ORIGINAL ARTICLE

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'Sea-glass survivors': Autistic testimonies about education experiences

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Abstract

This article is different. Original testimonies are reproduced, in full, from three autistic adults who reflect on their education experiences. These accounts evolved from a webinar which explored autistic 'voice' through research presentations and lived experiences, and this co-authored article seeks to communicate these reflections to a wider audience. The testimonies are brought together, interpreted and analysed through the lens of the social model of disability exposing the ableist systems in which these adults had to operate. All share the challenge of trying to fit in to a socially, neuronormatively constructed education system, experiencing marginalisation, lack of understanding and lack of appropriate support. However, all three writers emerge as more than 'sea-glass survivors', weathered and worn, having developed survival strategies, but demonstrate their determination to improve lives for those who follow in their wake. This article draws attention to the need to listen to autistic people more frequently, but more importantly to involve them as architects of change for the future. The article was co-created by three autistic people, who identify as neurodivergent, in discussion and collaboration with the lead author who is an autism ally, autism and education researcher, and parent to an autistic son.

KEYWORDS
autism, education, higher education, inclusion, neurodiversity, social model of disability, voice

Key Points

- This article gives space to three autistic adults' reflections on their education experiences in the form of original testimonies.
- The idea for the testimonies emerged from the three writers in discussions with the lead author after an autism webinar event.
- The accounts reveal the challenges of having to fit in to a system which was not flexible or agile enough to accommodate their needs.
- The evidence from these reflections suggests that while some autistic people 'survive' education, there needs to be greater involvement of autistic people in improving education for the future, so that all can flourish rather than merely survive.

INTRODUCTION

This article reflects on autistic experiences of education through first-person written accounts. All the accounts were written independently of each other, coming together only in the later stages of the article production. They are vignettes; they do not reveal lengthy biographical details, nor do they recite

a complete narrative account through all phases of education, but they all take the reader on aspects of their journey through education to where they are now. Consequently, we have three very different articulations which nonetheless expose recurring themes and struggles in UK mainstream education systems. This article presents the educational context and the methodological approach taken, and then presents the testimonies in full, before drawing together thematic connections across the accounts, interpreting them through the lens of the social model of disability.

Language

We begin with a word on language, as we use identity-first language in concurrence with prevailing autistic preferences (Kenny et al., 2016), while acknowledging that this is not necessarily as important for all of our writers or for all autistic people; 'there is no single, correct form of language to describe autism' (Fletcher-Watson, 2016).

Equally the term 'autistic voice' is not without difficulty and this article privileges three autistic people who are able to write and convey their experiences powerfully, albeit overcoming challenges of social communication and, in Beth's case, dyslexia. However, it does not obviate the need for researchers to continue to seek a wider representation of autistic voices, especially from those who have more limited communication or no physical voice (DePape & Lindsay, 2016; Fletcher-Watson et al., 2018; Horgan et al., 2023).

UK education context for autistic children and young people

Despite progress in understanding the concept of neurodiversity and improved acknowledgement of autistic strengths, diagnoses of autism are still predicated on criteria that construct it as a deficit 'disorder', primarily as deficits in social communication and social interaction and 'restricted, repetitive patterns of behavior, interests, or activities' (APA, 2013, p. 50; WHO, 2022). The UK strives to create an inclusive education system where all children are welcome, through both legislative imperative where discrimination is illegal (the 2010 Equality Act; the 2014 Children and Families Act) and through non-statutory guidance such as the Special Educational Needs and Disability (SEND) Code of Practice (DfE & DoH, 2015). Internationally, the UK has been guided by the inclusive education principles of the Salamanca Statement (UNESCO, 1994), the rights-based United Nations conventions (UN, 1989, 2006) as well as commitment to the Sustainable Development Goals, in particular to 'ensure inclusive and equitable quality education and promote lifelong learning opportunities for all' (UN, 2015, SDG4). While most autistic children in the UK (over 70%) are educated in mainstream schools (NAS, 2021), there is still a parallel system of special education which potentially challenges the philosophy and principles of inclusion. However, the inculcation of a truly inclusive education landscape seems elusive, not just in the UK, according to Haug (2017, p. 206): 'No country has yet succeeded in constructing a school system that lives up to the ideals and intentions of inclusion, as defined by different international organizations'.

The dominance of the medical model in education systems has been perpetuated by the link between diagnosis and labelling, the pursuit of Education, Health and Care Plans and the consequent benefit of additional resources and legal legitimacy (Woods, 2017). As a result, Woods (2017) argues that the social model has not been implemented in the UK for autistic people not least because of the construction of the deficit model of autism diagnosis and labelling, as well as the ableist structures and expectations of the education environment (Slater & Chapman, 2017). Though not without its limitations (Shakespeare, 2014), the social model of disability seeks to move away from the focus on the individual's impairment to the removal of barriers in wider systems and structures (Oliver, 1990). Education systems have been largely constructed by and for non-autistic people and show a real inflexibility in accommodating for autism (NAS, 2023), or they could be said to have a 'double-empathy problem'. The double-empathy problem highlights the mutual responsibility between autistic and non-autistic people because both have a problem in terms of empathising with the other (Milton, 2012). The medical model ensures that the burden of that lack of empathy is located firmly with the autistic individual as a form of internalised ableism, which often has a significant impact on health and well-being (Jóhannsdóttir et al., 2022). In grappling with those systems, autistic children and young people are twice as likely to be excluded as children who do not have special educational needs (Guldberg et al., 2021).

School experiences for autistic children have been well documented, but are often interpreted through the lens of researchers, parents, teachers and carers rather than through directly voiced experiences from the children themselves. Systematic reviews of autistic students reflecting on their schooling (DePape & Lindsay, 2016; Horgan et al., 2023) identify challenges in academic demands, transition, social relationships with peers, sensory issues and bullying as key themes, as well as highlighting the significance of positive relationships with key teachers. Students have also reported high levels of anxiety and stress which impact on their ability to progress at school (Humphrey & Lewis, 2008), typically experiencing higher levels of anxiety than the general population (Bellini, 2004), and having friendship difficulties and being bullied (Hebron & Humphrey, 2014). Equally, some features of autism, such as 'intense interests', can interfere with learning and present a barrier to

progress unless these are harnessed as potential motivators in teaching and learning approaches (Wood, 2021). Intense preoccupation with a single task or thing to the exclusion of all others (Grandin & Scariano, 1986), or monotropism, if channelled, can be immensely valuable (Murray et al., 2005). The impact of all this on autistic identity and mental health is significant, as many students in these studies reported feelings of difference and alienation (Cook et al., 2018; Goodall, 2018; Horgan et al., 2023). It is perhaps not surprising, then, that autistic teachers have also struggled with the lack of inclusion in school environments, causing some to leave the profession (Wood & Happé, 2023).

Teachers have not always had appropriate training, understanding or pedagogical expertise to teach in a way that includes autistic children and allows them to harness their strengths (NAS, 2023), nor are all schools uniformly successful at inclusion, as their interpretations of the concept vary, which prompts Dunleavy and Sorte (2022) to suggest that a complete overhaul of the SEND system is required to ensure that children's rights to inclusive education are being met. Indeed Lilley (2014) suggests that we need to look more closely at the practices of schools that exhibit a deficit model and do not meet the needs of autistic children, thus in themselves displaying symptoms of 'Autism Inclusion Disorder'.

Autistic student experiences in further and higher education are less well documented (Gelbar et al., 2014), but there is evidence that autistic students in these settings also have their needs overlooked (Chown & Beavan, 2012; Chown et al., 2018). McPeake et al. (2023, p. 11) highlight 'significant sources of stress' for autistic students in French universities as 'difficulties planning and managing workload, sensory overstimulation and administrative stress associated with accessing supports', with anxiety, loneliness and depression also prevalent (Gelbar et al., 2014), echoing some of the reported school experiences. While diagnosis was seen as an aid to self-understanding of autism, it also set up further barriers and required additional emotional and administrative labour by higher education students (MacLeod et al., 2017). Barriers to accessing support for all students with disabilities in higher education can result in marginalisation, despite institutional rhetoric related to inclusion (Kim & Crowley, 2021; Long & Stabler, 2022), and perpetuate the 'academic ableism' of universities (Dolmage, 2017). Lecturers, like school teachers, are also likely to have limited access to autism training and awareness (Chown et al., 2018).

Education systems have been largely constructed by and for the neuronormative majority (neuromajority), although the increasing numbers of neurodivergent teachers may be helping to change that landscape (Wood et al., 2022; Wood & Happé, 2023). It is therefore vitally important that we harness and harvest the views, perceptions and suggestions of autistic people, as evidenced in this article. The testimonies that follow expose autistic experiences of education from three very different viewpoints, and at different times, but they all show how the writers had to try to fit into a system that did not understand them as individuals, or indeed autism as a condition. The complete raw data are retained through the presentation of these detailed accounts to bring richness and depth to our understanding.

METHODS

The article was developed collaboratively between the lead author (Jacqui Shepherd), who is not neurodivergent but has vicarious lived experience through her autistic son, a second author (Beth Sutton) who is a multiply neurodivergent researcher, and two other autistic adults (Simon Smith and Marysia Szlenkier); all contributed to different extents.

The testimonies were written by the second, third and fourth authors. The project evolved from a webinar curated by ACORNS (Autism Community Research Network Sussex) which focused on exploring autistic 'voice' through a number of research presentations and through lived experiences. Post-event reflections between the lead author with the three autistic writers about their similar, yet different, experiences of education led to the writing up of these accounts. Initial meetings involved the whole group in discussion but as the writing progressed, individual meetings and email discussions between the lead author and the co-authors became the method of choice. The third and fourth authors were happy to write the testimony and for the lead author to consult the second author on the data analysis, although all contributors read the drafts. Our flexible approach allowed each writer to participate in a way that suited their area of interest in the production of the article, without putting undue pressure on them to contribute to all aspects of writing (such as the literature review or data analysis).

We adopted an autoethnographic approach to reflecting on, and exploring, individual experiences of education to create dialogue, discussion and debate by presenting unexpurgated testimonies as data (Ellis & Bochner, 2000). The decision was collectively made by the authors to use a narrative method to express their experiences of education in a free-style, written format, in order to acknowledge the writing preferences of each author and to allow their free expression. All three writers included some visual representation of their ideas or experiences and they all used metaphor and imagery, albeit to different degrees, to explore their experiences. The only parameters were to contribute approximately 1000 words in order to manage the overall article length.

The analysis of the testimonies was initially proposed by the lead author, with subsequent discussion and negotiation with the testimony writers, particularly with

Beth, whose metaphor inspired the title and the thematic headings, and met with approval from the other writers. The data were coded in an iterative and reflexive process, leading to the identification of patterns linking to themes (Braun & Clarke, 2006). The theme labels encapsulated the shared experiences of the writers as they ricocheted across their testimonies.

Ethics

Ethical consent was sought to ensure co-authors understood the scope of the resulting academic journal article, clarifying the extent to which they wished to preserve anonymity and to give clear consent to the publication of their words.

The minimum contribution to the article was to write the testimony and agree to read a final draft of the article prior to publication, and this meant that we could be inclusive of all the authors according to the extent that they wanted to be involved. They all wanted to waive their right to anonymity and this was accepted by the Ethics Committee as their right to own their narrative and to be published, named authors.

The degrees of participation varied according to individual circumstances, academic and work pressures, prior experience and available time to commit. There are some power imbalances as a result, with the lead author acting as facilitator, and autism ally, to support the delivery of the article within a specific timeframe. However, the lead author (Jacqui) engaged in rich dialogue with the second author (Beth), an early career researcher, to discuss and develop the data analysis, to finalise the work and to learn from each other. All authors were kept informed at every stage of the progress of the article and, for added continuity, everybody was invited to comment on all drafts. The second author, Beth (she/they) is a multiply neurodivergent doctoral student based at the University of Sussex, working professionally with the NHS Neurodevelopmental Service, an adult diagnostic pathway.

The remaining testimonies are written by Simon Smith (he/him) who was diagnosed with autism at the age of five; he works as a teaching assistant at a post-19 college for young people with a range of complex needs and also as an autism advisor who gives presentations on autism to schools and families; and Marysia Szlenkier (she/her) who was born in London and grew up there before moving to Warsaw, Poland at the age of 10. She attended a British school for six years where she completed her IGCSEs. During her second year of university, Marysia received a diagnosis of Autism with a Pathological Demand Avoidance (PDA) profile at the age of 21, which has shaped much of her undergraduate research and interests to focus on the struggles in education for neurodivergent students. She is currently finishing her undergraduate degree in Sociology with a Pathway in Education.

THE TESTIMONIES

Beth: The system that left its mark

This is a *story*[1] about falling through the net. About treading water in unchartered seas. Feeling adrift, but also how the tides can change.

In *primary school*, I was taken out of mainstream class for additional English and Maths. This is where I began falling behind, missing foundational learning that would never be repeated. Today, there are still vast gaps in my knowledge, anchored to this time. For instance, I still cannot make sense of the 24-h clock or tell you what '8 + 6' is, without counting on my fingers[2].
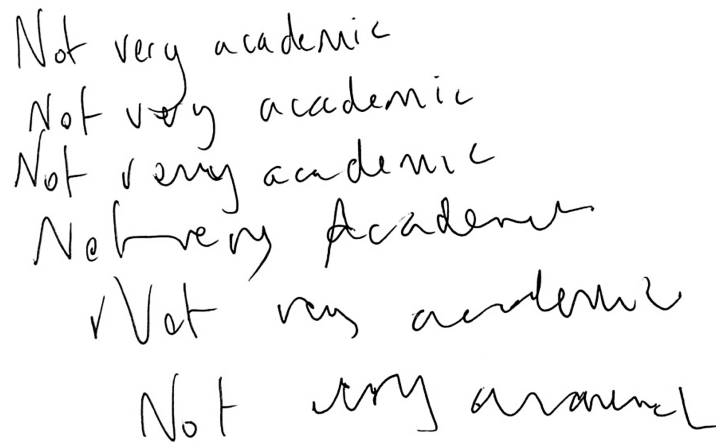
In *secondary school*, written work I produced was considered 'ungradable'. 'Bottom set', 'C-D borderline student' and 'not very academic' are some examples of language used to describe me. This is where the loud internal critic (Figure 1) I endure today began to find its voice.

In terms of educational support and diagnosis, I continued to fall through the net. The extent of my learning support amounted to 25% extra time and a word processor. Routinely, as peers caught their breath before plunging back into the water, I was still submerged in formative assessments, sometimes working in cupboards with only a sliver of natural daylight. Every school holiday, break or early finish, I was treading that extra 25%. Beneath the surface, I scrambled to stay afloat.

An English teacher once said: 'You have the vocabulary of Stephen Fry, but you have never read a book' and there was truth to that. I was a living paradox, lifting words from television, music and cassette tapes, rather than books, and placing these in conversation. Awash with ideas, but when it came to putting pen to paper, a wake of spelling mistakes was left behind.

In the latter years, there was a gifted and talented programme reserved for 'the academic students' in English. The first soiree was to see a live performance by renowned punk poet, John Cooper Clarke. However, attendance was strictly by invitation and that invitation did not extend to me. Frustrated, the teacher bent the rules and asked if I would like to come along. They saw past the incoherent writing, relentless punctuation and grammatical errors, and found a student trying their absolute best. This was a formative moment where I learnt about the power of being let in. I began to view the system for what it was and how interrupting it, even at a microscopic level, meant the tides could change. Despite a lifetime moored to the 'C-D borderline', grappling with the subject, I came out of secondary school with a 'C' and 'B'.

At *college*, I went on to study English Literature. First on the agenda was *The Great Gatsby*. The class sat in a horseshoe formation, with the teacher at the helm.

FIGURE 1 Beth's loud internal critic.

In a synchronised motion, the class would quieten to read extracts of the text independently, as though their heads were submerged in water—page turn—before resurfacing for group discussion. Page turn. An index finger slowly moving from left to right—page turn—was simply no match to the pace of the—page turn—class. Those around me would be in the depths of discussion, while my eyes watered with shame. Amidst the rapids, I was left to drown. It appears the message about access arrangements, suspected Dyslexia and/or special educational needs did not make its way to shore. Weighed down, I advocated for doing fewer A-levels than my peers, dropping English Literature in the process, only to find myself back at the 'C-D borderline'.

Around this time, there was a particular instance where I was sent out of a social science class. After the class left, I was subject to the teacher's questioning when they noticed genuine intentions within the swell of behaviour. They cast out a life ring. I went on to complete additional work for the teacher. We went back to basics, the basics I had never mastered. I always say: 'I learnt to write at college' and by this, I mean composing ideas onto the page. The teacher believed I could ultimately achieve more than the 'D' I was limited to from the first year. Therefore, I decided to re-sit these alongside the second-year exams. And they were right, I went from a 'D' to an 'A'.

Sea change

University then became a possibility, especially in terms of pursuing a text-based subject, although previously inconceivable. On the approach, I underwent neurodevelopmental assessment in the context of Autism, only to find I did not meet the diagnostic criteria. Another instance where l fell through the net. In first year, I finally received a Dyslexia diagnosis. Although I had identified as being dyslexic since secondary school, the sense of confirmation was useful. Access arrangements and a degree of additional support were also set in motion.

However, after years of treading water in unchartered seas, I began to struggle for breath. Limbs heavy, I became enveloped in darkness, heading toward a diagnosis of Borderline Personality Disorder, BPD, also referred to as Emotionally Unstable Personality Disorder, a common trajectory among mis/undiagnosed autistic and/or ADHD women, non-binary and trans people, until a second neurodevelopmental assessment confirmed the presence of Autism and ADHD.

Following this diagnostic formulation, also rerouting to another institution, university became a place where I had access to appropriate support. At this time, I met a university lecturer who not only identified as dyslexic but was open about navigating Dyslexia within a system built for certain people to thrive (neuromajority), at the cost of nurturing neurodivergent potential. Also from humble beginnings, I felt seen and heard.

While I have done well at university, having achieved a bachelor's and master's degree, then a *doctoral scholarship*, there is still much to be learnt in terms of appropriately supporting neurodivergent students. Many are anxious about additional support being rescinded, or the tide retreating. Many are worn down by ableist processes and systems. I have also found myself swimming against the current on both sides of a diagnosis, with fluctuating levels of support. Therefore, diagnoses are not always a life raft in themselves because concessions and reasonable adjustments are uncertain. In a seminar, I was asked whether I was 'the Beth with the red flags', revealing the implicit sense that red flags—warnings of danger—are synonymous with neurodivergence.

Ableist legacies ebb and flow

Sea glass is weathered by what it has endured at sea (Figure 2), a process that can be related to education. I am fundamentally marked by the system. Confidence eroded. Anxiety wavering. Now, overcompensation is a form of self-preservation, taking breaks is still unnatural
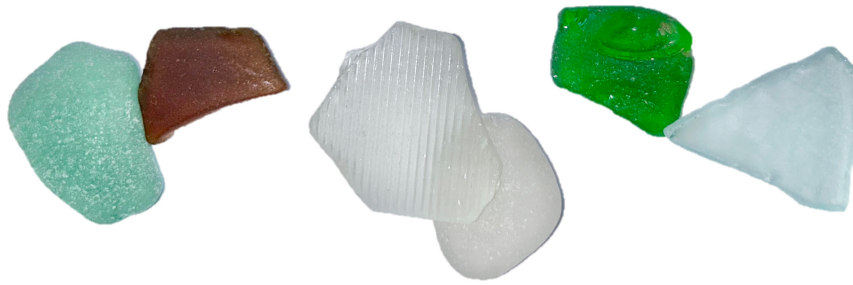
FIGURE 2 Sea glass.

and achievements come with a little sense of pride. Just as sea glass is ground down by every knock, its eventual form is a sum of its aquatic endurance.

Positive memories of education have been flooded by the negative. Instead, I course through the ocean propelled to defy the lack of expectations imposed on me, but also by defiance, to disprove those who wrote me off.

However, a life tussling with the tide—against the odds—has also left its mark more positively. The researcher, practitioner, colleague and peer I am today refuses to entertain ideas or set up environments that make some people (neurominority) feel less intelligent, inadequate or inferior, than others (neuromajority), just as my secondary school English teacher and other curious individuals did. In many ways, these moments anchor my practice.

Simon: Reflections on school

Growing up with autism has not always been easy and a lot of people seem to think of negatives when thinking of autism. However, having autism as part of my life has helped me achieve things in life. This is my story about my autism and some of the challenges I have faced at school and like everyone who has autism, they have their own stories to tell and all have their own accomplishments.

During my time in education, it was quite tough, it was around a time where autism was not well understood and I always had difficulties in engaging or feeling that was quite different from others in the way I learnt and how I communicated. Often enough I could never get my point of view across or feel like I was understood. There was an almost invisible barrier in front of me and this expectation that I could understand all the social rules and know how to communicate back. It was quite frustrating, it was like being on a soap opera where everyone has their own scripts and knows how to act out the scene. For me, I had a blank script which I had to kind of try to make up as I went along and do what some would say would be method acting—of course completely against the script of everyone else which led to some conflicts at school.

I can remember the teacher saying 'good morning' to each of my peers with them responding with 'good morning' back. When came to me, I was a little confused, I did not quite understand why, in this scene, what was

so good about the morning? I did not feel good so why is it a good morning? These were my internal thoughts when people were staring at me waiting for an answer while I was in deep thought about how to respond. I just got more annoyed, in the end I just refused to say it. Of course, everyone thought I was being rude and that I should know that I am being rude.

This was only the start of some of the issues at school and, added onto my difficulties socialising, I also had sensory issues too which affected me during my time at school, such as not being able to read whiteboards/white paper and worksheets, since the white would reflect the light of the room and makes things so bright it was like trying to read while someone was shining a torch in your eye.

Having autism means having powers, and like someone with powers, they can be very good and sometimes they can work against you, but I am here to tell you about the good part. Having autism, I got this ability to get fixated on certain things when I was younger—the things had to be part of my interests. When I did this, it slowed things down and I can remember everything around me blending in, it was like a trance and was a very nice feeling. Of course, people around me didn't quite understand what I was doing at the time, but I only did this to help deal with the world around me, it was like an escape place in my own mind. As I got older, I found out with practice I could do this to any object at will which was handy when dealing with things such as school/college.

Of course, people at my school were more social so sometimes I had to learn with my memory what sort of language to use so I started my own word library in my head. Starting with basics like what words make people laugh and what words annoy people but, as I got older, I started to develop a personal library of people almost like a biography of that person.

One of key things with having autism and most important is how to use your interests to help you. Of course interests can start off with very basic things such as spinning objects moving in one direction but, then with the fixation that can happen, you can get even more interested in something and something that perhaps was boring then becomes interesting. Take for example Maths, I really didn't find numbers that interesting until one day a friend of mine told me that

numbers are used a lot in games/football and then my brain was like wow, maths is actually kind of interesting now! And once I am interested in something that's when I can fixate on it and want to know everything about it! Handy, right?

Thanks to my autism and understanding the strengths of it I was able to do lots of amazing things such as becoming a teaching assistant in a specialist college and, of course, become a so-called expert on autism offering support and advice that I do today. At work my autism allows me to think outside the box and really help students who find social communication hard and have sensory issues, since I can relate to them but I have the ability to communicate, I can talk for them and give teachers/staff/parents information to help. When it comes to autism I know using interests is very key in getting students who have ASC (autism spectrum condition) engaged so I create specialist work sheets, say maths for example, based around their interests, like Mr Bean maths instead of regular maths, I keep it around their interest.

I also use my experiences of having autism in doing talks about it. This started off as a small thing at first, with just a few parents' queries, and I didn't realise how much impact it had for them. I was then asked by a special needs family support group to do one for 30 people and, with all the amazing feedback, it took off to the point that I am now giving talks on autism to people such as trainee teachers, council workers, social workers, nursery workers to name a few. I then became focused on my autism and what I could do to help improve the lives of those who were on the spectrum and those who wanted to help and learn more about it. To help them give the best support by developing strategies, I developed a diagram, 'The Maze Brain of Thought Processing' (Figure 3), giving my own insight into autism.

Things that really helped me through school and college were understanding my own autism and how it affects me and knowing I am not being rude and am just a person like you who thinks differently. Being positive about autism as it's easy to think of negatives but there are some amazing things people with autism can do. Having great support workers and reassurance as I had very low morale sometimes and it helps to have a bit of reassurance. I have people who understand me at work and know that sometimes I find it hard when it comes to interactions, and that sometimes I can get socially tired, and sometimes I require a bit of alone time, so I don't get so tired.

Marysia: Reflections on university—A slam poem

I have been asked to use my voice to explain what it's like to be an autistic and PDA university student,
some of the challenges and some things that can help.
And after weeks of trying to figure out how on earth I can put it into words, my brain screamed at me to just write it and perform it because my brain is a constant jumble of jungle plants that I'm trying to get through and sometimes it is easier to just show the plants rather than describe them.
I was diagnosed autistic with a pathological demand avoidant profile halfway through my degree,
all of my education including half of my
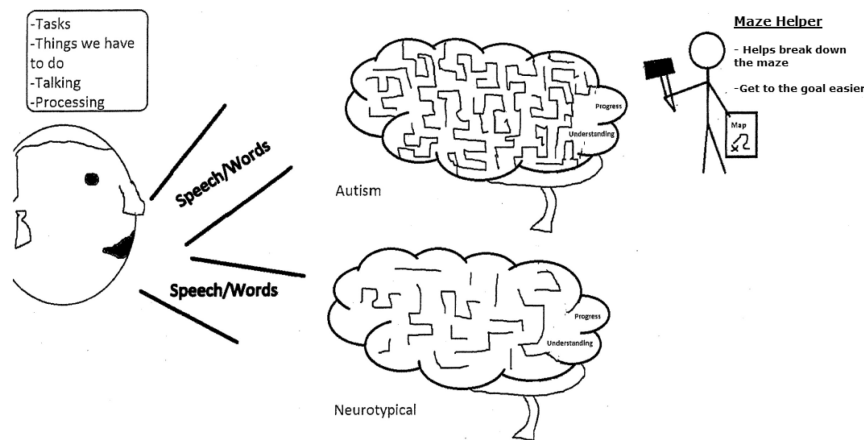
FIGURE 3   Simon's maze brain of thought processing.

degree I spent wondering what was wrong with me,
why I couldn't cope as well as everyone else,
why assignments and exams terrified me to no end and what I could do to 'fix' myself.
I spent years hiding and cowering, too afraid to be my true authentic self in fear that this would be rejected in its entirety and I would be made to feel once again like I have no place here,
and this didn't stop when I went to university.
I was told that Uni would bring the best years of my life but,
how—
How?
How were they supposed to be the best years of my life when to me, all it's been is a system I've been trying desperately to fit into and thrive in that in reality feels like it's built to try and kill me?
That constantly feels like it's trying to catch me out with its cruel games and nonsensical methods;
having conversations where I've dared be honest to say 'I'm struggling' only to be met with a glance and response which says
'Oh, you get good grades, I'm not worried about you'
and
'Honestly, your peers would kill for those grades'.
Excuse me, but what makes you think I didn't kill for those grades?
What makes you think that I sailed through my last essay with ease?
Honestly, I'm not sure my peers would kill for this,
I have pathological demand avoidance—a condition which is characterised by an uncontrollable need to avoid demands—
do you have any idea how many demands are involved in writing an essay?
It isn't just 'writing an essay', it's getting up to sit at the computer, it's lifting my hands to type, it's creating a plan and executing that plan, it's reading the marking scheme,
it's focusing on a specific thing when your brain is going a hundred million miles a minute and won't stop.
It's
breathing.
But of course, 'we all go through this', I'm not in any different position to anyone else,
except
not everyone's brains are wired the same as mine—

not everyone's brains are wired the same, full stop.
Do my peers really cry and shout and scream when they know they need to sit down to write?
Do they have heat and fury and confusion and helplessness shooting through every inch of their bodies as they think about having to find a source to back up what they're saying,
a feeling that then leads to such weight in their arms that they feel they cannot get up,
and they want to scream this at the institution that makes them do these things and that strips them from every aspect of control and autonomy?
I hear my peers groan and moan at essays, but I haven't heard the average peer contemplate dark escape routes because their brain is not wired to cope with copious amounts of tasks that require copious amounts of planning and concentration and fixed time sitting in the same spot doing the same thing over,
and over,
and over again.
Torment.
This institution
feels
like it's
tormenting me.
And
I'm
tired.
I'm tired from running from these demands because that is the way I'm built,
only to be captured by the institution's next task for me.
It makes no sense—I could spend hours unpicking all the aspects of university that make absolutely zero sense to me
—call it my special interest if you will—
but I have been taught to repress this;
my voice silenced by prejudice and stereotypes that mean you don't hear the internal screaming when I need to maintain eye contact,
and you don't hear the internal
'Should I have said that?'
'Did I cross a boundary that I didn't even know was there again?'
in every interaction with someone at university I have.
You don't hear the panic inside me when someone is sitting in a seat I classed as mine the first seminar I attended,
and you don't hear the thoughts in my head as I am told that I have to do an assignment

by a particular date or there will be grave
consequences.
You don't hear the agonising cry when I am
left with just those thoughts as I try and
complete what feels like an impossible task.
I want choice.
I want the ability to choose how I do things
and when they are done by,
the institution expects so much from me but
doesn't give me an independent choice in how I
reach those expectations,
a bizarre 'one size fits all' while also priding
itself in catering to our needs,
but every time I've had a conversation about
my needs I've been silenced.
by the scream
of 'equality'.
But where,
where,
is the mention
of equity?
Until equity is taken into account, I will never
fit into this system.
And so,
until then,
back to running
I go.

The poem above provides a real, raw representation of my experience at university as someone who is autistic and PDA, but I would like to share that my experiences as an autistic individual are normally wonderful away from societal institutions, such as education. I make deep and meaningful connections with the humans that lie behind 'roles'; I swim in a sea of gratitude and elation every time I am with my horse; I allow myself to see the beauty in the mundane and the new every time I take my dog to explore different places.

When I was at school, teachers, despite their efforts, could not understand how to help me or meet my needs as I went through school undiagnosed, labelled as 'anxious' and 'depressed'—a common occurrence for many autistic girls. I was privileged enough to be able to go back and give a talk to staff at my old school, some of whom taught me around a decade ago. My talk was received exceptionally well, with staff becoming emotional at how much my diagnosis has empowered me and expressed how pleased they were that I had been provided with some closure thanks to my diagnosis. Many were not aware that autistic females typically present differently, and none were aware of PDA and the complexities behind it. Being able to share all I have learnt from my struggles and help others understand the needs of Neurodivergent students has been one of the single greatest aspects of my entire life.

A truly heartfelt thank you goes also to my assistance dog, Phoebe (Figure 4), who has changed my life in ways it is hard to put into words. She is often my key to accessibility and is happy anywhere we go, as long as it's with me. Life is so much brighter with her by my side.

FIGURE 4 Phoebe, Marysia's assistance dog.

DISCUSSION

The discussion of these testimonies is articulated through the lens of the social model which focuses on the social construction of barriers within education which further disable autistic people. While the social model is not without limitations and critiques (Shakespeare, 2014; Thomas, 2004), the recognition and removal of barriers is still key to understanding these testimonies and redistributing the responsibility and the burden from them as individuals to the socially constructed systems of education that they had (and Beth and Marysia still have) to navigate (Dunleavy & Sorte, 2022; Oliver, 2013). The medical or individual model (Barnes et al., 2002) locates the onus of disability with the disabled person and renders them responsible for effecting adaptations and accommodations to their environments on an individual basis. This model is clearly in evidence when we see how systemic barriers impacted on the education experiences described in these testimonies, ultimately making the writers feel excluded, marginalised and that they were the problem. This lack of understanding and lack of double-empathy (Milton, 2012) had a profound impact on the writers and contrasts sharply with the moments where those who did take time to listen had a transformational effect on their journeys.

'Falling through the net'

Accessing appropriate support during their time in education was problematic for all three writers. The medical model of education notwithstanding, Simon was diagnosed and labelled as autistic prior to school, and yet he did not receive appropriate support or accommodation and felt that it was a time when 'autism was not well understood' (NAS, 2023; Woods, 2017). The challenges he faced through not understanding the social script and his sensory discomfort at the brightness of the whiteboard and white paper (Goodall, 2018) are indicative of a lack of double-empathy, but also show that he was having to work harder than his non-autistic peers by devising his own systems (MacLeod et al., 2017; Milton, 2012).

Beth and Marysia both had late diagnoses when much of their formal education had finished, which for Beth meant 'falling through the net' at school. Even when Beth did receive diagnoses, these were not enough to ensure consistency and stability of support (Kim & Crowley, 2021). Indeed, the articulation of additional support being highlighted as 'red flags', as indicated in Beth's testimony, implied the danger of neurodivergence and was further stigmatising. For Marysia, the additional demand avoidant profile caused real challenges in negotiating the academic and administrative demands of the higher education system (McPeake et al., 2023).

'Weighed down'

All three writers have felt the burden of their own diagnosis, that they were at fault, that they did not fit in and that there must be something wrong with them. This demonstrates a consequence of a medical model approach, where children and young people are expected to 'fit in' (Woods, 2017), thus relieving educators of a responsibility to adapt (Hodge et al., 2019). Beth's loud internal critic, 'not very academic', haunted them during school, not surprising when they were labelled as 'ungradable' or 'bottom set', a legacy that lives on today even as a doctoral researcher. Simon felt he was quite different from the others in the way that he learned and communicated as he did not understand the 'social script' and believing that everyone thought he was rude. Marysia also wondered what she could do to 'fix herself' and talked of 'contemplating dark escape routes'. This echoes Beth's feeling of being 'enveloped in darkness'. These were the significant mental health consequences of individualising and pathologising autism and the negative effects of internalising ableist norms (Jóhannsdóttir et al., 2022).

'Ableist processes and systems'

Both Beth and Marysia experience the constraints and limitations of the education system. For Beth, the lack of appropriate reasonable adjustments made during school was problematic and even punitive, at times completing assessments 'in cupboards with only a sliver of natural daylight' or being given the visible trappings of support such as extra time and a word processor without the pedagogical support that might have enabled them to progress more effectively. Perhaps not surprisingly Beth talks of being worn down by 'ableist processes and systems' where the social model was not applied for autism (Beardon, 2017; Slater & Chapman, 2017; Woods, 2017) and where those systems were displaying deficits in their own approaches (Lilley, 2014). Marysia's experience of higher education is more viscerally described as a 'system that feels like it has been built to kill' her (McPeake et al., 2023). The relentless demands of assignments and deadlines make Marysia want to 'scream at the institution' because she feels robbed of autonomy and control by a system that makes 'absolutely zero sense' (MacLeod et al., 2017). There were many ways in which the writers felt excluded and marginalised (Guldberg et al., 2021) during their education, quite literally at times when Beth was 'taken' or 'sent out' of class but also when she was excluded from spaces reserved for those considered 'gifted and talented'—a further invocation of labelling that results in segregation and negative consequences. Equally Marysia felt that she was not heard, 'my voice silenced', and when she tried to talk to her tutor when she was struggling, her tutor could not understand

what the difficulty was as she was outwardly showing that she was a very competent student. Simon also talks of his experience at school being 'tough' when autism was not 'well understood' and he felt that he could not get his point of view across.

'Trying their absolute best'

All three writers were able to understand themselves and their autism, identify strengths and develop strategies to help them to manage their education experiences and to push back against the deficit model of autism (WHO, 2022). It has mainly been through their own agency and determination rather than external support that they are emerging so positively from education. Simon focuses on the positives of autism and how it has helped him to achieve in life: his ability to understand the benefits of his special interests (Wood, 2021) and the power of his monotropism (Murray et al., 2005) to help others. He also develops social scripts and even mini biographies of people to help him in social situations and, of course, prepares customised worksheets for the autistic students he is working with. Beth's strengths are little trumpeted in her testimony but she has triumphed academically through getting a Bachelor's and Master's degree, securing a doctoral scholarship and having an article published in a high-ranking academic journal (Sutton, 2021), all this despite her challenging experiences in formal education and, not least, the gaps in her foundation learning. All the writers challenge the deficit model of autism by demonstrating their strengths in terms of strong interpersonal connections, creative imaginations and harnessing the power of monotropism to help others.

'Tides can change'

Despite some of the negative experiences of a system predicated on a medical model approach, there is evidence of transformative change and progress where support was put in place, where adjustments were made or where a significant individual took notice of the needs of the writers (DePape & Lindsay, 2016; Horgan et al., 2023). For Beth, this was first through the English teacher who 'bent the rules' to allow them to attend the poetry event, then the social science teacher who 'cast out a life ring' and later the dyslexic university tutor whose impact was profound to the point that Beth ultimately 'felt seen and heard'. These actions demonstrate the power of the social model approach where barriers were removed or renegotiated. Simon was able to identify what helps him, as he knows that he needs time out when he is socially tired and also needs reassurance at times when his morale is low, so he has been able to communicate this to those around him. The 'key to accessibility' for Marysia has

been her therapy dog and both her horse and dog have brought her profound pleasure.

'Tussling with the tide'

Beth, Simon and Marysia appear (to use Beth's analogy) as sea-glass survivors emerging from the education system, weathered and worn but well-crafted as adults wanting to give back to those following in their wake. All the writers acquired a deep understanding of themselves (Hodge et al., 2019) and the system they were navigating to develop a sense of agency and control over their future lives as well as a desire to enable and enrich the lives of others. This fits with autism self-advocacy approaches (Leadbitter et al., 2021) which insist on the centrality of autistic people to decision-making and prioritising research and action agendas.

Beth saw that the 'tides could change', that the system could be disrupted, when a teacher reached out and could see her potential. Once 'let in', they were able to defy expectations and gain higher grades and progress to the highest levels of education, now nurturing a commitment to ensuring parity of access, irrespective of neurotype, by challenging neuronormative systems, structures and related privileges.

Simon devotes much of his working life as a teaching assistant to supporting autistic students, communicating with them through his empathic understanding of sensory sensitivities, and his own experience of monotropism and flow states (Milton, 2012; Murray et al., 2005), and can therefore connect with his students on a deep level, beyond that of a neuronormative teacher and neurodivergent student. Giving talks to professionals and families for which he creates his own resources also shows his commitment to improving the life experiences of autistic people.

Marysia had a really positive experience in going back to her old school to explain autism, especially for girls, and PDA to her old teachers, redressing some of the experiences she had at school and developing knowledge and understanding among teachers.

CONCLUSION

As we consider these testimonies in the light of the social model, we identify the barriers to inclusion as evidenced by the lack of consistent and appropriate support, the individualising of autism diagnoses and the inflexibility of systems. And yet, the emergence of three flourishing young people who, despite the system, have identified strategies, developed their strengths and determined to improve the experiences of others, gives hope for the power of self-advocacy approaches, and their impact on education and beyond. This does not excuse the burden on the education system, nor does it require autistic

people to do the work, but it does call for more informed and empathetic dialogue to explore how education is experienced from a neurodivergent perspective in order to address the 'double-empathy problem' and effect real change (Milton, 2012).

The writers testify their powerful intent to feed forward to ensure that neurominorities are not made to feel 'inadequate or inferior' (Beth), 'to improve the lives of those on the spectrum' (Simon) and to go back and talk to school staff to improve their understanding of autism and PDA (Marysia). These activist interventions demonstrate how the writers have been able to author their own stories in a more positive and celebratory way and give recognition to the strengths rather than 'deficits' of autism (Hodge et al., 2019). This chimes with the re-investment and concerted contributions seen in other professions and organisations from determining the academic research agenda (Cusack, 2017; Fletcher-Watson et al., 2018; Grant & Kara, 2021), to celebrating and improving the experience of autistic doctors (McCowan et al., 2021; Shaw et al., 2023), to hearing the experiences of autistic teachers (StEvens, 2022; Wood et al., 2022; Wood & Happé, 2023), to the experiences of autistic mentoring in the performing arts (Buckley et al., 2021).

Through recognition of autistic testimony and reflective narratives such as these, and acknowledging the significance of autistic people as architects of, catalysts for and agents of change, there is hope that we can move forward in making our education system a better place to be autistic—for staff and students. Despite the ongoing inflexibility of the education system, three young people here have washed up, with all their experiences, into their adult lives, not just as 'sea-glass survivors', but as pioneers who are demonstrably leading the way, giving back and enriching the lives of others.

CONFLICT OF INTEREST STATEMENT
There is no conflict of interest associated with this article.

DATA AVAILABILITY STATEMENT
The data for this article is reproduced in full as the three testimonies from three of the authors so it is already available within the text of the article.

ETHICS STATEMENT
Ethical approval was obtained from the University of Sussex Social Sciences and Arts C-REC.

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ENDNOTE
[1] Evidence suggests that memories of particularly difficult periods of time, including traumatic events, are processed differently from more normative or mundane memories (van der Kolk, 2015), often cited as a form of self-preservation, which I relate to, especially in writing this vignette.

[2] Oh and it is '14' by the way.

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