Your autism assessment is finally booked. Now what?
How to prepare for a consultation for an autism assessment and make sure you get the best support available

Suspicion and scrutiny behind parent-blaming
How criticizing the parent-carers of autistic children is entrenched in society and can cause profound harm to families

Official media partner of the National Neurodiversity Shows

Autism|eye

For parents and professionals

Issue 62
Summer 2026

The growing ranks of older carers – a looming crisis

Regressive autism: you *can* fight back

Successful approaches for transitions to adulthood

How visceral osteopathy addresses gut issues

Research

News

Books

Animal magic

Life-changing support dogs

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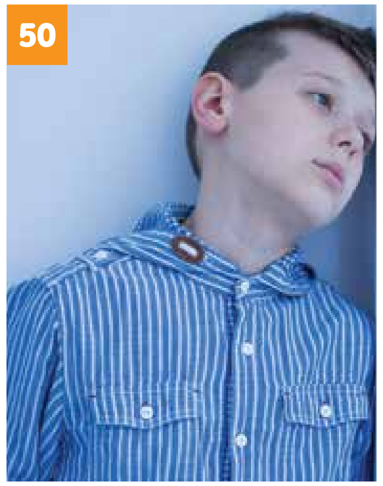
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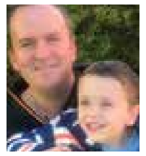
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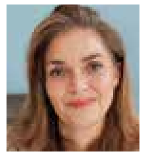
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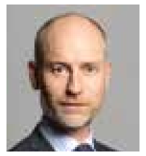
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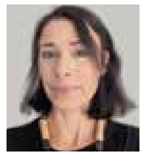
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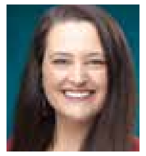
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Parent-blame culture may get worse


Gillian Loughran

For well over a decade Autism Eye has raised awareness of issues that have a devasting impact on autistic people and their families.

We were the first to raise awareness of the abuse of chillout rooms in schools, and of parents being accused of fabricating illness when they sought a diagnosis or asked for support for their children. We highlighted the ongoing plight of families whose autistic children are locked up in long-stay hospitals, and the way they are refused contact when they complain.

Now, in this edition, we raise a new issue that may blight the lives of our community. The existing 'blame culture' (page 14), whereby parents are judged for their autistic child's 'ways of being', could get a whole lot worse. Under proposed legislation, the Government plans to take tougher action against parents when their children end up on the wrong side of the law. For the autism community this is worrying, since even the Government has admitted to Autism Eye that already "children with neurodiversity are overrepresented in the Criminal Justice System" (page 19).

This blame game has a devasting effect on the entire family, especially siblings, because we know their parents experience significant mental health decline when the blame leads, as it often does, to child protection and safeguarding enquiries.

On a positive note, we keep hearing how specially trained dogs, like Peggy on page 22, help autistic people navigate life with calmer and safer experiences.

Transitioning to adulthood is not something all families look forward to because it can be fraught with difficulties. It doesn't have to be like that. On page 32 we hear from professionals in specialist provisions who have devised a host of approaches to make the journey run smoother.

Autism Eye wants to hear of other success stories we can report in these pages and across our social media, where we have thousands of followers. Please get in touch if you have a story to tell. Until the next time...

Gillian Loughran FRSA,
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Found: a common cause of severe epilepsy

Researchers have identified one of the most common genetic causes of severe epilepsy.

The scientists say it results in severe developmental delays in children and causes seizures that are difficult to control, often appearing in the first year of life. They have named the condition recessive RNU2-2-related neurodevelopmental disorder. .

The scientists, from Manchester University NHS Foundation Trust (MFT) and Manchester University, say the research has so far identified 84 people living with the condition. But they believe thousands more remain undiagnosed throughout the world and that millions of people globally could be carriers of the faulty gene behind the disorder.

Epilepsy can be common in children on the autism spectrum. Studies suggest that anywhere between two and 46 per cent of autistic people are also epileptic.

Dr Adam Jackson, an academic clinical fellow at the MFT, led the study. He said the work "brings hope for many patients and families" and is already "having a positive impact around the world". He believes that one in 100 people could be unknowing carriers of the condition.

Professor Siddharth Banka, of MFT and a senior author of the research, said the discovery paves the way to "unlock life-changing treatments".

Ava Begley, aged six, is one of the 84 people identified as having the condition. Parents Daniel Begley and Elizabeth Dowd, pictured with her above, said they felt "relief at finally having a diagnosis, but also sadness in understanding the seriousness of the condition".

The researchers published their findings in the journal *Nature Genetics*.

Some carers 'are still being wrongly pursued for benefit overpayments'

Campaigners say carers are still being wrongly pursued for benefit overpayments even after the UK Government changed its guidance.

They claim that the Department for Work and Pensions (DWP) billed around 1,400 carers in January based on unlawful guidance. The bills were sent out when carers were calculated to have earned more than they were allowed under benefit rules.

Carers are allowed to earn up to £196 per week. This is after taking into account tax, national insurance, and half of any pension contributions.

Some business expenses and care costs can also be deducted from earnings.

The DWP was found to be using unlawful guidance when telling some carers they had earned too much. Under the guidance, carers were still billed by the DWP if their earnings were found to be under the limit when averaged over the year, but went over during some months.

Reports in *The Guardian* suggest there have been mounting concerns over delays by the DWP to offer payments to carers issued with overpayment bills for Carer's Allowance, which is now £86.45 per week.

One of the campaigners is Katy Styles, founder of the We Care Campaign. She is a full-time carer for her husband, Mark, who has motor neurone disease (the couple are pictured, left). She also cares for her 88-year-old mother, who is almost blind and has had a series of strokes.

Styles said that unless debts were "halted and fairness restored", carers would feel they were being "punished for a system that failed us".

Bipolar adults face life of struggles

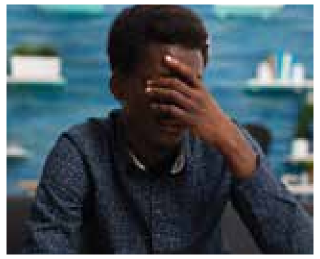
Autistic adults with bipolar disorder (BD) struggle more with emotional problems and are less likely to accept treatment, according to a new study.

The Italian researchers said that personalised treatment is needed for autistic adults with BD.

Professor Giulio Perugi led the research team at the University Hospital of Pisa. They found that autistic patients with BD showed an earlier onset of mood problems and had higher rates of anxiety and depression. In addition, they experienced greater struggles to manage in daily life and higher rates of negative reactions to antidepressants and antipsychotics. People with the dual diagnosis were also less tolerant of treatment.

The researchers say their findings show a need for greater diagnostic accuracy and personalised treatment.

Anita Kugelstadt, chair of the biomedical charity Thinking Autism, said the research shows how "common symptoms of bipolar disorder" can be overlooked due to the "similarity in presentation to certain autism traits".



When medics attribute all of someone's health challenges to their autism without considering other conditions, it is called "diagnostic overshadowing". This can lead to failures to recognise issues such as self-harm caused by pain from dental, gastrointestinal or other problems. Medics may simply attribute the issues to autism.

Kugelstadt said Perugi's research findings highlighted "yet another example of the widespread phenomenon of diagnostic overshadowing in autism", which she said contributes to "systemic health inequalities faced by individuals with autism".

Unpaid carers 'prop up failing services'

Unpaid carers are propping up failing social services.

That's the view of Joleen Cunningham (picured), public affairs manager for charity Carers Northern Ireland, who made the comment after it emerged that 84-year-old Alphie Lonergan had his support hours stopped for his two disabled sons.

The pensioner from Loughgilly, in County Armagh, Northern Ireland, cares for sons Ronan and Donall (all three are pictured right). The sons are both in their 40s and have severe learning disabilities. Their care package was cut from three hours per day to one, but then stopped altogether.

Cunningham said unpaid carers prop up social services to the tune of £16 million per day in Northern Ireland. She said reliable social care is an "essential lifeline", adding that Lonergan's case was a "stark reminder of the urgent need for investment".

Lonergan has told the BBC that while physically he feels okay, mentally he is "under awful, awful stress".

Ronan's care package stopped in March 2024. However, Donall, who also has autism and obsessive compulsive disorder, was still supported for just an hour per day, when a carer would visit and get him up and dressed.

The brothers go to day centres, but Lonergan is their sole carer in the evenings.

He said his wife's last words were: "Look after the children". He has vowed to "definitely" continue caring for his sons.

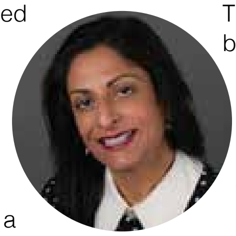
Lonergan says he has two daughters who help, but they have children and commitments of their own.

● **Read more on this story in our feature on older carers, page 25**

Families pay the price for councils' transport confusion

Councils across the country are confused about the rules over transport provision – and families are paying the price.

According to Amerdeep Clarke (pictured), the Local Government and Social Care Ombudsman, councils are getting mixed up over transport rules for people with education, health and care (EHC) plans. The result is that families are suffering distress, financial hardship and wasted time.



Clarke highlighted the national problem after deciding on the case of a young woman with complex learning difficulties who is unable to travel independently. Windsor and Maidenhead council had therefore provided free transport to her education setting since the age of three.

But when the woman started college in September 2024, the council offered her family just £1,200 a year towards travel costs. This was despite its own figures showing the cost of suitable transport could be as much as £15,200 a year.

It meant the young woman's mother spent more than a year driving her daughter to college. Eventually, the mother had to use money from her daughter's care budget to pay for transport. This was money that should have supported her independence, not been used for taking her to college.

The mother appealed twice but lost both cases. However, there are different legal requirements for disabled adult learners aged 19 to 25 with an EHC Plan, compared to sixth-form students. The Ombudsman found the council had confused the two.

Clarke said: "This is not an isolated case, and we are finding similar faults being made by councils up and down the country when they confuse the different rules for pupils of compulsory school age, sixth form, and adult learners with an EHC Plan.

"Councils have a clear duty to look at each person's circumstances individually, and to apply the right rules for adult learners with an EHC Plan."

Windsor and Maidenhead council agreed to apologise and pay the mother £500 in recognition of the trouble caused, and said it would look again at the young woman's case.

Government to strengthen visiting rights

The UK Government is stepping in to create stronger visiting rights for people in health and care settings.

The move follows an ITV News investigation that exposed how the relatives of severely learning disabled people living in care were being restricted or banned from visiting them after complaining about negligent care.

In response, the Government said it would offer better protection for people's visitation rights in health and care settings.

There have been ongoing reports of unnecessary barriers to visiting. This is despite families and friends playing a vital role in care, well-being and dignity. These barriers have included being excluded from key decisions about their loved one's care.

The Government will distribute guidance and resources to make visitation rights clear and said it will work closely with the Care Quality Commission (CQC) to protect people's rights. The collaboration would monitor compliance and intervene where necessary.

Stephen Kinnock (pictured), Minister of State for Care, said: "No one should be separated from their loved ones unnecessarily. Contact with family and friends should not be seen as a luxury, but a basic part of good care.

"This system must work for residents, patients and their loved ones, and we are ensuring it does."

Invention tackles needle phobia

Medics are using a ‘virtually painless’ blood test for people with learning disabilities who have a needle phobia.

Doctors in Morecambe, Lancashire, have been using the touch-activated phlebotomy (TAP) device (pictured) on patients’ upper arms to collect blood.

The team at the University Hospitals of Morecambe Bay NHS Foundation Trust (UHMBT) say since last April they have managed to take blood from almost 50 patients who previously could not give samples.

Six other NHS trusts have now expressed an interest in the device, developed by US firm Your Bio Health. The company says the device is “virtually painless”.

Dr Karen Perkins, the principal clinical scientist for UHMBT, said for those with learning disabilities, blood tests could involve months of “stressful and time-consuming desensitisation, general anaesthetic or even physical restraint”.

Perkins said the TAP device means blood can be collected “quickly, comfortably and with dignity”.

Fifteen-year-old Abi Gooch (pictured with her mother), who has Down syndrome, is among those to have benefited. She needs regular thyroid monitoring. However, she found blood tests traumatic, despite months of preparation with social stories, desensitising and practising on dolls.

But Abi’s mother, Heather, says her daughter found TAP “great fun”.

The UHMBT says the device is improving patients’ health. In a pilot of 19 patients with a history of resistance to blood tests, the Trust obtained samples from all but one.

Perkins said the device was a way of making “reasonable adjustments” so that an underserved patient group could experience the same quality of healthcare as everyone else.

It hopes the device will be rolled out nationally so no patient is “left behind”.

Autism assessments ‘too narrow’

The charity Autistica is calling for autism assessments to have a wider “neurodevelopmental and mental health focus”.

Rebecca Sterry (pictured), the charity’s chief executive, said a diagnosis often fails to give a real picture of the individual.

She said the diagnosis often overlooks the person’s “strengths, needs and any other neurodevelopmental differences that they might have”. She also said many people are waiting too long for an autism diagnosis.

Her charity is calling for more autism assessments, and for them to have a wider neurodevelopmental and mental health focus.

She argued that this would cut waiting lists, protect lives and support accurate diagnoses.

Autistica has costed the additional diagnoses at £443 million for two years, before falling to £200 million. The charity is one of several that came together to compile a report that calls for “substantial systemic investment and change”.

The National Autistic Society, Ambitious about Autism and Autism Action also contributed to the report, *A New Path Ahead.*

NHS figures show there were 254,108 patients with a referral for suspected autism in England in December 2025.

Just over 90 per cent had been waiting at least 13 weeks. It represented an increase of more than 11 per cent on three months earlier, when there were 227,813 people with a referral for suspected autism.

Sterry said she wants to see “earlier, personalised support which will prevent needs escalating, save the UK economy money and change people’s lives”.

Autism Eye approached the Department for Health and Social Care for comment, but it did not respond.

● See our feature on diagnosis, page 42.

Study confirms worse health issues

Children and adolescents on the autism spectrum are more likely to suffer gut problems, sleep difficulties, eating disorders and anxiety, according to a new study.

US researchers found that the higher rates of additional health issues emphasise the need for more comprehensive healthcare for autistic people. They used a dataset of more than three million patients in North Carolina.

Dr April Braswell (pictured), of the University of North Carolina, was the ‘corresponding author’ of the study. In an email, she said screening autistic children for other illnesses is “the key”. She wrote of how the findings highlight a “critical intersection between physical and mental health among autistic paediatric patients”.

She said the other illnesses the researchers found in autistic children “are not uncommon in kids and most providers can easily address them…”

The academic said the first step is “starting the conversation with patients and caregivers about problems their children are having”.

And she said medics should liaise with each other because a “team-based approach is always best” for recognising and managing co-occurring conditions in autistic patients.

The researchers published their findings in the *Journal of Paediatric Health Care.*

Biomedical charity Thinking Autism said treating issues such as gut problems, sleep difficulties, eating disorders and anxiety could reduce some of the “disabling symptoms of autism”. In a statement, a spokesperson for the charity said it had heard “numerous reports” from families of how medics dismissed their children’s symptoms as “just a part of autism”. The medics did not investigate or treat the symptoms.

£2.8 million study focuses on whole-family support

Well-being undermined? The project aims to offset the cumulative impact of a diagnosis on families

Autism is experienced by entire family units. Could a family-centred package of support help? A £2.8 million study involving nearly 500 families is set to find out, reports Isabel Scott

Autism doesn't just affect the person with a diagnosis: it affects their whole family. The National Institute for Health and Care Research (NIHR) is providing £2.8 million for a study to find out how useful it would be to roll out a specially developed package of family-wide support.

The study is called SAFE, which stands for Systemic Autism-related Family Enabling. Its aim is to give family members coping mechanisms that build their capability to manage the challenges that often surround an autism diagnosis.

The University of Plymouth is leading the four-year project. It will involve voluntary, community and healthcare organisations, those working at universities, and almost 500 families across the UK.

The interventions SAFE will trial have already been developed and tested, funded by NIHR and the charity Autistica. The new project will be the largest yet to explore the interventions' potential benefits for families.

How will it work in the NHS?

The trial will explore how SAFE might be applied across the NHS. The aim is to see if it might benefit autistic children and their families every day, and the clinicians and practitioners working to improve the process of autism diagnosis and the provision of follow-up care packages. It will also have an eye whether the interventions might save money, with the most recent estimates suggesting that diagnostic and support costs for autism total more than £32 billion a year.

Dr Rebecca Stancer, associate professor in Early Childhood at the University of Plymouth, is the project's chief investigator. She said: "Our work to this point has indicated that SAFE can be transformative for families, providing tools that build on the strengths they already have to care for their child, while ensuring they are also looking after themselves."

'Very real challenges'

Dr Tara Vassallo, lecturer in Education and Early Childhood Studies at the University of Plymouth, leads the coproduction of SAFE and has her own neurodivergent family. She said: "Autistic children and their families have told us that despite their strengths, they do experience very real challenges, such as difficulties with social inclusion, lack of opportunity due to differences in presentation, communication, and sensorial preference, or preventing episodes of significant distress.

"These challenges are often contextually triggered as autistic children and families navigate a world that does not always positively reflect or support their experience. Such experiences can have a cumulative impact over time, depleting personal resources and undermining family well-being."

LINK:

- **SAFE: https://shorturl.at/R63Hm**

What is SAFE?

SAFE works through a series of interventions to support families to build on their strengths and enhance their problem-solving and coping strategies to manage everyday challenges. It uses talk, images and play activities to explore the difficult parts of life connected to autism and aims to provide help around conflict, solving problems, well-being, and developing ways of coping.

A Bespoke Approach:
AUTISM AND THERAPEUTICALLY INFORMED CARE

For young people with learning disabilities, autism and highly complex needs, traditional residential and educational settings are not always the right fit. Busy, shared environments can increase anxiety, sensory overwhelm and behaviours of concern, creating barriers to regulation, learning and progress.

That is why Kisimul is expanding its bespoke solo apartment provision, providing a calm, highly personalised environment designed entirely around the complex needs of each individual.

Specialist Apartments Built Around the Individual

Developed in response to growing demand and the success of existing placements, these specialist apartments are designed for young people who require quieter surroundings, more intensive support and a highly flexible approach to care, education and therapy. In some cases, education is delivered directly within the apartment, reducing unnecessary pressures and helping learning happen in ways that feel structured, manageable and meaningful.

The approach is simple: instead of expecting young people to adapt to environments that may not meet their needs, the environment is designed around them.

Meaningful Life Model

At the heart of the model is Kisimul's therapeutically led Meaningful Life Model, which prioritises relationships, emotional safety and co-regulation. Rather than relying on rewards and consequences, staff use trauma-informed approaches to build trust, communication and emotional resilience over time.

Specialist Solo Apartment Living Environments:

- **Enhanced 2:1 staffing ratios**
- **In-house therapeutic support, including psychology, speech and language therapy, and occupational therapy**
- **Flexible education delivered in ways that feel safe and achievable**
- **Adaptable sensory environments and personalised daily routines**

Every aspect of the environment is designed to be therapeutic, from sensory considerations and daily routines to interactions with staff and opportunities for learning. Kisimul believes meaningful progress comes through consistent lived experiences that support emotional regulation, neurological development and growing independence.

Integrated Support Strategies

Each young person receives a fully bespoke package built around their individual strengths, needs and aspirations. Multidisciplinary teams work together to create integrated support strategies, while communication approaches such as Intensive Interaction, augmentative communication and therapeutically informed practice help young people develop confidence and connection at their own pace.

> “...instead of expecting young people to adapt to environments that may not meet their needs, the environment is designed around them.”

Education is equally flexible. Learning may take place within the apartment, in the community or through practical daily experiences, with programmes tailored to each young person's learning style, regulation needs and developmental goals.

Importantly, the aim is not to limit a young person's world, but to help them develop the resilience, social skills and coping strategies needed to feel more comfortable and confident in shared environments over time. Ultimately, Kisimul's bespoke provision offers a safe, nurturing and highly individualised environment where young people can feel understood, regulated and empowered to progress towards a meaningful future, whatever that looks like for them.

To find out more about our bespoke offering, contact **referrals@kisimul.co.uk**

Parent-carers: scapegoats for entrenched bias and cost-cutting

Parent-carers of autistic people have long lived with being judged. Writer and author Alice Running describes her own experience of 'blame culture' and how she and other parents have identified the profound harm this causes to autistic people and their families

From being scapegoated as the 'cause of autism' (Bettelheim's theory of detached mothering), to being accused of inventing our children's neurotype (allegations of Fabricated and Induced Illness – FII), parent-carers of autistic people have been consistently met with suspicion and scrutiny from the non-autistic world.

Blaming parents for their autistic children's ways of being is perhaps deeply embedded across many social environments. Narratives depicting misleading or harmful ideas of what autism is or isn't fuel political positioning and mainstream media reporting.

These narratives do not exist in isolation: they determine policy and guidance relating to autistic people, and they influence how non-autistic people perceive autism. Such bias towards autistic people (whether subconscious or otherwise) impacts access to public spaces and quality of life across all aspects of society, from health and education provision to community and neighbourhood interactions.

My own experiences of raising autistic children as an autistic mother are littered with examples of being blamed rather than adequately understood. One neighbour made multiple (and embellished) safeguarding referrals and noise-nuisance complaints relating to my children, while simultaneously banging on our adjoining walls and shouting obscenities when my children were in distress.

Blame the parents: it's easier than accessing funding or providing support

In school, I was repeatedly told my children were absolutely not autistic and I needed firmer boundaries at home. When I applied for an Education, Health and Care (EHC) needs assessment, the school raised queries around FII (Fabricated and Induced Illness). When access to the school environment became too distressing, safeguarding referrals (rather than adequate provision) were made.

Blaming parents of autistic folk is easier than taking the time to properly understand and consider what life is like from an autistic perspective. Similarly, blaming parents is easier than accessing funding and providing useful accommodations and support.

Misleading narratives

Unfortunately, my story is commonplace. Families of autistic people can quickly find themselves under scrutiny, whereby misleading narratives are constructed, influenced by misunderstandings relating to autistic ways of being and lifestyle preferences. Parent-carers report how professionals around their child may often robustly disagree with a parental assertion that their child may be autistic, because the child 'seems fine in school', 'has friends', 'can talk', 'is clever', or 'can make eye contact'. For many families, misunderstandings relating to being autistic lead to safeguarding concerns, where there need not be any concern at all.

Awareness of this inclination towards blaming parenting for the needs of autistic people is slowly growing, particularly in relation to the treatment of autistic families by those public services entrusted to assist. Over the past few years, research into the treatment of parent-carers when seeking either assessment or support for their autistic children has identified that around 86 per cent of the parents receive blame instead of appropriate help[1].

This finding sits within a wider context of 'institutional parent-carer blame'[2]. Child protection enquiries are increasing for families with disabled children[3], and autistic parents of autistic children appear more vulnerable to being wrongly subjected to safeguarding procedures[1,4]. Parent-carers responding to a 2023 survey of parental blame in relation to a Pathological Demand Avoidance profile of autism[5] reported

>

> Parents report mental health decline caused by receiving blame instead of help"

instances where they believed parent blame was levied to gatekeep access to dwindling autism and generic SEND resources. Certainly, there is a belief among parents of autistic young people that practical matters such as lengthy waiting times for assessments and chronic underfunding for autism-appropriate provisions contribute to parents being blamed for system failures.

We only need to look at school attendance for autistic young people to notice the interconnectivity between unsuitable provision, distress and burnout for our children, and blame responses such as fining parents or referrals to safeguarding pathways.

Tangible harm

By listening to the accounts of parent-carers, it becomes clear that interactions with autism-related services can cause tangible harm for all family members. Parents report significant mental health decline caused by receiving blame instead of help[1,5]. For many parents, the irony is that they are often accused of being 'overly anxious' at the beginning of advocating for their children, when they are not, yet begin to suffer with varying mental health conditions as a result of being repeatedly told they are at fault.

Some parents describe their interactions with SEND pathways as comparable to being in an abusive, intimate relationship[5]. Other parents note how being repeatedly blamed for their child's needs caused longer-term trauma and symptoms of post-traumatic stress disorder (PTSD)[6].

Many families who have suffered parent-carer blame live with an entrenched fear of having their children removed – a fear that persists even when there is no current safeguarding involvement. Daily occurrences, such as the telephone ringing or the post arriving, have been described by parents as triggering panic that safeguarding enquiries are imminent.

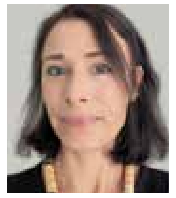
Sadly, living with such levels of stress and anxiety has caused many parent-carers to struggle with their physical health as well as their mental health. As I document in *We Need to Talk About Autism and Parent-Carer Blame*, my own physical health suffered in response to receiving blame from the professionals around my child. I lost a significant amount of weight – which was also noted as a safeguarding concern – and my fingertips turned orange ahead of crucial safeguarding meetings on more than one occasion. I was lucky. Parents have reported the development of heart conditions, suffering strokes, and even being detained, or 'sectioned', in a psychiatric hospital under the Mental Health Act.

> “My own physical health suffered in response to receiving blame from professionals”

It is no easy fix for parent-carers to recover from. Traditional talking therapies work best when a traumatic event has passed, but for parent-carers of autistic individuals, interactions with public services are often ongoing. To live in this way must cause harm – to have no choice but to seek support from the services responsible for causing harm, and in doing so, being in an almost constant state of fear and panic that blame should begin again (or get worse).

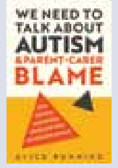
The blame autistic people and their families endure, and the associated harm this causes, is not for autistic people and their families to fix. It is for service practices to reflect and review any entrenched biases that may be present within their interactions with parent-carers. It is for service practices to ensure their understandings around autism accurately represent the lived experiences of autistic folk.

Most important to consider, however, is the harm that parent blaming causes each child. Not only does parent-blaming create barriers to the timely access to support for a child, but it also places parent-carers under extreme pressure, weakening their already stretched resilience. In short, parental blame hurts children – children that public services have a duty to support. Ae



Alice Running has a postgraduate certificate in autism and is a neuroaffirming autism specialist, providing autistic-led advocacy and consultancy services, as well as being an author and writer. www.alicerunningautismadvocacy.com/

Further reading



We Need to Talk About Autism and Parent-Carer Blame by Alice Running is a research-informed exploration of the complex issue of parental blame within autistic families, including lived-experience testimony and advice for parents and professionals on how to navigate these issues to deliver the best outcomes for the children involved.
Jessica Kingsley Publishers, £13.99/$17.95

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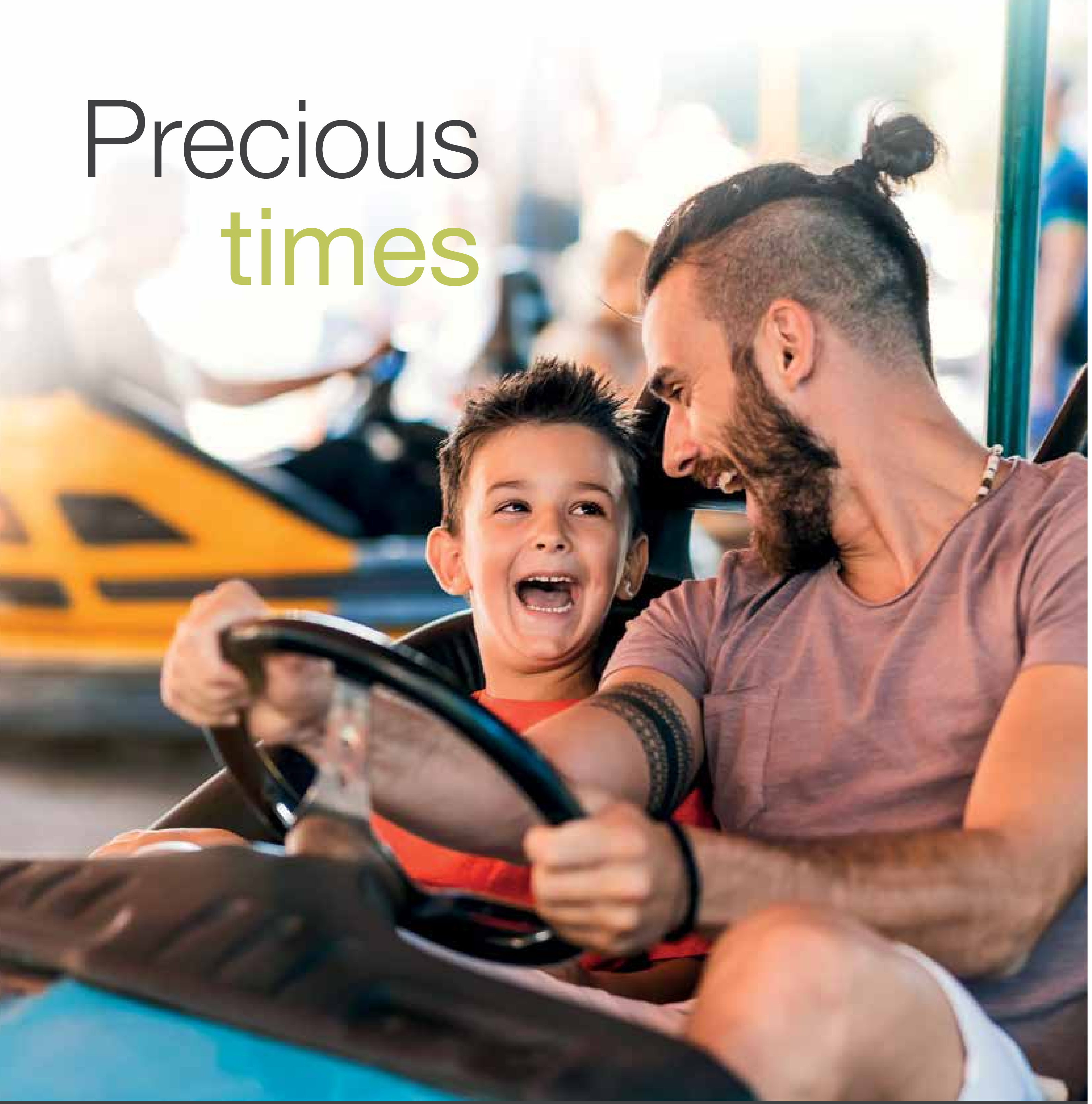


Is more parent blaming on the way?

Speaking out: Venessa Swaby, who runs autism not-for-profit group A2ndvoice, believes moves to toughen penalties on parents when their children break the law could signal a rise in parent blaming from authorities

Parents may face tougher action when their children end up on the wrong side of the law under new Government plans. Darren Devine looks at how this could create fear in families of neurodivergent children, who are statistically more at risk

Dr Venessa Swaby knows all too well how condemnation can masquerade as concern. How, from a charade of sympathy and understanding, the authorities can quickly turn to pointing a finger of blame.

Her three children, Michaela, 20, Nathaniel, 23, and Louise, 25, have all been diagnosed with neurodevelopmental conditions, and her family has experienced its fair share of struggles. The social workers, special educational needs co-ordinators (SENCOs) and teachers she went to for help would often end up citing her as the reason for the children's challenges, rather than their conditions.

It is an experience all too common for families of children struggling with autism or attention deficit hyperactivity disorder (ADHD). Blaming families reduces or removes the obligation to help. And when children and families are deprived of support, their needs can escalate, ending in suspensions and exclusions from school.

Research by Dr Hope Kent, of the University of Exeter, has documented that the more school exclusions a student experiences, the earlier they receive their first criminal conviction. The 'school to prison pipeline' sees many children with neurodisabilities being excluded from school, with pupils who were excluded once, two to three times, and four or more times receiving their first conviction three, five and six years later on average.

And now the Government has published a Youth Justice White Paper suggesting parents may face tougher action if their children break the law.

Swaby, who runs the autism community interest company, A2ndvoice, is concerned that the White Paper is another expression of the British state's default response of parent-blaming when confronted with the complexities of youth offending.

Need for education

It is estimated that up to half the adult prison population has some form of neurodevelopmental condition. Swaby says: "People still need to be educated about autism or anything linked with behaviours, but not to be so quick to blame and say it's the parents' fault."

Swaby's not-for-profit group, based in Wandsworth, south-west London, specialises in autism in black, Asian and mixed-race communities. It attempts to counter prejudice when families are in denial about their child's condition. "Everybody has a part to play," she says, in helping children through their problems, including teachers, SENCOs and headteachers.

Swaby, 57, from Clapham, in south-west London, says when Nathaniel was diagnosed, she was "constantly" told it was her fault. The mother-of-three, who was herself diagnosed with autism in her 50s, was accused of lying and

> "People still need to be educated about autism or anything linked with behaviours"

>

told there was nothing “wrong with him” and that autism was “just an excuse”. People still need to be “educated” about the condition and the social struggles it brings, she says.

Under the Youth Justice White Paper, the Government will strengthen the use of parenting orders, which can compel parents or guardians to address their child’s behaviour. This can mean going to counselling or guidance sessions, or facing penalties such as fines. Under the current system, the maximum fine for breaching an order is £1,000. But in the most extreme cases, the Government is saying parents could be jailed.

Repeat offending

The Government refers to statistics showing that 80 per cent of prolific offenders in England and Wales broke the law for the first time as a child, and two-thirds of those who leave prison commit another offence within a year.

Courts must consider issuing a parenting order when a child under 16 has been convicted of an offence. They can also issue orders for 16- and 17-year-olds to prevent more offending.

The Ministry of Justice (MoJ) says figures show the use of parenting orders has fallen sharply, with more than 1,000 issued in 2009/10, but just 33 in 2022/23.

The proposed legislation was announced after the publication of the Southport inquiry report, which suggested that if Axel Rudakubana’s parents had been stronger before the 2024 attack, it may have been prevented. The then-18 year-old Rudakubana murdered Alice da Silva Aguiar, nine, Elsie Dot Stancombe, seven, and Bebe King, six, in a knife attack in July 2024.

Rudakubana’s previous behaviour, which included convictions for assault and carrying a knife, was “wrongly attributed” to his autism, the report’s author Sir Adrian Fulford found. He said this mistake led to a failure to address his previous behaviours.

Professor Clare Allely, author of *Autism Spectrum Disorder in the Criminal Justice System*, has reservations about the Government’s plans. Psychologist Allely, of Salford University, says: “This is concerning, particularly for many parents with children who are autistic and/or ADHD. These parents have no support.”

In an email, the academic suggests there is a “good amount of research” on how much more vulnerable children with neurodevelopmental conditions are to ending up on the wrong side of the law.

Her view is echoed by Dr Anne-Marie Day, of Manchester Metropolitan University, who believes there is growing evidence of how children with neurodevelopmental conditions are overrepresented in youth justice systems across the world. In a piece published in the journal *Societies* last December, she referenced how the UK Department for Education recently found that 80 per cent of children in the English and Welsh youth justice system had special needs or disabilities.

Review of 25 studies

Day, a youth justice researcher, wrote of how a review of 25 studies of children in custody found 12 per cent of boys had ADHD and 19 per cent of girls.

Meanwhile, an Australian study found 48 per cent of children in its justice system who had been subjected to child protection procedures had a neurodisability. And in the US, a national survey found that 33 per cent of children in custody had a disability, half of whom had a neurodisability.

Reservations: Professor Clare Allely calls the move towards stiffer penalties for parents “concerning”

> “This is concerning, particularly for many parents with children who are autistic and/or ADHD”

‘Parenting orders are not about blaming parents’

A Ministry of Justice spokesperson responds to Autism Eye over fears about the consequences of the Youth Justice White Paper

“Children with neurodiversity are overrepresented in the criminal justice system, and the Government recognises that tailored support is essential to ensure these children are helped effectively.

Parenting orders are not about blaming or criminalising parents, they’re about setting a clear expectation that voluntary engagement alone is not always enough.

Our reforms lay the foundation to support families and tackle the drivers of offending, so that fewer young people become trapped in cycles of crime.

Guidance:

- Parenting Orders can compel parents or guardians to address their child’s behaviour – including attending counselling or guidance sessions – or face a fine.
- Our new Youth Justice White Paper provides the blueprint for earlier intervention, more targeted support, and tackling the root causes of youth crime to create safer communities and fewer victims.
- This includes commitments to strengthen and encourage use of parenting orders and ensure there are more meaningful consequences for non-compliance.
- Figures show that eight out of ten prolific offenders committed their first crime as a child, while two-thirds of those released from custody reoffend within a year.
- Further measures announced include:

- Piloting new Youth Intervention Courts, which will for the first time bring together judges, youth justice services and specialist support to tackle the drivers of offending and keep young people on track.

- An extra £15.4 million per year investment in the Government’s flagship Turnaround programme to help a further 12,000 children at risk of entering the youth justice system, over the next three years.

- A commitment to end unnecessary custodial remand for children – cutting its use by 25 per cent this Parliament to ensure children awaiting trial or sentencing are not held unless public protection requires it.

- Consulting on childhood criminal records reform by the end of the year. This will consider potentially ending lifelong disclosure requirements for childhood offences, so people aren’t forever held back by mistakes made as children.”

Beyond ‘Outstanding’: what boarding’s like for autistic young people

At Gretton School in Cambridgeshire, a specialist residential and day provision, boarding has been judged Outstanding for the fifth consecutive time.

For many families exploring specialist education, the word ‘Outstanding’ offers reassurance. But beyond this, an important question remains: what does that look like in everyday life for a young person in boarding?

Mornings begin in a familiar setting, supported by adults who know each learner well. Staff are “knowledgeable, empathetic and committed to their roles”, allowing children to move into the day at an individual pace – whether that involves quiet preparation, structured prompts, or time simply to settle.

The day has a steady rhythm that young people come to recognise. Transitions are supported in a way that feels calm, predictable, and manageable. That same steadiness continues into the evening. The return from school is not a change into a different environment, but a return to familiar people, routines, and expectations, helping children feel secure in what comes next.

Within this consistent daily rhythm, relationships naturally develop over time. Ofsted described how “relational practice runs through the core of the school”, highlighting how staff patiently persevere with children and build substantive, meaningful relationships.

Because learners are supported by a consistent team across education and residential life, adults develop a shared understanding of each young person through daily interaction. Over time, staff become attuned to small changes in communication, behaviour, and emotional state, responding in a calm and supportive way. Rather than being defined by single moments, relationships are shaped through repeated, familiar interactions. Children experience the same adults across different parts of their day, helping trust and recognition to build steadily.

Peer relationships also develop within this environment. Everyday routines, such as mealtimes and activities, create natural opportunities for interaction, where social understanding and confidence grow.

Meaningful interactions

Ofsted described the residential provision as a “home from home”, where children experience positive, meaningful interactions and shared moments that are remembered with warmth. Within this environment, independence is supported in a structured and thoughtful way.

Ofsted noted that “children are taught to navigate relationships”, while staff are “effectively challenging children to become as independent as they can be”. These skills are developed gradually through daily life, where guidance and space are carefully balanced.

For families exploring residential specialist education, it is often these everyday experiences – the predictability of daily routines, the consistency of relationships, and the gradual development of independence – that make the biggest difference.

Outstanding provision is reflected not in a single moment, but in the way daily life is experienced: through familiarity, support, and neuro-affirming relationships that allow children to grow in confidence and independence at a pace that is right for them.

“Home from home”: one of the boarders at Gretton School enjoys the calmness of reading a book

If you would like to see if boarding at Gretton would be a good fit for your child, you can book onto one of our open tours via our website, or contact our admissions team on 01223 277438.

GRETTON SCHOOL

www.grettonschool.com

Two years of life-changing love

Peggy the Labrador has become inseparable from Noah Shone, a 10-year-old autistic boy from Rugby. Isabel Scott relays how specially trained dogs like Peggy can help autistic people and their families navigate life's challenges, becoming a social shield, adding calmness, and enabling joyful social occasions

"The perfect match": Noah with Peggy, his support dog

BATSONELLI PHOTOGRAPHY

It's heartening to hear stories about the remarkable change that support dogs make in the lives of autistic children and adults. That's certainly the case with Peggy, a Red Fox Labrador. She has made a hugely positive contribution to the life of 10-year-old Noah Shone, who is autistic.

The youngster, from Rugby, had refused to leave the house, apart from attending school.

Then Peggy bounded into his life – and two years on, as Noah heads into his final year of primary school, the Shone family has looked back on how far Noah has come. There have been trips out, holidays and hairdresser visits, all taken in Noah's stride because Peggy is by his side.

Trained and provided by the national Support Dogs charity, the loveable Lab arrived at a time when the family was navigating daily challenges – struggles with getting to school, going out, and helping Noah to regulate overwhelming emotions. Fast forward to today, and Noah is now 10 and much more settled.

Dad Robert says of Noah: "He's grown so much, and alongside him every step of the way has been Peggy, his autism assistance dog – his calming presence, his constant companion, and, as we often say, his 'dog twin'."

How Peggy helps

Peggy helps Noah through so much – calming him when he's overwhelmed, keeping him anchored during transitions, and being his social shield in unfamiliar or busy environments. Thanks to Peggy's support, Noah will now happily go out for birthday meals, visit restaurants, and even pop out for breakfast. He's discovered a passion for reading, and with Peggy by his side, he's now able to visit Rugby Library and the family's local bookshop, Hunt's. Noah has also found the confidence to attend salon appointments, something that once seemed impossible.

Peggy has enabled new experiences and unforgettable memories. Since her arrival, the Shones' world has expanded. They've gone on holidays to Butlins in Bognor Regis, had close-up animal encounters, and even attended Crufts – twice. Noah now contributes to fundraising for Support Dogs, something he takes pride in.

He has been able to perform in a school play, with Peggy watching from the audience. He's taken emotional breaks during family events by walking Peggy outside. And he's had swimming lessons while she watches, loyally stationed at the poolside.

The Shones describe Peggy as "the perfect match we never expected". When she first visited their home for a suitability assessment, they fell for her instantly. "At the time, we never dreamed she could be ***our*** dog. But when we were told we'd been matched with her, it felt like winning the lottery," says Robert.

> "He's grown so much, and alongside him every step of the way has been Peggy"

Getting to grips with giraffes: trainee support dogs Louis and Garry on a visit to Dudley Zoo

As well as Noah, dad Robert and mum Kay have also been diagnosed with autism. Robert is a 41-year-old information security engineer for Simply Business, and Kay is a 46-year-old administration manager. Although Support Dogs provides autism assistance dogs for children rather than adults, Peggy brings comfort, calm and structure to the whole family. Robert says: "The bond between Noah and Peggy is something beyond words. It transcends categories like 'handler' and 'support animal'. She is a part of us.

"For those families currently waiting, or considering applying to Support Dogs, we want to say this: It's life-changing. It's worth the wait. It's worth the effort. The journey isn't always easy, but it's absolutely, 100% worth it."

Rita Howson, chief executive of Support Dogs, which also trains and provides assistance dogs to help adults affected by epilepsy or physical disability, says: "We are so pleased to hear about the amazing impact Peggy has had. This is why we do what we do."

The organisation's work can be seen throughout the country, and more recently on a trip to Dudley Zoo and Castle, as trainee support dogs Louis and Garry were preparing for their future life supporting autistic youngsters.

Enjoyable visit

Zoos can be daunting, with different sights, smells and sounds, so the two two-year-old black Labs needed to get accustomed to such an environment, especially as their young humans will want to visit places like this. Accompanied by trainers Jemima McLanaghan and Emily High, they got to grips with the giraffes, apes and more.

Jemima says: "The children these dogs are going to assist both like to visit the zoo, so it was a brilliant opportunity for us to practise with the dogs to get them used to the sights, sounds and smells of a zoo environment.

"Louis and Garry have been to farms and stables before, but hadn't had the opportunity to see animals much larger than a cow.

"Both of us trainers and the dogs really enjoyed our visit. Everyone was so friendly and accommodating, it really helped us build the dogs' confidence."

Matt Lewis, the zoo director, says: "We understand a zoo environment can be a daunting experience for some, with lots of different smells and noises.

"As the first zoo certified as being autism-friendly by Dimensions back in 2024, we're committed to being as accessible as possible as we strive to connect everyone with nature and recognise the importance of assistance dogs in allowing people to visit attractions like ours.

"We were pleased to welcome Louis and Garry to Dudley Zoo and Castle as part of their training and hope to welcome them back as fully-fledged working support dogs with their new families in the future."

LINK:

- **Support Dogs: www.supportdogs.org.uk, 0114 2617800**

Years march on, but caring never stops

It's the question that haunts family carers: what happens when we're too old? Darren Devine reports on older carers who are devoting every last breath to ensure their loved ones can stay living at home

"Look after the children." These were the last words of Alphie Lonergan's wife, Nellie, before her tragic death aged just 36 after labour with the couple's youngest child, Ronan.

While battling high blood pressure during the birth, Nellie was wracked with worry over the couple's four children: Katrina, 10, Roisin, eight, Donall, six and newly born Ronan. She was given a syntometrine injection, which is used to prevent excessive bleeding after birth. Nellie died 43 hours later of a brain haemorrhage.

But Lonergan has remained true and ever faithful to his beloved wife's words – and even at the advanced age of 84 continues to devote himself to the care of the couple's two disabled sons, Donall and Ronan. They are both now in their 40s and have severe learning disabilities.

Earlier this year, it emerged that Lonergan, from Loughgilly in County Armagh, Northern Ireland, had his support hours stopped for his two sons. His care package was cut from three hours per day to one, then stopped altogether.

Now, a single hour of this original three-hour package has been restored.

Awake until early hours

Adding to the strain, Donall does not go to bed until the early hours, which affects Lonergan's rest. Lonergan told the BBC that while physically he feels okay, mentally he is "under awful, awful stress".

Ronan's care package stopped in March 2024, but Donall, who also has autism and obsessive-compulsive disorder, was still supported for an hour per day. A carer would visit and get him up and dressed before the support was axed and then restored.

The brothers go to day centres, but Lonergan is their sole carer in the evenings. He has vowed to "definitely" continue caring for his sons out of respect for Nellie. He says his daughters, Katrina and Roisin, help, but they have children and commitments of their own.

When all of Lonergan's hours were cut, Northern Ireland's Southern Health and Social Care Trust apologised for the stress caused and said it was withdrawn because of a lack of staff. It blamed recruitment problems in

> "While physically he feels okay, mentally he is 'under awful, awful stress'"

>

Above: Joleen Cunningham of Carers NI feels carers are sacrificing their own physical and mental health

Left: Alphie Lonergan with sons Ronan and Donall (left). The 84-year-old has had one hour of a three-hour support package restored

rural areas like Loughgilly.

What's behind the recruitment problems? Pay is a key issue. Last November, social care staff were left out of a pay offer made to doctors, nurses and auxiliary healthcare staff.

This followed a report in 2019 by Bath University that said older, informal family carers of adults with learning disabilities and conditions such as autism and Down syndrome were being driven to "breaking point".

The findings suggested growing numbers of older family carers, some in their 80s and 90s, were providing care to support adult children with severe learning disabilities or autism.

Greater support needed

The report, *Confronting a looming crisis*, suggested much greater support is needed to help elderly carers cope. Professor Rachel Forrester-Jones, who wrote the report, said at the time that carers did not feel they were "partners with professionals", but "still fighting with the authorities to gain benefits and formal care". She added that in the face of depleted and disappearing daily activities and services, "they end up organising everything themselves".

According to the National Institute for Health and Care Excellence (NICE) in 2018, two in every three adults with learning disabilities live with their families, mainly with parents.

> **"Unpaid carers are too often left to pick up the pieces, at significant cost to their own health"**

In the late 1940s, life expectancy for people with conditions such as Down syndrome was just 12 years. Now, the mid-range, or median, life expectancy for those with Down's has increased by almost 500 per cent to 58. This means many very frail and elderly adult carers are now looking after adult children in their 50s and 60s.

Drawing on a small-scale study carried out in the New Forest during 2018-19, Professor Forrester-Jones found that older carers are forced to take on more responsibility for finding, financing, and managing appropriate support for their loved ones.

Her findings also highlighted a collective fear faced by older parents, centring on what happens to their disabled children if they die first. It's a well-founded fear, with 60 per cent of the more than five million people providing unpaid care in 2021 across England and Wales being over 50.

Joleen Cunningham, public affairs manager for Carers NI (Northern Ireland), says stories like Lonergan's are "not isolated". She says that in Northern Ireland, around 21,000 people over the age of 65 are providing round-the-clock care, more than 50 hours per week, to family or friends. Unpaid carers are "propping up" failing social services there, she says, to the tune of £16 million every day.

Carers should not be left feeling they have no choice but to cope alone, she says. Reliable social care is an essential "lifeline" that can stop families reaching breaking point.

Planning for the future with housing and support options explored long before families hit crisis or emergency situations is also crucial. Cunningham adds: "When support is withdrawn or unavailable, unpaid carers are too often left to pick up the pieces, frequently at significant cost to their own physical health, mental well-being, and ability to continue caring.

"Carers must be properly recognised, identified at the earliest opportunity, and able to access practical support, regular respite breaks, and dependable care services when they need them most."

LINKS:
- Carers NI: https://www.carersuk.org/ni/
- Confronting a looming crisis report: https://www.bath.ac.uk/publications/report-confronting-a-looming-crisis/

When a brain protein is hyperactive

Dr Ben Marlow highlights how overactivity of the protein mTOR in the brain causes neurodevelopmental challenges, and how research may lead to treatments

I have previously written about autism related to the protein mTOR (mechanistic target of Rapamycin) and the idea of 'brain overgrowth' and 'hyperconnectivity' in certain subtypes.

mTOR is a complex regulator of many biological processes. As part of the PI3K/Akt/mTOR pathway, it is a central regulator of cell growth and metabolism. The protein plays a crucial role in brain development, where its hyperactivation leads to abnormal neuroplasticity (the brain reorganising itself), tumour formation and heightened neuronal excitability[1]. mTOR specifically regulates catabolism (where the body breaks down complex molecules), immune response, autophagy (cellular recycling), cell survival, proliferation and migration.

Much of this knowledge is gleaned from well-understood 'monogenic' (caused by a single gene) mTORopathies (disorders caused by mutations in the mTOR). These include Tuberous Sclerosis Complex (TSC), Focal Cortical Dysplasia type 2 (FCD2), Smith–Kingsmore Syndrome (SKS), PTEN syndrome and PI3K-related overgrowth syndrome (PROS)[1]. They are typically characterised by overactivation of mTOR signalling and its effects on neuronal growth patterns, proliferation, and differentiation. mTORopathies often manifest clinically with epilepsy, cognitive impairment and, in some cases, structural brain anomalies related to neuronal overgrowth and deficits in synaptic pruning (the brain getting rid of bad connections).

Significant effects

These clinical challenges are commonly seen in profound autism, and in those children without confirmed gene variants within this pathway. Excessive activation of the mTOR pathway is associated with significant effects: structural alterations, inhibition of autophagy (cellular recycling), increased neuroinflammation and heightened neuronal excitability.

More than 90 per cent of autism cases remain idiopathic, meaning they arise spontaneously or don't have a known cause. But for many children who don't have a monogenetic cause (originating from a single source), they share many overlapping symptoms with monogenic mTORopathies (rare genetic disorders caused by single-cell mutations that hyperactivate the mTOR pathway). This leads to the hypothesis that mTOR is perturbed by convergent pathways that aren't as well defined or understood.

Studies have demonstrated that increased density of excitatory synapses in the brains of autistic individuals is linked to aberrant mTOR-dependent synaptic pruning (impaired macroautophagy, a cell's natural recycling process)[2]. This is also characterised by atypical

>

macroscale (broad) functional connectivity, as detected on a resting-state fMRI scan[3]. This increased density has also been linked functionally to ASD-like stereotypy (repeated, ritualistic behaviour) and, in mice, cortico-striatal hyperconnectivity (an overactive connection between the parts of the brain responsible for conscious thought and for habit formation, reward processing and movement). This can be reversed by pharmacological inhibition of mTOR activity.[3]

More research has focused on pathways regulating mTOR. A team led by Professor Haitham Amal has published a paper on deciphering a novel mechanism of 'cross-talk' between Nitric Oxide (NO) and mTOR[4]. NO is a gaseous molecule that regulates multiple aspects of neuronal physiology, including neurotransmission, synaptic plasticity and immune response[5]. Elevated NO levels have been reported in post-mortem brains of autistic individuals, and increased NO levels in the brain have been linked with neuroinflammation[6]. Previously, Amal's team has demonstrated increased NO levels in mouse models of autism and in blood samples of autistic individuals.[7]

Professor Amal's team showed that the mechanism through which NO causes biological changes is S-Nitrosylation (a modification in the body where NO attaches to a sulphur group of a cysteine residue). This is called S-nitrosothiol, or SNO.

SNO exhibits broad physiological functions: cell signalling, autophagy and neurotransmission. However, if this nitrosylation is excessive, it can lead to aberrant protein missfolding, mitochondrial fragmentation and autophagy inhibition. In turn, this can lead to dysregulated cell growth.[8]

Upstream of mTOR, the team found that S-Nitrosylation (SNO) of TSC2 (Tuberous Sclerosis Complex 2) promoted its degradation and the overactivation of mTOR. This was seen in both Shank3 and Cntnap2 mouse models. Inhibition of nNOS using the chemical 7-Nitroindazole prevented nitrosylation of TSC-2 and normalised mTOR activity. Importantly, it improved autism-like behaviours in the mice.[8]

> **“Dysregulation of the mTOR pathway … might play a role in a subtype of autism”**

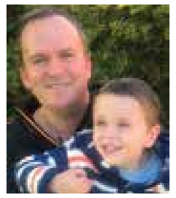
The team then looked at mTOR signalling proteins in plasma samples of autistic children and age-matched controls. There was a significant increase in the plasma biomarkers p-mTOR and p-RP56 in the autism samples compared to the neurotypical group. The researchers also found decreased levels of TSC-2 in the autism samples, suggesting a correlation with the mouse model experiments.[8]

Clinical implication

The involvement of mTOR and its signalling pathway in the regulation of protein synthesis, autophagy, synaptogenesis and neuronal metabolism has been well published.[1] mTOR's hyperactivation has been previously associated with monogenic conditions (TSC, PTEN) and idiopathic autism.

This study provides evidence that in mouse models and human cases, dysregulation of the mTOR pathway through SNO of TSC-2 might play a role in a subtype of autism. It suggests the therapeutic potential of targeting S-Nitrosylation sites within key regulatory proteins (such as TSC-2) to alleviate mTOR-related overgrowth and neurodevelopmental challenges in certain autism phenotypes. Inhibition of nNOS may hold significant potential in regulating mTOR through TSC-2, and in other 'upstream' regulators.

Importantly, the plasma markers of p-mTOR and total TSC-2 may be potential biomarkers for certain autism groups that might give indications of the severity of symptoms and response to treatment. Clinical research looking at these biomarkers in children with profound autism may be a useful tool to uncover why some children have such significant neurodisability and medical co-occurring conditions, such as epilepsy, that could be amenable to treatment options and improved quality of life.



Dr Ben Marlow (pictured with his son, Freddie) is a paediatric consultant (neurodisability) at Colchester General Hospital, Essex, and clinical director of the hospital's Synapse Centre for Neurodevelopment, which seeks to translate biomedical research into practical therapies. https://www.synapsecentre.co.uk

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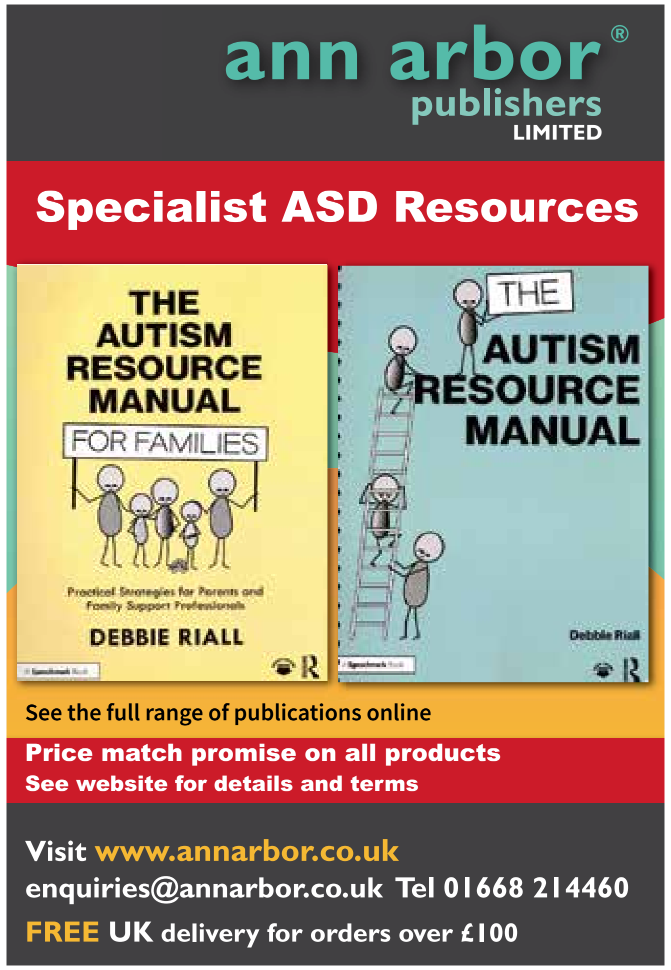

Moving on up

Fiona McNeill looks at a range of initiatives that specialist schools and colleges are using to support young people with additional needs in transitioning through their important life stages

The outside world: work experience in a shop is one of the options often offered for transitions training

Neurotypical young people inevitably grow up and progress from school to further education, employment, or living independently. For youngsters with special educational needs and disabilities (SEND), these transitions can present extra challenges. And for schools where pupils on the autism spectrum might stay for years, transitions are an ongoing consideration for the staff.

“Qualifications are important, but they’re not the only thing that matters,” says Vicky Sellars, head of Key Stages 4 and 5 at Gretton School in Cambridgeshire, a day and boarding provision for autistic youngsters aged five to 19.

“We want to pass on life skills, too,” she says. “Most of our students have a ‘spiky profile’ (marked strengths and difficulties). For example, we had one lad who was doing A-levels but couldn’t tie his shoelaces. We get to know them as individuals to find out exactly where they need support.”

With this in mind, the school has developed a ‘Preparing for Adulthood’ course. Pupils are introduced to aspects of everyday life, such as budgeting, laundry and shopping, and receive talks from the emergency services on staying safe. They also visit a pub (for a soft drink) to explore socialising. In addition to work experience, Gretton also invites potential employers into the school for autism awareness training.

“Every year, we have a leavers’ assembly where previous students come back to tell us about their experiences in the outside world,” Vicky says. “It’s so valuable to hear that from other young people, rather than teachers or parents.”

Likewise, Alice James, transitions manager at Coleg Elidyr in Llandovery, Wales, says that she and her colleagues are planning for the students’ next steps as soon as they arrive. The college is a residential placement for people aged 18 – 25 with moderate to severe disabilities. Young people generally embark on the two-to-three-year education programme when they arrive, moving on to the ‘Life Skills’ programme for two years after that.

“We present transitions as a positive thing,” she explains. “We praise the students for their achievements and also support the parents. It’s also important to build good relationships with social workers and the local authority.

“Our Life Skills course shows young people how to do household tasks, for example, and there are a lot of symbols and signs around the college, reminding students how to do things. It’s baby steps. Everything we do is about getting them as ready as possible to move on. They also complete work experience for one or two days a week in the local area.”

Derwen College in Oswestry, Shropshire, is a residential and day provision for people aged 16 – 25 with a variety of SEND. The organisation aims to equip students with life skills via academic pathways – for example, students studying performing arts gain transferable skills such as confidence and teamwork alongside the qualification.

Preparing for adulthood: a teacher in a one-to-one session with a pupil at Gretton School

However, there is also a focused programme of independent living activities. Here, young people learn things such as housework, finance, cooking and ‘green’ issues through enjoyable activities such as a cookery competition or making recycled Christmas decorations. Learning is reinforced via visual resources or QR codes (if the student is IT literate).

“It’s important to adapt the programme to what the young people need and want,” says Jude Cottrell, care quality manager with the college. “There’s a weekly residents’ meeting where they express what they’d like to do.

“We also adapt travel training. Two or three of our students are on the Paralympic swimming team and need to go to a local swimming pool every week, so they’ve all learned to book a taxi. Another student comes from London and is already used to taking the Tube, so we’ve built on his existing skills. We also keep families involved so students can practise their skills in the holidays.”

> “Previous students come back to tell us about their experiences in the outside world”

The Donaldson Trust is Scotland’s national advisory centre for neurodiversity, campaigning for positive change and offering training and support to families and professionals. The organisation also runs a school for young people with complex needs. As part of this, the Trust’s ‘Gate’ programme offers life skills training for those over 16 to help them transition to adulthood. In addition, its ‘Vibe’ service offers well-being support and living skills for neurodivergent students aged 13-18 who are unable to attend mainstream education full-time.

Lynn Wassell, chief executive of Donaldson’s, points out that the transition process is not ‘one-size-fits-all’ and that each student needs tailored support and to go at a pace that suits them.

“Transition involves more than leaving school,” she continues. “It includes navigating new systems, changing eligibility for support, and often a loss of structure, routine, and established relationships and friendships – leading to increased feelings of disconnect and isolation for young people.”

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Lynn stresses that not every young person the organisation works with will be ready to go straight into further education, employment or independent living. A 'stepping stone' approach works best for these students, she says, helping them to set their own small, achievable goals and develop readiness.

Russ Kennedy is the managing director of the Welsh division at Dimensions. The organisation specialises in supported living and residential care for people with learning disabilities and autism across the UK. He echoes others in saying that getting to know clients' individual needs and triggers is crucial when facilitating a smooth transition.

"People don't exist in a vacuum, and it's important to also understand their family dynamics," he says. "Often, parents will have had an enhanced caring role and may have had to battle for support. They may not know when it's 'safe' to let go and allow their son or daughter greater independence.

"We make it clear that we will support the young person in developing their ability to make healthy choices and that sometimes they'll make mistakes. Our family consultants have lived experience and play a vital role in understanding the families' perspectives and liaising with Dimensions colleagues.

"Time is also important," he adds. "For example, if we're helping someone to learn to do laundry, maybe all they'll manage at first is putting the clothes on the floor in front of the machine, but that's enough to start with. We have a policy of offering 'just enough' support and allowing the person to do as much as they can themselves." AE

CONTACTS:

- Coleg Elidyr: https://elidyrct.ac.uk/provision/coleg-elidyr
- Dimensions: https://www.dimensions-uk.org/
- Derwen College: https://www.derwen.ac.uk/
- The Donaldson Trust: https://www.donaldsons.org.uk/
- Gretton School: https://www.grettonschool.com/

What employers need to know

If your autistic loved one is making a transition into the workplace, it's worth knowing what their rights are and the reasonable adjustments their employer needs to make for them, says solicitor Aparna Sudhir

Statistics from HM Courts & Tribunals Service showed that in 2020, 265 employment tribunal cases involved neurodivergent conditions. By 2025, this had risen to 517. Within the neurodiverse definition here, autism and ADHD are among the most common. The financial and reputational risk for employers is therefore significant.

'Neurodiversity' itself is not a protected characteristic under the Equality Act 2010. Rather, protection depends on whether an individual's neurodivergence meets the s.6 definition of disability: a physical or mental impairment that has a substantial and long-term adverse effect on normal day-to-day activities. A formal medical diagnosis is therefore not required for an individual to be considered disabled under the Equality Act 2010; it is a question of fact for the employment judge to determine.

To reduce the risk of a disability discrimination claim, employers should take the following steps – particularly where an employee has self-diagnosed or is awaiting a formal neurodivergence diagnosis:

1. Training, awareness and early action – Managers must be equipped to understand neurodivergence and to respond appropriately if an employee raises concerns.

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If an employee mentions difficulties that are commonly associated with autism or ADHD – such as difficulties with concentration, focus or time management, that they may be autistic, or are on a waiting list for an assessment – this should prompt supportive action. Managers should proceed with particular caution if performance issues arise, especially if an issue could be down to their specific neurodivergence, for which they require support.

For example, some individuals with ADHD need explicit instructions before undertaking a task. If vague instructions are given, it may be difficult for the employee to carry out that task to the best of their ability, or even at all.

Even if an employer does not have knowledge of a disability (because there is no formal medical diagnosis), the case law recognises that if an employer **ought reasonably to have known about a disability** – for example, if an employee's working pattern or behaviour is indicative of autism or ADHD and they are awaiting a formal assessment – then they can be deemed to have constructive knowledge of a disability. This triggers the employer's duty to actively manage the employee's health condition and possibly make reasonable adjustments (see below).

2. Referral to Occupational health (OH) – OH can play a crucial role in helping employers understand the impact of an employee's neurodivergence on their work and identify adjustments. OH will not determine whether an employee has a disability under the Equality Act 2010, but it can help ascertain the approach the employer should take. For example, if there are underlying neurodivergent issues for an underperforming employee, OH can be useful to ensure that an employer is not assessing performance in a way that is discriminatory.

From the perspective of the relationship between an employer and an employee – who may themselves be struggling with their condition and its impact on them – a referral to OH may also reassure the employee that their health and wellbeing are being taken seriously.

All smiles: a student at Coleg Elidyr

Cheers! Students at a station cafe run by Derwen College

A word of warning, however: employers should note that once an OH report is received, it will be extremely difficult to argue that they did not know (actual knowledge) or could not reasonably have known (constructive knowledge) that the employee may have a disability. This makes it essential to engage proactively and constructively with the recommendations that follow.

A further caution is that information about neurodivergence, including any health information and OH reports, constitutes special category health data under data protection legislation. Employers are required to handle such information confidentially and in compliance with the General Data Protection Regulation (GDPR).

> "A formal medical diagnosis is not required for an individual to be considered disabled"

3. Reasonable adjustments – Employers have a statutory duty to make reasonable adjustments under the Equality Act 2010 with respect to employees with a disability. OH advice can help shape what adjustments may be beneficial; ultimately, though, the most effective approach is often a direct, open conversation with the employee regarding assistance they consider would be useful to help them in the workplace.

What is a 'reasonable' adjustment will depend on the context. It has to be an adjustment with the effect of reducing or removing any disadvantage suffered by the employee due to their disability. It must also be reasonable in and of itself.

Larger organisations with more resources may, for example, be expected to make more significant adjustments than smaller employers. However, many adjustments carry little or no cost – taking an autistic employee who requires explicit instructions as an example, a reasonable adjustment may be that a line manager sets up a short call to explain their instructions in more detail, or sets it out in writing instead of verbally.

The key message for employers supporting employees with self-diagnosed or suspected neurodivergence is easy: do not assume they are not disabled. They should act promptly, ensure managers understand how to respond, and avoid requiring a medical or OH diagnosis before exploring appropriate assistance. Simple or helpful adjustments in any event may remove the need for medical intervention.

Early, informed and compassionate engagement not only reduces legal risk – it fosters a more inclusive workplace and productive employees, whether neurodivergent or not.

Aparna Sudhir is a solicitor at Winckworth Sherwood, https://wslaw.co.uk/

A Quality of Life approach helps prepare for transitions

Leaving school is an exciting rite of passage, but can be an anxious time for many of our students and their families.

At Swalcliffe Park School (SPS), a specialist residential and day school for autistic boys, preparation for adulthood begins as soon as students join us, often after families have faced a journey to secure the right support.

Our recent research shows how a Quality of Life (QoL) approach supports students and families to make successful transitions through and beyond school... but what is a QoL approach?

Our QoL approach

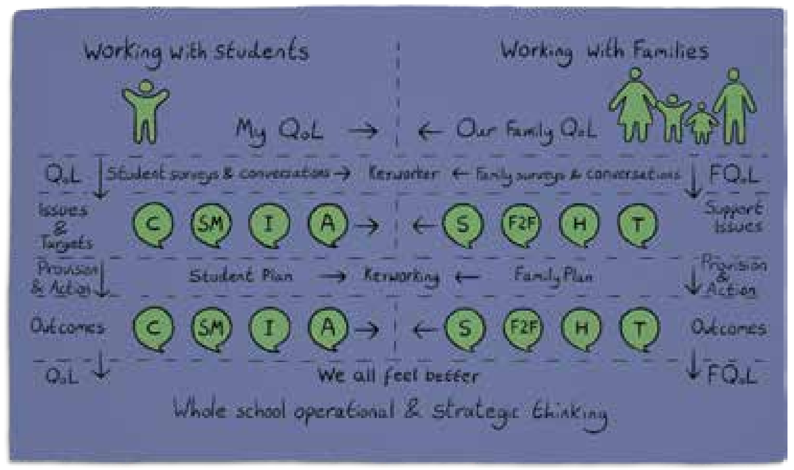
QoL refers to a person's sense of well-being, satisfaction and ability to participate meaningfully in life. Research from the Office for National Statistics shows that families of children with Special Educational Needs and Disabilities report lower QoL than those without, with families of autistic children reporting the lowest levels.

Our approach draws on Professor Robert Schalock's internationally recognised model, adapted for into four key areas:

- Communication
- Self-Management
- Independence
- Achievement

Our expert multidisciplinary team supports each area, with a collaborative culture focused on improving QoL outcomes for students and families.

Each student and family is supported by a keyworker who acts as their advocate. Through weekly sessions and termly surveys, students and families share their aspirations and concerns, creating a rich and evolving picture of what matters most as they prepare for adulthood.



Student and family voices

As school comes towards the end, uncertainties can arise around destinations, independence and support. Families describe growing pressure, including concerns about losing support, navigating unfamiliar systems and, for many, the cessation of EHCPs and challenges accessing adult services.

This is where our QoL approach provides reassurance and consistency of support. Strong keyworking relationships ensure everyone works together to achieve meaningful outcomes.

The four QoL pillars ensure a balanced focus on how students develop, and individualised pathways combine curriculum choices with building independence. Opportunities to hear from a variety of employers, visits to colleges and universities, careers advice and work experience placements are central to transition planning and support aspirational yet realistic goals. The approach also helps students develop greater self-awareness of their strengths and independence, enabling appropriate support planning.

Families report reduced anxiety through being genuine partners in the process and having their concerns addressed as well. One family said: "It's the connectedness between sixth form planning, therapeutic approaches, and best use of time during the school day and out of school."

A process, not an event

A whole-school QoL approach strengthens transition planning by aligning student voice, family perspectives and multi-disciplinary working. Ultimately, it reframes transition as more than a destination, but a school-wide process ensuring young people leave feeling empowered and confident about their future. It ensures that families are also best prepared for what is to come.

"From the moment children join the school, leaders and managers are thinking about their futures." Ofsted, 2026

If you would like to know more about our QoL framework and approach or about joining the QoL Network, please contact Kiran Hingorani on khingorani@swalcliffepark.co.uk. We'd love to hear from you!

AUTISM ACCREDITATION
ADVANCED

Ofsted
Outstanding Provider

DfE No: 931/7007
CIO Registered Charity No: 1173113
Principal: Robert Piner
CEO: Kiran Hingorani MEd

Swalcliffe Park School

www.swalcliffepark.co.uk

Beyond behaviour

Parents have long been told they were imagining a link between gut issues and concerning behaviours in their autistic children. Dr Iona Bramati says parents were probably right all along, and a technique called visceral osteopathy has been shown to improve gastrointestinal issues and behaviours in her patients

If your autistic child struggles with chronic constipation, diarrhoea, abdominal pain, vomiting or bloating, you are navigating one of the most under-addressed aspects of autism. You may have been told these problems are behavioural. But you may have long suspected that when the gut is bad, everything else gets worse. You are right. And the science is finally catching up.

How common are GI problems – and why does it matter?

Between 46 per cent and 84 per cent of autistic children experience clinically significant gastrointestinal (GI) symptoms. This compares with only around one in four (26 per cent) of neurotypical children.

A landmark 2024 review in *Nature Reviews Gastroenterology & Hepatology* confirmed that GI disorders are among the most prevalent medical co-occurring conditions in autism, and are consistently associated with greater severity of irritability, rigid compulsive behaviours, social withdrawal, and aggression (Margolis & Bhatt, 2024). Children on the spectrum experience GI disorders 4.4 times more often than their neurotypical peers.

Yet GI complaints remain chronically under-identified — because many autistic children simply cannot tell us they are in pain. What parents observe as a spike in meltdowns, increased self-injury, or unusual posturing, such as pressing the abdomen against furniture, may be the only available signal that a child is in significant physical discomfort.

Behaviours including facial grimacing, teeth-gritting, screaming, and applying pressure to the stomach should all be considered potential expressions of GI distress in non-verbal or minimally verbal children (Robas *et al*, 2025). Pain that goes unrecognised goes untreated – and its behavioural consequences are borne by the whole family.

Constipation: more than a digestive problem

Of all GI symptoms in autism, constipation is the most consistently reported and the most complex. It arises from a convergence of factors rarely seen together in any other population: enteric nervous system dysfunction, altered gut microbiota, abnormal serotonin signalling, food selectivity, and medication side effects – all interacting simultaneously (Jamka & Gulbransen, 2024).

The enteric nervous system – the 'second brain' – is a network of more than 500 million neurons embedded in the gut wall. Research shows that many gene variants associated with autism directly impair enteric neuron function and cause gastrointestinal dysmotility, suggesting gut problems may share a common biological origin with autism's neurological features (Margolis & Bhatt, 2024).

Around 95 per cent of the body's serotonin (which regulates mood, sleep cycles, digestion, wound healing, and bone health) is produced in the gut, where it drives peristalsis (involuntary muscle contractions that move food and waste through the digestive tract). Abnormalities in the serotonin reuptake transporter (SERT) – overrepresented in autism – simultaneously disrupt serotonin balance in the gut and brain.

A 2023 population cohort study found a statistically significant association between early childhood constipation and subsequent autism diagnosis (Lee *et al*, *Frontiers in Psychiatry*). A 2025 study confirmed that constipation measurably worsens autism-related behavioural symptoms through specific gut microbiota alterations (Li *et al*, *npj Biofilms and Microbiomes*). The relationship is causal, not coincidental.

The gut–brain axis: what it means

The gut–brain axis is not a metaphor. It is a bidirectional communication network operating through the vagus nerve (the body's longest nerve, connecting the brain to major organs), the immune system, the endocrine system (glands and organs that release hormones into the

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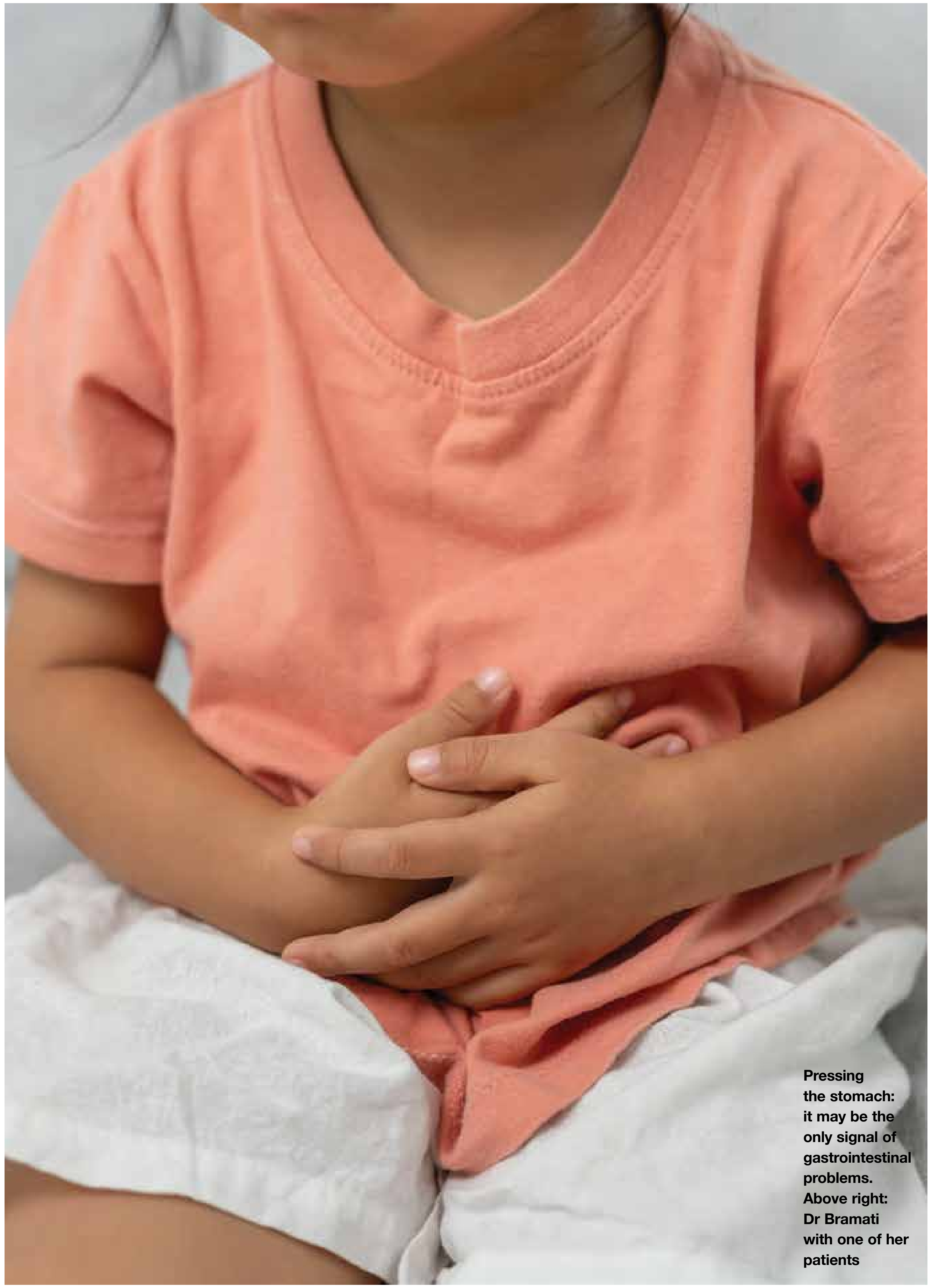
> “GI disorders are among the most prevalent medical co-occurring conditions in autism”

What parents can do

- **Document GI symptoms systematically** — bowel frequency, consistency, and any link to behavioural changes. The Bristol Stool Chart is a useful tool when speaking with clinicians.
- **Request a faecal calprotectin test** from your GP — recommended by NICE (DG11, 2013) as a non-invasive first-line screen for bowel inflammation, particularly where endoscopy would be distressing or impractical.
- **Recognise pain signals** in non-verbal children — pressing the abdomen against surfaces, unusual posturing, increased self-injury, and mealtime distress should prompt GI assessment, not purely behavioural intervention.
- **Consider visceral osteopathy** from a specialist experienced with autistic children as a safe, evidence-informed complementary approach — not a replacement for medical management, but a meaningful addition to it.

The science of the gut–brain axis in autism is advancing rapidly. Parents who have long observed the connection between their child's gut and their behaviour were not imagining it. The task now is to translate this evidence into clinical pathways that reach the families who need them.



Pressing the stomach: it may be the only signal of gastrointestinal problems. Above right: Dr Bramati with one of her patients

bloodstream), and the enteric nervous system, the ‘second brain’. Disruption in any one pathway generates downstream effects in the others.

In autism, gut dysbiosis – measurable bacterial imbalances – affects production of short-chain fatty acids and neuroactive compounds that communicate directly with the brain (Mishra *et al*, 2025; Zhang *et al*, 2025).

Increased intestinal permeability, or ‘leaky gut’, allows inflammatory cytokines (small proteins that normally help fight infections) to cross the blood–brain barrier, driving neuroinflammation and amplifying anxiety, social disengagement, and repetitive behaviours (Dargenio *et al*, 2023). For children whose behaviour is being driven by GI dysfunction, addressing the gut may be one of the most direct routes to improvement available.

The evidence for visceral osteopathy: a gentle, non-invasive approach

My PhD research – conducted with King’s College Hospital London, the University of Westminster, and the British College of Osteopathic Medicine – investigated the effects of Visceral Osteopathic Technique (VOT) on 49 autistic children.

They were aged three and a half to eight years, and presented with GI symptoms and behavioural regression, including loss of previously acquired skills alongside classic lower-spectrum autism presentations (Bramati-Castellarin, Patel & Drysdale, 2016).

VOT involves gentle, rhythmic mobilisation of the abdominal organs – the duodenum, ileo-caecal valve, sigmoid colon, and pancreas – aiming to improve circulation, peristalsis, and neuroregulatory responses via the enteric nervous system.

Children received six weekly 30-minute sessions, with parents completing validated questionnaires throughout. Results showed statistically significant improvement in vomiting ($p=0.00029$), poor appetite ($p=0.039$), and, notably, eye contact ($p=0.035$), alongside overall improvement across the digestive signs and social behaviour subscales.

While reduced eye contact is present in many, but by no means all, autistic children, its improvement following gut-targeted treatment points to something broader: that behavioural features in autism may, in at least a subset of children, be mediated or worsened by undiagnosed physical discomfort.

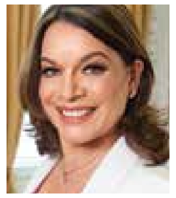
> **“Addressing the gut may be one of the most direct routes to improvement available”**

For parents whose child does not present with reduced eye contact, the principle still holds: if your child’s gut is inflamed and they cannot tell you, that pain will express itself somewhere in their behaviour.

A second published study used faecal calprotectin, also a non-invasive stool marker of gut inflammation, alongside a 24-parameter questionnaire. It found that “need for a fixed routine” and “constipation” together act as independent predictors of bowel inflammation, offering parents and clinicians a simple, non-invasive screening tool (Bramati-Castellarin, Patel & Drysdale, 2017).

Since the research, these techniques – now developed into what is known as the Bramati Method – have been applied across a much wider range of autistic children, from non-verbal to fully verbal. The results continue to reflect the original findings.

What remains constant is this: the intervention is entirely non-invasive, carries no pharmaceutical side effects, and is guided at every stage by the comfort and well-being of the child.



Dr Iona Bramati, a director of www.ibccare.co.uk, has been awarded a PhD in recognition of her work on the ‘Effectiveness of Visceral Osteopathic Treatment on Gastrointestinal Indicators and Behaviour Patterns in Autistic Children; Using Questionnaire and Biochemical Markers to Measure Outcomes’. Her PhD was awarded by the University of Westminster in collaboration with King’s College Hospital, endorsed by the National Autistic Society (NAS), supported by BCOM and sponsored via the British Naturopathic and Osteopathic Association (BNOA) grant. Dr Bramati was recognised at the ICAOR10 for her outstanding research.

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A lot hanging on the appointment: but getting a diagnosis is just the start to getting the right support

Preparing for diagnosis

Thousands of children and adults are awaiting an autism diagnosis, but what should those on a frequently long waiting list do to prepare for the assessment day? Fiona McNeill speaks to experts to gather advice for the journey ahead

You've finally got an appointment to start the process of getting an autism diagnosis for your child or yourself. You might have waited a long time for this and battled teachers and health professionals for your concerns to be taken seriously. Now it's here, how do you prepare for the consultation and make sure you get the best help?

Dr Sylvia Baker is a consultant child psychiatrist who specialises in autism and ADHD. She works for Re:Cognition Health, an organisation that supports people with neurodiversity, brain injury and Alzheimer's.

She points out that an autism assessment – where professionals consider a patient's behaviours, difficulties and strengths – is different from the diagnosis, which might follow on later and is more formal and structured.

"I always advise families to put together as much information about their child as they can before they start the process," Dr Baker says. "Speak to teachers or adults who know your child well. Did the challenges start in their early years, or are they more recent?"

It's common, she continues, for parents to report that the young person 'masks' and is well-behaved at school, while 'losing it' at home. In these cases, she recommends parents video the meltdowns as evidence.

"The diagnosis is only the start," she cautions. "The whole point is to get the right support. Caring mums often say to me, 'If I don't know what the problem is, how can I help?' We also offer post-diagnostic support. This comes about four weeks later, so the family has had time to process the information."

The Owl Centre offers NHS and private assessments for autism and ADHD and has produced 'Waiting Well' – a free, online video for anyone preparing for a diagnosis. Charlotte Forsyth, the organisation's chief commercial officer, advises helping a child prepare for their appointment by showing them pictures of the people they'll be meeting or doing a test run to the clinic.

> “You often find that teenagers are more open to a diagnosis”

"There can be a lot hanging on the appointment," she acknowledges. "People might worry that the child won't 'perform' on the day. But, I would say, don't *over*-prepare. Our clinicians are very astute, and they listen to parents. It can be quite emotive for families, but getting a diagnosis doesn't have to be this big, defining moment."

Colleague Nicola Lathey, Owl's founder and director of clinical services, recommends talking about the upcoming appointment in a low-key way. "Keep the conversation informal. For younger children, you might want to say, 'someone's going to have a chat with you about how your brain works'."

For older children, she suggests talking about neurodiversity in a general way, perhaps drawing attention to autistic people in the media. "You often find that teenagers are more open to a diagnosis because they're beginning to realise their social difficulties. My partner's daughter, for example, is 15 and waiting for an assessment. People keep telling her she's 'rude' when she doesn't mean to be, and we're pretty sure she's autistic. She's keen to find out if that's the case."

The number of adults seeking an autism diagnosis hasn't increased in recent years, Lathey says, but they see a broad age range. "Whenever I've diagnosed an older person, it's been very emotional. They realise the impact the condition has had on relationship breakdowns, job losses and family problems over the years."

Spectrum Sisters offers remote autism and ADHD assessment solely for females aged 12 and above. The organisation was set up by counsellor and former social worker Chay Thompson in response to the number of girls and women she'd encountered whose neurodiversity had been missed or attributed to something else. All members of staff are female and neurodivergent.

The assessment process is not for the faint-hearted, Chay cautions. "It takes five or six weeks. We have a multi-disciplinary team, 28 questionnaires, and the first interview lasts three hours. It can be quite daunting, but we need to rule out co-occurring conditions.

"About 70 per cent of our clients are women in their forties and fifties who are high-functioning and present 'normally', but they may have been internalising their difficulties and 'masking' for years. Often, their symptoms have been exacerbated by menopause. It can take time to find out what's really going on."

She advises women seeking a diagnosis to be as open as

>

Assessment in numbers

- **254,108:** number of people with a referral for suspected autism in England in December 2025, according to the NHS.
- **90%:** the proportion of those with a referral who had been waiting for an assessment for longer than the recommended 13 weeks.
- **More than 17 months:** the average waiting time for an autism assessment in England, though wait times can vary from a few months to more than four years.
- **11%:** the increase in the waiting list compared to three months earlier, in September 2025.
- **More than 65,000:** the number of people waiting for autism and ADHD assessments in Scotland.
- **More than 20,000:** the number of children waiting for autism and ADHD assessments in Wales.

possible during the consultation process and try not to mask or suppress a need to stim – though she acknowledges that can be difficult. "We always ask our clients what they're hoping to achieve with a possible diagnosis. Some want reasonable adjustments at work, some want to claim PIP. Mostly, they want to understand why they've always felt 'a bit different'."

Dani Samuel is the principal at Strathmore College in Stoke-on-Trent, a facility for students aged between 16 and 25 who are autistic or have social, emotional or mental health difficulties, or physical challenges. She speculates that parents may be relieved when their child receives a diagnosis of autism because it provides validation.

"They may have been feeling guilty that their child's difficulties might be the result of poor parenting," she says. "The diagnosis shows other people – who might even be other family members – that this is not the case."

At the school, Dani has noticed that, sometimes, students want to discuss their diagnosis with staff. "We're completely open if a young person wants to talk about it, but we only mention autism in a positive sense," she continues. "It's a difference, not a deficit. We say that a diagnosis is simply an 'opportunity for the world to understand you better'. It means they can access support and a community of other autistic people.

"Ultimately, we want all young people to thrive and have a fabulous life, no matter who they are. Everyone needs to learn how to behave and access life, but with autistic youngsters, you just need to approach it in a different way." Ⓐ

LINK:
- The Owl Therapy Centre: http://www.theowltherapycentre.co.uk
- Re:Cognition Health: https://recognitionhealth.com/
- Spectrum Sisters: https://spectrumsisters.com/
- Strathmore College: https://www.aspris.com/strathmore-college/
- Waiting Well: https://waitingwell.co.uk/support/understanding-the-process/

Girls with ADHD: why it's important to get an early diagnosis

Greater support is needed to help girls with ADHD, who often go without a diagnosis and bear the long-term consequences, says consultant psychiatrist Mukesh Kripalani

Dr Mukesh Kripalani is the lead adult consultant psychiatrist at The ADHD Centre. He is a Fellow of the Royal College of Psychiatrists and was a regional representative for the General and Community Faculty of the Royal College of Psychiatrists. He has been awarded Clinical Excellence Awards by the NHS trusts he has worked for. https://www.adhdcentre.co.uk/

Diagnosis of ADHD in girls is still being overlooked, and the consequences are significant.

New large-scale research[1] shows that girls are not only less likely to be diagnosed with ADHD in childhood, they are also typically diagnosed years later than boys, often in their teens or early twenties. By that point, the impact has already taken hold across mental health, education and wider life outcomes.

The study found that young women diagnosed later, between the ages of 12 and 25, experienced markedly worse outcomes than those diagnosed earlier, and significantly worse outcomes than females without ADHD.

One of the most important findings is that these girls were not symptom-free in childhood. Even those diagnosed later showed clear evidence of earlier struggles, including mental health challenges and difficulties at school, when compared with their peers. This reflects what clinicians see every day. ADHD in girls often does not look like ADHD, as it is traditionally understood. It is less visible, less disruptive and far easier to miss. Rather than externalised behaviour, it tends to present as:

- Inattention
- Anxiety
- Emotional overwhelm
- Perfectionism
- Quiet disorganisation

Many girls try hard to compensate, masking their difficulties and meeting expectations, at least on the surface.

ADHD in girls is often not picked up because they don't fit the stereotype, which is usually focused on how boys present. They are not the ones causing problems in the classroom or playground. They are the ones who are trying very hard to hold everything together, often at a significant personal cost.

By adolescence and early adulthood, the picture changes. The same study found that females diagnosed later had higher use of healthcare services, poorer mental health, lower educational attainment and more challenging socioeconomic outcomes. In clinical practice, this often presents as anxiety, depression, chronic stress and burnout, layered on top of years of feeling out of step but not understanding why.

By the time many women come to us, they are exhausted. They have spent years trying to manage something they don't have a name for. A diagnosis can be a huge relief, but it also comes with a sense of what might have been different if it had been recognised earlier.

The disparity is not accidental. ADHD has historically been defined through a male lens, with diagnostic criteria and awareness shaped around more visible, hyperactive presentations. Girls are less likely to be referred for assessment, more likely to internalise their difficulties, and more likely to be labelled as anxious, sensitive or simply not coping well. The result is a consistent pattern of late diagnosis, and a group of young women who are disproportionately affected.

There has been a noticeable rise in adult women seeking ADHD assessments, many of whom describe the same experience of high functioning on the outside, paired with internal overwhelm and eventual burnout. While this shift in awareness is important, it does not address the underlying issue.

Adult diagnosis matters, but it is not enough. We need to get better at recognising ADHD in girls much earlier. The signs are there, but they are different. If we can identify it sooner, we can change outcomes in a very real way. The evidence is now clear. Later diagnosis is associated with significantly worse outcomes, and girls are the ones most affected.

REFERENCE:

[1] Martin, J et al: Antecedents and outcomes of a later attention-deficit hyperactivity disorder (ADHD) diagnosis in females', *Br J Psychiatry*, 2026, https://pubmed.ncbi.nlm.nih.gov/41804225/

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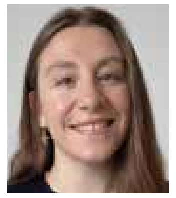
Jumping: this movement could be part of a sensory plan – see the table of possible strategies on page 49

How families can help

What can parents do to help if their child is waiting for a diagnosis? Understanding sensory processing and supporting regulation can boost their well-being, says occupational therapist Olivia Hodges



Olivia Hodges is a specialist paediatric occupational therapist at Starjumpz, https://www.starjumpz.com/

Wait times for an autism assessment can vary across the UK and are often far longer than families expect, leaving parents and carers feeling uncertain, emotionally stretched, and trying to support their child without the clarity they deserve.

While an assessment outcome can open doors to formal recognition and support, helpful adjustments do not need to wait. One way that families can begin understanding their child's needs is by exploring sensory processing and how this may influence regulation and confidence at home and school.

Understanding sensory processing

Sensory processing refers to how we notice and respond to information received through our sensory systems. These differences are part of everyday human diversity and can change depending on environment, stress, or support.

Child-led strategies

Important: Sensory strategies should always be child-led and consent-based. If a strategy increases distress, pain, or shutdown, stop and reassess. Seek professional advice if you have safety concerns (for example, risk-taking, self-injury, sleep, eating/drinking, or toileting).

The strategies in the table overleaf (page 49) are general ideas and should be adapted and reviewed for each child. What helps one child may not help another, and needs can change over time.

Why multidisciplinary support matters

Although families are often encouraged to try strategies while

> “Children benefit most when understanding and support are shared across systems”

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Area	Home strategies	School strategies	Sensory linking
Environment	Calm colours, reduced clutter, soft furnishings, gentle lighting. Ear defenders or white noise during sleep.	Reduced background noise, soft furnishings, access to ear defenders and clear visuals.	Supports regulation and reduces sensory overload.
Calm space	Quiet retreat with soft seating and familiar sensory items.	Calm corner with soft lighting and sensory tools.	Provides a safe space for selfregulation.
Seating	909090 posture rule (three 90-degree angles at elbows, hips and knees) and flexible seating options.	Wobble cushions, kick bands, or bean bags.	Provides proprioceptive input to support attention.
Movement breaks	Jumping, climbing, or fidgets matched to the child's needs.	Timetabled movement breaks using active or calming movement.	Supports arousal levels and regulation.
Heavy work	Carrying shopping, pushing furniture, animal walks, wall pushups.	Carrying equipment, moving chairs, playground climbing.	Proprioceptive input helps organise the nervous system.
Transitions	Predictable routines, visual cues, and advance notice	Visual timetables, now and next, clear instructions.	Increases predictability and reduces anxiety.

waiting, children benefit most when understanding and support are shared by different people across the various systems around them (home, school, and health services) and they are shaped with the family's involvement.

A multidisciplinary team brings together different professional perspectives to build a fuller picture of a child's strengths, needs, and environment.

When professionals work in partnership with families (and with the child or young person where appropriate), support is more likely to be flexible, respectful, and practical.

The focus is on improving access and well-being while the diagnosis is in process.

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When a child slips backwards

It can be heartbreaking to see your child lose skills they had. Stella Chadwick's advice to parents is never give up trying to find out what caused the regression, because there are ways of fighting back

There's a particular kind of heartbreak that comes from watching your child lose what they had. The words. The eye contact. The way they used to climb into your lap. One day it's there, and then it isn't.

In our clinic, we hear a version of this story every week. For some families, there is a clear before and after, a fever, a course of antibiotics, a hospital stay. For others, there is no single moment, just a slow realisation that something has changed. Whatever the path, regression is biological. It has a cause; in most cases, that cause can be investigated and addressed.

Learning from 'long Covid'

Parents of autistic children have been telling doctors for years that their child was different after a fever, a virus, or a course of antibiotics. And for years, they've been told it was a coincidence, that there was no link, that it was all in their head.

Then Covid-19 came along, and suddenly millions were describing brain fog, exhaustion, low mood and sleep problems that hung around long after the infection had cleared. Long Covid gave the world some insight into what these parents of autistic children had been describing. In some people, the immune system carries on producing inflammation for weeks or months after the infection itself has cleared. That ongoing inflammation is what causes the lingering symptoms.

For the children we work with, something similar is happening, just earlier in life.

An immune event

In our clinic, we have a name for what we're looking at. We call it an immune event.

An immune event is anything that switches the immune system on in such a way that it can't quite switch off. Often, the cause is something obvious: a high fever, a serious illness, a heavy course of antibiotics. Sometimes it's something the parent didn't notice at the time. It can also be slow and ongoing, such as low-grade inflammation from gut problems, mould, environmental toxins or chronic stress. Or several small things stacking up over months until the body can't keep up.

Most parents come to us looking for the one thing that explains everything. There usually isn't one thing. In some children, the immune system reacts to a challenge and then settles back down. In others, it doesn't. It keeps reacting, keeps signalling the brain a long time after the trigger has gone. In our clinical experience, that is what we find underneath many of the regressions we see.

Not in your head

Most autistic children who regress do so between 12 and 24 months old. Some lose skills suddenly, over days or weeks. Others slide more gradually.

The biology behind it has been visible in the literature for nearly 20 years. In 2005, researchers at Johns Hopkins University examined brain tissue from autistic children who had died of unrelated causes and found something striking. The brain's immune cells, the microglia, were active and inflamed across multiple regions. It was the first study to show this kind of widespread neuroinflammation in autism.

> "If a clinician dismisses your questions … they are not the clinician you need"

Six years later, a team at the MIND Institute in California turned to the blood. They compared 40 children with regressive autism with 53 children whose autism developed without regression, and with typically developing controls. Four inflammatory cytokines, IL-1β, IL-6, IL-8 and IL-12p40, were raised in the autistic group, and the rise was driven by the children who had regressed. IL-1β was running at more than double the level seen in the non-regressed group.

A 2019 meta-analysis of 38 studies confirmed that autistic children, as a group, carry higher levels of IL-6 in their blood than neurotypical children. IL-6 is what the body releases to fight infection. Once the infection is gone, it should fall. In many of these children, it never falls.

The fever clue

There's an observation parents have been making for years that I think is one of the most striking clues we have.

When some autistic children develop a high fever, they change. They make more eye contact, use more words, and become more engaged with the world. Once the fever is gone, so is the change. A 2007 study followed 30 autistic children through febrile illnesses and found that more than four in five of them (83 per cent) showed fewer autism-associated behaviours during the fever.

Most parents who describe this have been told it doesn't mean anything. But it does. If autism were purely a matter of fixed brain wiring, a fever wouldn't change a thing. The fact that it does, in some children quite dramatically, tells us something important about the brain in autism.

In neurotypical children, infections work the other way round. Each one tips them into a worse state, with sleep, mood and gut symptoms flaring up. Whichever direction it runs, it appears the immune system is influencing the brain.

Same biology, different name

You may have come across the terms PANS and PANDAS. The latter stands for Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infection; it describes children who suddenly develop obsessive-compulsive behaviour (OCD) or tics following a strep infection.

PANS, short for Paediatric Acute-onset Neuropsychiatric Syndrome, broadens the picture. The child experiences a wider range of immune triggers and a wider range of symptoms, including

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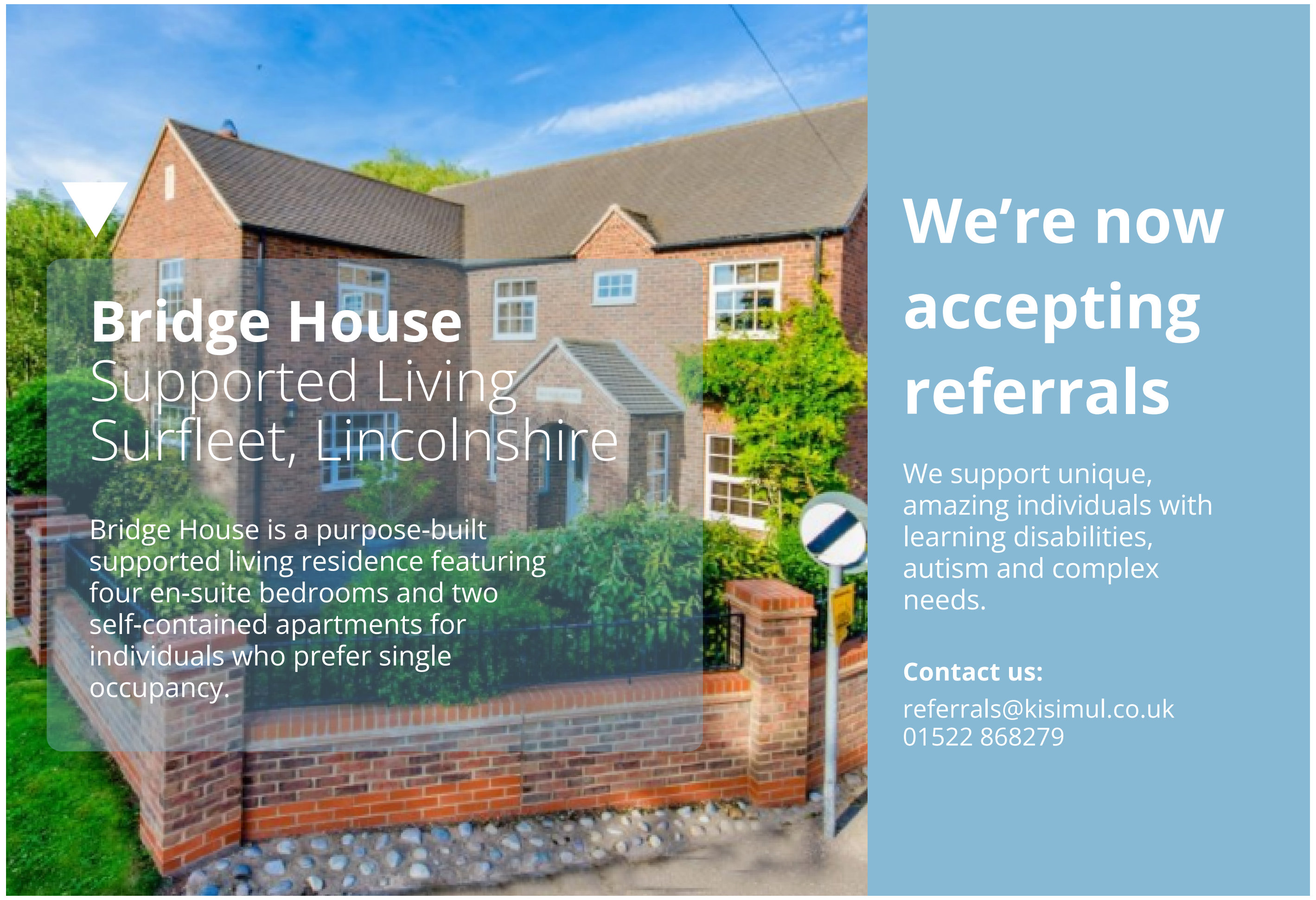

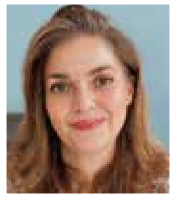

Stella Chadwick is the founder of Brainstorm Health® and an experienced nutritional and biomedical consultant who specialises in working with adults and young children on the autism spectrum. www.brainstormhealth.co.uk

food refusal, rage, sleep disruption, deteriorating handwriting, urinary frequency, sometimes appearing almost overnight, and more often developing over weeks and months.

After 13 years working with around 3,500 families, my view is this: a subset of autism, particularly including children who have regressed, may share underlying biology with PANS, PANDAS and chronic fatigue. Their immune system reacts to a challenge and then fails to switch off properly, presenting differently depending on the age of the child when it happens.

In a small child, this can drive regression and skill loss, and the child ends up with an autism diagnosis. The same biology in an older child often appears, with OCD, rage and handwriting deterioration, and is labelled PANS or PANDAS. In an adolescent, it tends to shift towards fatigue and cognitive decline and is labelled chronic fatigue. It is a hypothesis, not a textbook position. But the consistency of the pattern across thousands of cases is, in my view, too striking to be incidental.

In these children, this matters practically. A PANS-type flare-up is easy to miss because new symptoms get folded into the existing diagnosis. The handwriting problem is called a fine motor issue. New rituals are called sensory regression. New rages are called dysregulation. Nobody steps back and asks what changed, and when, and what came just before.

The wider picture

The children we work with are rarely just autistic. A 2018 CDC study using Autism and Developmental Disabilities Monitoring Network data found that more than 95 per cent of autistic children had at least one co-occurring medical or behavioural condition. For children who have regressed, the picture is usually busier still.

Most of them have allergies, eczema, asthma or food intolerances. A Taiwanese study of nearly 1,600 autistic children found asthma was around 74 per cent more common, hay fever 70 per cent more common, and eczema around 50 per cent more common than in children without autism. These are surface signs of an immune system that is already running hot.

Many also have ongoing gut symptoms. The gut is one of the most active immune organs in the body; when it's inflamed, that inflammation reaches the brain.

What to ask

Standard NHS bloods rarely capture what's going on in these children. They are designed to spot sudden, acute illness, not the slow, low-grade inflammation we are describing.

Ask for basic inflammatory markers, including CRP, ESR and ferritin. Ask for thyroid antibodies. Ask for your child's history of infection, antibiotic use and sudden changes to be looked at as a single timeline, not as separate problems on separate visits. Ask whether sudden changes in behaviour, sleep, eating or movement might be part of the same picture. And ask whether the clinician would refer you on to someone who works specifically with the immune side of autism.

If a clinician dismisses your questions, or tells you that medical issues stop being relevant once an autism diagnosis is in place, they are not the clinician you need.

Where to begin

You don't have to wait for tests to start working on the foundations. Sleep is probably the most underrated of these. A nervous system that has been on alert for a long time will not settle without proper sleep, and that often means treating sleep itself as the first intervention. Food matters, too: simple, real food the gut can handle, with less of the ultra-processed kind that keeps inflammation simmering. The basic nutrients most of these children are short of are zinc, magnesium and the B vitamins.

The most useful thing any parent can bring to a clinician is a written history. Symptoms, illnesses, courses of antibiotics, sudden changes, and when each thing happened, and what came just before. Patterns that have felt invisible for years often become obvious once they are on paper.

None of this replaces proper investigation or treatment. But getting the foundations in place takes pressure off a body that has been under strain for a long time, and gives anything else you do a better chance of working.

A different starting point

Regression in a child is not a fixed state. In the children we work with, it often turns out to be the outward expression of an immune event that is still going on. Once you understand what is driving it, there is a great deal that can be done.

Some children recover most of what was lost. Others recover less. How well a child does depends a great deal on how early the immune issue is spotted and how seriously it is treated.

If you have watched your own child go backwards, trust what you have seen. Then find a clinician willing to look at the whole child, not just the diagnosis. You may not get all the answers. But you will be looking properly, which is more than most of these children ever get.

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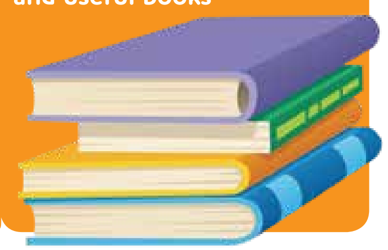


Supporting Autistic People with Eating Disorders

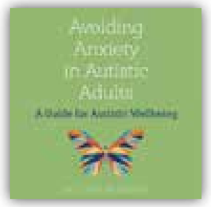
This book explores the link between autism and eating disorders through testimonies from practitioners, service users and carers. Combining research findings, case studies and first-hand accounts, it provides insights into how individuals on the autism spectrum can be supported towards full recovery from an eating disorder.

It's edited by the lead clinical psychologist at the Maudsley Eating Disorder National Service, informed by their team's research. Chapters focus on the unique issues arising when autism and eating disorders coexist.

The contributors suggest treatment adaptations from a multi-disciplinary perspective, and touch more broadly on the topic of poor mental health outcomes for autistic individuals, and how these might be improved.

● **Jessica Kingsley, £21.99/$30.95**

Avoiding Anxiety in Autistic Adults



One of the biggest challenges if you are an autistic adult (or suspect you might be) is navigating the situations that to the predominantly neurotypical population might appear completely benign, but which cause you huge stress, anxiety and worry.

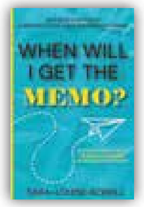
In school, at work, at university, in social situations, in friendships, relationships, in shops, in unfamiliar environments – there are a wealth of situations that can make you feel overwhelmed. The world may be full of things that you feel nobody else notices, but which cause you distress.

Dr Luke Beardon has put together an optimistic, upbeat and readable guide that will be essential reading, not just for autistic adults, but for anyone who loves, lives with or works with an autistic person. Emphasising that autism is not behaviour, but at the same time acknowledging that there are risks of increased anxiety specific to autism, this practical book gives clear strategies that the autistic person can adopt to minimise their anxiety and live comfortably in a world full of what may seem to be noise and chaos.

The book gives clear guidelines and mission statements to those who live or work with autistic people that they, too, can implement to accommodate needs that are different to their own. The aim is to take a step towards an inclusive world in which autistic people don't just survive, but thrive.

● **Sheldon Press/Hachette UK, £10.99**

When Will I Get the Memo?



Sara-Louise Ackrill's book is an unfiltered and compassionate look at the emotional intensity that can accompany ADHD and autism, particularly the pain of perceived rejection, criticism, misunderstanding, and chronic self-doubt.

Social rejection is often deeply debilitating, yet widely misunderstood. *When Will I Get the Memo?* breaks down social rejection into its many component parts, acting as a guide for anyone who finds it difficult to understand or articulate their reactions to it.

The book offers readers validation, reframes, and practical tools to support emotional understanding and self-awareness. It encourages readers to see themselves as part of the wider human experience, particularly in a world where the social costs of "me versus them" thinking are so often overlooked.

Written with warmth, honesty, and relatability, the book speaks directly to readers who have spent years feeling "too sensitive", emotionally exhausted, or disconnected from others.

As Sarah Louise explains: "Many neurodivergent people grow up feeling like everyone else was handed instructions for life that they somehow never received. This book is about giving language to those experiences and helping people understand themselves with more compassion and less shame."

● **Wired Differently, £12.99 online**

A Clinician's Guide to Mental Health in Adults with Autism Spectrum Disorders

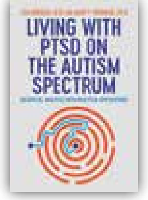
This comprehensive guide addresses the issues faced by clinicians in assessing and treating the range of mental health conditions that can affect autistic adults. Its particular focus on adults fills a notable gap in professional literature about autism.

It features an array of contributors from the psychology and healthcare professions and covers a wide variety of common co-occurring mental health conditions, including mood disorders, anxiety, psychosis, obsessive-compulsive disorder, personality disorders, and eating disorders.

This guide also explores broader issues in promoting positive mental health and wellbeing. Authoritative and detailed, this is a valuable resource for all clinicians and professionals looking to understand and tailor their approach to mental health in autistic adults, and the need for specific methods and strategies to enhance assessment and treatment.

● **Jessica Kingsley, £38.99/$49.95**

Living with PTSD on the Autism Spectrum



The relationship between autism and post-traumatic stress disorder (PTSD) has historically been neglected in research, but it impacts the lives of many. Autistic people are intrinsically vulnerable to traumatic social situations and relationships, which can later manifest as PTSD. It can lead to seemingly commonplace events being processed as traumatic experiences.

In this collaboration, Lisa Morgan and Mary Donahue explore PTSD in autistic adults as patient and practitioner. Lisa shares her experiences as an autistic adult, reflecting on emotionally traumatic events and their effect on her daily life. Mary examines the challenges surrounding diagnosis, reworking and developing communication and clarifying the symptoms of PTSD within the autistic population.

Combining lived experience with professional expertise, this clear and accessible guide will provide a better understanding of autism and PTSD, providing support and direction to autistic adults processing trauma and those involved in their care.

● **Jessica Kingsley, £17.99/$25.95**

oraNurse®

UNFLAVOURED TOOTHPASTE

AUTISM FRIENDLY

OraNurse® is an unflavoured toothpaste specially formulated for people sensitive to strong flavours. It contains the daily recommended fluoride, is SLS free (non-foaming) and gentle on teeth with an RDA (relative dentin abrasion) value of 29.68

3 great reasons to smile!

- 1000ppm/ 1450ppm FLUORIDE PROTECTION ✓
- NON FOAMING ✓
- UNFLAVOURED ✓

OraNurse Unflavoured Toothpaste is designed with sensory sensitivities in mind, making it a trusted choice for autistic individuals who find traditional toothpastes overwhelming.

Free from flavourings, colourings, and sodium lauryl sulphate (SLS), it offers a gentle, neutral brushing experience without strong tastes or foaming agents. This makes daily oral care more manageable and less stressful for those with heightened sensory awareness.

Despite its mild formulation, OraNurse still provides excellent protection against cavities and plaque. Recommended by dental professionals and carers alike, it is ideal for both children and adults. Whether at home, in schools, or care environments, OraNurse helps promote independence and comfort in oral hygiene routines. Make brushing a positive experience with OraNurse.