

BEYOND
THE
SPECTRUM

Rhyme & Reason

**autistic writers creatively interpret
research on autistic writers**

B E Y O N D
T H E
S P E C T R U M

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research on autistic writers**

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*Hush, we speak at last
Words as ink in the warm air
Spring has come early*

Jo Plumbe

With thanks to Writing East Midlands for setting up Beyond the Spectrum and continuing to believe in autistic writers, to the organisations who have funded the project, and to the adult and young writers who prove time and again that we're only just starting to discover the true benefits of Beyond the Spectrum.

Further thanks to Rachel Phillips and Lai-Sang lao from NTU Psychology for carrying out the research described in this book, and to Inspire for kindly hosting the book launch and celebration event.

Rhyme and Reason writers were:

*Anna Cotton, Jasmine Donnelly, Chloë Hunt,
Pippa Hennessy, Ann Penn, Jo Plumbe, Deborah Potter,
April Wakefield, and Courtney Ward*



writingeastmidlands.co.uk/projects/beyond-the-spectrum/

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Introductions

Sian Tower

Head of Programmes, Writing East Midlands

For the last three years, hundreds of autistic writers across the country have given their time to meet online and in person: to share ideas and writing, to listen to each other, to be inspired, and above all, to feel moments of connection and shared understanding.

Beyond the Spectrum workshops have become powerful crucibles for forging new relationships and generating new writing. Anyone reading this book will appreciate how powerful and precious they have become.

We are working hard to try and ensure they continue well into the future, attracting more new voices of all ages to this emerging canon, which is changing the way the world sees autistic people, and the way autistic people see themselves.

It has been a true privilege to work with these writers, and we thank them for their creativity which knows no limits.

Best of luck to you all and keep writing.

Sian Tower

Rachel Phillips

Senior Lecturer, NTU Psychology

It was easy to collect anecdotal evidence of the many benefits for participants of the Beyond the Spectrum writing project. The aim of this research project was to quantify those benefits and conduct qualitative research to identify and dig deeper into the overarching themes of participants' experiences. Thanks to the dedication of lead writers and project participants, we have also been able to give autistic writers the opportunity to interpret the research and creatively represent those themes back into their own words, some of which are reproduced in this anthology.

[continued on page 10]

Evaluating Beyond the Spectrum

CONTEXT

Poor provision of social and cultural activities for autistic people, autism seen as a disorder defined by a set of deficits, autistic people judged to be 'less' than neurotypical people

BEYOND THE SPECTRUM PRINCIPLES

- 1 Positive view of autism rather than deficit-based view
- 2 Creative writing workshops run by autistic writers for autistic writers
- 3 Open to all autistic adults and young people

AIMS Phase 1 (2021)

Establish a creative community of autistic people through a series of free writing workshops for autistic adults and young people living in Notts and Derbyshire, led by autistic professional writers.

EVALUATION RESULTS Phase 1 (post-project participant survey)

1. Improved sense of community and belonging
2. Increase in self-confidence
3. Improved self-expression
4. Improved ability to cope with distress/overwhelm
5. Increased understanding of autism
6. More positive view of autistic identity
7. Feeling more understood by others

AIMS Phase 2 (2022-23)

- 1 Strengthen and widen the Beyond the Spectrum creative community
- 2 Continue to achieve the outcomes from Phase 1
- 3 Carry out in-depth evaluation to verify benefits to participants identified in Phase 1

EVALUATION RESULTS Phase 2

(pre + post-project participant surveys,
semi-structured interviews)

Themes identified	Sub-themes identified
It's Tough Out There	fear, rejection, masking
Community	belonging, support
All Autistic, All Different	autistic joy, self-acceptance, validation
Confidence	achievement, writing skills, socialising, reduced perception of support needs, taking up other opportunities, improved life/work achievement, writing skills, socialising
Understanding Autism	dispelling myths

+ all Phase 1 outcomes except #3

[continued from p7]

The creativity and talent evident from these writers is breathtaking, and I feel thankful to have been a part of bringing their words to a wider audience. As an autistic person myself, I'm so proud of this example of autistic expression. Projects such as this allow autistic people to unmask, challenge myths and be heard.

Thank you to the writers who trusted me to listen to your experiences in the interviews I conducted, and those who took the time to complete the surveys.

Rachel Phillips

Pippa Hennessy

Beyond the Spectrum Lead Writer

There's undoubtedly something special about Beyond the Spectrum – I feel it every time I start the Zoom meeting at the end of a long day, and start to feel my physical and emotional batteries recharge with the energy that each session generates.

We've been immensely privileged to collaborate with researchers from NTU Psychology to qualify and quantify what that special something is, and produce clear incontrovertible evidence of the benefits of taking part in Beyond the Spectrum. It's given me a great sense of pride to see that our work indeed has huge positive impacts on the lives of the people we write with from week to week, month to month, year to year.

Rhyme and Reason has brought the evaluation full cycle. We have worked with participants to understand and creatively interpret the results of the research, leading to the astonishingly perceptive and profound work you can read in this anthology.

For me, this aspect of the project has multiplied the benefits from taking part for every participant. In particular, the session we spent writing about how much our confidence and understanding of autism has increased through taking part in Beyond the Spectrum served to cement those benefits in place in our minds, and was a true celebration of all we've achieved. I couldn't be prouder to be a part of it.

Pippa Hennessy



artwork by April Wakefield

Theme 1

It's Tough Out There

In here, I can be soft. I can be sad. I can laugh until I wheeze. I can rage against what's out there. I can live freely, and love ardently. I can be weird. I can sing at the top of my lungs and dance it out. I can feel safe.

But out there, I am tough. Because it's tough out there.

Chloë Hunt

It's Tough Out There

Autistic people, almost without exception, struggle with life to a lesser or greater extent. We are expected to function to the same standard as neurotypical people in a world that is geared towards the needs of those people.

To us, the world is bright, noisy and smelly. There are rules we are expected to live by that we cannot identify or can't see the sense of. Other people are inconsistent and confusing. We often struggle to understand our own feelings, let alone those of the people around us.

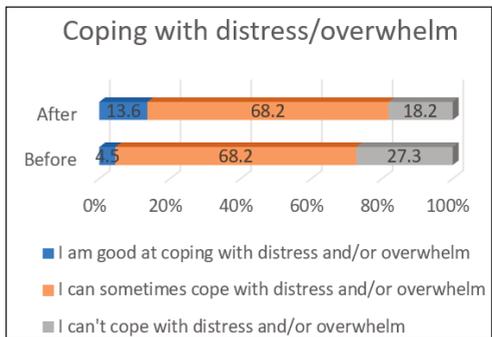
We hide our self-soothing behaviours and pretend to be like everyone else, and it's exhausting. We keep getting things 'wrong', or find ourselves in situations where our basic needs are not being met, or just have a particularly tiring day... and we melt down or shut down: behaviours that lead us and others to the erroneous conclusion that we're not making the grade, we're suffering from a 'disorder'.

For many Beyond the Spectrum participants, sessions were energising rather than exhausting. We were built up and strengthened by writing together in a supportive non-judgemental environment geared towards autistic people's needs, rather than worn down by trying to survive in a hostile neurotypical world.

Research Findings

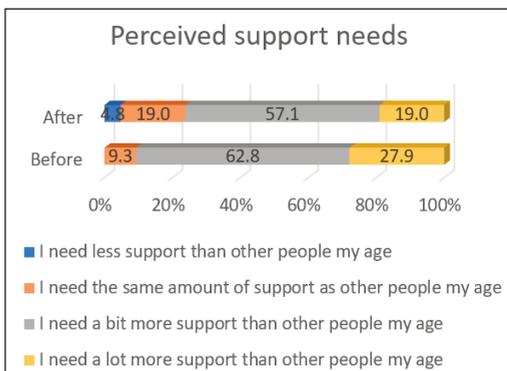
When comparing the pre-project survey responses with the responses given to the same survey after participating in BtS workshops, we found that there was an increase of 9% in respondents reporting:

“I am good at coping with distress/overwhelm” after participating in BtS, with a corresponding decrease in those reporting: “I can't cope with distress / overwhelm”.



The ability to cope successfully with distress and overwhelm is vital for autistic people living within a neurotypical world – it could mean the difference between being housebound and being able to leave the house, and/or it could lead to a reduction in the level of support required.

We asked participants to tell us how they perceived their own support needs in comparison to other people of their age. We were surprised to find that participants showed a clear reduction in their perception of their support needs after taking part in BtS.



It is possible that improved self-confidence and ability to cope with distress and/or overwhelm has enabled some participants to function more successfully in the neurotypical world.

In future phases of this project we propose further investigation of the nature of the observed reduction in support needs, and the mechanisms by which participation in BtS leads to this reduction.

Writing more often helps me to release my emotions. It calms me.

Before I just focused more on the things that I feel like I can't do, or that I'm limited by, and it's really helped me think more about, actually, these are the things I can do and to kind of lean into them.

We're trying to live up to a standard of what people perceive as 'normal'. And obviously, so often, the way that autistic people approach things is so far off from 'normal' that you don't think it's ever going to be something you can do.

The real magic happens when you realise that your own unique approach often holds the key to new discoveries, and that is where the joy is found.

It's Tough Out There

Rhyme & Reason Group

Reality. It hits like a bucket of icy water
on a bitterly cold morning.
Every sound, sensation, scent
stirs anxiety from hibernation,
amplifies the nervous system
and makes the heart race.

At the back of my mind
my special interest dwells
ready to make itself known
at the end of a long day.
It comes and goes - like a sixth sense
acting as a weighted blanket
amid chaos and overload.

Fish don't actually grow to fit the size of their container.
If only they did. When the container is your mind,
you have to try to shrink the fish in your head,
for fear of what people will say.
No one outside sees, but you can feel the fish's pain
when you do it for too long.

Don't know how to stop being cynical,
people leave trails across my buzzing night-time mind,
leading different ways, doubling back and turning around,
dropping breadcrumbs to mark the path,
but they've run out, run away, run around,
and given up.

Sometimes parts of me bulge out of the hole
my square peg has been hammered into.
The reactions make me retreat, heartsore,
questioning myself constantly for the next few days.
I can squeeze myself flatter if I try harder.

Thought I was broken –
diagnosis fixed the cracks.
Kintsugi, whole.

I can almost see it if I squint,
almost feel it if I focus,
but then people tend to look at me funny,
because my faux-normal isn't quite the same 'normal'
as their 'normal', and for some reason,
they seem to hate that even more.

autistic strangers
our own thoughts, our shared language
easier this way



Not Fitting In

Jo Plumbe

nearly winter, as autumn hangs in misty air
orange leaves abound, yet still a green tree stands its ground
the only one, on its own amongst the crowded woods
forest whispering with the hushed voices of silent creatures
immortal, yet falling all around
today, green tree, don't feel alone as over winter
you remain through howling storms and freezing rain
tomorrow's spring will bring fresh leaves, green leaves
in which good company you'll find
new friends amongst the birds that fly free from your branches
growing every day taller with your tribe
in time for summer to flourish as the sun feeds you
and the bees need you
not fitting in, now a thing of autumn gone



image by Jeremy Thomas on Unsplash

On the Other Hand

Jasmine Donnelly

On the other hand, I want to escape,
go to a place where no one knows me,
clean the blank white canvas,
and just be.

On the other hand,
I want to talk, I want to sit down
with everyone who ever misunderstood me,
or refused to listen, or didn't want to see me
as another person, not just a list of defects.
And I want to talk. I want to spend hours
just telling them all the things they never let me say.

On the other hand,
I want to imagine turning away from everyone
who can't understand me, and just run...
don't look back, and just run.

On the other hand,
people always say things like:
"You can't run away from your problems, you know."
It's not my problem.
So let me run.

Hiding and Biding Time

Jasmine Donnelly

My ears swim with angry noise...

I can breathe, but the air's too hot and doesn't come fast enough... Eyes
water, but not with tears,

Just worry. I worry too much, can't sleep for thoughts scratching the
inside of my head, trying to get out.

When rats are scared, or overwhelmed, they burrow deep under any
debris lying around, so I'd burrow deep inside my books, angry that when
I do so, people assume I cannot cope, angry at the so-called comforting
smiles, and overacted reassuring tones, just stop, just talk to me like I am
capable of talking back. I can cope. I exist in other ways than how they
see me. Even if they care, they care too much.

I am functioning, much like a machine, for them.

I don't stay calm and act nice for me,

I do it for them, because when I don't...

they think the world is ending.

Naked Pain of Thought

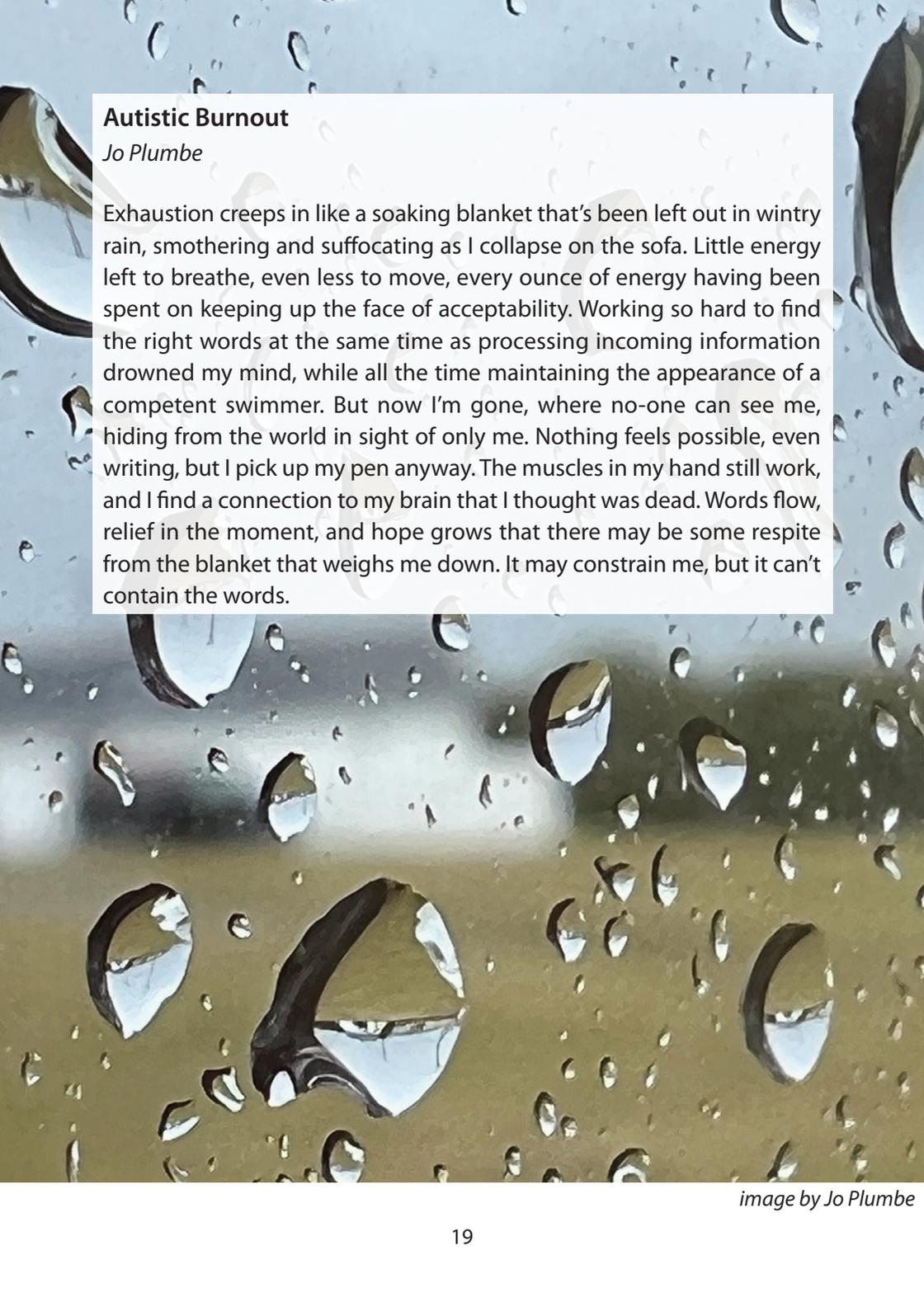
Deborah Potter

Naked pain of thought

fractures all our memories

and wakes us from sleep.

('naked pain of thought' is a DH Lawrence quote)

A close-up photograph of water droplets of various sizes on a dark, reflective surface. The droplets are in sharp focus, showing their rounded shapes and the way they reflect light. The background is a blurred mix of dark and light tones, suggesting a wet surface like a window or a car windshield. The overall mood is somber and reflective, matching the theme of the text.

Autistic Burnout

Jo Plumbe

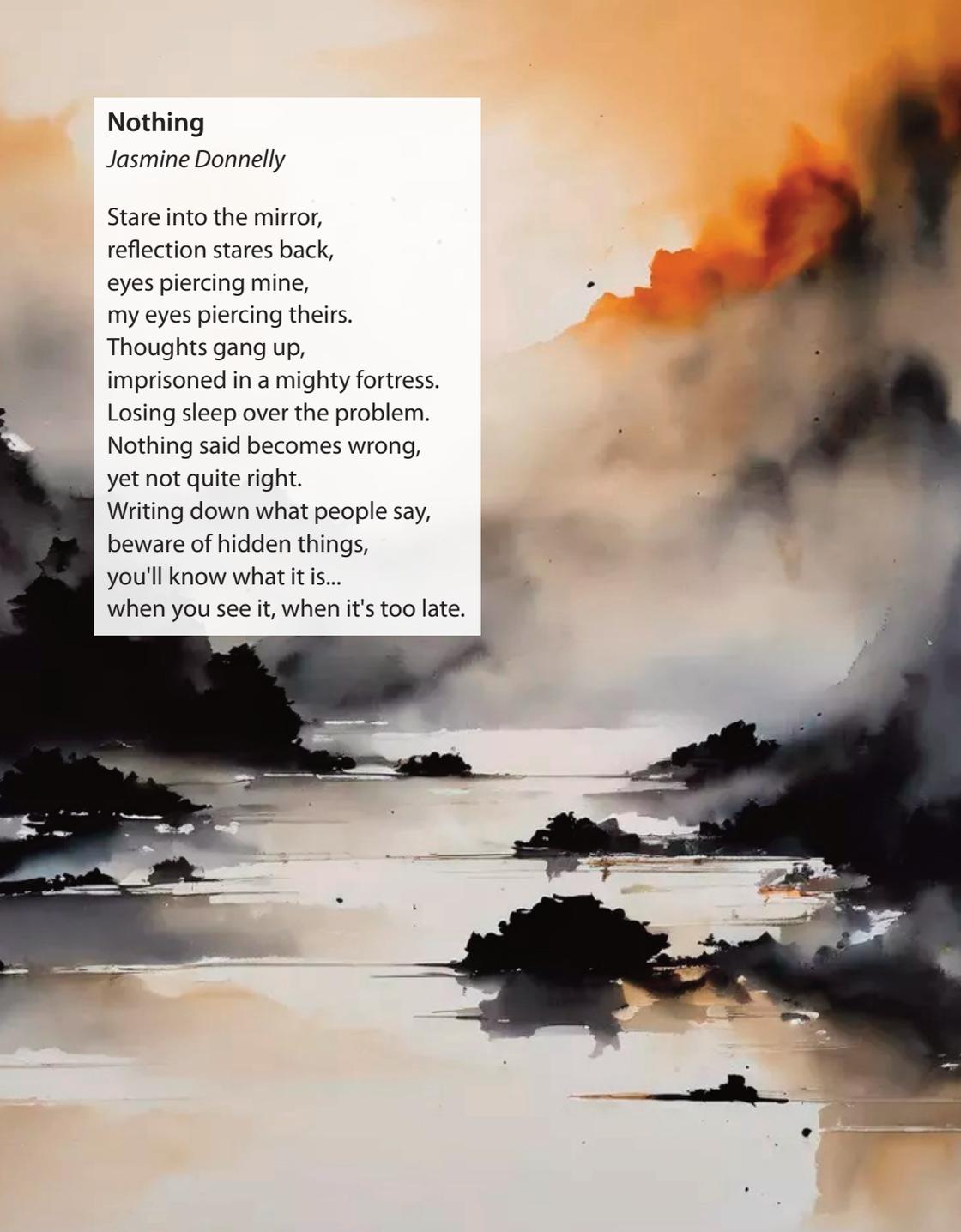
Exhaustion creeps in like a soaking blanket that's been left out in wintry rain, smothering and suffocating as I collapse on the sofa. Little energy left to breathe, even less to move, every ounce of energy having been spent on keeping up the face of acceptability. Working so hard to find the right words at the same time as processing incoming information drowned my mind, while all the time maintaining the appearance of a competent swimmer. But now I'm gone, where no-one can see me, hiding from the world in sight of only me. Nothing feels possible, even writing, but I pick up my pen anyway. The muscles in my hand still work, and I find a connection to my brain that I thought was dead. Words flow, relief in the moment, and hope grows that there may be some respite from the blanket that weighs me down. It may constrain me, but it can't contain the words.

image by Jo Plumbe

Nothing

Jasmine Donnelly

Stare into the mirror,
reflection stares back,
eyes piercing mine,
my eyes piercing theirs.
Thoughts gang up,
imprisoned in a mighty fortress.
Losing sleep over the problem.
Nothing said becomes wrong,
yet not quite right.
Writing down what people say,
beware of hidden things,
you'll know what it is...
when you see it, when it's too late.



AI image generated by Jasmine Donnelly

Let Loose

Courtney Ward

I see my reflection
in the shops, glass mirror.
A glare is all that I receive,
on this bright, sunny day.
'This isn't me,' I think to myself
as I know, this is just the aftermath
of another troubled day.
I've not been able to be my true authentic self.

Constantly having to hide,
always pretending,
because it's too much out here.
I feel incredibly unsafe, with nowhere to go.
I'm wandering the streets in the dark,
I've been let loose into the wild.
So you can hear my cry at midnight,
as I am, yet again, betrayed.

Masking

April Wakefield

When I'm with people
I can't let down my disguise,
it's suffocating.

From what I can see
they seem to know what to do
without practicing.

Are there others who
struggle like I am right now,
thinking they're alone?

I Don't Go Places On My Own...

Chloë Hunt

I don't go places on my own. I used to, before I realised that analysing everyone's words and actions is exhausting. I miss the days of being trusting in other people, where what they said and what they meant was indistinguishable.

Of course, not going anywhere alone is fairly impractical when you actually have to exist, and have no choice but to leave the comfort of home to do so. So, every time I leave, I pack my backpack and become 'chronically overprepared'.

There are places where it feels easier. The forest, or a graveyard, for what I like to call a 'morbid stroll'.

Last week I had to get to an appointment and it was almost three hours each way. A total of four buses and four trains. Ironically, the appointment lasted less than five minutes. If that wasn't bad enough, I decided to make the most of a day out and stop off in Birmingham on my way home. The day they were setting up the German Market, during half term. What a mistake.

So as I sat there in the Waterstones café (because I don't know where the independent cafés are in Birmingham anymore and I suddenly needed to not be vertical) with a pot of tea, bottle of water and a muffin, I turned up my music and tried to take my mind anywhere else.

A sudden chill snapped my eyes open. What was Waterstones was now an expanse of water. Cold water too, by the look of it. Mist hung delicately over it, obscuring much of it from view. But I imagined that it went on for miles. I pulled my coat tighter around me and was grateful for the hat I'd put on to help shut the world out, back when there was a world to shut out.

After I catch my breath, easier said than done in the cold, I'm aware that I'm standing on a pier. When I turn around I can't see the other end.

It's just me, in the fog.



Image from Wikimedia Commons, artist unknown

Angst Poem Pudding

Jo Plumbe

Recipe Difficulty: Extreme

Making time: 55 years

Equipment needed:

Paper

Pen

Ingredients:

236 words

4 verses

40 line breaks

1 title

2 tsp alliteration

¼ tsp rhyme

1 poetic device

55 tbsp neurodivergence

47 tbsp self-blame

3 tbsp Beyond the Spectrum

100ml hope

Method:

- 1) Turn off Facebook notifications
- 2) Pick up pen and stare at blank page
- 3) Doodle
- 4) Stare at blank page some more
- 5) Cast mind back over the last 55 years. Ruminates on being bullied, being weird, different, finding socialising excruciating
- 6) Add 55 tbsp neurodivergence

- 7) Ruminare on how much easier it would have been to have had a diagnosis 47 years earlier
- 8) Add 47 tbs of self-blame
- 9) Write prize-winning first line. Genius
- 10) Realise that it's a hard one to follow
- 11) Cross out first line and write another, easier to follow first line
- 12) Stir in 3 tbs Beyond the Spectrum
- 13) Write 236 words of award-winning poetry
- 14) Try to remember the rules of poetry
- 15) Break them
- 16) Realise just in time you've added quadruple quantities of rhyme.
Delete. Delete. Delete.
- 17) But literally alliterate the hot hell out of it
- 18) Remove all punctuation because that's where it's at
- 19) Add line breaks in random
- 20) Places to ensure it's at least shortlisted
- 21) Create a bizarre attention-seeking title of no relevance to the poem

Serving Suggestion:

Take 100ml of hope, and drizzle freely until saturated

Mouth Wide Shut

Courtney Ward

My mouth wide shut,
by you,
yes my dear, all by you and your prejudices and attitudes.
Why are you always getting involved
in something you have no idea about?

You try to talk for me,
know what it's like to be me,
think you know better than me,
think you know it all.
But let me tell you something
You hardly know at all.

That's what happens on the outside world.
Ever so unfortunately.
People gossip about me,
treat me like an alien.
But their words are the opposite,
apparently on our side.

So as you keep supergluing
my own mouth shut,
you're placing yourself in a position
where you're down for disappointment.

You wonder why I can't change.
It's making me impossible to breathe



Flocking Together by April Wakefield

Theme 2

Community

When you feel out of sync with the rest of the world, it's easy to feel lonely, even with other people.

Community is about finding people who are not just like-minded, but like-souled.

April Wakefield

Community

Autistic people often feel isolated. We usually struggle in social situations because we don't communicate the way neurotypical people communicate. We're seen as awkward, rude and troublesome. We have 'persistent deficits in social communication and social interaction'.¹

In fact, Damien Milton's research has shown that there is a 'double empathy problem' – we communicate perfectly well with each other, albeit using different conventions, and any neurotypical person can be seen as the one with the deficits in a social situation with a group of autistic people.

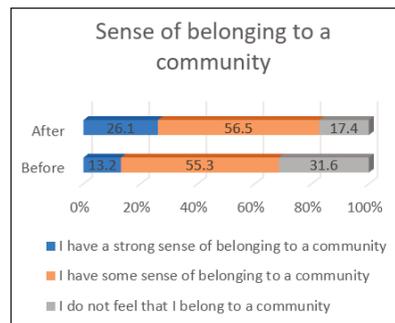
However, because of the way we're perceived by the majority, we can internalise the message that we are unable to socialise, and become lonely and isolated through not belonging to any communities.

Beyond the Spectrum has provided a community for autistic people, facilitated by autistic writers, where people with a common interest in writing their stories can spend time together and relate to each other in what is a natural way for us, without having to mask or suffer anxiety over unknowingly breaking neurotypical social rules.

Research Findings

There was an increase of nearly 13% in respondents reporting: "I have a strong sense of belonging to a community" after participating in BtS, with a corresponding decrease in those reporting: "I do not feel that I belong to a community". To put it another way, nearly one third of our participants did not feel that they belonged to a community before participating, and nearly half of that third did feel that they belonged to a community after participation.

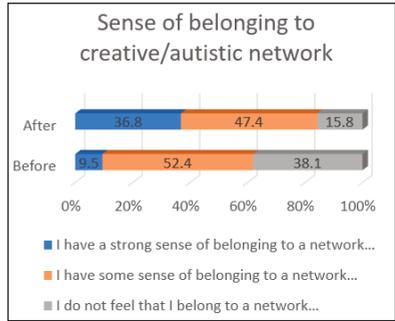
We wanted to find out whether the creative nature of the community



¹ *Diagnostic and Statistical Manual, 5th ed, American Psychiatric Association*

made a difference to our participants, so we specifically asked about their sense of belonging to a network of creative autistic people.

Before participating in BtS, only 9.5% of participants had a strong sense of belonging to a network of creative autistic people, and 38.1% had no such sense. After participation, these percentages had almost completely reversed, with 36.8% feeling a strong sense of belonging to a network of creative autistic people and only 15% having no such sense.



These findings bear witness to the efforts of Writing East Midlands and all the lead and shadow writers towards using the workshops to establish a cohesive and supportive community of autistic writers, and the research outcomes confirm that our participants greatly appreciated this consequence of joining Beyond the Spectrum.

In future research, it would be useful to identify which aspects of the project most engendered this feeling of community, and how to build on those to create a long-lasting community of creative autistic people.

I have enjoyed feeling part of a group to interact and have understanding and a laugh.

It's nice being around people that get it. We don't necessarily always talk about autism, but it feels a bit easier to accept yourself.

A regular meet-up with like-minded people to follow a passion of mine is an important anchor in my life. It is validating and a forum to listen, be heard and learn.

In that group, you're not the different one. It's just validation that people with autism are doing all these things. I think it's been really positive and to have those connections with other autistic adults has been really, really great.

Seeing other autistic adults has been so beneficial. It's that not aloneness. Knowing there are other autistic people out there and doing things is really positive.

Community

Rhyme & Reason Group

Community is
like the warmth of a blanket
a mug of fresh tea

A match to kindling
Flames of creativity
keep our group cosy

Anchor in my life,
In tempests of confusion
It holds me steady

Like minds, equal hearts
"I was going to say that"
Never felt so seen

I thought I was weird.
Abnormal. Wrong. Now I know
Our minds are so strong.

Worked hard to blend in
Years, feeling I was alone
But here you all were

Not the different one
Once lonely on a tall tree
Now free in a flock

this time
no judgements
this time

for the way I talk, or write
or just am
small squares on a screen
open windows into my world
this time
precious time



image by Ann Penn

Renga

Jo Plumbe (taken directly from research quotes on Community)

Like-minded people
we write, listen and are heard
an anchor in life.

A place where I was wanted
where I was greeted nicely.

We meet and we share
feel less alienated
enjoyment and fun.

New friends I can understand
enjoyable company.

Beyond the Spectrum
allowed me to meet others
who lead fulfilled lives.

Community inclusion
we are creative like-minds.

Relax after school
no peer pressure to conform
people understand.

Getting out there and doing
it is that not aloneness.

Accepting myself
with people I fit in with
sharing our own jokes.

Things were not easy for me
thankful for safe connections.

No more difference
only validation here
connections are great.

No more awkwardness for me
everything was positive.

Individuals
in all our autistic ways
we are accepted.

Holding Your Hand

Courtney Ward

Thank you for showing me the light.
The ability to continue the fight.
As we all stand together,
holding each other up so bright,
never forgetting the night.

I got your back,
as you feel as you will give in to the big cats.
We stand in unison, creating a wall
so large that you are protected.
We all are,
forever, holding your hand.

I Remember Too

(after Joe Brainard)

Jo Plumbe

I remember the NHS letter, my invitation to an ASD assessment. "Please fill in the enclosed forms". Endless forms

I remember my name being called, but not looking up

I remember his shoes, the door handles, the light switches, the radiator pipes, the voices in the corridor, the ticking of the clock

I remember the tapping of his fingers on the keyboard as he wrote down all my 'tisms

I remember wondering who I was, if I'd know by the end of this

I remember the long long wait, ended by the thump on the doormat as my diagnosis landed. Autism Spectrum Disorder

I remember relief, huge relief, then

I remember not knowing, not understanding, not accepting. Why had I been alone with this?

I remember anger

I remember a kind man who saw me, saw my questions

I remember the first time I saw him. He was a National Autistic Society counsellor

I remember not understanding that I needed to speak to have a conversation with him, and that was ok

I remember beginning to grow into my own skin, learning I wasn't to blame

I remember the NAS inviting me to join a writing group – Beyond The Spectrum

I remember that first Zoom session. I was excited and frightened

I remember seeing the other Zoom faces and thinking "It's ok, they're all autistic, so it's ok that I feel different. No-one is going to judge me"

I remember the gentleness of the tutors, the understanding, the empathy. I felt safe

I remember writing and laughing, expressing myself through my pen

I remember feeling as though I'd come home

I'm Not Having To Pretend

Ann Penn

I can relax on Beyond the Spectrum nights,
leave the 'normal' world behind
tough outer skin sloughing away as I
brush the day's stresses from my shoulders.
Yes, I am among my own kind here.
Nobody blinks if I stim, or
holds it against me if I go off piste.
Tuesday evenings are my time to be me –
playing with poetry with my friends.

In Sync

Courtney Ward

A breath of fresh air,
that is finally seen.
A heartbeat so in sync,
finally felt by many.
A sight thought lost,
now seen by all, in harmony.
The music being played,
in such harmony and grace.

A protector for all,
in unison we stand,
No one left behind.
Always safe knowing
that when I walk down the street,
somebody has got me when I fall.
No judgements, no hate,
always able to be myself.
My world is finally wide open,
and I am able to roam free.

One Day at School

Pippa Hennessy

is it the same now as it was half a century ago?

alarm rings | switch it off | go back to
sleep | mum yells | go back to sleep |
mum yells again | crawl out of bed |
throw on clothes | no time for breakfast
| walk to school | ignore Michelle and
Wendy | don't hit back | assembly |
pretend to sing | english | maths | stare
into space | morning break | read my
book | rescue book from Michelle |
science | art | lunchtime | hide from
Wendy | miss lunch | double PE | home
time bell | walk home | lose my rag
with Michelle | suck sore knuckles |
headache | home | forgot my PE kit |
mum yells at me | I yell at her louder

**I find my notebook
and my purple pen
I go to Alison's house**

we sit together

I tell her
about my day

she tells me
about hers

and we write
make up stories

Wendy and Michelle
meet giant
orange frogs
which flick
impossibly long
tongues
and

pull

Wendy

and

Michelle

into

their

mouths

and crunch them
up like deformed
lacewings

I read my story
Alison laughs
she hugs me

and we write
and we write
and we write

What Other People Think

Jo Plumbe

When I'm on my own it's easy, much easier
Having to speak to non-autistic people is a mystery, exhausting
always
to write is a relief.

Other autistic people speak my language.
They don't think me strange, or if they do they accept it.
Here we can all be ourselves without judgement,
eking out every last minute of zoom time, until Pippa is yawning.
Righting the wrongs of our daily lives.

Problems that I thought I had, disappear for those 90 minutes.
Every Tuesday that we meet I don't have to pretend any more.
Only other autistic people understand,
people who know what it is to live in a tough world
letting go with the flow of the pen,
the tapping of fingers on keyboards,
emerging words finding their way
to express what they haven't been able to say.
It's hard sometimes to write,
it's always a release to be able to speak
where I haven't spoken before.
Now I've met you all
I know that I'm not alone



image by Jo Plumbe

Theme 3

All Autistic, All Different

The best thing about being autistic is getting lost in my own imagination, and having to find the way out... Watching the words dance into the air and create an entire reality...

All Autistic, All Different

*"If you've met one autistic person, you've met one autistic person."*¹

There is a well-known stereotype of autistic people – Sheldon from *The Big Bang Theory*, Dustin Hoffman's character in *Rain Man* – and many people (including many autistic people) firmly believe that to be autistic you have to match this stereotype. You have to be male, you have to have rigid patterns of behaviour, you have to not make any effort to fit into 'normal' social patterns. Many of us (especially girls and women) have been told, "You can't be autistic, you're nothing like Sheldon / a boy I knew at school / my cousin who's autistic."

There are so many reasons this stereotyping is inaccurate and unhelpful. Many autistic people (particularly females) do their best to conform, and will mask their autistic traits. Many autistic people shut down rather than melt down, or are persistent people-pleasers, or hide their stimming. Many autistic people can make eye contact, many have hyper-empathy rather than lack of empathy, many are insensitive rather than hyper-sensitive to sensory input. It is invalidating and damaging to be told, "You can't be autistic..." because you don't match the stereotype.

In short, although there is a range of traits that autistic people share, it's more like a pick-and-mix rather than a recipe. During Beyond the Spectrum sessions, we enjoyed discovering our common traits and the ways we were all different.

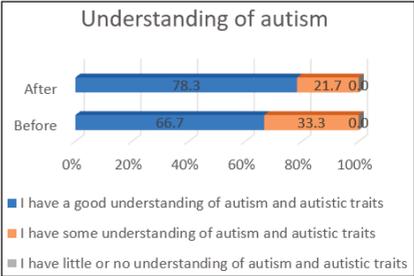
Research Findings

The survey we carried out didn't directly address this theme – it emerged from the semi-structured interviews carried out with participants, and is closely related to the 'Understanding Autism' theme.

As one might expect, individuals with autism, who often have strong interests in particular subjects and investigate those topics in depth, tend to have a good understanding of autism and are likely to have researched the associated theories and concepts. Our research shows this is the case

¹ *paraphrased quote from Dr Stephen Shore – the original used person-first language ("person with autism") whereas many autistic people prefer identity-first language*

with over two-thirds of participants saying they have a good understanding of autism and autistic traits. Interestingly, this proportion rose from 66.7% to 78.3% over the course of the workshops.



Participants strongly appreciated spending time with other autistic people ('All Autistic'), but it was interesting to hear, from the qualitative research and free-text answers on the survey, how much participants were surprised and interested by the differences between themselves and other participants ('All Different') – it's possible that understanding this accounts for the increase in the proportion of participants who said they had a good understanding of autism. It would be interesting to investigate this further in future research.

Finally, participants were delighted to be able to prove that autistic people do not lack imagination, can use imagery and metaphor, and can be astonishingly creative. That stereotype is well and truly smashed.

The way you are being autistic changes depending on what situation you're in – if you're overloaded or not, who you're with. I think that's interesting.

Now I know we are all individual people, we don't fit the stereotype. And we can be creative. We can have fun, we can understand sarcasm, we laugh our socks off.

There's this general view that we don't have any creativity, that everything's black and white. But the majority of autistic people's brains work in a whole rainbow.

BtS has changed the way I feel because I see other people giving an example of living their own lives. I can't know how they're feeling, but they seem to be happy and enjoying themselves. Yeah, you can be happy and enjoy yourselves and be creative as an autistic person.

It's nice to meet other people and see all the different ways that autistic people present. People think that it's just low functioning, high functioning, but it isn't.

The Best Things About Being Autistic

Rhyme & Reason Group

The best thing about being autistic is...

how I speak with sincerity and refuse to subject others
to confusing verbal mind games and emotional obscurity.

the excitement I feel over minor events.

watching the words dance into the air
and create an entire reality.

knowing I'm not broken –
I'm just wired differently, and that's okay.

I feel so much empathy
I understand others' experiences,
which makes me a great listener

seeing a problem clearly and logically –
I can cut the Gordian knot!

the connection that I feel to nature.

being super-direct
where others beat about the bush with social niceties

standing strong for truth, justice and equality.

No need to call for Superman
when you have an autistic person around!

my vivid imagination.

being able to find joy in something
many wouldn't take the time to appreciate.

not following the crowd.
Individuality and creativity for the win!

wandering around in the corridors
of a book-filled, whispering library.

connecting with other autistic people –
if I suddenly say 'it's like ducks'
in the middle of a conversation
about something completely different,
you can follow the wild tangent.

being logical in an illogical world.

the empathy that I feel towards people's emotions.

my ability to notice patterns,
especially if they are mathematical.

the warmth that I feel
towards my special interest.

being enveloped by tie-dye rainbows
in a paint-by-numbers world.

the loyalty I feel towards others
and my morals.

the joy I feel when writing mini essays
about my favourite anime characters
and posting them on tumblr.

going down a fascinating rabbit hole
while others meander in small talk.

the comfort of stimming.

getting lost in my own imagination
and having to find the way out

the excitement of diving into a new special interest –
a whole world awaits.

the bliss of listening to the same soundtracks
over and over again.

writing about my experiences.

Always, Sometimes, Never

Jo Plumbe

always standing loyal with friends
sometimes attempting social occasions
never coming home unscathed

always creating something
sometimes thinking it's not too bad
never having the self-belief to submit it

always empathising with others
sometimes reassures me I'm not abnormal
never leaving anyone to suffer alone

always very interested in campervans
sometimes talking too much about them
never had the typically good memory for facts

always have loved music
sometimes go to loud concerts
never can tolerate someone eating a packet of crisps five seats away

always ruminating on things months old
sometimes wonder what a clear mind might feel like
never have conquered this one

always struggling with uncertainty
sometimes facing the challenge
never a season goes by without attempting something new

always thought I'd end up on the scrap heap
sometimes now believing I have purpose
never forgetting the help I've received

always have disliked multiple choice questionnaires
sometimes trying new ways of doing them
never yet said no to Beyond the Spectrum



image by Jo Plumbe

Thought Experiment

Ann Penn

Nothing will change between today and tomorrow
apart from our knowledge.

For us, the experiment is still in progress,
but the result is already fixed.

The pendulum is held taut mid-swing
and my stomach is rigid as well,
tense for the rollercoaster swoop of gravity.
The carriage is preparing to set off,

and we will discover if we will soar or drop.
I am a fly trapped in amber, frozen in this moment of time,
existing in a state of suspended animation.
If I had a choice, I don't know which I'd pick –

staying in limbo, waiting for judgement,
or leaping into the unknown future.
I've always hated uncertainty,
so the answer should be easy.

Yet I've had ten years to practise living with this stage,
and I fear that new knowledge now
will merely bring more change and trauma.
But we have no say in this. The result is already fixed

and nothing we can do can change it.
The sand in the egg timer has nearly run through
and we must march onwards towards tomorrow
and open the box to discover the truth.

Dreamcoat

Anna Cotton

Don't label me
disorderly
because I'm wrestling
with parasite-coated arms

I'm chewing scouring pads
I'm inhaling prickly pears
don't tell me to cut it out
do you think I haven't tried?

I'm seeing cymbals again
the stars are C sharp minor
my collar's made of pins
each thread
hand-stitched by fire ants

This porcupine around my neck
is rendering me irate
quick
unpick it
from my straitjacket's nape

I've got my eye on Joseph's coat
it sings to me in spirals
but he won't play let's pretend
with the girl who swallows spiders

My condition is critical
so don't be alarmed
if my skin bleeds tangerine
and bruises technicolour

Autistic Chameleon

Rachel Phillips

She is the swirling colours of oil
on water, each view
a different tone, purples, blues,
grey to black and pink,
iridescent in the streetlights.

She moves like a hammock
strung between apple trees,
her swaying simultaneously
stimulates and soothes
in the soft, evening air.

She is the cloak that enfolds my body,
protecting me from the elements
as I walk along the sea wall,
breathing in such angry spray.

She is a murmuration of starlings, swooping,
turning, creating meaning
in shapes as night gathers them
to their roosting sites.

She is the power of water
to move from solid ice
through surging water
and, when heat is applied,
steam...

The Best Things About Being Autistic

Notts Adult Group 2021

The best thing about being autistic is...

I get to see the world in different way
from so many others
as I'm not blinded by looking for what's normal

my friends always trust me
to give them an honest answer

blending into the background
before shocking people with my knowledge
about my special interests

I can put different ideas together
and see how they relate to each other,
and I don't just know things,
I know how to use that knowledge

I think about things slightly differently
and don't just accept received wisdom

my encyclopaedic memory,
especially for conversations

my integrity,
my commitment to truth, justice and loyalty

how deeply I experience emotions
because my capacity for love and joy is endless

I can find beauty and wonder in the little things,
the things which other people miss

Spiky Profiles

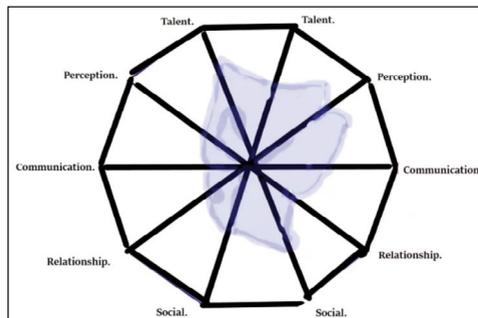
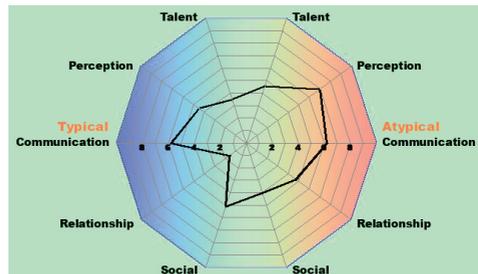
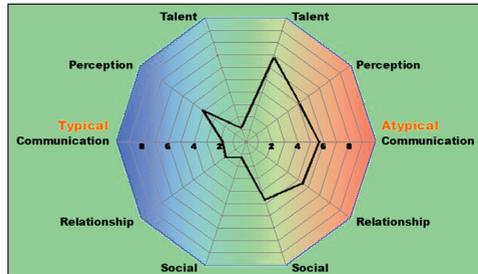
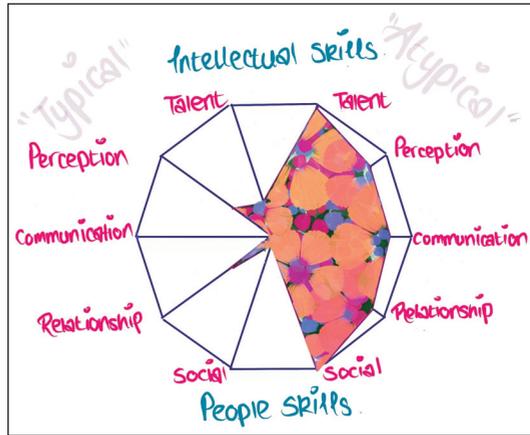
Rhyme & Reason group

There are many ways of 'quantifying' one person's autistic traits in such a way that they are comparable (in some sense) with another person's traits.

Most involve answering lots of questions – it's a good job autistic people tend to like doing that sort of thing – and producing a profile like those on the right. For each trait a score is given, and those scores are plotted on the spokes of a wheel-shaped graph. This usually produces a spiky shape, hence the euphemism 'spiky profiles'.

As you can see, and as you'd expect, our profiles all show a distinct bias towards the right-hand side (autistic) traits.

However, you can also see that they're different from each other in several ways, giving the lie to the stereotypical singular 'autistic profile'.



some of our results from <https://rdos.net/eng/Aspie-quiz.php> – all autistic, all different.

One of Many

Deborah Potter

I thought that I was the only one,
now I know that I am one of many.
A group of autistic writers,
each of us unique,
while connected by neurodiversity,
and a thirst for creativity.

I thought that I had to scream to be heard
before I joined a community
where we could amplify our voices
without familiar judgement or rejection
in doing so, proving
that we are more than a single archetype.

Don't Misunderstand

Jasmine Donnelly

Don't misunderstand, we're not all the same.

We don't all fit together like pieces of the same puzzle, we are our own people, we only understand each other in the same things, we're not "special" with hidden superpowers, and no, don't misunderstand, we do not have a secret language that only we know, only a list of experiences of being misunderstood, we don't all know what the other thinks, or believe the same.

We're all different, to tell you the truth.

Superhero

Courtney Ward

I feel you.
Trust. Me. I. Really. Do.
And that's my superpower,
here I come to the rescue.

I stand so tall, loyally
holding your hand all the way.
I don't want you to be hurt like I have,
I. Care. Way. Too. Much.

I play dress up.
I wear a cape and all.
Flying so high into the sky,
ever so willingly wanting to get caught.
Because why not?
Everyone needs someone there, right?

And trust me, I do get some weird looks.
Just because I love painting face paint on
and have the wildest hair ever.
Having the loudest laugh and
pulling those funny faces and dancing.

Letting it out...
But trust me,
I can feel those energies floating around the tiny gaps
of those underground trains of London.
But I still wanna be a superhero,
always and will be.



image by Ann Penn

Theme 4

Confidence

I'm more confident to say: this is how I write, this is my style. And I do think I've got quite a distinctive style.

Is it really weird to say I've become more confidently autistic in the sense of I'm not as bothered about people knowing now?

Confidence

As autistic people in a neurotypical world, we're constantly (explicitly or implicitly) told we're wrong. Right from a very young age, when we can't deal with a noisy environment or a scratchy item of clothing but don't have the words to say what's wrong, we're labelled 'fussy', and told to stop whining. As older children, if we say something honest that upsets people, we're the ones who are insensitive – despite agonising over what we've said for hours and days afterwards. If we question an unfair school rule we get into trouble. And as adults we're made to feel odd because we pursue our special interests, and bullied or held back at work because we can't play the social games expected of us.

As a result, most autistic people are sorely lacking in self-confidence and self-esteem. This is particularly true for those who are undiagnosed or late-diagnosed – instead of being able to acknowledge that our brains work differently to most of the people we meet and interact with, we assume there's something wrong with us. We're broken, we're aliens, we're not fit to be allowed into 'normal' human society. That's a powerful message, and once it's become internalised it's really hard to shift.

Because everyone involved in Beyond the Spectrum workshops is neurodivergent in one way or another, including the lead writers, we've rediscovered our confidence in ourselves through supporting and acknowledging the validity of each others' way of thinking. The importance of this cannot be underestimated.

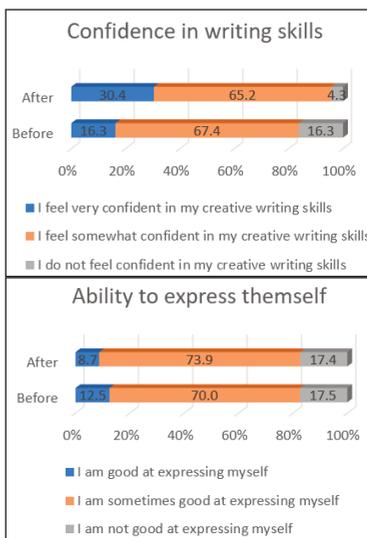
Research Findings

Both the survey and the interviews showed a clear increase in confidence of participants. Before participating, 7.5% said they had a lot of self-confidence and 10% said they didn't have any. Afterwards these figures were 19% and 4.5% respectively, indicating that participating in Beyond the Spectrum has a strong effect on an autistic person's perception of their own self-confidence.



An increase in confidence in writing skills was also shown, although this may be cast into some doubt by a slight reduction in the proportion of participants who thought they were good at expressing themselves. This might be a reduction in perception alongside an increase in ability, but we can't be sure.

Answers to free-text questions in the surveys and comments on self-confidence in the interviews bore out the observation that many participants increase in self-confidence, for example, some gained the confidence needed to perform better at school or change their careers, and others became able to join groups and find ways to combat loneliness and isolation they had previously experienced.



As I joined BtS I had mocks and GCSEs going on and it helped me with that.

I am autistic. I'm not going to change that. If you don't like that, it's a you problem, not a me problem.

I discovered I do like being part of the group. So I'm now a member of various other things.

BtS has made me a lot more confident in my writing... my confidence in different genres has developed as well.

BtS has changed my life. It's unlocked so much for me and really increased my confidence.

I didn't think I was going to be capable of working, and BtS really helped my mental health and helped my self-confidence. I really put getting that job down to those BtS workshops.

Before I'd be scared to even talk to someone if I didn't know him... I refused to do lots of things but BtS has made me feel more open & brave.

Voice

Jo Plumbe

All my life I'd had little confidence to speak in front of other people. I couldn't introduce myself in meetings – I usually had to get someone else to do it for me. When I was diagnosed as autistic I was in a pretty desperate place, having recently gone through a protracted period of autistic burnout. I felt hopeless, and thought I'd never be able to work again as I felt I had no ability.

When I started with Beyond the Spectrum (BtS), I remember being worried about being in a new group, but soon realised that it was ok to be nervous as everyone understood and no-one judged. It felt good to be amongst other people who not only accepted difference but embraced it. It was inspiring to hear so much creativity and different styles of writing, and I soon gained confidence not only to share my work, but to enjoy doing so. It was fun, and I discovered that I love injecting a bit of dark humour into my writing – a means of expressing my way of thinking that I find difficult in social situations. The writing sessions are the highlight of my week and are often the only time I get to express the real me.

And then came the real test – a live online BtS event where people read their own work. I took the leap and chose to read a poem I'd written. Whilst I was extremely nervous, I managed it and felt a huge sense of accomplishment afterwards.

This was the springboard I needed, and an opportunity came up for some co-produced work with the NHS which involved speaking in front of people online. My experiences with BtS stood me in good stead, and I managed it, albeit with a dry mouth! From there I moved forward to gain further employment in Autism Support training, none of which would have been possible without the confidence I gained in myself with BtS. I'm now involved with the rollout of the Oliver McGowan training in the NHS, which will entail lots of public speaking – something I never dreamt I could do (and am still losing sleep over). Reading my work at the BtS event is a huge step for me and will no doubt give me the confidence boost that I need.

When I look back to where I started, Beyond the Spectrum has helped me go from feeling hopeless about life, to feeling confident, happy and fulfilled, and I'm so grateful for this.

Beyond

Ann Penn

Dorothy travelled behind the moon,
beyond the rain,
over the rainbow.

I travelled Beyond the Spectrum
and discovered a new world.

In the company of friends, I found my heart
And you all gave me the courage to sing.

What Shape is a 'Meek Little Thing'?

Ann Penn

It's over forty years ago now, since I found out
the neighbours over the road had called me

"A quiet, meek little thing."

I still remember the burning anger.

Inside my head, I was powerful, strong, important.

Inside my house I was intense, focussed, argumentative.

Inside my family, I was wanted, loved, and understood.

But to be truthful, to the outside world, I was quiet and meek

– though I draw the line at thing.

But looking back now, with over forty years of wisdom

maybe it was the world that was the wrong shape

not me.

It's Nice to be a Crone

Pippa Hennessy

The maiden always hid
under the coats at parties,
hands over ears, rocking.

The mother creeps out now
and then, talks to a few people,
sometimes doesn't creep back.

The crone doesn't need the coats,
she talks while she's having fun,
leaves when she's not.

I Can Deal With It

Jasmine Donnelly

It's not that I can't deal with people,
They can't deal with me,

The life I wanted was never one
of constantly depending on someone else
to sort everything out for me and make it all ok.

I don't want my life to be made easy for me.
If life is a path of struggle,
then let me walk that path,
even if I stop sometimes and want to turn back,

I don't want looking after...

I don't want to be still stuck
in the same place in a years time,
I want to be making my own path...
wherever it takes me.

Don't presume
that the fact that I'm considered disabled
means that I can't make my own choices.

And if my choice is to walk my own path,
who's to stop that?

Confidence Cake

Jo Plumbe

Recipe difficulty: Moderate

Preparation time: Several years

Equipment needed:

Computer

WiFi

Clock

Baking tin

Two incredibly creative and all-round generally wonderful lead writers

Ingredients:

A sprinkle of chat

2 Padlets of shared writing

8 skies of creativity

2 dollops of improved mental health

4 deep breaths of self confidence

1 new job

1 bus-load of new-found travelling ability

Unlimited coming out as autistic

2 mouthfuls of speaking in public

3 buckets of self esteem

A generous spread of social confidence

1 tsp solvent for unmasking

1 alphabet of improved reading skills

A ton of bravery

Method:

1) Turn on your computer

2) Click the Zoom link from Beyond the Spectrum. If desired check your hair in the preview window

- 3) Turn camera on, or off, or on and off, or off and on. It's all ok
- 4) Take a couple of deep breaths of self-confidence and combine with a sprinkle of chat
- 5) Listen to or read the writing exercise, pour in the 8 skies of creativity, and mix thoroughly
- 6) Abandon self-doubt and write
- 7) When the time is up, take 1 deep breath of self-confidence and post your writing onto Padlet
- 8) Take the remaining 1 deep breath of self-confidence and fold it gently into a ton of bravery
- 9) If, and only if, you'd like to read out your writing, add in 2 mouthfuls of speaking in public and go for it. We're all rooting for you
- 10) Revel in your 3 buckets of newfound self-esteem
- 11) Line a baking tin with 1 tsp of solvent to allow easier unmasking
- 12) Spoon all the ingredients into the tin and bake for 90 minutes
- 13) While the cake is baking, you can make the icing. Mix together 2 dollops of improved mental health, 1 bus-load of travel and stir in 1 alphabet of improved reading skills
- 14) Allow the cake to come out from the oven and ice with the mixture
- 15) Finish the cake with a generous spread of social confidence

Serving suggestion:

Serve warm to your co-workers at your new job

Knock Knock Confidence

Courtney Ward

I was once the girl in the corner,
quiet as a mouse,
afraid to talk and meet others, open up the jar.
I am now the girl in the circle,
just ever so shy,
but involved I am.
I will shoot my aim into the circle more,
so I can build my army,
and feel more connected.

I was once so scared,
of coming out safely from under the duvet.
Internalising, always backing away, afraid.
I am now more openly saying,
that I am needing a step back.
A work in progress, currently baking.
I will continue to take the stand,
to voice my words and act
in honour of myself.

A frozen carousel I once was,
not able to move, scratches left behind,
nobody notices.
Now able to meet in harmony,
everyone in love
despite the imperfections.
Flying high in the future,
believing in myself, polished up.
Able to see more clearly then.

Hiding myself under my bed I once did,
unable to get out of this squared cage.
All because I'd get hurt at every direction I went.
Now, I don't hide away,
I forget to think twice about them,
and letting go for a while.
I break the chains, eventually, one day.
From the old rusty cage,
that will be non-existent.

On Reflection

Jasmine Donnelly

Used to hide myself deep inside,
trust too much, get ignored,
become a mouse and creep away,
think to change myself.

Forget what they think of me,
and simply enjoy the reality I create,
becoming truly myself for a while,
moving long words like chess pieces.

Left the past far behind,
with mirrors reflecting wrong decisions,
a reversed image of the failures,
free to reveal the truth I've hidden.

Work in Progress

Chloë Hunt

I was perfectly happy just to listen. Existing on the sidelines and never sharing my own thoughts, ideas or writing. I thought that I only get to be genuinely good at one thing, and 22 years of singing and songwriting would be it for me, and that was probably fine.

But, when you think about it, writing poems, prose, dialogue, scripts, menus, words, that's not so different than writing songs. Plus, most of those don't even have to rhyme! Goodbye rhymezone.com, it's been real.

Several pieces are published in an anthology. I'm so proud, but when it comes to it, I can't bring myself to read in front of people. I cry at home when I should be on a train. I shut down.

So I try again, I share something in the group, a stanza or a paragraph. I flush as the kind words come and want to believe them. But maybe they're just being nice. Wait, we don't do that fake nice thing here, do we? So, they mean it? Ok. Next week I'll speak on the microphone, the week after that, I might turn my video on briefly. But hiding behind a photo of me that I realise is now four years old still feels the safest, for now.

I read an email, Pippa is looking for cover art for the anthology. I eye my art journals, canvasses, half a room stuffed with art supplies. I think it's probably not what she's looking for. It's just paper ripped up and stuck back together. But then I have a brave ten minutes and I take a few photos and send them over, the worst she can say is no, and at least I tried.

It looks like I'm going to be making cover art for the next anthology.

I'm going to stand up in front of people and read words that I've written.

It feels infinitely different to standing on a stage with my Dad, or bandmate, and singing songs that I've written. There's less to think about, and more room for anxiety to grow. Maybe I'll trip over my words, and even if I don't quite catch myself, I know that there's a safety net of people who understand and will hold out a hand to help me to my feet again.

Possibility

Jo Plumbe

The old wooden box
has cracks creeping over
like vines on an ancient wall.
must and dust crawl out
as I lift its heavy lid,
hinges of frost shattering
never to be closed again

I find in the box
freedom
from the sea of confinement
words on a blank sheet of paper
laughter of a child
who didn't know she was there
relief of warmth in the cold

I find in the box
the key to the box,
dimension where all was flat
memories of tomorrow where I will go.
the lid, once mighty,
now light as the dust that left,
lowers but will not close

Multifaceted

Jasmine Donnelly

So careful, hiding anger and smiling,
So sensitive, shaking and crying,
So ruthless, laughing at their failures,
 why is it so funny when someone makes a spelling mistake?
So distant, ignoring, turned away, pretend it doesn't exist,
So macabre, cackling loudly, are scary stories really this funny?
So quiet, sitting alone, doesn't care about the gossip, why should I?
So talkative, on and on about all the things I've read,
 till their ears bleed.
So interested, listening into conversations,
 have to be the first to know a secret.
So serious, hiding behind exceptionally long words,
 overthinking every simple comment,
So forgetful, might even forget my own name
 if I didn't write it down.
So whole,
 embracing every part of myself, good and bad.
So confident, I am who I am, don't seek to change it.



image by Ann Penn

Theme 5

Understanding Autism

It makes me feel better about myself that things that I would always have thought have been failures and faults before are actually just part of the autistic brain. And they are normal.

Understanding Autism

To find out about the history of autism, its medicalisation, public and academic views of what autism is, and where we are now, read *Neurotribes* by Steve Silberman. Frankly, it's quite horrific in parts, and not just the parts that talk about the first half of the 20th century. There are still parents forcing their children to drink bleach to 'cure' them, and organisations promoting Applied Behaviour Analysis and similar 'therapies' to force autistic children to behave neurotypically despite sensory overload and mental overwhelm – punishing them for exhibiting self-soothing behaviour, trying to block out unpleasant noises or bright lights, or simply avoiding eye contact.

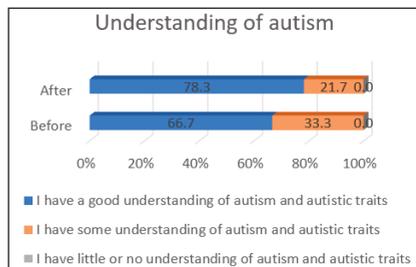
This century the emphasis has moved away from 'fixing' neurodivergent people and towards enabling us to live as comfortably and be as fulfilled as we can within a society that is not set up for our needs. Academia is shifting towards participatory research, where autistic people are included in the design, implementation and interpretation of research studies into our condition and, increasingly, it is autistic researchers who carry out those studies rather than neurotypical academics who can only ever look at us from the outside.

It was not one of Beyond the Spectrum's initial aims to increase understanding of autism within and outside the autistic community, but we noticed right from the start that not only were participants beginning to understand and accept their own autistic traits and identity more, but that some of the work we produced was contributing to a wider understanding of the autistic experience.

Research Findings

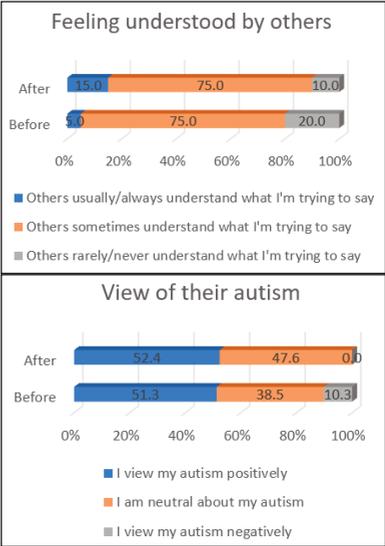
The increase in understanding of autism shown here is discussed in 'All Autistic, All Different' on page 40.

There was also a clear rise in the proportion of participants who felt understood by others, with a corresponding fall in those who



didn't feel understood. It's likely that this is because participants felt others in their groups understood them, rather than other people in general.

Importantly, we asked participants about their view of their own autism, and although the proportion who viewed their autism positively hardly changed (and was pleasingly high at just over 50%), the proportion who viewed it negatively decreased from 10.3% to 0% – this is a great outcome which could have a significant positive effect on those participants' mental wellbeing.



The trauma of masking and feeling broken is profound and still affects me every day. I now realise the strengths of being autistic for me...

... learning more about autism, how it's prevalent throughout society, and seeing other autistic adults has been really beneficial.

I've learned loads new about autism, because you see different people, and different ways of speaking, different ways of creativity.

It's nice being around people that get it. We don't necessarily always talk about it, but I guess it's easier to accept yourself...

BtS cemented that knowledge that ... we're actually doing the vast majority of things that neurotypical people are doing, and in a lot of cases more, because we're having to fit in with a society that's not really built for us.

People in my school used 'autistic' as an insult and I joined in not knowing what it meant, but BtS and learning about autism helped me realise that that isn't okay and understand what it actually means and there's nothing wrong with being different.

The Colours of Autism

Notts Adults 2021

My autism is blood red, in many shades,
from the slow deep garnet ruby of spent blood,
to the shocking scarlet slash of arterial blood,
pulsing and dynamic. It is such a part of me
I could not live without it.

My autism is red. Once it was a red flag
for those who don't understand.
A warning flag to me, telling me
how I need to behave.
Now it's a big red button
launching missiles of understanding
and altering what you think you know.

My autism shines scarlet in my mother's blood,
my brother and my grandmother also bleed brightly.
How could something that intense have hidden
for so many lifetimes? Thank you for that gift—
now I see through a red-rose-coloured lens,
what we are, why we are and who we are,
and everything fits.

My autism is black and red
a passion hidden in the dark.

My autism is sunshine yellow—
people like to tell me I stand out too much,
but this is who I am,
and I will always shine this bright.



image by Jo Plumbe

My autism is orange
sanguine dawn ablaze
wildfire on my pithy tongue
I don't need your permission
to be a strange fruit

My autism tries to camouflage
in any given environment.
Hiding in plain sight,
it defies the norms of society,
while imitating the standards
by which we are judged.

My autism is a kaleidoscope,
multiple tiny glass shards
of clashing colours.
But look from a different angle
and the vibrant flecks combine
into one whole, intricate pattern.

You Can't Be Autistic Because...

Deborah Potter

"You can't be autistic because you're too sociable,
you do not defy the norm as far as I can tell.
and for someone who is anxious, you manage pretty well."

"You can't be autistic because you look at me when I am speaking to you.
You talk and make facial expressions,
even if they are a bit repetitive at times..."

"You can't be autistic because you do not complain
about the noises that you claim to hate,
nor do you seem bothered by smell or taste or touch."

"You cannot be autistic
because you do not match my definition of autism."

Well, let me explain.

Every day I am flooded with uncertainties and worries
too overwhelming to be expressed.

I will hold my gaze for as long as I am able when I am talking to you
but I will look away when it becomes too painful.

I may not complain about the noises that I claim to hate,
or the headache-inducing odours
that escape from cleansing products, perfumes and diffusers.
But the anxiety that comes with these sensations
can be debilitating,
to the point where I am but an immovable statue
unable to communicate my needs to others.

As for the definition of autism, I can only speak for myself
as every one of us will make you come to a different conclusion.

The Autistic Pill

April Wakefield

Allistics. Do you enjoy small talk to an unhealthy degree?

Are you more interested in people than trains or dinosaurs?

Do your interests consume your mind for only a minute portion of your waking hours?

You should try Autzims! The pill that turns you autistic!

Memorise irrelevant facts, understand animals better than your peers. Immerse yourself in the pure rhythmic enjoyment of rocking back and forth.*

Eye contact is overrated. Throw away those social norms and focus on what really matters: trains.

Live life the autistic way, with Autzims!

WARNING: SIDE-EFFECTS MAY INCLUDE: DISCRIMINATION, INABILITY TO WEAR LOTION WITHOUT WANTING TO TURN INSIDE-OUT, INEXPLICABLE GUT ISSUES, AND EXTREME ATTACHMENT TO FICTIONAL CHARACTERS.

** Please note, effects may vary.*

A Different Kind of Fiction

Deborah Potter

My childhood was a void
of unanswered questions.
I was never a party animal,
wanting to talk to others
but not having the skills to do so.

An alternate world was preferable,
like ones created by fiction and roleplay,
drama, writing and artistic display.

When video games were introduced to me,
they conveyed a different kind of fiction
where everything was predictable
and clear instructions were given.
Role playing games were a liberating escape—
a filter for thoughts and rumination.

As a nine-year-old,
I held the smooth membrane of the console:
An infinite construction of rigid coding.
A way to decipher a world which I didn't understand.

As narrow as my interests were,
after being shown a demo
of Pokémon games,
I fell in love with the franchise.

The moving pixels measured
my growing understanding
of my surroundings,
interactions with characters
acting as a template for communication.

I indulged in my thirty minutes after school,
until the adults said:

“Don’t stare at that for too long,
your eyes will go square.”
Something else which I took literally.

As my hobbies changed,
so did time set aside for gaming.
Despite this, the activity remained
close to my heart.

By the time I reached my early teens
I was even less of a party animal.
We put it down to shyness,
anxiety and avoidance.

When I sat, a fifteen year old
speaking to the ed. psych.
they adjusted their glasses at the sentence:
“I never know what to say to people.”
“Have you ever thought
that you might be autistic?” they asked.
From then, my life was unmasked.

When I look back on my nine-year-old self,
holding a console for the first time,
I wonder if my eagerness
was fuelled
by a longing for acceptance
through a fictional concept:

An infinite construction of rigid coding.
The way to decipher a world which I didn’t understand.

Amongst the adventures experienced
during the thirty minutes after school,
the one towards my diagnosis
made all the others worthwhile.

Spoons

Ann Penn

I collect spoons
eke out their use from day to day
so I have enough when the cutlery drawer runs low.
Noise makes my spoons empty fast
of common sense
and fill with annoyance;
my brains melt down into the spoons.
I wish I could eat it like ice cream, but
I am forever afraid of getting the blame for something -
even worse if I've actually done that something.
The terror seeps into me, joins my melted brains
and solidifies into rock, a solid stone
that wedges in my gullet and stops me eating
stops me feeling anything but the terror.
Sometimes talking to someone with common sense
and a little bit of nonsense so they can understand me
gives me the power to question the previously indisputable fact
that the rock is permanent, solid, unmoving, eternal.
Join several of us together, a laser beam of power
and pieces chip off the rock – til it has broken
in two, and I pickaxe the rock into dust.
Joy fills me, taking the place of the rock.
and giving me back my focus.
The laser beam of the binoculars helps me to see
beyond my eyesight, beyond the normal spectrum.
It's true, it's true, it's true, I cry.
I can see beyond the creation of the rock, beyond
the surge of power, beyond the joy
to the beginning and the end
and they are the same, a constant ouroboros
mouth to tail, one and all.

I will stick a label on the snake and post it to myself
so it will appear and be proof that snakes exist
and joy exists and power exists
and all labels are different.
I will peel the snake and wriggle into its skin
and let it protect me
against the normality of me
the awkward, maladjusted, hiding, scared
little me inside the snake skin.
And the skin will make me strong.



The Office

Jo Plumbe

07:00 She'd been kept awake all night by the low level voices of her neighbours talking into the night. Quietly, but a cacophony to her ears. When they eventually stopped she hadn't been able to sleep in case they started again. Exhausted, she rolled out of bed and stumbled to the shower in a daze, eyes narrow slits. The bathroom had an uneasy smell of damp which she flinched at as she did every morning, as she turned on the dreaded water. Two minutes was all she could bear under the torrent of needles on her skin. Having dried herself on the scratchy towel, she put in her earplugs and dried her hair.

07:20 Choosing her clothes for the day, all with their irritating labels removed, she dressed in blue, as usual, and went downstairs for breakfast.

07:30 Exactly on schedule, she ate her customary bowl of Shreddies, had a cup of coffee in the blue mug, took her anxiety medication, washed up the bowl, spoon and mug, and looked at her watch.

07:42 With mounting tension, she put on her noise-cancelling headphones and blue coat, and headed out onto the rush-hour street. The smell of petrol fumes was overwhelming – no wonder there was a climate crisis.

08:00 Momentarily soothed by having executed her routine to the minute, she walked in through the door of her office block.

The relief was fleeting as the fluorescent lights burnt her eyes, and people rushed past, crowding her space. The TV screens in reception blared their kaleidoscopic marketing messages in technicolour, and eyes stared at her wherever she looked. Ducking her head, she slipped on her tinted glasses.

Her office was on the fifth floor but the packed lifts weren't an option. The stairs had become part of her fitness routine anyway in lieu of the

chaotically noisy gym. Slightly out of breath, she arrived at a free desk and collapsed into the chair, feeling as though she'd already done a day's work. Technically her floor didn't start work until 09:00 so the desks around her were empty at 08:08. She had 52 wonderful minutes of peace and quiet before her colleagues arrived and phones started ringing. Taking her phone off the hook just in case, she settled down to do some work.

She smelt his aftershave before she saw him, and to her horror he sat down at the desk next to her. Her brain clouded over and she could barely see her screen, the smell was so strong. It was intolerable, and she was going to have to move. Much as she loathed the uncertainty of hot-desking, at least she had the freedom to escape. As people arrived, the noise levels in the open-plan office rose to the point where she had no choice but to put on her noise-cancelling headphones. With relief, she started working again. Minutes later she shuddered as someone touched her shoulder without permission. It was her manager.

"You can't wear headphones at work."

Blushing, she replied, "I'm autistic, I need them to block the noise out."

"If you wear them, everyone's going to want them. Take them off, or go home."

It had only been a week since she'd started this job and she was scared she'd lose it. Her employment record wasn't exactly rosy, so she removed the headphones and winced as the noise hit her. Then her phone rang. She hadn't been expecting any calls so was thrown into a panic. Knowing that her manager was watching, she picked up the call. As usual it didn't go well. She found phone calls difficult, not knowing when it was her turn to speak, and feeling pressure to get away. As often happened, she agreed to a deal that she didn't want to agree to, just to get off the phone.

Lunchtime arrived. Some of her colleagues went in chattering groups to the busy canteen, and some had brought packed lunches, as she had. As the office emptied, she breathed a sigh of relief, until her neighbour opened his sandwich box. Marmite! It filled her senses until she could no longer focus on her own lunch. How could anyone be so inconsiderate? She had to get away, so she went to the kitchen to make a cup of coffee that she didn't really want, waiting there until the offensive smell had

dissipated. As she leant against the wall observing the sign that asked people to wash up their own cups, it angered her that there were dirty cups by the sink. Why couldn't people just follow the rules?

The afternoon dragged, her muscles ached more and more as she sat on high alert. By now she was ignoring the strange looks she was getting for wearing her tinted glasses indoors.

"Hi, I didn't know you were working here. I haven't seen you for ages. How are you?" A stranger was standing at her desk smiling at her. She hadn't a clue who he was, which was not unusual.

"Err, I'm fine thanks, how are you?"

They made uncomfortable small-talk for five long minutes, and he went on his way. She was none the wiser who he was. Breathing a sigh of relief, she was on her own again, tired after concentrating on copying his body language. She'd been focusing so hard on trying to look normal that she hadn't been able to take in what he'd said. Hopefully it hadn't been important.

Rocking in her chair, she returned to her work but soon noticed that the man beside her was staring. She tried to ignore him but could feel the colour rising in her cheeks. He couldn't contain himself any longer.

"What's wrong with you?"

Avoiding his accusing stare, she replied, "Nothing, I just need to rock."

"That's just weird." he muttered.

She stopped rocking and, becoming aware that the noise of the office was fading, she rushed to the toilets. By the time she got there her hearing had totally gone, and everything looked a little surreal. She locked herself in a cubicle and sat down with her head in her hands, rocking and unable to hear or speak. Time stood still.

17:30 Her phone alarm went off. She must have been in there for at least an hour. What a way to end the week, with a shutdown. Thank goodness it was Friday; she didn't think she could take much more of this. Her mind wandered to the weekend, and her desire for peace and quiet. She needed to think about whether she could cope with another week in this office, and her means of relaxation was to walk in the countryside. She had an idea where to go as she'd heard strange rumour of a hill that had answers...

word cloud generated by
Rhyme & Reason group

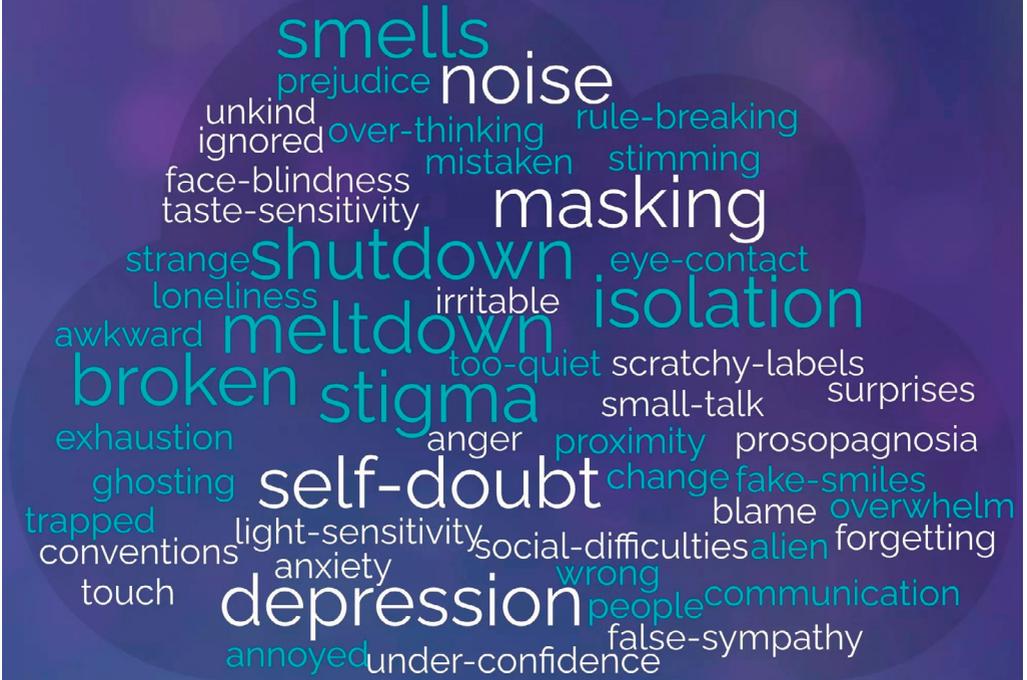


image by Arlington Research on Unsplash

The Lake

Jo Plumbe

She'd had a terrible week at work, having struggled to cope with endless noise of the open plan office and too many unexpected phone calls. She felt exhausted, and was wondering if she was going to be able to hold down a job.

For weeks she'd been wanting to climb the hill just outside town as she'd heard a strange rumour that the hill had answers, and so she'd left the tiresome noise and rush behind and set off for some peace and quiet, and hopefully some enlightenment.

It wasn't proving so easy though. For two hours she'd been wading aimlessly through the marsh at the foot of the hill, every now and then glancing up with tired eyes at the top. How could she ever get there if she couldn't even find a path? She trudged with muddied boots through squelching moss, head down with dogged determination, until she reached yet another stone wall that blocked her way.

About to turn around, a streak of colour amongst the stones caught her eye. Reaching for it, she pulled out a well-worn map. It had her name along the top edge. She tore open the map and realised it showed her the route to the top of the hill. Wasting no time, she followed its direction along the wall until she found a creaking wooden gate. Beside the gate stood a signpost pointing along a path up the hill, and on its lichen-covered finger it said 'Understanding'. Intrigued, she looked at the map and indeed the path led to the top, but along the route were marked the mysterious instructions 'Stop and look'.

Without hesitation she followed the path signed 'Understanding' until she reached the first 'Stop and look'. Initially, she could see nothing unusual, and then she saw it. Another map, this time with a pen attached on a piece of string, hidden under a rock. She took it and saw it had a note attached: "This map is meant to be the same as yours, yet it has errors that no one can spot. Please resolve."

She opened the map, laid it alongside hers and studied them both. Well, the errors jumped out at her almost immediately. Within five

minutes she'd circled them all. Puzzled, she moved on, but as she walked she realised that she'd found the task remarkably easy. Maybe seeing detail was a strength she'd never realised she had.

She followed the path to the next 'Stop and look' point on the map, this time finding an intriguing logic puzzle attached to a stone, with a pencil and note attached: "Only 1 in 100 people can solve this." She sat down and studied it, chewing the pencil. Five minutes later she'd solved the puzzle. She moved on, but while she was walking it occurred to her that she'd just solved an apparently difficult puzzle very quickly.

After half a mile she came to a fork in the path with a signpost. Left pointed to 'Understanding' and right pointed to 'Shortcut to the Top'. There were two more 'Stop and look's on the path to 'Understanding'. She felt that it was an easy decision, as despite her wearying legs, she was learning about herself as she followed the 'Understanding' signposts. And so she turned left, noticing that her mind was clearing in the velvet silence of the hill.

Before long she came upon another walker sitting on a rock beside the path. He was not in a good way... cold and hungry. Immediately she took off her jacket, put it around his shoulders and reached into her rucksack for her sandwiches and chocolate. He accepted them keenly, and before long they started to chat. He'd also had a bad week at the office and had left in a hurry, unprepared for his walk. They laughed about how awful offices could be and agreed that the silence of the hill was far preferable. He thanked her for her kindness as she said goodbye. Cold and hungry, but happy, she went on her way.

And then she came to it. A large rock with a sign on it saying: 'Move me'. Exhausted, she slumped down onto the grass and stared at it. This was impossible, surely. Then with a stubborn will she got up and tried to push the rock. Much as she heaved, it wouldn't budge.

She stepped back from it in frustration, and as she did so she nearly tripped over a large piece of wood that was lying on the ground. Not to be defeated, she jammed the wood under the rock and leant on it with all her weight. The rock rolled aside to reveal a small tunnel, just big enough to crawl through, and with another sign to 'Understanding' pointing into it. She peered into the darkness and could see a tiny dot of

light in the distance. It reminded her of trips she'd taken on a canalboat through a half mile tunnel, and the feeling of success when she'd reached the other end. She felt as though the sign was almost urging her on. There was only one thing for it, and so she entered the tunnel.

It was pitch dark and damp, but she remembered the awful week she'd had at work and the tunnel seemed less daunting. All the while she focused on the spot of light at the far end. Her heart was racing but, undeterred, she crawled for what seemed like an age until she emerged on the other side.

And what a view awaited her. All around were hills with a great lake below. As her eyes became accustomed to the light, she realised that there were other people also standing at the openings of small tunnels, dotted all around the hills.

Not being one to initiate contact with others, she wasn't sure what to do, but the situation seemed so extraordinary that she decided to risk calling "Hello!" To her surprise the hills echoed back with shouts of "Hello!" There seemed to be an unexpected unity amongst these scattered strangers.

She looked back at the lake and realised that what she'd thought were ripples were a sea of words. Not knowing what to make of it, but filled with newfound confidence, she shouted out the word "Understanding," and before her eyes the word *Understanding* rose up out of the lake and floated above the hills. Then someone else called "Determination" and the word *Determination* rose to join *Understanding*.

Quickly, people joined in... "Kindness," "Detail," "Logic," and before long a huge word cloud of strengths formed above them. And then someone shouted "Creativity."

The words started swirling around as if in a thermal. Everyone watched in awe as the words aligned to form a poem, a huge group poem, its title 'Now We Can Fly'.

Ignorance is bliss?
Ignorance is brave.
No prior awareness of social tricks –
so no adherence to those limits.

Saying the first thing that drifts through the mind,
seconds on seconds of frozen time,
randomly existing, like an empty picture frame,
nothing, just something without a name.

Not shackled by shame
from fear of others' judgment.
Radiant honesty and unabashed joy –
which banishes deception and mistrust.

When I was a child, we had an honesty bush.
I used to love flaking the rough outer seed pods
to reveal the gleaming silver truth within.
I think more people should grow honesty.

A twitch of the ears, hearing things lost,
a blink of the screen, the flutter of a page,
interested, motionless, trapped in a dream,
realms yet unknown, as far as it seems.

Deemed negative by some, pessimistic by others,
realistic... Although neither can agree,
the worst may still happen, or perhaps it may not.
Dark clouds drift in, there's still light in lightning.

Integrity is a ship in forlorn waters.
It presses on, undeterred by the direction of the wind,
the unprecedented storms,
or the plummeting temperatures.

As the mechanism of the ship ploughs on
a faraway land comes into sight –
no more than a speck in the distance,
but a reason to keep going.

I'll stop for that tired stranger by the path
to give him the last of my chocolate
as you would wrap him in your coat –
shared kindness amongst our community.

The backs of my knees want to break through the front.
If I scrunch my eyes shut, maybe I can pretend
that he didn't just sit at the wrong table
and he wasn't Mrs Doubtfire the whole time (the whole time?!).

Stopping to analyse
what is often ignored –
sometimes the smallest things
are the most intricate and significant.

It is grounding and humbling
to notice the tiny beautiful things.
Peering closely at the lichen and the cities of invertebrates
can make one feel more connected to the world
than any social gathering.

Detail in the vein of an autumn leaf
or pictures, lists, for work or play.
Nothing unmissed in my world of detail –
a richness I am grateful for.

Look closely, and no two snowflakes are the same.
I imagine us as snowflakes –
our different patterns each unique and infinite,
yet when together we fit seamlessly.

Wildly myself, specifically unique,
no-one else is exactly like me.
I own this power of uniqueness,
loving this version of the unmasked me.

I am non-judgemental, I'm here for you.
I have so much empathy, it is overflowing.
A piece of myself on the line,
always ready to lay with you.

Nobody talks about the shackles of 'should' –
I think they don't want you to know that they're not actually locked,
because once I slipped one shaking hand out, then the other
there were a lot more colours, stories and songs
that suddenly made sense.

We are the Ginger Rogers of existing,
managing the world backwards and in high heels.
But we don't know any other way.
Resilient, whether out of necessity or not.

Constant struggling between the ideal world and what we're stuck with,
wanting to fight for equity, truth and justice.
Fighting exhaustion and frequently disappointment.
But we keep fighting, because tomorrow is more ideal than yesterday was.

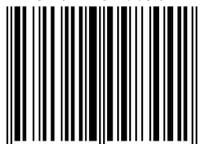
My love for others is out of this world,
always smiling, making people feel welcome.
In a world full of disconnection,
I like to connect through compassion.

In your time of need,
when you need your people...
We all understand each other here.
We are one large family, a community, as one.

BEYOND THE SPECTRUM

In October 2023, a small group of Beyond the Spectrum participants undertook a six-month project. They examined the outcomes of a study NTU Psychology researchers had carried out into the effects on autistic writers of taking part in Beyond the Spectrum, and interpreted those results creatively. The result is this collection of writing that beautifully expresses the benefits that the *Rhyme & Reason* writers and other participants experienced, in language that anyone can understand.

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