volunteer my time, to write this article. Difficult though it is for us auties, I can go out shopping for supplies even if I have to do this at quiet times. I have the freedom to wear my ear defenders and sunflower lanyard. Let's face it, being autistic can be tough at times so why not take the opportunity to flaunt it to the world? I have some great, joke autistic t-shirts and love spotting people's reactions to them. Again, I value the freedom to be able to wear such clothing.

Living alone grants me freedom to be able to indulge in my many interests and to continue lining my living room with books. I plan to wall myself in with books over time and am well on course to do so. Again, I value the freedoms we have to be able to read political books that

criticise governments freely. I have the freedom to spend time maintaining my nineteen-seventy-six Land Rover, *Lucy*. I have a passion for pre- and post-war engineering and love to indulge in a project or two. To make a fool of myself. Yes, this happens more than I would like but it does make life more interesting trying to resolve the latest situation I find myself in. It may allow me to make millionaires' shortbread and to enjoy the batch in one helping. Comfort eating indeed! As mentioned, I have the freedom to travel and love to explore London as it is such a vibrant city. Even if it does take so much out of me, I come back with so many happy memories and experiences.

Cycling is, for me, pure freedom as you fly along the road and rely purely on leg power. I have always enjoyed the feeling of being out and love nothing more than exploring the local roads and cafés. Exercise is such a

positive thing and one that allows me to cope with life by being able to escape and be alone or with other riders. The ever-changing landscape fascinates me and I am thankful to be able to live in such a beautiful place.

Freedoms I would like are: being able to live in peace without nuclear war hanging over us. These are frightening times right now and I deeply worry and wonder how we have returned to such cold-war-type fears?

The freedom to love whom you want. This is so important as I struggle to understand how people can think they have a right to say whom others can love?

The freedom to be myself and not be afraid. I am in a bad situation with an anti-social neighbour so this is an important freedom for me. I long for peace and quiet and not be kept awake at all hours and being verbally abused.

To relax is having learned and therefore backed away from the fascination you had for some subject, caused by not knowing and wanting to understand (fear makes us back away from something, so that with distance we can look and learn about what frightens us — the unknown). Respect is keeping your distance, so that you can observe and learn.

Paigetheoracle

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"You've become more autistic since your diagnosis"

by **August Grace**

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Phrases such as or similar to the one above are sometimes heard by people later diagnosed with autism from those around them, suggesting that certain traits weren't "there" prior to a diagnosis or realisation.

Sure, certain traits may not have been visible to you but nor was the burnout, isolation and anxiety that came from hiding said traits.

Learning what is authentic to any individual is a process, and learning to unmask is often a large part of that for an autistic individual. Being told that we're "being more autistic" is hard and damaging to hear and is made more difficult when it comes from those who supposedly "know us best". Likelihood is, we did everything we could to hide our differences and moulded even our own sense of self in trying to best fit the expectations of a neurotypical world. We were critiqued and bullied by ourselves and others for things that directly correlate to a diagnosis. I for one did everything possible to suppress and hide the things that made me different for fear of being shouted at or picked on, thinking I was fundamentally wrong and broken. My whole identity was built on social

niceties and false conceptions. I wanted to, and believed that I should, hide, but now I'm learning that this isn't true.

Instead of being "odd" or "strange" I am normal, inside of autism.

I'm learning that if I flap my hands, away goes the tightness in my chest and the sickness in my stomach; that a coloured light on my ceiling helps me sleep; that ear defenders mean I can see what's on the shop shelves; that a weighted blanket makes me feel weightless and safe. I'm also learning that I shouldn't be ashamed of these things, and that they don't make me "less".

Living by, around or up to the expectations of a world built by and for neurotypical people is unsustainable for people with autism. In the long run it can lead to the development of unhealthy, sometimes harmful, coping mechanisms, burnout and a breakdown of their mental health.

Learning new ways to better, sustainably and safely cope should be celebrated and encouraged, not be the source of more reprimanding. While your comment may come from a place of curiosity

or misunderstanding, it can imply to the individual that they are becoming more difficult to handle, should suppress their instincts to still appear "normal". This could mean they turn back to their unhealthy ways of coping.

It's okay if you are curious or don't understand something, so please instead try going about understanding a different way; for example you could pose a question in place of a comment: "I've noticed that since your diagnosis you have (or haven't) been doing x, please could you try to explain why? Would you like me to do (or not do) anything when I notice this happening?" By changing your wording you can help support someone on their journey of self-acceptance and discovery, while also opening a space where they might feel they can express themselves authentically, freely and safely.

ND Pride

O different minds,
Rainbow infinity sign.
Pride, in who I am.

by **Shan Lena**

© Shan Lena 2022

Autism and melodrama

by C A Thompson

Emotions are a difficult thing. Strong emotions are, strangely, not such a difficult thing. If I watch a gritty, serious, realistic show (most BBC dramas or pretty much anything with police in) I have issues with telling what characters are feeling: they communicate with glances, grunts and other non-verbal methods. As such, I can only ever take a guess at how these characters feel (I typically guess they're upset, the shows are upsetting so it makes sense to me) and as such, I feel a disconnect with the characters, find them hard to support or to relate to. There exists media that is often melodramatic, very over the top in every way, especially in regards to emotions. I've found and I know other autistic people that find melodramatic works more enjoyable than more mature dramas due to making emotions obvious, easy to read and easy to relate to.

For something that I find easy to relate to, I'm going somewhere unusual. The larger-than-life world of professional wrestling. Wrestlers are not hard to understand, they usually tell you exactly how they're feeling and what they're going to do about it (usually challenging an opponent to a match). They wear colourful, extravagant outfits, shout and jump around, their every expression raised to a level that makes them seem almost superhuman. I've loved professional wrestling for over twenty years, partly due to the fact of how easy it is to understand the emotions, the motivations and the overall stories being told.

It is over-the-top and is better for it. In the worlds of boxing or mma (mixed martial arts, also known as cage fighting) some of the most popular fighters are the ones that have huge personalities

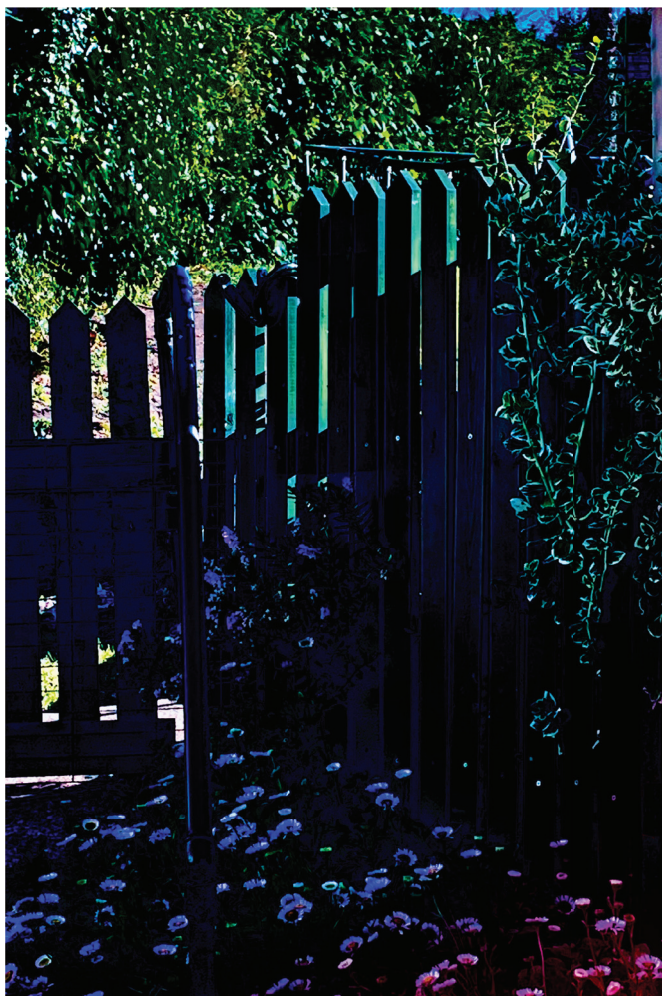
and cause drama; in wrestling, everyone has big personalities and there is always drama. Wrestlers like John Cena, The Rock, Stone-Cold Steve Austin and Hulk Hogan have entertained millions around the world through being easy to grasp, passionate and expressive. I've known myself and others on the spectrum to find themselves obsessed with these individuals. In a confusing world of hidden meanings, small facial expressions and a general lack of clarity, these wrestlers let you know who they are, what they are here to do and how they feel. Their melodramatic flair is their greatest strength and the cause of wrestling's enduring popularity. If wrestlers acted like average human beings, wrestling would have failed and died out a long time ago.

Another form of media that people on the spectrum commonly find easy

to enjoy and relate to is anime (basically, cartoons from Japan). The characters are drawn with big, expressive eyes that make facial expressions easier to read than on a real human face. The stories are commonly over-the-top and feature heroes shouting out their emotions for all to hear. Series like Pokémon, Dragon Ball, Sailor Moon and Yu-Gi-Oh have all become global successes, I'd argue, due to how relatable their characters are while also being clear with their emotions, no subtlety, and as such neurotypicals and neurodivergents can both enjoy these characters fully, no confusion possible.

To conclude, autistic people aren't allergic to strong emotions like the stereotypes suggest. We understand strong emotions better than subtle ones and enjoy works that overflow with passion and make us feel powerful stirrings in our soul.

letters to the Editor and a notice



Dear Editor

I was forced not to use my kitchen and see that lovely view due to neighbours occasionally passing by, which led to them initiating conversation. I can enjoy my garden in other areas which are private but when in the kitchen — ugh!

The solution! One-way mirror film! I can now stand and observe nature and my garden without getting anxious at all. It's great. Remember to close blinds at night — people can see you but you can't see them when it is dark outdoors!

Mr Chakotay

© Mr Chakotay 2022

Dear Goth,

what this latest issue (July 2022) has made me realise is that I hated work and hated school because of stress. At seventy, ten years longer than the NAS has been in existence, I want those following me into this world to know little has changed.

One particular teacher at secondary school picked on me by asking me a question in front of the class because he knew I couldn't answer, not because I didn't know but nerves turned my mouth to jibbering jelly and nothing decipherable came out of it.

At college I rehearsed for a play which was fine until I stepped out beyond the footlights, saw the audience and a speech of a dozen lines was curtailed violently and rapidly, to two or three.

Work was no better. Every interview left me a sweaty wreck because I didn't know what was expected of me (all these questions). It was like when I was in Hampton Court maze on a primary school trip and I was the last one to get out. The rest of the class shouted at me through a gate in the hedge, where to go and I thought why as I was going in that direction anyway?

Paigetheoracle

© Paigetheoracle 2022

If sufficient material is sent in, the theme for January will be **art and creativity**. Vote with your contributions: the more submissions on a subject sent in (from different people) the more likely that that subject will be the theme. Writing on any subject is still welcome as are ideas for new themes, small pieces to fill awkward spaces like this, and art. **Please fill in a permissions form** when you submit something, as all published pieces require a completed permissions form. Remember, if you want to see different content in *the Spectrum*, the best way to change it is to send something in!

The National Autistic Society art competition

descriptions by the three artists

Winner (on the front cover):

Shining time station celebration

by **Jordan**

Painting and collage of lots of people celebrating and enjoying the things they like. If you zoom in, you will be able to see all the small individual drawings cut out and stuck on: they all represent the things Jordan likes and are important to him. Everybody should be able to enjoy the things they like, even if they are not the same things that everyone else likes.

Runners-up:

Identity anti-crisis

by **Luci** (top image)

Self-portrait at 46. Taken after many years of identity crisis due to late diagnosis and processing what it means to be autistic. I can now see myself in simplistic black and white. Both who I am and who I am now.

Disconnection

by **Tyrone**

The figure expresses vulnerability, insecurity and shame by the way the figure covers the face. It's crossed legs shows the feeling of being small and everything around you being much bigger and more important. Losing your confidence to confront the situation.

The chair shows emphasis of the figure's emotions. The chair is much bigger than the figure making the figure lack confidence. Personification is used mimicking the figure being eaten by the chair in the form of a metaphor.



© Luci Danica 2022



© Tyrone Vera 2022

My experience

by Sarah

© Sarah Holden 2022

My experience of asking for reasonable adjustments as a newly diagnosed autistic adult.

A little bit about me

My name is Sarah, and I was diagnosed as autistic in 2020 at the age of 47. In 2022, I got a job as a Peer Support Worker for the NHS.

This is my first job as a newly diagnosed autistic adult. It is also the first time where my needs as an autistic person have become visible to the people around me. I have spent the last thirty years of my working life hiding my struggles, and for me this has resulted in many periods of being signed off work with anxiety and depression because I repeatedly burnt out. Alternatively, I would book my “holidays” but would be using them as sick leave so that nobody would find me out.

Trying my best to cope at work by hiding how I felt was not a helpful strategy for me, and neither was it a self-compassionate one. But at that time in my life, it was the only strategy I had. Without a diagnosis, I didn't have the language to explain to myself or others why being at work felt so hard. Without this self-understanding I simply couldn't accept the way that I was, and it was a common experience for me to feel like a failure.

If you relate to any of this, know that you are not alone.

This is only my experience, do what feels right for you.

I am sharing my experience of going through this process in the hope that it may help to inform and empower other autistic adults who are themselves struggling with indecision around whether to disclose their diagnosis at work and

make a request for reasonable adjustments too. However, this is only my experience, and you can only do what feels right for you.

How I felt going through this process – the challenges and the benefits

Ultimately, disclosing my diagnosis at work, and having reasonable adjustments in place has made a real positive difference in my life. We all know that doing anything new for the first time can feel really anxiety-provoking, and even more so for an autistic person. For me, both asking for, and accepting, reasonable adjustments in my job felt quite uncomfortable.

Although this will be different for everybody, for me initially, I experienced feelings of shame for “needing help”, and I felt very vulnerable knowing that my colleagues would all know that I needed help. And this triggered some feelings of inadequacy.

Perhaps you may feel like this too in your current situation. At least you know I also felt this sense of discomfort and vulnerability and it really is okay that you do too.

Why I found it difficult to ask for and accept my adjustments at first

Autistic people often do not like drawing attention to themselves. The process of asking for my reasonable adjustments felt like I was drawing attention to all the things that I found challenging, and I felt almost embarrassed and ashamed about this. All of a sudden, the things

that I had hidden or masked for a long time were now being made visible for all to see.

Late-diagnosed autistic adults in particular are likely to have experienced decades of low self-esteem and feelings of inadequacy. I certainly felt like there was “something wrong with me” after a lifetime of comparing myself to non-autistic people. When I made these comparisons, I always seemed to be falling short. And that is why I felt it necessary to hide myself.

Here are some of the difficult thoughts and emotions I experienced the first time I asked for reasonable adjustments:

- I worried that my colleagues would see me as “high-maintenance”
- I felt like I was putting people out in some way
- Why should I get “special treatment”? Why can’t I just get on with it?
- I felt like I was being an awkward and difficult employee and colleague
- I felt ashamed for needing these adjustments, and I felt inadequate.

Perhaps some of those may sound familiar to you too.

Navigating my way through the difficult moments – what helped me

The ability to be kind to yourself when you are struggling is so important, but it is not always easy. Ingrained feelings of low self-esteem made this quite hard for me, but the kindness and understanding I needed came from my colleagues, friends, and family members. These people who I felt safe with helped to mirror back to me the kindness and reassurance I needed. Gradually I am becoming more able to do that for myself.

These people enabled me to see that I was being empowered through having these reasonable adjustments and that I didn’t need to feel ashamed of them.

What my reasonable adjustments look like and how they helped me

Since starting my job, both my team and I are learning what reasonable adjustments are helpful to me. I have summarised a few of these here so you can see what this looks like:

- Lower screen on laptop. Reduces visual input. Only have to listen, helps me take in information more easily
- Training is emailed to me beforehand. I have more time to process information. I leave the room if feeling overwhelmed
- I have a work buddy who is on hand to listen, to reassure, to answer questions. This is an invaluable resource for me. It prevents overwhelm.

If you have not asked for reasonable adjustments before, the whole thing can feel like a very unfamiliar process. You may not have a clue, as I didn’t, about what those reasonable adjustments may even look like for you. Hopefully, as I have shared my own adjustments, this may make the process feel a little clearer for you, and less daunting.

Autism post-diagnostic support services can give you support by helping you to identify your own individual adjustments. They can also write a letter that you can give to your employer and even meet with them to help them understand what your particular needs in the workplace are.

To summarise

With the right support, and by gradually reframing how I think and feel about reasonable adjustments, the difficult emotions that I initially

an article (continued) and another article

felt have begun to lessen. I am learning, with the help of an extremely supportive and caring team, to give myself permission to ask for the things I need, and to accept that help, to make my job more accessible and sustainable.

It was really important for me to be patient and give myself the time to move through the anxiety of allowing myself to be “known” as autistic.

Asking for reasonable adjustments has really empowered me to do my job; but it is important for me to say that my life as an autistic individual still throws up the often-painful challenges of daily living that many autistic people face. But by having made my employer and colleagues aware of my diagnosis, I have already provided myself with an open door to discuss the difficult days, because they do still come. But at least now, I don't have to hide. And I have never felt so supported in a job in my entire working life.

If you can, and I know it's hard sometimes, try to remember that it is okay to not be okay. It's not nice, but it doesn't mean you're failing. I still

have bad days. But I don't have to struggle alone now.

I have come to see my disclosure, and my reasonable adjustments, not only as an act of self-care, but it is also extremely beneficial for my team too, because it means they get the best out of me. It increases my productivity, my creativity, and it improves my overall emotional and mental wellbeing both in and out of the workplace. Being at work no longer feels like a constant uphill battle.

For me, disclosure and choosing reasonable adjustments have been a positive and life-transforming thing to do.

Whatever your decision, my wish for you is that you are able to embrace your autistic identity and lead a life that feels right for you. Autistic people have incredible strength, determination, and resilience that comes from a lifetime of overcoming challenges. You will have a skill set and positive qualities that are unique to you, and given the right opportunity, they will shine very brightly. I genuinely wish you all the best!

PDA: a Preventable Delicate Activity

by **Richard Woods**

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There are many ongoing historical debates surrounding “Pathological” Demand Avoidance (PDA), mirroring the intense interest in it. One of these debates centres on PDA's name, due to a strong aversion for the “pathological” descriptor, often perceived as being demeaning and derogatory to those identifying with PDA. Leading to about a dozen different names in print, referring to PDA. More common alternatives terms include Rational Demand Avoidance and Extreme Demand Avoidance. Anecdotally, one's preferred term for PDA seems to be based upon ideological lines.

Broader context is that much of the autism research, policy, and practice has entrenched, inferior-quality ethics and standards. Often informed by autism theories which have poor-quality evidence, and little explanatory value of autistic lived experience. Autistic persons are rarely meaningfully engaged in autism research, policy, and practice. From this vacuum, PDA as a “Profile of ASD”, has become a “culture-bound concept” in the UK.

Since 2020, the National Institute for Health and Care Excellence (NICE), the Royal College

of Psychiatrists (RCP), the British Psychological Society (BPS), and two systematic reviews have all concluded there is no good-quality evidence to suggest what PDA is, what features are associated with PDA, and acknowledged the controversies and existing divergent viewpoints on PDA. There is no consensus over how to diagnose PDA in the literature, or between topic experts. This is partly due to the ongoing historical debates in PDA. For example, is PDA seen in non-autistic persons (including in Newson's research)?

NICE, RCP, and BPS have not produced guidance on PDA, as it is unethical to do so, lacking good-quality evidence for PDA and lack of consensus between topic experts.

PDA's evidence base is small and generally poor quality. Still, PDA's evidence base is conflicted, with certain studies indicating PDA is linked to autism, while others do not. Similarly, some studies indicate PDA is seen in non-autistic persons, while other studies indicate PDA is exclusive to autistic persons. Some studies suggest PDA is a distinct syndrome, some others do not. Thus, it appears unwise to assume any one outlook on PDA is valid and other worldviews are not.

PDA is a positive source for many vulnerable people, who can be in crisis. Subsequently, there are strong power differentials present. Even those critical of PDA accept there is a genuine need for support for both those expressing PDA features and their caregivers.

However, it can be said there is a need for all autistic persons and their caregivers to be suitably supported. It remains to be seen if "PDA Profile of ASD" is beneficial to those being assigned a PDA diagnosis, such as with the report of Kent's Special Education Needs Disability schools, who denied educational placements to those diagnosed with PDA. Furthermore, concerns over who would wish to employ someone who has a "pathological" or "extreme" response to "ordinary" (others') demands?

Many bold claims are made about PDA, like autism has expanded and now includes PDA. Many autism experts view the breadth of autism to be static over the last decade. Comparison studies between *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-4)* and *DSM-5* autism criteria suggests autism's breadth contracted by at least a fifth with the *DSM-5*. Some argue autism has been expanded too far. Autism subtypes were removed from the *DSM-5* as all attempts to successfully divide autism have failed. Autism subtypes were excluded from the *DSM-5* to reduce stigma, for all autistic persons; partly upon the lobbying of Autistic Self-Advocacy Network, as most autistic persons do not want autism to be divided. Simultaneously, PDA literature acknowledges PDA has many characteristics which make it difficult to fit PDA within autism. There is a need to follow typical ethical practice and to be restrained in the claims surrounding PDA.

Some supporters who strongly identify with the "PDA Profile of ASD" narrative are claiming they have extra rights to PDA, like they should be platformed over those with different perspectives on PDA. No stakeholder group has a monopoly on PDA. Under Academic Freedom, researchers can investigate PDA's competing viewpoints. Crucially, under *The Equality Act*, the threshold when someone counts as disabled with PDA is when their demand avoidance has a substantially impairing effect upon them for at least twelve months. This is applicable to individuals regardless of if they are autistic or not, and if they believe in "PDA Profile of ASD", or not. Those with divergent viewpoints to "PDA Profile of ASD" have done and will continue to investigate PDA, contributing to how PDA is understood.

Overall, PDA is a passionate topic for many, and for good reasons, both for its supporters and those hesitant of reifying PDA. There is a need for more caution and nuanced discussion surrounding PDA, while following typical ethical standards. Both autistic persons and those identifying with PDA deserve better than how PDA is frequently portrayed.

Bridal make-up artist

by **Eleanor Norman**

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My name is Eleanor Norman and I am a bridal make-up artist — with a twist! At age 3, I was diagnosed with Asperger’s syndrome — a form of Autism that makes communication and processing social cues extremely challenging. As a result, it took me longer to reach the usual milestones most children achieve such as saying my first words. The help for my parents was minimal, and so unsurprisingly they found raising me a challenge — there wasn’t the information!

School was very hard, partially because I found processing questions difficult but also due to not feeling part of any group. Asperger’s can

be a lonely condition, especially for a child, as many scenarios in school life reminded me that I thought differently to my peers. I was bullied and teased; punished for having a disability.

After leaving school, I attended Cambridge Regional College to study Hair and Media Make-up, as I had developed a flair and interest in beauty. Whilst I struggled still with social aspects of the setting, I finally found something that allowed me to be “me”. It was here that I attended a masterclass with BBC Three *Glow Up* presenter Dominic Skinner. To see someone who has such creativity and vision only served to spur me on.



Make-up fixing spray being used

an article (continued)



I decided to begin my own business, Ellie Norman Make-up Artist. Work was initially slow, and I found the social side of the role kept me outside of my comfort zone. But I learnt, I challenged myself, and I persevered.

In 2021, I took my next big plunge into the unknown by quitting my part-time job to focus entirely on my own business. The decision caused me great anxiety as this overwhelmed my Asperger's way of thinking, but I was determined to make it work. I had to.

I enrolled with a bridal make-up agency to supplement my income and have received nothing but praise from the incredible brides and families that I have been lucky enough to meet. Did I inform them that I have a form of Autism? No, but why not? I felt this was something to be hidden thanks to my negative experiences at school.

What changed? I recently had to do the make-up for the sister of a bride who also had Asperger's. This information was presented

to me almost with a sense of concern, that I may recoil in horror at this news. Instead, I informed the bride that I too had the condition, and I could almost feel the relief from the bride in knowing that this potential issue was resolved. A kindred spirit was here to help her sister.

I shouldn't hide my condition, it has made me who I am today. My condition allows me to see the finer details and to follow every instruction to the smallest details. I have provided make-up for brides all over East Anglia. I have assisted with make-up for proms, marketing and production videos. I am in control of my own social-media marketing, a beautiful website and a blog. I plan to create videos to show that despite being neurodivergent, you *can* achieve your dreams. Do not let it weigh down your motivation — your goals are there for you to grab!

My condition doesn't hold me back, it encourages me to push harder for my clients. My brides deserve the level of attention that someone with my condition can provide. Embrace yourself, and your work will speak for itself.



Virulon SL26

A Rascal story

fan fiction by **Alexandra Stobiecka**

Rascal, speedcott, Lloviant, Draxa Virulon, kegai and the Rascal universe are all
individually

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I am curled up in a little barren area in what was once the city of Japan. I have probably left my nest. I opened my right eye. Several lights glowed, which lit the place against the night sky. Then I closed my right eye, thinking that a vehicle would deliver me to the nearest junk space to there. But, weirdly, this place is, at the time, not an all-pieces-will-go-to-dumping zone. I leaped further, trying to feel less like thinking about being junk. I curled up, then ran in a streamlined way, which is because this place reminds me of the “poor Lloviant had been in the waste pile” situation, making me desperate to run that way. As I have run fast, I had reached a desolate area of buildings. I knew what to do. I sat on a speedcott (I should fix the term as it should be “speedcarriage”) and ignited it (the term for switching on a speedcott). I rode on it. A several or more metres later, I found one of the last mile-high skyscrapers that has been built before transformation started completing, nowadays pwned and in rocky condition. As this speedcott hovers above the diamond-studded plane surrounded by even older skyscrapers, I lay with my chest touching near the cockpit and my head poked out at the front.

At day, it levitates on a road in a canyon. Then I switched it off and left the seat, and knew my performance was low as I used some of the latest cyborg riding skills. I checked my kegai communicator information, and it said “Draxa Virulon SL26 – AS 7.5 – © 2119 Draxa Inc.”.

I found out that Virulon SL26s are redundant for kegai communicators as new as that, making me have low intelligence. A Virulon SL26 is capable of not much efficiency, which is, proneness to low performance.

I turned my head to the vast ravine. I leaped off the cliff I had stood on, and grasped on the side of the sandstone below the surface. I began to climb down. This proves my status as a descender.



stuff you might like to know about *the Spectrum*

The rules of *the Spectrum*

(contact information for *the Spectrum* is on page 2 and again on page 20)

- 1) *The Spectrum* is funded by the National Autistic Society and readers' subscriptions. We welcome submissions on any topic from people across the whole of the autism spectrum.
- 2) *The Spectrum* is quarterly, published in January, April, July and October. If you do not receive a copy when you expect to, please contact the magazine.
- 3) Pieces that appear in *the Spectrum* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 4) Book reviews are the most popular thing with readers of *the Spectrum*, so please consider submitting one. They can be about any book, not just books about autism. If you do not want your review to appear in other National Autistic Society publicity about that book, please make this clear.
- 5) When you send in a piece for publication in *the Spectrum*, you need to complete a permissions form. The online permissions form is at

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- 6) The National Autistic Society promotes *the Spectrum* on social media using pieces taken from the magazine.
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- 14) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.

A bit different

by Tom

I

Incompetence manifest.
But at what?
Each interaction an overstimulating lesson
About innate intuitions
That ping around in amongst
Ethics and dopamine.

A medium between two layers
Of the languages we speak exists
In constant migraine, twisted
And frayed, burnt and fried,
And floats right behind your head
In my eyes as I untwist and mend for
What you want from me. No harm
But an invisible exclusion from
Navigable, hive mind normality
That I presume.

One step behind experience.
Outside sound and scent,
Light reflects and I can see
But the bubble admits all but me.

II

Every assertion is a mould
Of forever folds of Blu-Tack
To cling to.
Clinging on to reality
As discussed

Because no reality is,
There must only be what is told.
Who to be
Is never enough
Is up for refining
Needs to be laid out
In a book or something

Don't let me breathe
For the procedures
You see and I believe.

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