



Education meets therapy and fun

Sensational gift ideas, from puzzle playmats to a sophisticated smartwatch



Diets with the strength of iron

How to spot the common deficiency of this mineral and redress the balance



Our family's precious gift

Dame Stephanie Shirley explains why she donated her son's brain for research

Autism | eye

For parents and professionals

Issue 48
Winter 2022/23

Where is the appliance of science?

Spotlight on dire autism research

Why we need a profound autism diagnosis

Legal advice on an alternative to school

Support after hospital release

Showtime: relaxed performances galore

When sociability is disrupted, can it be reversed?

News, books and more



UK's Largest Family-Led Specialist Residential Care Provider

Home From Home Care

For individuals with complex needs, we create bespoke residential services with meaningful pathways to greater independence

Our services incorporate homely environments of varying styles and sizes, designed for small groups of compatible individuals to live within an extended family ethos, on their own terms.



Parents - We deliver fulfilled days for your sons and daughters through effective care and support, focusing on independence, self-worth and new opportunities.

Teachers - We build on your dedication and life skills, to ensure your students progress and develop to their fullest potential.

Commissioners - We are a proven and successful social care alternative to ATUs for adults with learning disabilities and high acuity needs, autism and complex health & mental health.

Learning Disabilities, Autism and Complex Physical and Mental Health

Call 0800 587 0372
homefromhomecare.com



In this issue



On the cover
16 Autism, Alzheimer's and Covid
Dr Ben Marlow looks at similarities between different conditions where there is a wide disparity in research funding, and urges more collaboration.

Features
06 News
Police 'must act' as hate crimes soar but prosecutions plummet.

12 We exist: the case for profound autism
Alison Singer, head of the Autism Science Foundation, says it's time to end the 'ludicrous' one-size-fits-all autism diagnosis.

20 A valuable gift
Dame Stephanie Shirley, whose autistic son died suddenly at the age of only 35, explains why she chose to donate his brain for autism research.

23 Is there life after hospital?
Relatives call for appropriate accommodation in the community to end stays in mental health hospitals.

26 Lessons for life
Innovative and successful ideas for delivering personal, social, health and economic education.

32 It's showtime
A host of panto, theatre and film events that have been adapted for audiences on the autism spectrum.

38 Seasonal gift ideas
Take your pick from fabulously fun items that are also therapeutically or educationally useful.

44 When school doesn't work
An expert legal guide to accessing education at home if formal schooling for your child has failed.

49 The science of sociability
A lack of sociability may relate to environmental factors – and be reversible, research suggests.

52 Mighty iron
Iron deficiency is common in autistic children. We look at what you can do to combat the problem.

54 Library Corner

Empowering through diagnosis, play-based interventions and meeting underlying health needs

Re:Cognition Health is a pioneering brain & mind clinic providing autism and ADHD diagnostics, developmental programmes and a bespoke multidisciplinary service to clinically evaluate and manage underlying medical difficulties.

The team are leading providers in evidence-based and play-based interventions for children with autism. Programmes include:

Paediatric Autism Communication Therapy (PACT) for children aged 2-10 years which comprises parent/carer-led video feedback

Early Start Denver Model (ESDM) for babies and toddlers showing early autism signs, which consists of play-based parent coaching

The team are also motivated to help better understand unmet health needs in neurodevelopmental conditions that can impact on development including sleep, learning and quality of life. They have expertise in helping manage a variety of conditions commonly affecting individuals on the autistic spectrum such as constipation/ bowel dysmotility, gastroesophageal reflux, migraine, immune and metabolic differences.

Re:Cognition Health: supporting individuals through a 'whole system' approach to mental and physical health.

Re:Cognition Health
77 Wimpole Street
London W1G 9RU

Take action today
020 3355 3536
www.recognitionhealth.com
f @ReCogHealth

Involved in this issue



Dame Stephanie Shirley
Entrepreneur, philanthropist, founder of Autistica & Prior's Court



Dr Ben Marlow
Paediatric consultant, clinical director



Stella Chadwick
Nutritional therapist



Tim Nicholls
Head of research, National Autistic Society



Lydia Dunford
Specialist solicitor, Boyes Turner



Alison Singer
President & co-founder, Autism Science Foundation



Dr Gina Gómez de la Cuesta
Clinical psychologist & founder, Play Included



Risca Solomon
Director, Skybound Therapies



Dr Randall Peterson
Dean, University of Utah College of Pharmacy



Lisa Harker
Director, Nuffield Family Justice Observatory



Brigene McNeilly
Autism advocate



Dr Rosena Allin-Khan MP
Shadow minister for mental health



Nicola Trotman
Autism mother

We need a differentiated diagnosis



Gillian Loughran

As we prepare for the New Year, with all its surprises – good and bad – spare a thought for families whose children are impacted by the challenges of profound autism. Many understandably struggle with the 'autism is a gift' message that is commonplace. Their children don't even have a specific diagnosis that accurately identifies their profound needs and how to support them.

For these parents, it is distressing that people with profound autism fall under an ASD umbrella that is given for everyone diagnosed with autism today. Their children are bundled in with the likes of multi-billionaires Elon Musk and Bill Gates.

On page 12, Alison Singer, of the US-based Autism Science Foundation, describes the march of a determined movement of parents and scientists that aims to shine a spotlight on the reality of life for people with profound autism.

We know that many suffer from painful and life-limiting co-occurring health issues and many die young as a result. Some, for instance, suffer Sudden Unexpected Death In Epilepsy (SUDEP), which is highlighted by Dame Stephanie Shirley in her heartfelt feature on page 20.

Families tell us they want more research into their child's condition. As I write this, news of a drug, Lecanemab, that seems to slow the progress of Alzheimer's disease, has come to the fore. This is a cause for celebration. However, Dr Ben Marlow asks on page 16 why the same energy and dedicated research has not been focused on alleviating the medical issues that blight the lives of people with profound autism.

One has to ask how a drug might halt the loss of language and previously acquired skills seen in regressive autism. If only research was dedicated to understanding why this happens, just as science has tried to understand similar symptoms in Alzheimer's disease.

We always try to give a voice to families and raise awareness of important issues here at *Autism Eye*. In the year ahead we will continue to highlight the plight of families who feel they are being silenced when they try to speak out about the plight of their profoundly autistic children. Do get in touch with us and let us know your story.

Until the next time...

Gillian Loughran FRSA,
Editor



Autism|eye

ISSN 2046-424X

Hillbury Publishing, 25A Hillbury Road,
London SW17 8JT, United Kingdom

+44 (0)20 8673 8496
www.autismeye.com

Editor Gillian Loughran FRSA
gillian.loughran@autismeye.com

Publisher Mark Hayes FRSA
mark.hayes@autismeye.com
+44 (0)20 8133 6259

Designer Mark Richardson

SUBSCRIPTIONS Online: go to www.autismeye.com, where prices are from £16 a year for printed issues. By post: send a cheque/Postal Order for £20 (parents & carers) or £30 (organisations) to Autism Eye at our address, left. 20% discounts are available on renewing subscriptions – see our website.

© Hillbury Publishing Ltd 2022. All rights reserved. IMPORTANT: subscribers are reminded that Autism Eye is circulated to named individuals only, on the understanding that material contained herein is not copied, reproduced, stored in a retrieval system or otherwise disseminated, whether inside or outside subscribers' homes or organisations, without the express consent of the publisher. Breach of this condition will void the subscription and may render the subscriber liable to further proceedings. The views expressed in articles are not necessarily those of the editor, publisher or printer.

No information published by Autism Eye is to be construed as medical advice. Neither the editor, publisher, nor contributors take any responsibility for any decision taken by readers as a result of information contained herein. If you need medical advice, please seek it from a suitably qualified practitioner.

Mandatory autism training underway for NHS staff

New training has been launched to ensure people with autism and learning disabilities are treated fairly by the NHS. The Oliver McGowan Mandatory Training will be rolled out for health and care staff.

Oliver's mother Paula fought a long campaign for the scheme after the death of her son (pictured) in 2016. The 18-year-old suffered an allergic reaction to antipsychotic medication that left his brain so swollen it began to come out of the base of his skull.

McGowan maintains that her family warned medics at Bristol's Southmead Hospital, who gave her son the drug, that it was unsuitable.

The training rollout follows a two-year trial involving 8,300 staff.

But McGowan, 57, who now lives in New South Wales, Australia, said two recent cases show it will be a massive job to change attitudes among NHS staff.

One of the cases concerns William Verden, 17, who has autism, ADHD and a learning disability. NHS medics tried to deny Verden a life-saving kidney transplant. But his mother Ami McLennan, from Lancaster, fought successfully to have the decision overturned. (See story, right, for more about the Verden case.)

The other case concerns Robert Bourn, 32, who has autism, Fragile



X syndrome and a learning disability. When health staff diagnosed him with testicular cancer, they said he should get end-of-life care.

But his mother Sharon, from Gateshead, fought for a second opinion. It resulted in her son receiving a modified form of chemotherapy. He has now been given the all-clear. (See story, below, for more about the Bourn case).

McGowan said the "journey has just begun" for the new training, which is designed to challenge "inequality in healthcare".

The training is in two parts. The first includes e-learning for staff who need general awareness. The second is for those who care for autistic and learning-disabled people, who will undergo face-to-face training.

... while children still 'failed' in hospital

A mother who won the right for her autistic son to be given a kidney transplant says children and young people are being "badly failed".

Ami McLennan says 17-year-old son William Verden (pictured more than three weeks after his operation) is "doing great" after the transplant.

McLennan fought medics who said giving William a transplant was futile. Had she listened to the medics her son would have "died for nothing", she added.

McLennan, from Lancaster, said she "100 per cent" feels "there's an unnecessary battle for health equality for children/young adults with additional needs". This "shouldn't be allowed to be the case". Those with special needs should "receive the same care as anyone else", she added.

William, who also has attention deficit hyperactivity disorder (ADHD) and a learning disability, was kept alive by dialysis at Manchester Children's Hospital. Medics believed a transplant offered a 50 per cent chance of success. But they maintained it was almost 100 per cent certain that the disease would come back.

At the Court of Protection, Mrs Justice Arbutnot ruled a transplant was in William's best interests.

Mum Paula McGowan (see story, left) led a campaign for mandatory autism training for all NHS staff.

Her son Oliver, 18, died after he suffered an allergic reaction to antipsychotics. His family say medics should never have given them to him.

McGowan alleged the medics who treated him displayed "subconscious bias, discrimination, diagnostic overshadowing".



...and while mum saves son after medics say he will die

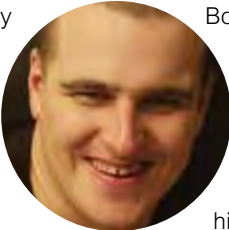
The mother of an autistic man diagnosed with testicular cancer has told how she fought to save his life after medics recommended end-of-life care.

Medics told Sharon Bourn, from Gateshead, they had done all they could for her son Robert (pictured), 32, after he had an operation to remove a tumour. But when the cancer spread he needed follow-up treatment with 72 hours of chemotherapy.

When Bourn told them Robert's autism meant he

would not tolerate the treatment, staff at Newcastle upon Tyne Hospitals NHS Foundation Trust said there was nothing more they could do.

But Bourn refused to give up on Robert, who, as well as autism, has Fragile X syndrome and a learning disability. Bourn fought for a second opinion and contacted law firm Irwin Mitchell. The case went to the Court of Protection before



Robert received a modified form of chemotherapy. He has now been given the all-clear.

Speaking on BBC Radio, Bourn said: "He's absolutely fantastic. He's back to normal.

The cancer's completely gone." Bourn, 54,

added: "He's back to his day centre now. He's living his life and he's absolutely fine."

Kirsty Stuart is an associate solicitor with Irwin Mitchell. She said Robert's

case reveals "the difficulties too many families face in ensuring loved ones who are autistic and those who have learning disabilities access the care they deserve for their loved ones".

In a statement, Newcastle upon Tyne Hospitals NHS Foundation Trust said it worked "very hard to support people with learning disabilities to have a positive experience of care".

Robert's story features in a BBC *Panorama* documentary, 'Will the NHS care for me?'

Police 'must act' as hate crimes soar but prosecutions plummet

Police forces "must take action" over a dramatic fall in prosecutions for disability hate crimes at the same time as reports of them have mushroomed.

Clare Hughes (pictured), criminal justice manager at charity the National Autistic Society (NAS), made the comment after new figures revealed that hate crime prosecutions have dropped from 1,009 in 2016-17 to just 345 a year, according to the Disability News Service (DNS).

In a statement, Hughes said: "No autistic person should face hate crime of any kind and the police must take action when these crimes are reported." She said the NAS is "campaigning for better autism understanding across society, including within the criminal justice system".

Figures show police forces are passing on far fewer cases to the Crown Prosecution Service (CPS), which assesses cases and decides whether prosecutions should go ahead. In 2014/15, police forces passed 924 cases on to the CPS. But by 2018/19, this had fallen by more than half to only 367 cases. Last year, the figure stood at just 243 cases.

It's unclear how many of these



alleged offences saw autistic people targeted.

But while courts are convicting fewer people, the number of offences that the public report to the police is rising.

Disability hate crime allegations passed to the police have risen by more than 40 per cent to over 14,000, according to the DNS.

Reports suggest that just 1 per cent of disability hate crimes reported to police were referred to the CPS or resulted in charges.

Mark Hamilton is the National Police Chiefs' Council (NPCC) hate crime lead. He told the DNS that forces had concentrated on race and religious hate crimes after Brexit "to the detriment" of disability hate crimes.

Eczema linked to autism, study finds

A new study has found a link between eczema and increased autistic traits in children on the autism spectrum.

Australian researchers led by Professor Adam Guastella (pictured) say autism is "often accompanied by skin disorders". They believe the link could be due to the shared "embryonic origin" of skin and brain tissue.

Neurodevelopment specialist Guastella and colleagues at the University of Sydney looked at 138 autistic children. Up to 45 of the children taking part had hypersensitive immune systems. This resulted in conditions including asthma, allergies, eczema and hay fever.

The researchers assessed the children's autism through observing their communication skills, interaction, play and repetitive behaviours.

Children with immune disorders showed a greater degree of autism overall, including in social skills. They were up to 2.4 times more likely to experience overall impairments classified as being at the highest level of severity. And they were 2.7 times more likely to show the most severe social difficulties.

In an email, Guastella said there is a shared origin of a "skin-brain connection" in the ectoderm, which is one of the main layers of cells in the embryo. He added that "skin development at birth could provide important clues to inform on brain development".

In a statement, biomedical charity Thinking Autism said the study added to the "large amount of research showing a potential link between immune dysregulation and some autism".



Families refuse to give statements to abuse inquiry

Families of loved ones held at a mental health hospital at the centre of a massive abuse probe are refusing to give statements to a public inquiry into the allegations.

The probe concerns Muckamore Abbey Hospital, in Northern Ireland.

The families have formed a group, Action for Muckamore (AFM). It says members will not give statements because they do not yet know the full extent of the allegations.

The leader of AFM is Glynn Brown, whose son, Aaron, was

a patient at Muckamore Abbey for around 18 months. (Brown is pictured with Aaron, right.) Retired prison officer Brown, 62, from Belfast, said the AFM families are only willing to make statements when they get "full disclosure".

Senior barrister Tom Kark KC is leading the public inquiry, while the police are conducting a separate safeguarding investigation.

Brown said the police probe is the largest adult safeguarding investigation since the formation of the NHS



in 1948. And that investigation was constantly unearthing fresh evidence.

He said he was assured when the scandal broke that Aaron, 26, who has autism, attention deficit hyperactivity disorder, epilepsy, a learning disability and hypertrophic

cardiomyopathy (a heart complaint), was involved in only one incident at Muckamore. But according to his last update, Brown said his son has been caught up in 200 incidents. He said families would be "extremely foolish" to make statements without knowing the full extent of the alleged abuse.

Reports suggest that AFM families want access to all medical records. Brown said it's more important that the inquiry is thorough and robust than swift.

Sleep problems may be genetic

Sleep problems in autism may have a genetic basis, a new study suggests. Student researcher Rackeb Tesfaye, of McGill University in Montreal, Canada, studied records taking in 15,461 people.

She looked at circadian genes. These involve people's circadian rhythm, a natural process that regulates sleeping and waking patterns. It repeats roughly every 24 hours.

Tesfaye found that abnormalities, or missing or duplicated sections in circadian genes, were "overrepresented" in those with autism. She also found that insomnia-risk genes with deleted sections were "associated" with autism.

Tesfaye found abnormalities in circadian and insomnia-risk genes had a stronger connection to autism than mutations in other genes.

Although the study identified links between sleep-risk genes and autism, it could not show how these links impacted rest.

Tesfaye found that circadian genes did not impact the time spent sleeping or insomnia in autistic people. And though



circadian and insomnia-risk genes with missing or duplicated DNA increase the likelihood of autism, there were "little to no observable impacts on sleep disturbances".

In a statement, Tesfaye wrote that levels of the sleep hormone melatonin have been found to be different in people with autism. She added: "Emerging evidence from randomised control trials indicate supplemental melatonin can ameliorate sleep problems in autistic youth."

The biomedical charity Thinking Autism said Tesfaye's study has a "number of limitations".

But the charity added that these shortcomings do not "derogate from the fact that sleep issues can have a very negative impact on the health and quality of life for many individuals with autism and their families".

Bill aims to stop hospital admissions

Autism and learning disabilities must no longer be used as conditions that justify placing people in long-term hospitals.

That's the aim of the new draft Mental Health Bill. And MPs have been weighing up measures in the Bill designed to prevent people with autism and learning disabilities from ending up in mental health hospitals.

The Joint Committee of the draft Mental Health Bill looked at whether planned changes to the law are enough to keep people out of hospitals.

Tim Nicholls is head of research with the National Autistic Society. He told the committee that though changing the definition of who can be detained is a step in the right direction, it "will not end the crisis" of people being stuck in a mental health hospital for years on end.

Nicholls added: "It will take the right services in the community – be those both mental health community services and social care services, too."

The latest statistics show there are 1,965 people with learning disabilities and/or autism in hospitals. Just over half (57 per cent) have been there for more than two years.

Simone Aspis is the project manager of Free our People Now. The organisation aims to help people live in homes rather than hospitals.

She said the entire basis of the draft bill is wrong because it assumes there is a "right or wrong way of being, feeling and thinking and seeing the world".

Aspis said it was important to question the assumption of "compulsory treatment of all people, including people who are labelled as autistic and people with learning difficulties".

● See our feature on the new Mental Health Bill on page 23

Call for public inquiry into care failings

A charity has called for a public inquiry into failings in mental health care. Mental health charity Mind made the call after a BBC *Panorama* programme showed abuse at the NHS-run Edenfield Centre in Manchester.

The programme showed staff at the mental health unit using restraint inappropriately. It also revealed patients enduring long seclusions in small, bare rooms, sometimes for months.

There was footage of staff swearing at patients and slapping or pinching them.

They also mocked patients while they undressed and joked about their self-harm. A number of staff members have been suspended.

Mind said the programme raised "serious concerns". The charity now wants a "full statutory public inquiry into systemic failings of inpatient mental health services across England".

The scandal is one of several to engulf the sector over the past decade or so.



Dr Rosena Allin-Khan (pictured), Labour's shadow minister for mental health, said she has asked the UK Government for a "rapid review" into mental health services.

She added the treatment patients experience is "horrific". Such "dangerous practices" should be eradicated, she said.

In 2011, *Panorama* exposed abuse at private mental health hospital Winterbourne View, near Bristol. It showed some very

vulnerable patients repeatedly pinned down, slapped, dragged into showers fully clothed, taunted and teased. Six of 11 care workers went to jail, with five others given suspended sentences.

Then, in 2019, another *Panorama* investigation at Whorlton Hall, in County Durham, appeared to show support workers taunting and restraining vulnerable adults.

A spokesperson for the Department of Health and Social Care said its first priority was to "ensure anyone receiving treatment in a mental health facility receives safe, high-quality care". >>

ST. JOHN'S

School & College

Seaford and Brighton



● Communication
▲ Independence
▲ Sensory Aware
♥ Wellbeing

Specialist education (7-25 years) with autism and/or learning disabilities

www.st-johns.co.uk
01273 244000

DOUGLAS SILAS

s o l i c i t o r s
Specialising Exclusively in SEN

"The hope you give parents is nothing short of a miracle"
[a previous client]



020 8349 7700

info@dsslaw.co.uk

www.SpecialEducationalNeeds.co.uk

Could you adopt Nathan?*

Three year-old Nathan needs a new adoptive family.

Scan the code to find out more about Nathan, the financial support available and the rewards and challenges of adoption.



*Image posed by a model and not the child's real name



Vulnerable children placed in caravans

Social services are placing growing numbers of vulnerable children in unregulated accommodation such as caravans and holiday lets, new figures suggest. Even children with 'complex needs' are having to live in such places.

The children have become the subject of Deprivation of Liberty Safeguards (DoLS). These are made when people lack the capacity to consent to their care.

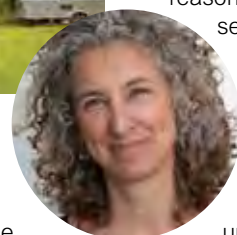
In July, a new court started to handle applications by social services for DoLS. The new National Deprivation of Liberty Court received 237 DoLS applications in July and August.

Figures collected by research group the Nuffield Family Justice Observatory show that in 2020/21 DoLS applications averaged 48 per month. The latest figures represent a rise of more than 145 per cent.



The Observatory has collected figures, but children who are subject to DoLS do not appear in published records. The Observatory believes there is a "relatively high prevalence of children with autism and other neurodevelopmental needs" among those subject to DoLS.

Lisa Harker (inset), director of the Observatory, said those being housed in unregulated accommodation "simply



disappear from view, with no data recording what happens".

Children can be subject to DoLS for safety, youth justice or mental health reasons. The children can be placed in secure children's homes, young offender institutions, secure training centres or mental health wards.

When no place is available in any of these settings, the High Court can use an unregulated placement.

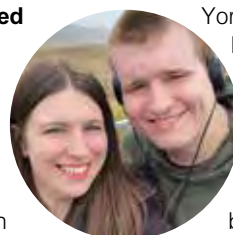
In April, then-education secretary Nadhim Zahawi said there was a shortage of secure placements that amounted to a "national crisis".

His comments came after an autistic girl spent at least five months alone in the locked annexe of a children's home.

Sister and her lawyers free man from assessment unit

An autistic man detained in a mental health hospital for more than four years has been freed – thanks to his sister and her lawyers.

Elliot Dodds and his sister Beckii Davis (both pictured) are celebrating after the 27-year-old was released into a community placement. Beckii, from North



Yorkshire, enabled her brother's release after contacting lawyers Irwin Mitchell. She instructed the firm to investigate her brother's care and help secure him a bespoke community care package in conjunction with care providers. He is now living in his own home with the support of carers.

Gut bacteria is linked to behaviours, study finds

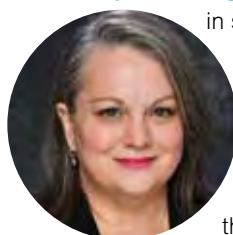
An altered bacteria profile in the gut is linked to behaviours that challenge in autism, a new study has found. The researchers discovered that differences in gut bacteria were "significantly" associated with "thought problems, delinquent behaviours, self dysregulation, and somatic (body pain) complaints".

They also found that those on the autism spectrum, compared to neurotypical children and youngsters, "had worse GI (gastrointestinal) symptoms". They believe their work supports the idea of a "complex relationship" between an altered bacteria profile in the gut, immune dysregulation and autism.

Parents of autistic children 'suffer lower quality of life'

Parents see their quality of life suffer when caring for an autistic child, says a new study. And the more severe the autism the greater the impact on the parents' quality of life.

Dr Dawn Turnage (pictured), of the University of Central Florida, conducted the review study. She found the quality of life was lower in parents of autistic children in physical, psychological and social health. It was also lower



in spirituality. Turnage is a lecturer in the university's college of nursing. She also serves on the leadership council of the US National Council on Severe Autism. Better educated parents saw their quality of life suffer less, Turnage found. The study concluded that nurses can support families coping with severe autism through "tailored resources" for early diagnosis and intervention.

International experts Prof Tony Attwood and Dr Garnett in London in January 2023

They are providing a two-day Masterclass on Autistic Girls and Women on 19th-20th January, 2023. Day 1 will provide professional training in diagnostic assessment of girls and women who may have autism. Day 2 will appeal to parents and professionals and will focus on the best ways to provide support and therapy for autistic girls and women. On Saturday 21st January Tony and Michelle will present Emotion Management for Autistic Children and Adolescents, a full-day seminar on how to assist autistic children and teenagers to understand and manage their strong emotions.

■ www.attwoodandgarnettevents.com/london-events/



ASDAN's My Independence programme helps autistic learners prepare for adulthood



'We highly recommend ASDAN's courses as the results speak for themselves'

The flexible provision empowers students with a wide range of learning difficulties



ASDAN is an education charity and awarding organisation providing courses, accredited curriculum programmes and regulated qualifications to engage, elevate and empower young people aged 11 to 25 in greatest need.

Making the transition to adulthood is not always straightforward for young people. The process is often even more complex for learners with special needs and disabilities (SEND), who face unique challenges and need purposeful support to assist them on their journey.

ASDAN specialises in supporting young people to develop the skills and qualities to learn for life. With a wealth of knowledge of the SEND landscape, they are highly experienced in working with expert practitioners to create transition programmes that help young people prepare for adulthood.

My Independence is ASDAN's flagship provision for those with special educational needs working from pre-Entry level to Entry level 3, with learning difficulty levels ranging from moderate through to profound and multiple.

The suite of four certificated programmes is designed around the four preparing-for-adulthood pathways, engaging young people

with SEND in:

- developing friends, relationships and playing an active in their communities
- looking after their health
- living independently
- preparing for employment

Focusing on young people's aspirations, interests and needs, the courses guide the development of core personal and social skills, empowering students to achieve successful outcomes and pursue future ambitions.

The flexibility of the courses enables learner-centred goals to be identified, and teaching and learning approaches to be tailored to individual students' needs, making them a powerful and engaging option for young people with a range of autistic spectrum needs.

My Independence was produced in close collaboration with the National Development Team for Inclusion (NDTI) and SEND practitioners, and has been designed

to link closely with the Education Health and Care Plan process.

Jaswinder Kaur is the Deputy Principal at Parkwood Hall Co-operative Academy and a specialist autism practitioner. She explains the importance of young people with SEND having aspirational pathways that are bespoke and enable them to grow both personally and socially:

"We selected ASDAN courses for our students who have a diagnosis of autism and learning disabilities as the flexibility enables our teachers to adapt the curriculum so students can achieve personal goals, work-related skills and realise a pathway to their independence. The courses have been very well received by our teachers, and parents have also seen the positive impact on their child's progress. We highly recommend ASDAN's courses as the results speak for themselves."

Philip Bruton, Nurture Teacher at New Barn School, describes the positive effect My Independence has on their learners:

"We cater for pupils with high-functioning autism and our nurture groups have thrived with the use of My Independence. The courses have worked really well in collaboration with organising extra-curricular activities.

"The pupils have found it exciting to be part of organising trips outside of the classroom... It has also been massive to see them achieve a recognised certificate – for some students this has been a first-time achievement!"



To learn more about My Independence:
<https://bit.ly/3GFkWYZ>
0117 941 1126 | info@asdan.org.uk

We exist: the case for people with profound autism

The combining of what used to be five types of autism into a single diagnosis is ‘ludicrous’ and is harming those who are unable to advocate for themselves, says Alison Singer. It’s time to give people who have profound autism their own diagnosis, she argues

In 2013, the autism world experienced a seismic shift with the release of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, widely known as the *DSM-5*.

This influential manual, which is published by the American Psychiatric Association and used by much of the world as the authoritative guide¹ to diagnosing and researching mental disorders, took a dramatic step: it collapsed the five types of autism recognized in the *DSM-4*, including classic autism and Asperger’s, and combined them into the single diagnosis of Autism Spectrum Disorder (ASD).

A primary concern at the time of the *DSM-5*’s release was that people on the higher, Asperger’s end of the autism spectrum would lose access to diagnoses and services. However, nearly ten years later, we can see that the opposite has happened. Broadening the autism diagnosis has led to those with the mildest forms of autism taking over the term ASD. To most of the public, the word “autism”

now only describes the more verbal, traditionally skilled, visible end of the spectrum – because people who meet those criteria are able to have a voice, attend conferences, represent themselves at policymaking meetings, appear in the media and skillfully communicate on social media.

The result is that individuals with profound autism have been left behind. However, I and other parents whose children face the challenging realities of autism are beginning to see glimmers of hope,

“Lumping everyone on the autism spectrum into one category has resulted in rancour and ill will as the needs of one group clash with the needs of the other”

as the term ‘profound autism’ gains traction in the scientific and advocacy communities.

In December 2021, The Lancet Commission released its report² on the future of care and clinical research in autism after more than three years of careful research and collaboration from more than 30 healthcare providers, researchers, advocates, self-advocates, and parents – including me – across six continents. The report called for personalized interventions for autistic people based on their specific needs. Importantly, the Commission also introduced a clinical definition of the term ‘profound autism’ and called for its use to distinguish between people with the most acute needs and those whose autism is milder.

Shouted down

Since the release of the Lancet Commission report, parents of children with profound autism have felt safer speaking out about the need to refocus efforts and energy on this group of people. These autistic individuals have been largely ignored by mainstream society because they are not equipped to participate in the successful and growing autistic self-advocacy movement that so often belittles and shouts down people who advocate for the needs of people with profound autism.

My daughter Jodie and my older brother Steven meet *The Lancet* criteria for profound autism. Jodie is minimally verbal, but thanks to intensive early intervention she can communicate her needs in simple terms. Steven is completely nonverbal; he was diagnosed in the 1960s and had no access to any type of treatment. Both have IQs

under 50 and both require round-the-clock care to keep them safe.

No one should argue that people across the autism spectrum need and are entitled to services. *The Lancet*’s goal in recommending personalized services was simply to recognize that the needs of people with profound autism are different from those with what used to be called Asperger’s.

For example, adults who are less impacted by autism often say their top needs are improved mental health care and better access to supported employment opportunities. I believe it is our

collective responsibility to meet these needs. But it is also our collective responsibility to meet the needs of people whose autism results in fecal smearing, pica, self-injury, aggression and seizures; in other words, people who are not able to participate in mainstream employment opportunities and for whom the focus on basic safety is often paramount.

Compare, for instance, Elon Musk, who has spoken publicly³ about being diagnosed with Asperger’s and now controls Twitter, to my 25-year-old daughter, whose favourite show is



Alison Singer is the president and co-founder of the Autism Science Foundation, a non-profit organization dedicated to funding autism research and supporting the needs of autistic people: <https://autismsciencefoundation.org>

Sesame Street and who has no concept of what Twitter is or how to use it. It’s absolutely ludicrous that they have the same diagnosis.

Lumping everyone on the autism spectrum into one category, autism, has also unfortunately resulted in rancour and ill will as the needs of one group clash with the needs of the other. Many self-advocates who are less impacted by autism claim that, because they are autistic, they are better positioned to understand and advocate for the needs of all people with autism, including those with profound autism.

Advocating for harm

If these self-advocates understood and actually advocated for the needs of people with profound autism I wouldn’t have an issue with it – and families like mine who face profound autism would welcome their input. However, many of them actively advocate for policies and programmes that directly harm profoundly autistic people, and refuse even to recognize the differences between themselves and those with profound autism.

For example, many of these autism advocates have actively tried to shut down residential communities that provide a safe environment for people with profound autism, erroneously claiming they are ‘segregated institutions’ where people with disabilities suffer abuse. While we all bristle at the word ‘institution’ because it harkens back to 1970s images of places like Willowbrook (the notoriously abusive New York institution where people with intellectual disabilities lived), community settings today are nothing like Willowbrook. My brother spent time in Willowbrook. >>

Left out: those with profound autism are often sidelined by self-advocates, Singer argues



How do you support Autistic young people?

Find the answer to this question and many more by accessing our free webinars, resources, and events designed to support you at every step.



A guide to Education, Health and Care Plans



Promoting behaviour support

Supporting your child with ADHD

Virtual conferences

Whether you're a parent or carer of an Autistic young person, or a professional working in the field, our resources will enable you to connect to some of the greatest thinkers, and expand your knowledge of all things SEN.

Building confidence and happiness

Learning more about Autism

Speech and communication

Supporting a child with PDA

SEN child and adolescent mental health



Find out more by visiting www.witherslackgroup.co.uk/support

Diagnosis

No one should live in a Willowbrook. On the other hand, my daughter currently lives in a community in upstate New York for adults with a wide range of severe disabilities, including profound autism. Residents live and work on a farm, raise animals and run a restaurant on campus, to which the full community is invited.

Her jobs have included food prep, cider making, animal husbandry and farming. She takes Zumba, yoga and painting classes at the town community centre. She is far more integrated into the broader community while living in that residential centre than many of my friends' kids, who seem to live in their parents' basements and play video games all day.

Just as the Lancet Commission concluded, we need a broad array of options to meet the very diverse needs of a diverse population.

Don't want to look

Some self-advocates don't even want to look at our kids, let alone advocate on their behalf. At the Autism-Europe International Congress in October this year, a video of a young adult with profound autism engaging in typical self-injurious behaviour was preceded by a trigger warning and an admonishment by the speaker that those in attendance (mostly self-advocates) may want to "cover your eyes and ears". Some attendees immediately lashed out at the speaker on social media. Others walked out of the room. If these adults can't even watch a video of our children, how can they advocate for their needs?

Some of these autism advocates also, disappointingly, claim that the language used by parents and scientists (including the language used in this article) is offensive and believe that only people on the autism spectrum are qualified to speak or write about autism. I have been to two scientific conferences

in the past month where presenters amended their slides at the last minute to remove any trace of language that might get them called out by neurodiversity advocates on social media. Soon, they may be afraid to present scientific findings at all, for fear of being cancelled. There is nothing beneficial or even neutral about cleansing the words needed to describe the scientific and practical realities of autism. Such so-called neutral language robs the community of the ability to even describe the day-to-day lives of people with profound autism.

Regarding research, autism advocates who are less impacted

“Many autism advocates have actively tried to shut down residential communities that provide a safe environment for people with profound autism”

by the condition also have different priorities that leave people with profound autism behind. Much of the research that these self-advocates call for is focused on mental health and well-being, whereas parents of children with profound autism are more focused on genetic, behavioural and pharmacological research that can ease co-occurring conditions such as epilepsy and gastrointestinal problems, reduce self-injurious and aggressive behaviours, and help keep their children safe.

Last year, research by scientists at the University of Cambridge, called the Spectrum 10K study,⁴ was shut down after autistic advocates complained that the

genetic data collected could (*could!*) be used to cure or eradicate autism. Spectrum 10K was clear from the outset that it was not seeking a cure for autism, but rather that its goals were to investigate genetic causes of conditions common to people with autism, such as epilepsy, which is exactly the type of research parents of kids with profound autism say they need.

Different needs

To me, it doesn't matter which end of the spectrum receives the new diagnostic label. I think it would be just as effective to bring back the term Asperger's as to introduce, as the *Lancet* report did, the term 'profound autism'. The goal is the same: to describe symptoms so that the correct interventions can be planned for and delivered.

Current reporting on the number of people with broad ASD does little to help policymakers plan for their needs because those needs vary so widely. A person with profound autism may need a residential placement, while an autistic graduate of Cambridge University would likely not. On the other hand, that graduate might need specific supports to work at Lloyd's of London, while a person with profound autism wouldn't even understand what Lloyd's is or does.

We have reached the point where I don't believe the autism community is a true community anymore. Rather, it's become two factions frequently at odds over research, policy and services. I care about all parts of the spectrum, but the infighting has become extreme.

There is a growing body of genetics and biological research that argues in favour of profound autism as its own psychiatric disorder. It's time for the *DSM* to recognize these differences and re-bifurcate the diagnosis to recognize profound autism.

REFERENCES

- ¹ The American Psychiatric Association: 'What is DSM and why is it important?', <https://psychiatry.org/psychiatrists/practice/dsm/frequently-asked-questions#:~:text=The%20Diagnostic%20and%20Statistical%20Manual,the%20diagnosis%20of%20mental%20disorders>
- ² 'The Lancet Commission on the future of care and clinical research in autism', *The Lancet*, January 2022, [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)01541-5/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)01541-5/fulltext)
- ³ 'Elon Musk opens up on how Asperger's has impacted his life', *Axios*, Apr 2022, <https://www.axios.com/2022/04/15/elon-musk-aspergers-syndrome>
- ⁴ 'High-profile autism genetics project paused amid backlash', *Nature*, September 2021, <https://www.nature.com/articles/d41586-021-02602-7>

Autism, Alzheimer's and Covid

It is understandable that parents whose children have 'profound' autism, with serious accompanying medical issues, are unhappy at the lack of research funding into the condition. Dr Ben Marlow reports on stark inequalities in the health system and urges a more joined-up approach



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>

Check out the NHS's website for a description of Alzheimer's disease and you will see a striking resemblance to people who have 'profound autism':

- Becoming less flexible and hesitant to try new things
- Confusion, disorientation
- Obsessive, repetitive and impulsive behaviour, disturbed sleep
- Problems with speech and language
- Changes in mood, increasingly anxious and frustrated
- Difficulty performing spatial tasks
- Seeing or hearing things that other people do not

This list of symptoms fits exactly with how my son Fred presents with autism, pretty consistently on a daily basis, creating a significantly negative impact on his physical and mental health, general development and his ability to lead a happy life. They are also pretty consistent with other children like Fred with 'profound' autism that I see in my clinic.

Yet the symptoms above are taken from an NHS website that is focused on Alzheimer's disease....

Could there, in fact, be a biological overlap between Alzheimer's, the kind of autism my son has, and long Covid?

As I have previously discussed in *Autism Eye Magazine*, there are many different phenotypes (observable traits) of autism. My particular interest is in the hypothesis of an 'immune' phenotype, which typically affects children more severely in learning and development (especially with regression or static development).

These children also have an abundance of other co-occurring health conditions, such as seizures, gut dysfunction, migraine, sleep problems and metabolic differences.¹ In addition, they have a significantly reduced life expectancy: they will die, on average, at just 39.5 years of age.

Therefore, research in this area is extremely important.²

The 'inflammatory autism' hypothesis relates to an over-exaggerated innate immune response to viruses/bacteria (trained immunity). This leads to stimulation of the NLRP3 inflammasome (a critical component of the innate immune system) and the immune system secreting toxic amounts of cytokines, which are substances such as interferon and interleukin-1 beta that affect other cells.

This triggers neuroinflammation, which is the activation of the brain's innate immune system and is characterized by a host of cellular and molecular changes within the brain.³

“Could there be a biological overlap between Alzheimer's, the kind of autism my son has, and long Covid?”

This NLRP3 inflammasome is also implicated in a wide range of diseases, including Alzheimer's, Covid-19 and other neuroinflammatory disorders.⁴ There is a real opportunity, especially given the overlap in symptoms between 'profound' autism and Alzheimer's, to explore research with medicines that have been trialled in these other conditions.

Alzheimer's disease

Research has shown that the cellular changes that Alzheimer's creates bear striking similarities to those produced by an inflammatory subtype of autism, with the NLRP3 inflammasome deemed to be the architect of neuroinflammation. The innate immune activation leading to NLRP3 inflammasome and interleukin-1 beta elevation is

thought to occur in both, although the plaques of amyloid B protein and neurofibrillary tangles (NFTs) (impairing axonal stability and neuronal plasticity⁵) seen in Alzheimer's are not seen in autism.

Covid-19

Recent publications have indicated that Covid-19 can induce innate immune activation through a spike glycoprotein of the virus, priming the microglia (the immune cells of the central nervous system) through signalling the NFkB protein complex. In mouse models, the invasion of SARS-CoV-2, the virus that causes Covid-19, leads to extensive microglial NLRP3 inflammasome activation.⁶

Post-mortem examinations of deceased Covid patients showed extensive microglial activation, with pronounced neuroinflammation. Symptoms also included headache, dizziness, encephalopathy (where the functioning of the brain is affected by a disease), confusion and even seizures and post-infective autoimmunity (where the immune system is reacting against itself).

Therapeutic targets

The field of Alzheimer's has received much more research interest, money and focus on underlying biological mechanisms over the past 20 years than autism (see *The Autism Dividend: the report*, published in 2017).

Therefore, better understanding and therapeutic trials are at a more advanced stage in this field. Covid-19 has also recently experienced a wealth of funding to manage acute and chronic symptoms of immune activation, which has also added to our understanding.

The emphasis on 'treating' and ameliorating the distressing symptoms listed earlier has focused minds on a collective goal in this disease area.

In my opinion, autism research should have an opportunity to follow a similar course. »

Targeting the inflammasome

Anakinra

The drug Anakinra7 has been shown to have a significant impact on supporting mitochondrial function in laboratory and animal tests relating to Alzheimer's. Also relevant to the field of autism is Anakinra's use in treatment-resistant seizures.

Efficacy has been indicated in case reports, with the medication



monocyte. This expresses in autoinflammatory mutations of the protein cryoprin. There are no current studies relating to autism.

Pterostilbene / Resveratrol
Pterostilbene¹⁰, an antioxidant and anti-inflammatory agent found in blueberries, almonds, peanuts, grape leaves and some trees, reduces the neuroinflammatory response induced by a particular peptide (A 1-42) in microglial cells.

It does this by inhibiting the NLRP3/caspase-1 inflammasome pathway, indicating that pterostilbene might be an effective therapy for Alzheimer's disease. Resveratrol, an antioxidant found in grapes, is

Collaborative research: it would help if scientists worked together in studying neuro-inflammatory disorders that appear to be related

closely related to pterostilbene.

NFκB inhibitors

Alpha lipoic acid, or ALA, suppresses the activation of NLRP3 inflammasomes (multiprotein complexes consisting of NLRP3 and caspase-1), which are involved in the innate immune response in microglia (brain immune cells in vitro).¹¹

Future directions

Chronic neuroinflammatory disorders such as Alzheimer's, chronic fatigue, long Covid and a subtype of autism (all focusing on chronic innate immune activation through the NLRP3 inflammasome) would benefit from collaborative research. It could focus on existing mechanisms of pathway inhibition, safety profiles of medications and repurposing of medication in different disease areas.

The use of inflammasome inhibition in medical comorbidities associated with autism, such as seizures, indicates the potential to target this pathway for reducing the health burden and premature mortality. It could also aim to improve the developmental trajectory and quality of life of those with profound autism.

● See our feature on profound autism, page 12

REFERENCES

- ¹ Sala R, et al: 'Bridging the Gap Between Physical Health and Autism Spectrum Disorder', *Neuropsychiatr Dis Treat*, 2020 Jun 30; 16:1605-1618. doi: 10.2147/NDT.S251394. PMID: 32636630; PMCID: PMC7335278: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7335278/>
- ² Hirvikoski T et al: 'Premature mortality in autism spectrum disorder', *Br J Psychiatry*, 2016 Mar;208(3):232-8. doi: 10.1192/bjp.bp.114.160192. Epub 2015 Nov 5. PMID: 26541693: <https://pubmed.ncbi.nlm.nih.gov/26541693/>
- ³ Jyonouchi H, Geng L: 'Associations between Monocyte and T Cell Cytokine Profiles in Autism Spectrum Disorders: Effects of Dysregulated Innate Immune Responses on Adaptive Responses to Recall Antigens in a Subset of ASD Children', *Int J Mol Sci*. 2019 Sep 24;20(19):4731. doi: 10.3390/ijms20194731. PMID: 31554204; PMCID: PMC6801811: <https://pubmed.ncbi.nlm.nih.gov/31554204/>
- ⁴ Wang Z, et al: 'NLRP3 Inflammasome and Inflammatory Diseases', *Oxid Med Cell Longev*, 2020 Feb 17;2020:4063562. doi: 10.1155/2020/4063562. PMID: 32148650; PMCID: PMC7049400: <https://pubmed.ncbi.nlm.nih.gov/32148650/>
- ⁵ Ising, C et al: 'NLRP3 inflammasome activation drives tau pathology', *Nature* 575, 669–673 (2019). <https://doi.org/10.1038/s41586-019-1769-z>
- ⁶ Albornoz EA et al: 'SARS-CoV-2 drives NLRP3 inflammasome activation in human microglia through spike protein', *Mol Psychiatry* (2022), <https://doi.org/10.1038/s41380-022-01831-0>
- ⁷ Batista AF, et al: 'Interleukin-1 mediates alterations in mitochondrial fusion/fission proteins and memory impairment induced by amyloid oligomers', *J Neuroinflammation* 18, 54 (2021), <https://doi.org/10.1186/s12974-021-02099-x>
- ⁸ Jyonouchi H, Geng L (2016): 'Intractable Epilepsy (IE) and Responses to Anakinra, a Human Recombinant IL-1 Receptor Agonist (IL-1ra): Case Reports', *J Clin Cell Immunol* 7:456, <https://www.longdom.org/open-access/intractable-epilepsy-ie-and-responses-to-anakinra-a-human-recombinant-il1-receptor-agonist-il1ra-case-reports-51182.html>
- ⁹ Lamkanfi M, et al: 'Glyburide inhibits the Cryopyrin/Nalp3 inflammasome', *J Cell Biol*. 2009 Oct 5, <https://pubmed.ncbi.nlm.nih.gov/19805629/>
- ¹⁰ Li Q et al: 'Pterostilbene inhibits amyloid- induced neuroinflammation in a microglia cell line by inactivating the NLRP3/caspase-1 inflammasome pathway', *J Cell Biochem* 2018 Aug;119(8):7053-7062. doi: 10.1002/jcb.27023. Epub 2018 May 8. PMID: 29737568;187(1):61-70. doi: 10.1083/jcb.200903124. PMID: 19805629; PMCID: PMC2762099, <https://pubmed.ncbi.nlm.nih.gov/29737568/>
- ¹¹ Kim SM et al: 'Effects of alpha-lipoic acid on LPS-induced neuroinflammation and NLRP3 inflammasome activation through the regulation of BV-2 microglial cells activation', *BMB Rep*. 2019 Oct;52(10):613-618. doi: 10.5483/BMBRep.2019.52.10.026. PMID: 30940325; PMCID: PMC6827572, <https://pubmed.ncbi.nlm.nih.gov/30940325/>



SOVEREIGN
Bringing imagination into play

- ✓ Free consultation, design and planning service
- ✓ Bespoke equipment to meet your children's needs
- ✓ Industry leading manufacture, installation and aftercare
- ✓ Best value



We have the experience and expertise to design and create outstanding outdoor play and learning environments

Need a specialist
for your play equipment?

FOR A FREE NO OBLIGATION CONSULTATION
T: 01702 291129
EMAIL: INFO@SOVEREIGNPLAY.COM
VISIT: WWW.SOVEREIGNPLAYEQUIPMENT.CO.UK

We have a growing need for Foster Parents to care for children with SEN and complex needs.



As a parent or Carer of a child with Autism, you already have the skills to Foster young people with similar needs.

You will receive 24/7 professional support; competitive Fostering allowances; and ongoing Therapeutic Parenting training and advice.

Could your family welcome a child living with complex needs?

Call: 0800 644 6230

Visit: www.bythebridge.co.uk/care

bythebridge
with Cambian

A valuable gift

Scientists have no idea why so many autistic people have epilepsy or why many have lower life expectancies. Research is the best way to improve understanding, says philanthropist Dame Stephanie Shirley. She explains why her family decided to contribute her autistic son Giles's brain for research when he died at a young age

Almost 30 years ago, my beloved autistic son Giles died at the age of 35. His death was unexpected, and we were naturally shocked and grieving, but we were able to take some consolation from the fact that it would not be entirely without purpose.

Before he died, we had agreed with researchers at the John Radcliffe Hospital in Oxford that Giles's brain would be donated to the Autism Brain Bank there, and that tiny slivers of precious tissue would thus be available to BrainNet and other international medical research collaborations.

Such 'harvested' fragments of brain can help medical understanding, not just of autism but of other conditions often associated with it, including epilepsy and, in particular, that still-puzzling phenomenon known as SUDEP, Sudden Unexpected Death in Epilepsy. Investigating brain tissue provides information that you simply cannot get from an MRI scan. It means a lot to me that Giles's brain can help others, now that it is no longer of use to him.

Donating one's organs after death for transplanting or for medical research is now commonplace. A great many people are happy for their kidneys, liver, heart and other organs to serve others after they have died. But when it comes to donating the brain, it seems many people are uncomfortable.

Some people reading this may fear the possible ramifications of scientific investigation of the autistic brain. High achievers on the autism spectrum may suspect it could be used to identify the characteristics of some autistic 'super-brain', with who knows what consequences. Others may fear that all this research is part of a eugenics-driven attempt to eliminate autism. Or some may simply feel that to meddle with the brain – the seat of consciousness and the very basis of personality – is inappropriate. Perhaps, too, the

discomfort or squeamishness is exacerbated by the terms we use for the process of donation and storage: 'brain harvesting' and 'brain banking'.

Whatever the reasons, the regrettable fact is that many do find the idea distasteful. That includes some of the professionals who work with autistic people and their families, who have proved oddly resistant to passing on information about donation, and about the research to which donated brains can contribute.

The Autism Brain Bank at the John Radcliffe was established by the UK's autism research charity,

"I feel that dedicating my Giles's brain to research gives dignity and meaning to his troubled life. It is not just an empty loss"

Autistica, which I founded in 2004, so I have a particular interest in it. It was one of Autistica's earliest projects, but I confess that none of us back then anticipated how strong and how widespread this negative response to the very concept of a brain bank would be.

The answer to overcoming this resistance is, as in so many similar cases, better understanding of what is involved. Once they have the information available to them, autistic people and their families appreciate how future generations may benefit, and how future individuals' quality of life can be improved.

Doubters can be reassured by the fact that the UK Network of Brain Banks was initiated by the Medical Research Council and is subject to a steering committee with expertise in ethics and law, as well as science. Post-mortem brain

tissue is treated – as it should be – as carefully and respectfully as a living subject.

The process in our case was very tactfully handled. Brains have to be removed and collected within two days of death. I saw my beloved son in his coffin after his brain had been removed. He was wearing some sort of bonnet and looked perfectly OK.

Later, we underwent a detailed two-hour interview to capture his social and medical history, and we were asked for instructions about what should be done with any remaining tissue deemed no longer to be of use. As I guess most people would, we gave consent for lawful disposal via hospital incineration.

The decision to donate a brain is essentially personal and must never be taken under pressure. Talking about these matters immediately after death, when families are still in shock, can be distressing. People making the pitch for brain banking need compassion and warmth, as well as scientific expertise. In our case they certainly had.

Personally, I feel that dedicating my Giles's brain to research gives dignity and meaning to his troubled life. It is not just an empty loss.

And, since control tissue is needed from people without autism for comparison, so my brain is scheduled to go to the brain bank after my death. I certainly shan't need it any longer. I was once a very rich woman, but I have spent decades giving away my fortune. Donating my brain tissue is the very last gift I shall make.

● **Brain Bank for Autism Helpline:**
+44 (0)1865 234204

Further reading

Dame Stephanie Shirley is the author of the moving memoir *Let It Go*, in which she describes her journey to help her beloved son, Giles. *Let It Go* is published by Penguin, around £9.95/\$11.35 in paperback



Dame Stephanie Shirley is a trail-blazing entrepreneur in the field of IT. She is also an ardent philanthropist, who has donated millions of pounds to improving the lives of autistic people, including the establishment of specialist school Priors Court and the charity Autistica



Introduction & Application to the SCERTS Model 2 DAY TRAINING COURSE

January **2 Day** 26-27. 2023 £287.00**

June **2 Day** 29-30. 2023 £TBA**

Venue: Kettering Conference Centre

Using the SCERTS curriculum
& practice principles to design
programming for children with Autism
Spectrum Disorder

Course Led by
Emily Rubin, MS, CCC-SLP Director.

**This training is appropriate for:
educators, therapists, administrators,
professionals and families**

AM/PM refreshments, light lunch.



Office: 199-203 Blandford Ave, Kettering,
Northants NN16 9AT. Tel/Fax: 01536 523274
autism@autismuk.com

Book online: www.autismuk.com

****(Covid-19): The training courses above will take place subject
to the safety concerns of delegates, ours & venue staff, including
restrictions that may be imposed by the UK or US governments.****



Is there **life** after **hospital?**

**A new Mental Health Bill is designed to sweep
away the decades of prejudice that have seen
people with autism and learning disabilities face
hospital stays that swallow huge chunks of their lives.
But where are the solutions? Report by Darren Devine**

Brigene McNeilly's brother

Bryan McCarry, 56, has spent almost all his adult life living in a hospital. He is now one of 35 patients left at Muckamore Abbey Hospital in Northern Ireland, a facility for adults with severe learning disabilities and mental health needs.

Across the UK, more than half (57 per cent) of the people with autism and learning disabilities who live in mental health hospitals have been there for more than two years. A BBC investigation has revealed that 100 of the patients have, in fact, been held for more than 20 years.

The UK government's new draft Mental Health Bill aims to ensure that autism or learning disabilities can no longer be used as conditions that justify long-term hospital stays.

Muckamore Abbey, in County Antrim, is in the midst of a fresh

**“They’ve
absolutely
destroyed him. He’s
45 and they’ve taken
his life away and
they’re still doing it”**

push to resettle its remaining patients in the community after an ongoing public inquiry and police probe into allegations of widespread abuse. Dr Patricia Donnelly, who led Northern Ireland's vaccination programme during the coronavirus pandemic, is overseeing the resettlement.

Brigene fully supports the resettlement effort, but says it is crucial that patients with complex needs get good quality support and accommodation that has been designed for them. Otherwise,



**Calling for
action: Tim
Nicholls of
the National
Autistic
Society calls
the number of
autistic people
still held in
hospitals a
“scandal” and
says urgent
funding is
needed for
community
mental health
support**

some may end up back in hospital or institutional settings, she fears.

Brigene says: “These places (properties being used in the community for people with learning disabilities and autism) are just there and there's nothing to say they have been built to suit the individual needs of the people who require them.”

Fit to leave for 25 years

In 2018, an attempt was made to move Bryan out of Muckamore Abbey and into a bungalow, but it failed because the staff could not cope. Bryan, who has autism, a profound learning disability and bipolar disorder, was just 21 when he went to Muckamore Abbey. He has been fit to leave for 25 years.

Pam Hickmott's struggle to get her autistic son Tony out of a secure unit seems to perfectly illustrate Brigene's point about community accommodation being





Dr Christina Corsello Orahovats



Glenna Osborne

TEACCH® Autism programme 3 DAY TRAINING COURSE

January **3 DAY** 23-25. 2023 £415.00

June **3 DAY** TBA. 2023 £TBA

Venue: Kettering Conference Centre

Course Led by **Dr Christina Corsello Orahovats**, Clinical Professor, Department of Psychiatry, Director of Clinical Services UNC TEACCH Program



These trainings are most appropriate for: educators, therapists, administrators, professionals, & families

AM/PM refreshments & light lunch



Office: 199-203 Blandford Ave, Kettering, Northants NN16 9AT.
Tel./Fax: 01536 523274 autism@autismuk.com

Book online: www.autismuk.com

****(Covid-19):** The training courses above will take place subject to the safety concerns of delegates, ours & venue staff, including restrictions that may be imposed by the UK or US governments.**

Mental Health Bill



Still in a mental health hospital: Bryan McCarry, who has been a patient at Muckamore Abbey since he was 21, is one of 35 patients left there waiting to be discharged

Inset: Brigene McNeilly, Bryan McCarry's sister, believes that people with complex needs must have community accommodation that has been designed for them

unsuitable. Tony, 45, spent 21 years in the unit. It was more than two hours away from the Brighton home of parents Pam and husband Roy, 82.

But after their two-decades-long fight, Pam and Roy finally saw their son moved to a bungalow nearby. It was not the happy ending they hoped for, however. Speaking just two weeks after the move, Pam said her son's limited freedom means the bungalow is little more than an institution in the community.

'It's an absolute abuse'

"I was promised that it was going to be an open-plan place," she says. "We weren't allowed to see it until it was finished. It's not. It's all locked up. It's a secure unit."

Pam says her son is "not settling there at all", though she and her husband are seeing more of him than when he was in the hospital.

She says Tony is monitored by a video when he goes to bed in the

"A hospital is not a home. The Government must do more to end this scandal"

"restricted" bungalow. "It's an absolute abuse of the mental health law to lock somebody up that has just got autism and they're not a danger to anybody," she fumes.

Pam, 79, adds: "They've absolutely destroyed him. He's 45 and they've taken his life away and they're still doing it."

The mother said her son is being "fed on a shoestring" and his treatment is tantamount to "abuse".

Tim Nicholls, head of research at the National Autistic Society, says it will take years for the new Mental Health Bill to come into force. But those stuck in hospitals

need help now, he adds. Nicholls says NHS figures show that 1,205 autistic people are being held in mental health hospitals. He adds that the figure has been rising, despite Government commitments to reduce it.

The 1,205 now being held is a higher figure than in 2015, when autistic people made up 38 per cent of those in mental health hospitals. Now, autistic people account for 61 per cent of patients held in the hospitals.

Official figures

The Government insists that the overall numbers have declined when people with learning disabilities, as well as those with autism, are factored in. Official figures bear this out, showing the numbers with autism and learning disabilities detained stood at 1,965 at the end of September this year. This is down by just over 30 per cent from 2,885 in March 2015.

But Nicholls adds: "We need urgent and significant funding for community mental health services and the social care system, so that autistic people get the right support."

"A hospital is not a home. The Government must do more to end this scandal."

New duties imposed

The Department of Health and Social Care (DHSC) says the draft Mental Health Bill will not only restrict the scope for hospital detentions, but will also impose new duties to ensure there are sufficient community-based services. In a statement, the DHSC pointed to its Building the Right Support Action Plan. It says the initiative aims to "improve access to community-based support for people with a learning disability and autistic people, supported by additional targeted funding of more than £90m by 2023".

A spokesperson for Brighton and Hove City Council said its staff speak to Tony's parents on a weekly basis and "are aware of some concerns they have raised".

The spokesperson added that the council has seen "no evidence of abuse", but a safeguarding referral has been made over the family's concerns.

Lessons for life

The teaching of personal, social, health and economic (PSHE) topics is a vital part of our children's education. The subject covers important life skills, from how to stay safe to ways of improving children's emotional wellbeing. Fiona McNeill goes in search of best practice in delivering PSHE and finds some innovative and successful ideas

Most young people on the autism spectrum, regardless of their individual challenges, will need support with independent living, finding employment and developing relationships as they grow up. These essential 'life skills' are usually covered in PSHE (Personal, Social, Health and Economic) lessons in schools. But when students have an autism diagnosis, teachers, health professionals and families often need to find innovative ways to boost their understanding in this

area and help them prepare for adult life.

Lecturer Claire Bowditch co-runs PSHE lessons at Beechwood College in south Wales, a post-16 provision for young people across the autism spectrum. One of the problems, she says, with teaching life skills to autistic students is that they can find it difficult to translate what they've learned in the classroom to their own lives.

"When it comes to relationships, neurotypical students can listen to

Improving social skills without realising it: children take part in a Brick-by-Brick club, run by Play Included

others talking or watch TV shows and apply these insights to themselves," she elaborates. "Some of my students, however, will give me all the right answers on paper, but when they're faced with a situation it goes out the window and they act on impulse."

Essential to be open

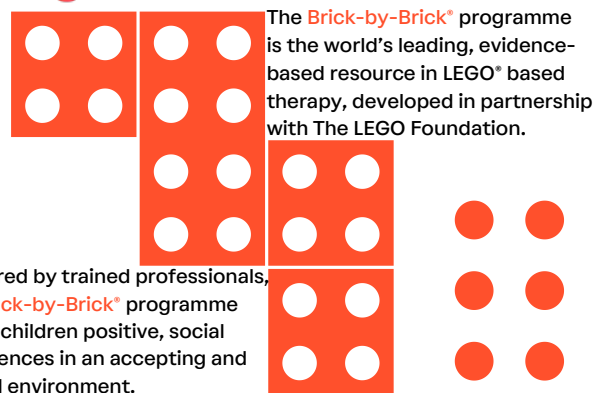
It's essential, Bowditch maintains, to be open when supporting autistic people through adolescence. "We've all been teenagers, struggling with

friendships and romantic relationships, and they're no different. We talk them through possible scenarios and different outcomes – we say, 'How will you feel if you ask this person for their number and they say 'no'?'"

It's also vital, she says, for schools and parents to work together and allow autistic youngsters to take calculated risks. "It's a huge key to building confidence. As parents, we want to protect, but it's important not to close doors. You have to prepare >>

Brick-by-Brick® Programme

The LEGO Foundation



Delivered by trained professionals, the **Brick-by-Brick®** programme offers children positive, social experiences in an accepting and playful environment.

Discover more and [download](#) our **free** resources for families and schools.



Book **Brick-by-Brick®** training at playincluded.com



*Professor Tony Attwood
and Dr Michelle Garnett in
London, January 2023*

*Tony and Michelle are Internationally
recognised authors and autism experts*

Book today and save on our
EARLY BIRD Rate

Visit: www.attwoodandgarnettevents.com/london-events
or email: events@attwoodandgarnettevents.com

Education



that your mind can beat you up."

For someone with good language skills, ACT can help them gradually move towards the kind of life they would like in adulthood, Solomon maintains. "We look at a person's values and the direction they'd like to move in rather than setting goals," she says. "Goals can feel like pressure and bring fear of failure."

Social understanding

Pegasus School in Derbyshire, part of the SENAD Group, caters for students with a diagnosis of autism and moderate-to-severe learning difficulties. Because of this, much of the school's focus is on developing life skills and social understanding, says headteacher Kerry Jefferson. Staff encourage this in many ways – for example, students eat together, taking turns to set the table or make toast for each other, and learn road safety by looking at pictures and then going on an outing to practise these skills in real life. Visual aids are also used to teach body parts or hygiene such as hand-washing.

One of Pegasus's most effective innovations has been the introduction of iPads as teaching aids, Jefferson says. "The students each have a communication iPad, which stays with them all day," she says. "These have PECS-style apps on them, which allow them to make simple sentences such as 'orange juice please', or just use single words."

The iPads are also used to prepare students for activities using a sequence of images, so they know what to expect. The iPads also capture photos of the young people meeting learning goals, which are then shared with parents. "We've noticed that incidents of challenging behaviour have reduced since we've been using the iPads," she adds. "We've given the students a voice and reduced their frustration levels."

Knowing how young people can sometimes get 'hooked' on technology, the school keeps separate, colour-coded iPads for fun activities.

Play Included in Cambridgeshire is an organisation that offers the 'Brick-by-Brick' programme. It's

Preparation: a Pegasus School pupil learns road safety skills in a PSHE lesson before practising them in real life

them – talking about internet safety or how to tell when someone is a 'safe' friend, for example – without taking opportunities away."

Risca Solomon, chief executive of Skybound Therapies, says this common difficulty in applying theoretical learning to 'real life' is now thought to be due to problems with interoception. This, she explains, is the awareness of how you are thinking and feeling within

yourself, moment to moment.

Acceptance and commitment therapy (ACT) can help enhance this self-awareness, enabling a youngster to make more sensible choices, Solomon says. "It's a newer version of cognitive behavioural therapy, but rather than ignoring difficult thoughts or feelings, you notice, name and accept them. It's about recognising that thoughts are just thoughts and

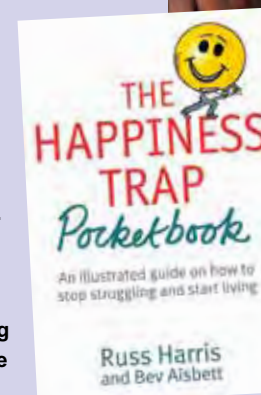
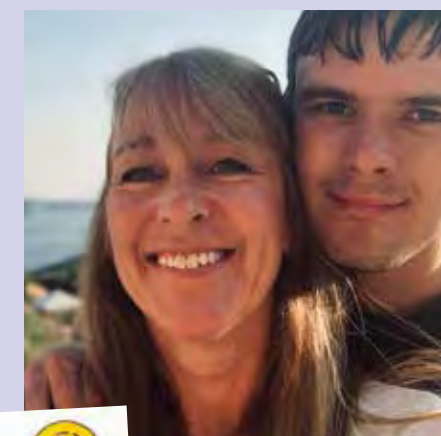
ACT therapy has 'transformed his life'

Mum praises the massive effect that acceptance and commitment therapy has had on her son's sense of well-being

Nicola Trotman, from Swansea, has an autistic son, Luke, aged 21, who was introduced to acceptance and commitment therapy (ACT) via Skybound Therapies.

"Luke has struggled with his thoughts and anxiety all his life," she explains. "He was really down on himself and, at his worst point, said he didn't want to live any more because he was a 'defective' person. Positive affirmations made him feel even worse because he thought he had to be happy all the time.

"ACT has been amazing. It's transformed his life," she continues. "It's about recognising that we all struggle. Before, he was always looking for something to get rid of uncomfortable thoughts and feelings. Now, instead of fighting them, he has learned to distance himself and say, 'I notice I am



having a thought/feeling'."

Trotman says the illustrated version of the book, *The Happiness Trap* (left), by ACT pioneer Dr Russ Harris, has been a fantastic teaching aid. It has given Luke strategies he can use, such as a body-scan meditation, or imagining difficult thoughts as passengers on a bus.

Quality therapies that make a real difference

Our primary focus
is on increasing
functional skills,
therefore decreasing
inappropriate or
challenging behaviours

Call us on: 01437 751 261

www.skyboundtherapies.co.uk

Email: info@skyboundtherapies.co.uk

[Twitter.com/SkyboundTherapy](https://twitter.com/SkyboundTherapy)

[Facebook.com/SkyboundAutismTherapies](https://facebook.com/SkyboundAutismTherapies)

**SKYBOUND
THERAPIES**

Call us now on 01978 820714
for a free home demonstration




www.kinderkey.co.uk

The Unique Kinderkey Bearhugzzz Bed
We can now offer our ever popular Bearhugzzz Bed on a height adjustable platform or as a floor based bed. It provides a soft, yet strong and safe environment for sleep, play and relaxation. Suitable for vulnerable children and adults, it is designed to accommodate the needs of people with Autism, Angelman Syndrome, Epilepsy, Challenging Behaviour and multiple learning difficulties.




Project Day Bed

- Multi-functional
- Space saving
- Superior Build quality

Designed with Autism in mind



Solving problems...with furniture

Call 01588 674340 | sales@toughfurniture.com | toughfurniture.com

Education



Helpful: a Pegasus School pupil uses visual prompts for PSHE skills

based on a simple idea – that children learn skills such as collaboration, turn-taking and problem-solving through carefully structured play using Lego bricks.

'They take pride'

As such, it's a great way for kids on the autism spectrum to improve their social skills without realising they are doing so, says the organisation's director, Dr Gina Gómez de la Cuesta, who studied Lego therapy for her PhD at Cambridge University.

"Children at the higher-functioning end of the autistic spectrum, especially, want to be with others, but aren't always included in friendship groups," she says. "Coming to our Brick-by-Brick clubs, they build models in small teams.

"They have a lot of say in what gets made, they feel they belong and take pride in what they've done. Sharing a mutual

interest is a genuine way to make friends."

Although Brick-by-Brick was originally devised for neurodivergent children, neurotypical children are also welcome at Play Included. And although there are trained therapists on hand to facilitate the groups, it's important, Gómez de la Cuesta says, that this is done sensitively.

"Too much hovering inhibits the kids," she explains. "There's a lot of praise and validating feelings and noticing when things go wrong to aid social problem-solving. The children learn to make mistakes and manage their feelings. Even so, the main thing is that it's a playful and joyful experience."

The organisation also runs training sessions, showing teachers, therapists and psychologists how to get the most out of the programme, and even visiting Mexico to spread the word.

CONTACTS

- Beechwood College: www.lshealthcare.co.uk/beechwood-college/overview
- Pegasus School: <https://senadgroup.com/pegasus/>
- Play Included: www.playincluded.com
- Skybound Therapies: www.skyboundtherapies.co.uk

www.autismeye.com

SENAD
Specialist education and care

Transforming the lives of children with Autism

Specialist day and residential placements.
Year round start dates.




Years of experience of providing high quality specialist Education and Support for people with Autism, learning difficulties and specialist health needs.

FIND OUT ABOUT OUR SPECIALIST SCHOOLS AT SENADGROUP.COM OR CALL US ON 01332 378840

We're social.   



Bright in Birmingham: Suzanne Shaw

Birmingham Hippodrome

● **Dick Whittington** Singer Marti Pellow returns to Birmingham as The Ratman in this action-packed adventure. Other cast members include panto stalwart Matt Slack, TV presenter Dr Ranj and singer and TV personality Suzanne Shaw.

Relaxed performance:

Wednesday 25 January at 12pm.
● www.birminghamhippodrome.com/calendar/dick-whittington-two/

The Brunton, Musselburgh

● **Sinbad the Pantomime** Join Sinbad on a fantastic journey as he voyages over the sea searching for fortune, and finding romance with a runaway princess.

Relaxed performance:

Wednesday 28 December at 2pm.
Tickets are £16.
● www.thebrunton.co.uk/

Dundee Rep Theatre

● **Cinderella** This re-telling of the classic panto is a musical festive fairytale. Young farmer Ella has big dreams, but her stepbrother and stepsister are more interested in their Insta posts than helping her.

Relaxed performance:

28 December at 2pm. Tickets are from £15.
● <https://dundeerep.co.uk/whats-on/cinderella>

Eden Court Theatre, Inverness

● Peter Pan

Relaxed performance: 6 January 2023 at 7pm. Tickets are from £14.



It's showtime

Celebrate Christmas and the New Year with an uplifting visit to the theatre or cinema. We highlight some fabulous shows over the festive season and into 2023 that have been specially adapted to be comfortable for audience members on the autism spectrum

● <https://eden-court.co.uk/event/peter-pan>

Festival Theatre, Edinburgh

● Snow White and the Seven Dwarfs

Relaxed performance: 4 January 2023 at 2pm. Tickets from £12.

● www.capitaltheatres.com/whats-on/all-shows/snow-white-and-the-seven-dwarfs-kings-panto-relaxed-performance/2064

Head2Head Sensory Theatre

● **Beauty and the Beast** This multi-sensory Christmas panto has been created especially for audiences of children with special needs and disabilities.

Join Belle, Hettie Harpic the Housekeeper and Fairy Fifi as they encounter the Beast. They stir up a stew, gad around a garden, feed some chickens, dabble in decorating, battle evil sprites and save the Beast before the last petal falls.

The production is filled with sensory moments, songs and silliness, led by a professional cast. All shows are Makaton signed and there is a chill-out zone available for anyone requiring a break.

This Surrey-based theatre company is touring the show around schools in nearby counties, so check online for upcoming dates and venues:

● <https://h2hsensorytheatre.com/live-panto/>

Sleeping Beauty as you've never seen it before: the National Theatre's new musical, Hex

Into Film

● The aim of this UK-wide charity is to put film at the heart of learning for children and young people. Its film clubs are available free to all state-funded schools and colleges and provide access to more than 4,000 films, plus curriculum-linked resources. It also holds autism-friendly free screenings for primary and secondary-aged children.

The charity's largest annual event is the Into Film Festival, which runs every November, and welcomes more than half a million children and young people to their local cinemas every year.

It also runs spring and summer film screenings, with 2023 spring screenings taking place between 6 and 31 March. There will be a wide range of autism-friendly films and events for children.

Bookings for free tickets open in mid-January, so save the date and check this link then:

● <https://www.intofilm.org/spring-screenings-2023>

Mercury Theatre, Colchester

● **Beauty and the Beast** The mysterious Beast imprisons Beauty in his enchanted castle. Can she escape and melt the Beast's icy heart before it's too late? Will Cupid's plan work before the last rose petal falls?

The Mercury's panto asks the age-old questions: what does it take for true love to conquer all? And is love all you really need? If it's anything like last year's panto, Aladdin, it should be spectacular.

Relaxed performance: Sunday 8 January at 12pm.

● www.mercurytheatre.co.uk/event/beauty-and-the-beast/

National Theatre, London

● **Hex** Playing on the National Theatre's biggest stage this Christmas is Hex, a new musical based on the story of Sleeping Beauty. When the fairy is summoned to the palace to help the princess sleep, her spell becomes a curse, and she is plunged into a hundred-year quest to make everything right.

It's recommended for audiences over the age of eight.

Sensory-adapted performance:

Relaxed and chilled performances



Thursday 22 December at 7.15pm.

● <https://events.nationaltheatre.org.uk/events/85035>

Perth Theatre

● Jack and the Beanstalk

Relaxed performance:

28 December at 2pm.

● www.horsecross.co.uk/whats-on/jack-and-the-beanstalk-176602

Picturehouse cinemas

● This group of UK-wide cinemas offers regular autism-friendly screenings. On the third Sunday of every month they show an older family film for just £3 per person, and where possible they also offer autism-friendly screenings of new releases at regular ticket prices - such as *Black Panther: Wakanda Forever* and Roald Dahl's *Matilda The Musical*.

Full details of the films coming up and the adaptations for each screening can be found at:

● www.picturehouses.com/autismfriendly

Royal Albert Hall

● There's a sleigh full of family-oriented events and shows at London's Royal Albert Hall this Christmas. There's something for everyone, from carols to traditional concerts, jazz, drag, soul and classic ballet.

Tickets for some events had already sold out when this magazine went to press, so we suggest you check out what's still available here:

● www.royalalberthall.com/tickets/series/christmas-at-the-royal-albert-hall

Salisbury Playhouse

There are three upcoming productions with relaxed performances at the Salisbury Playhouse - including one where every performance will be relaxed.

● **How the other half loves** Alan Ayckbourn's classic comedy takes us into a chaotic world of dysfunctional marriages, domestic drama and infidelity. The lives of

Ready to entertain you: comedian Joe Pasquale and members of the cast of Snow White and the Seven Dwarfs at the Theatre Royal Nottingham

Relaxed, sensory-adapted and chilled performances

Relaxed performances are adapted to be accessible to a wide range of audiences, including those on the autistic spectrum, those with a learning disability, or anyone with additional sensory needs. Lights and sounds are adjusted, there's a relaxed attitude to movement and audience responses, there are dedicated quiet areas inside the theatre should anyone need to leave their seat, and there are extra staff on hand. Often, a pre-show information pack is sent out so audiences can learn about the theatre and the production before their visit.

Sensory-adapted performances are similar to relaxed performances. The show is modified by reducing sound levels and special effects, and making other technical adaptations to soften contrasts within the show. They would suit those with an autism spectrum condition, epilepsy or a learning disability.

Chilled performances take a casual approach to noise and movement in the auditorium, but the performances are unchanged. They can be suitable for people who feel more at ease knowing they can go in and out of the auditorium during the show.

**RELAXED PERFORMANCE, WED 4 JAN 2.30PM
GREAT VALUE TICKETS - ONLY £16.50!**

JOE PASQUALE FAYE TOZER



**DAVID ROBBINS
JAMAL KANE CRAWFORD
LUCY IRELAND
NATALIA BROWN**

SAT 3 DEC 2022 - SUN 8 JAN 2023

**0115 989 5555
trch.co.uk**



Relaxed and chilled performances

three couples frantically intertwine in confusion and chaos. When one of the women arrives home suspiciously late one night, a chain of events unfolds that draws each of the couples ever deeper into hilarious misunderstanding. There's an age guidance of 12+. Tickets are from only £12.

Relaxed performance: 28 February 2023 at 2.15pm.

● <https://www.wiltshirecreative.co.uk/whats-on/main-house/how-the-other-half-loves/>

● **Brief Encounter** When a chance encounter in a train station tearoom kindles a timid, yet passionate, love affair between a married doctor and a suburban housewife, the two are forced to question if it's worth risking everything for the sake of love. Tender and joyous, this show aims to recreate the drama of the original film, with added live music, comedy and spectacle to take you on a



Spectacular: Colchester's Mercury Theatre promises to bring the same razzmatazz to Beauty and the Beast as it did for this production of Aladdin last year

rollercoaster ride through all of love's beautiful complications. There's an age guidance of 12+.

Relaxed performance: 13 April 2023 at 2.15pm; tickets from £12.

● www.wiltshirecreative.co.uk/whats-on/main-house/brief-encounter/

● **The Tempest** A mighty storm shipwrecks a king and his entourage on an island of magic and mystery. It is a place of music and visions, surprising encounters

and unlikely friendships. But what secrets does this island hold? Who or what is really in charge? And will the world ever be the same again?

This innovative re-imagining of Shakespeare's wonderful play is an outdoor walkabout production in a Salisbury park. This means that the theatre's professional actors and community contributors will take you from scene to scene at different locations, some of which will involve standing. Before booking, please be confident that you can move with the cast during this performance on a journey of about 1km.

All the performances will be relaxed for this production, running from 24 May to 4 June 2023. There are no age restrictions, with parents advised to bring children at their discretion. Tickets are from £12.

● www.wiltshirecreative.co.uk/whats-on/outdoor-events/the-tempest/

>>

CHRISTMAS AT THE ROYAL ALBERT HALL

FRI 9 - SAT 10 DEC

**BSL SESSIONS OF STORYTIME
WITH FATHER CHRISTMAS**

Use code BSLSanta to book online

WED 21 DEC

**FRIENDSHIP MATINEE: CAROLS
AT THE ROYAL ALBERT HALL**

£5 tickets | Relaxed performance



Relaxed and chilled performances

Theatre Royal Nottingham

● **Snow White and the Seven Dwarfs** Comedian Joe Pasquale and Faye Tozer, best known as a member of pop band Steps and a finalist on Strictly Come Dancing, will be aiming to make this production of Snow White the fairest panto in the land.

The show promises comedy, sensational song and dance numbers, fabulous costumes and stunning scenery. Throw in a magical mirror, seven friendly dwarfs, a beautiful princess, a handsome prince and plenty of audience participation and you have the perfect recipe to outwit the Wicked Queen and let love prevail in this glittering festive treat for all ages.

Relaxed performance:

Wednesday 4 January at 2.30pm. Tickets are reduced to £16.50.

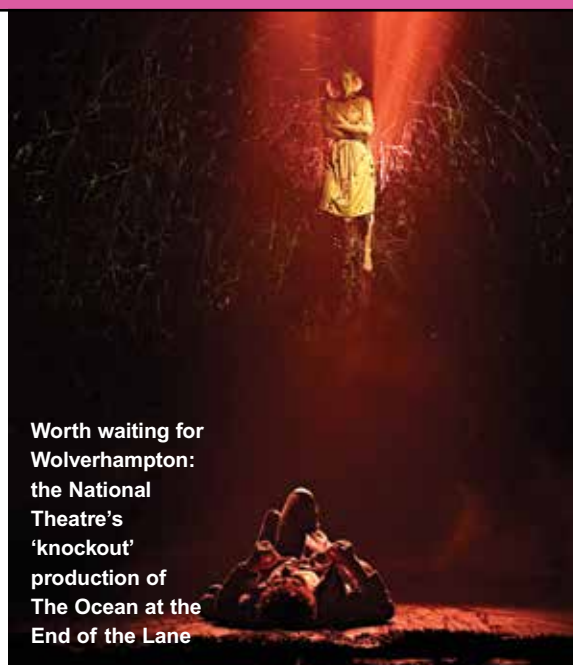
● www.trch.co.uk

Wolverhampton Grand Theatre

● **The Ocean at the End of the Lane** This story of adventure, fantasy, myth and friendship takes audiences on an epic journey to a childhood once forgotten.

You'll have to wait to see a relaxed performance of this touring National Theatre production, which came from London's West End and is at The Lowry in Salford over Christmas before visiting 28 towns and cities across the UK and Ireland. In fact, it won't be on at the Wolverhampton Grand until 2.30pm on 28 September 2023 – but promises to be worth the wait. *The Independent* called it: "Hauntingly memorable, this knockout production is theatre at its best."

● www.grandtheatre.co.uk/whats-on/the-ocean-at-the-end-of-the-lane/type%5Drelaxed%5D=relaxed&city-region&venuef&scroll=425



Worth waiting for
Wolverhampton:
the National
Theatre's
'knockout'
production of
The Ocean at the
End of the Lane

More Scottish productions

To see listings of relaxed productions in Scotland from March 2023 onwards, visit:
www.accessscottishtheatre.com/

Advertisement feature



How a personalised approach has a positive impact on sensory processing

Gail Withington, Service Manager of Yorkshire Day Opportunities Centre, shares her thoughts on the importance of the right environment for sensory processing



Above: Gail Withington.
Above right: Some of the team at the BROCS celebrating their recently awarded Advanced status Autism Accreditation from the National Autistic Society

Barnsley Road Outreach and Community Services (BROCS) in Wakefield is an independent specialist service for autistic people and adults with learning disabilities. Recently awarded Advanced Status Accreditation from the National Autistic Society, it's part of Voyage Care, the sector-leader in specialist care and support for adults across the UK with autism, learning disabilities and complex needs. Here, they create the right environment for those they support by understanding sensory processing.

Sensitive to sound

Autistic people often experience sensory processing disturbances, which means they are often over (hyper) or under (hypo) sensitive to external stimuli. The BROCS support several people who are hypersensitive to noise, with the range and volume of noise they can tolerate differing greatly.

Some may be able to tolerate loud music but need to put their hands over their ears if someone speaks. This is because individuals

who are 'hyper' sensitive to noise are not hypersensitive to all noise. Also, they're more noise tolerant if they know the noise is coming.

There are also people who are 'hypo' sensitive to hearing and they will seek out sounds, bang objects or shout. This can create anxiety in the people who are 'hyper' sensitive to noise. We ensure that people with these differences don't attend the same sessions. We also provide ear defenders and earphones to enable those with hypersensitivity to have some protection from the noise around them.

Types of fabrics

Some autistic people are hyper and hypo sensitive to touch, and this can mean they are unable to wear certain fabrics or types of clothing. Autistic people who are hyposensitive to touch are unable to feel light touches, pain or temperature changes. This can result in the individual seeking out deep pressure, such as rough playing, requesting deep-pressure

massage, wanting to wear tight clothing or use weighted blankets.

Fine motor skills

A large number of people who attend our day centre experience some form of sensory processing disorder. Our sessions support sensory problems, such as our craft room or gym promoting fine motor skills. We also have a sensory room that can be calming or stimulating through focusing on different senses.

A calming environment

Autistic people can find it difficult coping with surrounding sounds, sights and activities. Their sensory tolerance may be lower than others and this overload can lead to behaviours that may be challenging to those around them. To support this, we have quiet rooms for when individuals need a quiet and calming space.

Each person is unique and, because of that, each experience should be personalised to them and their sensory processing needs.



If you would like to find out more about the BROCS, or to discuss how we can help to support you or a loved one, please visit www.voyagecare.com

INTO FILM

SPRING SCREENINGS 2023

Free Autism friendly film screenings

6-31 MARCH 2023

Join us at next year's Into Film Spring Screenings for a curated selection of relaxed cinema showings across all four corners of the UK.

Into Film is the UK's leading charity for film in education, hosting educational and creative school trips for primary and secondary schools with year-round free film screenings.

Save the date to book your free seats in January

intofilm.org/spring-screenings-2023



For the ear and now

Make spiky sounds smooth with Calmer Kids Secure. Worn in the ear, they reduce stressful sounds so children can focus on the important ones. There's a built-in safe and flexible lanyard, which can be worn over or behind the head, helping to stop the in-ear devices from getting lost.

● £24.99 inc. VAT. www.flareaudio.com/products/calmer-kids-secure



Let's roll

Bright Sparks Roll & Glow, from SpaceKraft, is a wide, robust, transparent tube enclosing an opaque ball that rolls backwards and forwards. What makes it special is that the ball contains several light tiles that are activated with the rolling. The immediacy of this activity could engage sensory learners working at an early cause-and-effect level. The tube is 320mm high and 100mm in diameter.

● £64 plus VAT. www.spacekraft.co.uk/bright-sparks-roll-glow.html

Seasonal gift ideas

Our annual roundup of therapeutic, educational, fun and just downright useful products

Forever blowing bubbles

Who doesn't love a bubble machine? This one from Explore Your Senses comes in three options – a stand-alone machine, the machine plus flower-scented bubble liquid, and one that's switch-adapted (with a variety of switches available from the same supplier).

● £13.95 plus VAT (stand-alone)
 ● £19.95 plus VAT (with bubble liquid)
 ● £32.50 plus VAT (switch adapted)
www.exploreyoursenses.co.uk



Express emotions

Hamish & Milo Sensation & Emotion Cards help children to notice, recognise and begin to express how they feel. All children need repeated experiences of empathic adults labelling and validating their emotions. "This empathic engagement with a child enables a 'felt' sense of being understood and activates changes in the child's neurological system, allowing them to calm down, physiologically and psychologically," says the company's Clare Williams.

● **Special price for Autism Eye readers: £30 inc. VAT and P&P. Use the discount code AE22 at checkout.**
<https://hamishandmilo.org/sensation-emotion-cards/>



Let's dance

This Christmas card is from Spectrum of Misconception, a social enterprise set up to give work experience to young adults with autism and complex behavioural needs. Emma Saysell, the woman behind the organisation, set it up because she couldn't find anywhere that was willing to give her son, Zach, a chance. It now also sells products by other enterprises that have autistic people working in them.

Every card has a message on the inside. This one reads: 'Diversity is being invited to the party, inclusion is being asked to dance.'

● £4.99 for a pack of 10 cards with envelopes.
www.spectrumofmisconception.com

www.autismeye.com

Tap into this

Our image below shows a child working with a Rainbow Readers book from Discover SEN. It's part of a suite of books for teaching children with complex needs, including those with autism.

Rainbow Readers match to basic phonics and work on reading, vocabulary and language comprehension. Rainbow Speakers work on spoken/thought language, specifically the order of words in sentences and their relation to meaning. Rainbow Writers work on letter formation, spelling single words, writing sentences, writing a story and making a book.

● **From £14.99 for an introduction pack of Rainbow Readers or Writers.**
www.discoversen.com/products



Sensory sessions with sophistication

The young man pictured above is undergoing a personalised sensory regulation session in a Cubbie, a kind of smart, stand-alone cubicle that provides an immersive experience of sound and vision, free of disruptions. Just five to 15 minutes is said to be enough to regulate a child's senses, so one of these units could support up to 30 students a day. It's driven by sophisticated software that shows the progress of every student.

We don't expect families to afford one of these, but schools that have invested in one have left some glowing reviews.

● **Around £20,000.**
<http://www.cubbie.ie/>

Cosy and cocooned

Many autistic children and adults struggle with getting to sleep or staying asleep. Fitgetbum, made from breathable fabric and available up to king size, is designed to help by providing the pressure on the body that some seek, thereby helping to keep them calm. It snugly wraps under the mattress and zips up over the bed, offering a soft and stretchy cocoon.

● **£59.99 inc. VAT for a single-bed Fitgetbum, or £44.99 for a toddler-sized version.**
www.fidgetbum.com



Time for this smartwatch?

This is a new, high-definition, large-screen smartwatch from EasyLink UK. A carer/guardian can monitor the user's location, blood pressure, heart rate and daily physical activity via a secure app that works on Android or Apple phones.

The MMFA66 watch also has a fall sensor, which could be particularly useful for people with epilepsy while away from home. A detected fall is reported via the app, along with precise mapping location.

● **£89.99 inc. VAT. 10% discount for Autism Eye readers with the code MMFA66.**
www.easylinkuk.co.uk/health-conditions/health-conditions-autism?product_id=17821



For all your Multi-Sensory needs

**With 250 new and exciting products,
many of which are exclusive to SpaceKraft,
there's something for everyone**

Visit our website to find out more

www.spacekraft.co.uk

T: 01274 581007

E: enquiries@spacekraft.co.uk



Sssssso pleased to see you

This super smiley sensory snake is filled with around 1.7kg of beads. Soft and cuddly, it can hang around a child's shoulders or coil up to sit on their lap. The idea of the weight is to provide deep-pressure input throughout the day as part of a sensory diet.

● **£35.95 plus VAT.**
**www.exploreyoursenses.co.uk/
weighted-snake.html**

Monitor for meltdowns

Abrace is a smart bracelet designed to help children on the autism spectrum from going into a sensory meltdown.

The device collects a wide range of physical data to determine a child's emotional state. When sensory input levels exceed a threshold, it sends a notification via a smartphone application so that action can be taken quickly.

Abrace says this should give parents or professionals time to prepare for - or even prevent - meltdowns. It claims the mood analytics can be more than 90 per cent accurate after just ten days of wear.

The bracelet should be available in the UK from January. The developers have been raising funds for the launch on the crowdfunding platform Kickstarter, where it is available to pre-order for £83.

● **£124.99 in the UK from January, via
<https://abrace.ai>
Kickstarter page: [www.kickstarter.com/
projects/abrace-ai/abrace-the-worlds-
first-smart-ai-bracelet-for-autism](https://www.kickstarter.com/projects/abrace-ai/abrace-the-worlds-first-smart-ai-bracelet-for-autism)** >>



Calmer®

Small product. Huge benefits.

A small device worn in the ear to reduce stress.

Brilliant and discreet

I got these for my daughter, who struggles with noise. They are discreet and help my daughter cope when she would have previously struggled. The capsule is good as it can be easily attached to a school bag etc.



H.S.
Calmer Customer



FLARE
flareaudio.com





We are a trusted UK seller of sensory toys and resources for autism and sensory processing disorders.

What makes us unique?

We specialise in the UK manufacture of Weighted Blankets, Lap Pads and Clothing.

Subscribe for the latest **OFFERS** and **NEWS** and get **10% off** your first order



01905 670500 info@sensorydirect.com

sensorydirect.com



Autism|eye

Available as printed magazines as well as digital issues



Printed magazine subscriptions from just £16 a year

www.autismeye.com/subscribe-discount



Tile magic

Sensory Direct has become the exclusive UK supplier of Orto Nature playmats, which can help to develop the vestibular system (the sensory system that creates a sense of balance and spatial orientation in order to co-ordinate movement). The soft interlocking puzzle playmats are available in bright colours, multiple textures and a variety of designs. They are suitable for indoor or outdoor use and can be wiped clean.

There are smaller tiles, at 25cm x 25cm, which are called Orto Nature because they are inspired by the natural world. They even incorporate a variety of animal shapes, such as a crocodile and a hedgehog. There are also larger tiles, at 30cm x 30cm, which have been developed with input from physiotherapists.

● From £28.99 inc. VAT for a set of three tiles.

www.sensorydirect.com/products/ortoto-puzzle-sensory-playmats

Resources



May the Porg be with you

This friendly Porg from *Star Wars: The Last Jedi* flaps and waves his wings, waddles and moves forward while making Porg noises. It's a switch-adapted toy, meaning you can connect it to a wide variety of switches (all available from SpaceKraft) via its jack plug. It's said to be ideal for teaching cause and effect.

● £54.95 plus VAT. www.spacekraft.co.uk/star-wars-porg-switch-adapted.html

THROUGH DAY AND NIGHT WE HAVE THE RIGHT CARE SOLUTIONS FOR YOU

Cameras & Baby Monitors



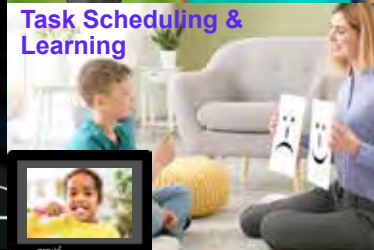
Trackers



Epilepsy Seizure Alarms



Task Scheduling & Learning



Enuresis Alarms



Door & Window Alarms



Easylink UK have supplied Assistive Technologies for over 35 Years. With a portfolio of over 100 own-brand products, designed to help people live more independently in their own homes, we have a passion for developing quality useful products at affordable prices.



Medpage Limited T/A Easylink UK

www.easylinkuk.co.uk

T: 01536 264869

3 Melbourne House, Corby Gate Business Park, Corby, Northants. NN17 5JG



explore your senses

- We are suppliers of sensory and educational toys and brain-stormers of a wide range of kits, to suit your specific sensory need.
- With over 50 years of combined experience in the sensory industry, our team is dedicated to ensuring you receive the highest quality products, speedy service and the ability to speak to a customer advisor easily.
- Explore Your Senses welcomes their 10th edition catalogue - request a copy by emailing your name and address to info@exploreyoursenses.co.uk alternatively, visit our website www.exploreyoursenses.co.uk, where new exciting product is updated weekly!

'A family business making customers part of the family'

When school doesn't work

It's that time of year. Your child went back to school in September, but perhaps things are just not working out. Specialist solicitor Lydia Dunford offers advice to parents whose children have been unable to fit into any kind of formal schooling and feel it's time to try accessing home education

A topic that is often of interest, and potential uncertainty, is that of EOTAS. What's that? Well, it's the abbreviation of Education Otherwise Than At School. It's the term used for pupils who a) have an Education, Health and Care Plan (EHCP) and b) it would be inappropriate for them to attend an educational institution.

EHCPs are legally binding documents prepared and maintained by a pupil's local

Happier at home? Some children are unable to fit into a school placement, but it can be a difficult process to get a local authority to fund Education Otherwise Than At School

authority to support their special educational needs. In most cases, they name either a specific, or type of educational institution that the pupil will attend.

An educational institution is one dedicated to providing education to pupils of compulsory school age. Section 4(1) of the Education Act (1996) (known as EA 1996) confirms that:

- (1) ... "school" means an educational institution... providing –
- (a) Primary education
 - (b) Secondary education, or
 - (c) Both primary and secondary education...

To explore what is meant by 'inappropriate' in terms of a pupil attending such an institution, we first need to consider what is meant by 'appropriate'. For this, Section 14 of the EA 1996 notes:

- (1) A local authority shall secure... sufficient schools for providing –
- (a) primary education, and
 - (b) education that is secondary...
- Are available for their area.
- (2)... schools... shall not be regarded as sufficient for the purposes of subsection (1) unless they are sufficient in number, character and equipment to provide for all pupils the opportunity of appropriate education.
- (3) In subsection (1) "appropriate education" means education which offers such variety and training as may be desirable in the view of –
- (a) the pupils' different ages, abilities and aptitudes...

Without stating as such, it would seem that pupils with special educational needs can arguably be covered under (3)(a). These are often pupils who struggle to access education in an educational institution. This may be due to the sheer size and noise of the classroom, the way lessons are taught, or having to navigate and respond to the ever-developing social rules and behaviours exhibited by their peers.

This description suggests a mainstream school but, as we will see further on, some pupils have attended both mainstream and

specialist placements and remain unable to access learning in either type of setting.

Therefore, sometimes it may be inappropriate for pupils to attend an educational institution, and the only option is for these pupils to be brought away from such environments entirely. The process then to secure EOTAS is rarely straightforward and can be litigious and complex, as we will examine in this article.

Now that we have an understanding of the law for pupils receiving an appropriate education in an educational institution, we can look into the specifics of:

- the relevant statute in terms of EOTAS;
- the factors to consider when EOTAS is required;
- what are the options if EOTAS is not agreed;
- how and in what part of an EHCP is EOTAS detailed;

“Some pupils have attended both mainstream and specialist placements and remain unable to access learning in either type of setting”

- if, and how, a Personal Budget relates to EOTAS;
- what is the ultimate aim for a pupil who is receiving EOTAS – is it a long-term solution?

EOTAS statute

The logical starting point is the law permitting local authorities to agree to detail EOTAS in a pupil's EHCP. This is set out in Section 61(1) of the Children and Families Act (2014) (known as CFA 2014) as follows:

- (1) A local authority in England may arrange for any special educational provision that it has decided is necessary for a child or young person for whom it is responsible to be made otherwise than in a school...
- (2) An authority may do so only if satisfied that it would be **inappropriate** (emphasis added) for the provision to be made in a school...
- (3) Before doing so, the authority must consult the child's parent or the young person.

Prior to the CFA 2014, the EA 1996 (in respect of the EHCP predecessor, Statements of SEN) confirmed at Section 319:

- (1) Where a local authority are satisfied that it would be **inappropriate** (emphasis added) for –
- (a) the special educational provision which a learning difficulty of a child in their area calls for, or
 - (b) any part of such provision, to be made in a school, they may arrange for the provision (or, as the case may be, for part of it) to be made otherwise than in a school.
- (2) Before making an arrangement under this section, a local authority shall consult the child's parent.

We will focus on the CFA 2014 in this article (given it specifically covers EHCPs), but the wording to take note of under both this and the EA 1996 is 'inappropriate', which, as with so much terminology in statute, allows for submissions on both sides.

Arguably, it needs to be considered when a pupil cannot attend school due to their special educational needs, and if a local authority therefore decides that the pupil is taught outside of a school environment altogether.

What are the options available if a pupil does not attend a school? In many cases, pupils are educated at home. The reasons for this can vary. Sometimes it is because parents have lost confidence in a school's ability to meet their child's needs, or there are health and safety concerns.

Often, it is down to the pupil feeling most secure in the home environment. At the very least, a pupil receiving EOTAS cannot do so in a setting that is classed as an educational institution (a 'school' or post-16 institution or a place at which relevant early years education is provided', Section 61 CFA 2014). Pupils could receive EOTAS provision through online/ in-person tuition, as well as

attending alternative education providers/centres. The specifics will depend on the needs of the individual pupil and the provisions they require.

It may even be the case that an educational institution can provide the EOTAS provision for a pupil outside of a classroom set-up. In such circumstances, consideration would need to be given about the physical practicalities of an arrangement. The question of how this would then be detailed in an EHCP will be examined further on.

Factors to consider when EOTAS is needed

Case law has developed the interpretation of when EOTAS is applicable in EHCPs. While not many cases have, to date, addressed EOTAS, let us consider some that do, which provide useful points to consider:

- *TM v London Borough of Hounslow*¹ concerned Section 319 EA 1996, Statements of SEN, but can still be given regard here. This case held that in determining if it is suitable, or indeed proper, for a child to attend school, then the following is an example of what needs to be considered (note, this is non-exhaustive):
 - the child's background
 - the child's needs
 - facilities that can be provided otherwise than at school
 - costs
 - parents' wishes
 - any other particular circumstances that might apply

It is usually a pupil's parent who initiates the request for EOTAS in the first place, rather than the local authority. It is important to note that under Section 9 EA 1996 (which has no equivalent under the CFA 2014):

"...local authorities shall have regard to the general principle that pupils are to be educated in accordance with the wishes of their parents, so far as that is compatible with the provision of efficient instruction and training and the avoidance of unreasonable public expenditure."

It is this Section 9 consideration that parents can, and often do, rely

on when asking for EOTAS for their child. Note that parental preference for EOTAS, including reliance on Section 9, is rarely sufficient for a local authority to agree to this, at least initially. The reasons for this, as well as the options available to parents, will be set out further on.

- *M v Hertfordshire County Council*² concerned a child who, as well as having a rumination disorder, suffered with school-related anxiety. This case found that a child's anxiety may lead for it to be 'inappropriate' for provision to be made at school.

School-based anxiety is a key reason that parents request EOTAS for their child. This can, and usually does, follow a breakdown in placements, sometimes after multiple placements. Families can find themselves left to try and work out where they can go from here,

Evidence from an educational psychologist, or similar, is what parents should aim to secure

usually having to support and educate their child at home, sometimes suddenly, but more likely after a period of reduced school attendance.

Factoring in a potential lack of local authority funding, staff and resources can result in very little, if any, input from them.

There is an important distinction that unless parents choose to electively home educate their child, as permitted under Section 42(5) CFA 2014, a local authority maintains legal responsibility for providing a suitable and appropriate education for a pupil who is not attending an educational institution. This is under Section 19 EA 1996. Parents do have recourse to legal action if their child is not receiving such an education and is not being electively home educated.

As we have already established, EOTAS is not an option that local authorities agree to lightly; it requires acknowledgment that it would be inappropriate for a pupil

to attend any educational institution. This is different to considering one or two schools in particular, and determining that one is unsuitable to meet needs but the other can.

Therefore, a request for EOTAS usually requires evidence to specifically address the possibility that no educational institution is appropriate. An educational psychologist, or clinical psychiatrist potentially, is well placed to advise about this, but that does not preclude other therapists – such as speech and language, occupational and even physiotherapy – commenting as well. Ultimately, though, evidence from an educational psychologist, or similar, is what parents should aim to secure when requesting EOTAS for their child.

There are several reasons why local authorities can be reluctant to agree to EOTAS (at least initially), even when there is supporting evidence. Reasons include:

- In most circumstances (except for some independent schools) a local authority can name a school in an EHCP, meaning that the school has to admit that pupil, even if they have expressed concerns about their ability to meet the pupil's needs. Local authorities may submit that the overall cost of a pupil attending a school, plus additional support through their EHCP to mitigate the school's concerns, is less than that of an EOTAS package, thereby avoiding "unreasonable public expenditure" (Section 9 EA 1996).
- The local authority may have concerns that the child's needs will not be met, or that by not attending a school/college setting they will miss out on necessary social interaction and risk isolation.

Gathering as much relevant and strong evidence as possible is often crucial when requesting EOTAS, particularly if parents need to challenge a local authority's decision in not agreeing to it.

REFERENCES

¹ [2009] EWCA Civ 859, [2011] ELR 137

² [2019] UKUT 37 (AAC)



Lydia Dunford is a solicitor at Boyes Turner, www.boyesturner.com. She has experience of special educational needs and disability (SEND) law, including all stages of the Education, Health and Care Plan (EHCP) process, from requesting an EHC Needs Assessment to advising on Local Authority refusals to assess or issue/amend an EHCP



WE'RE
hiring

Your clinical expertise
+
our technology
=
life-changing results



Change a child's life, without
even leaving your house!

Founded in 2013, Healios is a leading specialist digital healthcare company working to empower patients and families affected by mental health, autism and ADHD conditions to support long-term outcomes and wellbeing. Our mission is to bring exceptional healthcare to anyone, anytime, anywhere.

The opportunity

Autism Assessment Practitioner (Fully Remote)

POSITION: Permanent, Full & Part Time (minimum of 3 days per week)
LOCATION: Home based
SALARY: £41,500 - £50,200 FTE

We are seeking Autism Assessment Practitioners who are ADOS or ADIR trained, skilled at autism diagnostic assessment and interventions and who are committed to delivering the best outcomes for neurodiverse children, young people, adults and

their families. The successful candidate will be a member of a MDT, and will deliver part of the autism assessment alongside support, advice and interventions.

Requirements:

- Clinical qualification and registration in Occupational Therapy, Social Work, Nursing, Speech and Language Therapy or Psychology
- Registered with a statutory body (NMC, HCPC, ACP, BABCP, UKCP, BACP, SWE, SCW, SSSC or NISCC)
- ADOS or ADI-r trained and experienced

Join the largest Neurodevelopment team in the UK and at Healios you will have access to

- Fully remote and flexible working
- An extensive benefits package
- Commitment to your development with internal and external training
- Generous leave entitlement and family friendly policies
- Home working allowance



For more information
and to apply, visit
healios.org.uk/careers

Specialist day and residential provisions for children and adults with learning differences and disabilities in England, Wales and Scotland.

Ruskin Mill Trust's unique method *Practical Skills Therapeutic Education* enables individuals to forge a sense of identity, gain qualifications and independent living skills, and re-imagine their potential for a brighter future.



RUSKIN MILL TRUST IN ENGLAND

argent college
Birmingham, 16-25

grace garden school
Bristol, 9-16

sunfield school
Clent, 6-19

clervaux garden school
Darlington, 10-19

clervaux fold
Darlington, army families

clervauxrise
Darlington, 18+

ruskin mill college
Nailsworth, 16-25

brantwood specialist school
Sheffield, 7-19

freeman college
Sheffield, 16-25

glasshouse college
Stourbridge, 16-25

IN SCOTLAND

fairhillrise
East Lothian, 16+

IN WALES

coleg plas dwbl
Clynderwen, 16-25

ty'r eithin
Swansea, 16-25



Applications and referrals are taken all year round. Contact us today to find out more or to arrange a visit at a time to suit you.



0330 055 2653
admissions@rmt.org | rmt.org



The science of sociability

Not being able to socialise as a toddler or a young adolescent, or even throughout adulthood, can have a profound impact on an individual's well-being. A new study throws light on environmental risk factors that could tip autistic people into this situation and suggests it may be reversible

Little is known about how social behaviour develops in the earliest stages of life. But most animals, including humans, are born with an innate ability to interact socially or form bonds with others. And that can contribute to success and an easier path through life.

Now, a new animal study points to a gene that is important for the

earliest development of basic social behaviours.

The work also suggests that exposure to certain drugs and environmental risk factors during embryonic development can cause changes to this gene, leading to alterations in social behaviour that are similar to those found in individuals on the autism spectrum.

“This study helps us understand at the molecular level why sociability is disrupted during the earliest stages of life”

Much to their surprise, the researchers also found they could reverse some of the effects using an experimental drug.

Potential treatments

“This study helps us understand at the molecular level why sociability is disrupted during the earliest stages of life,” says Randall T Peterson, PhD, the corresponding author of the study and dean of the University of Utah College of Pharmacy. “It also gives us an opportunity to explore potential treatments that could restore sociability in these animals and, perhaps in time, eventually in humans as well.”

More broadly, the researchers' findings suggest that the gene, TOP2a, controls a large network of >>

genes that are known to increase the likelihood of autism. It may also serve as a link between genetic and environmental factors that contribute to onset of the condition, Peterson adds.

The study, conducted by University of Utah Health researchers and colleagues nationwide, appears in the November issue of *Science Advances Magazine*.

Anti-social animals

Scientists suspect many social traits are determined before birth. But the precise mechanisms involved in this process remain murky. One promising area of research suggests that social behaviour and other characteristics and traits are influenced not only by our genetic makeup, but also by how and where we live.

To test this model, the scientists evaluated whether environmental exposures during embryonic development could influence social behaviour. Peterson and his colleagues exposed zebrafish embryos to more than 1,100 known drugs – one drug per 20 embryos – for 72 hours, beginning three days after conception.

The researchers determined that four of the 1,120 tested drugs significantly reduced sociability among the zebrafish. Fish exposed to these drugs were less likely to interact with other fish. It turned out that the four medications all belonged to the same class of antibiotics, called fluoroquinolones. These drugs are used to treat upper and lower respiratory tract infections in people.

When the scientists gave a related drug to pregnant mice, the offspring behaved differently when they became adults. Even though they appeared normal, they communicated less with other mice and engaged in more repetitive acts.

A basis for sociability

Digging deeper, the researchers found that the drugs suppressed a gene called TOP2a, which, in turn, acted on a cluster of genes that are known to be involved in autism in humans.

They also found that the cluster



The scientists involved

In addition to Dr Randall Peterson (pictured), University of Utah Health scientists Yijie Geng, Tejia Zhang, Ivy G Alonzo, Sean C Godar, Christopher Yates, Brock Plummer and Marco Bortolato contributed to the Top 2a study. Other participating institutions included the University of Chicago; Beth Israel Deaconess Medical Center in Boston; Massachusetts General Hospital and Harvard Medical School; the Broad Institute, Cambridge, Massachusetts; and MDI Biological Laboratory, Bar Harbor, Maine.

“This study suggests that even in those individuals later in life, you can still come in and restore sociability”

of autism-associated genes shared another thing in common – a higher-than-usual tendency to bind a group of proteins called the PRC2. The researchers hypothesized that Top2a and the PRC2 work together to control the production of many autism-associated genes.

To determine whether the anti-social behaviours could be reversed, the research team gave embryonic and young zebrafish an experimental drug called UNC1999, which is known to inhibit

the PRC2. After treatment with the drug, fish exposed to fluoroquinolones were more likely to swim closer to other fish, demonstrating that the drug helped restore sociability. They saw similar results with other drugs known to inhibit the same key gene, TOP2a.

“That really surprised me because I would’ve thought disrupting brain development when you’re an embryo would be irreversible,” Peterson says. “If you don’t develop sociability as an embryo, you’ve missed the window. But this study suggests that even in those individuals later in life, you can still come in and inhibit this pathway and restore sociability.”

Moving forward, the researchers plan to explore how and why this drug had this effect.

Tip of the iceberg?

Although the scientists found only four compounds that are Top2a inhibitors, evidence suggests that hundreds of other drugs and naturally occurring compounds in our environment can inhibit its activity. “It’s possible that these four compounds are just the tip of the iceberg in terms of substances that could be problematic for embryonic exposure,” Peterson says.

However, Peterson notes that this study was conducted in animals, and more research needs to be done before any of its results can be confirmed in humans. Therefore, he cautions against drawing conclusions about real-world applications.

“We have no evidence that fluoroquinolones or any other antibiotic causes autism in humans,” Peterson says. “So, there is no reason to stop using antibiotics. What this paper does identify is a new molecular pathway that appears to control social development and is worthy of further exploration.”

FURTHER READING ABOUT THIS STUDY

● The study, ‘Top2a promotes the development of social behavior via PRC2 and H3K27me3’, appears in the November 2022 issue of *Science Advances*. This research was supported by the L S Skaggs Presidential Endowed Chair and the National Institute of Environmental Health Sciences at the National Institutes of Health. <https://www.science.org/doi/10.1126/sciadv.abm7069>

IMAGE OF DR PETERSON COURTESY OF UNIVERSITY OF UTAH



Swalcliffe Park... for a Quality of Life approach

We’d like to tell you what we offer students and families at Swalcliffe Park School



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

We want all our students to be happy, healthy and empowered young people. So, we think it is essential to ask them about what matters to them, what makes them happy and what they would like to do with their lives.

We also think it is important to work closely with families. So, we ask them about the impact of autism on family life, about what they would like to do but currently can't, and about what is important to them. We know that working together in this way leads to brighter futures and a better quality of life for our students and their families.

The starting point for helping our students to is find out about their personal strengths and difficulties, as well as their hopes and aspirations, so we can help them prepare for adulthood.

However, we believe it is also important to ask them, regularly, how things are going in their lives. To achieve this, all students have weekly keyworking sessions and

“All individuals with autism are entitled to a good education and a good quality of life”

Autism Education Trust

complete termly surveys. This gives students regular opportunities to evaluate their feelings about themselves, their relationships, their emotional and psychological well-being and their personal circumstances at the time.

By sharing this information, each student is giving us his personal perspective on what is going well in his life and what is not.

We then focus our support in four main areas:

- Communication
- Self-management
- Independence
- Achievement

Our approach also involves working closely with families. As student lives influence family lives, we recognise that some families will need direct support and guidance. This makes it essential for us to know how autism affects each family's life.

We do this through weekly keyworking conversations and termly surveys. These provide us with up-to-date information on what issues families are facing so we can see how best to support them.

We then focus our support to families in four main areas:

- Support for school-related issues
- Family-to-family support
- Support for home-based issues
- Training

We use 'Quality of Life' information from students and their families to target support on the issues that are important to them. This is 'why we do what we do' and are proud to have been awarded 'Advanced Level' Autism Accreditation for our approach.

We have also established the 'Quality of Life' network for other schools who are interested in adopting our approach.

If you would like to know more about anything you have read here, please visit our website www.swalcliffepark.co.uk or give school a call on 01295 780302 and ask to speak to either Kiran Hingorani, Chief Executive Officer, or Rob Piner, Principal.



Swalcliffe Park School

Swalcliffe, Banbury

Oxfordshire OX15 5EP

T: 01295 780 302

admin@swalcliffepark.co.uk

www.swalcliffepark.co.uk



“You can help your child or teen to maintain optimal iron levels by incorporating iron-rich foods into their diet”

Mighty iron

Tired, not focusing, being picky with food. These are just a few of the traits we see in children and adolescents on the autism spectrum, but they can also indicate iron deficiency. Nutritionist Stella Chadwick offers advice on what to do if you spot signs

Childhood and adolescence are times when the body's demand for iron naturally increases. In children on the autism spectrum, iron deficiency is a common problem, often accompanied by fatigue, poor weight gain, picky eating and pica (eating non-food items). Adolescent girls may also be

particularly at risk of iron deficiency when they begin menstruating. Yet signs of low-iron status may not always be obvious. Iron is an essential dietary mineral whose main role in the body is as a component of haemoglobin, the oxygen-carrying molecule found in every red blood

cell. However, iron also plays a role in many other metabolic processes, including growth and development, cellular respiration and DNA repair and synthesis. Iron deficiency is one of the most common nutrient deficiencies worldwide. More than 1.2 billion people globally suffer from iron deficiency anaemia, and up to twice this many are iron deficient without symptoms of anaemia. See the table opposite. In our clinic, iron deficiency is one of the most common issues we see in autistic children and teens. At times of rapid growth – childhood, adolescence and pregnancy – the body's demand for iron is higher, and the risk of depletion rises. Girls and women who are menstruating are also at high risk of iron deficiency, especially if they experience heavy periods due to the regular loss of iron through the blood. Even when dietary iron

intake is plentiful, deficiency may still occur because of poor iron absorption in the gut. Internal bleeding, chronic illness or bacterial infection, regularly donating blood or following a strict vegetarian or vegan diet also render people susceptible to iron depletion. **Unusual symptoms** Low iron levels without anaemia can manifest in more unusual symptoms, such as pica – the urge to consume non-foods such as paper, soil or clay. Studies have also found that low iron can directly contribute to poor cognitive performance because of reduced oxygen supply to the brain, impaired development of neurons, or impaired neurotransmitter synthesis. In children, this may result in hyperactivity or reduced attention span. Difficulty swallowing or frequent infections may also indicate depleted iron levels. If your child or teen is displaying



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

Main image: a selection of iron-rich foods

any of the above symptoms, consider visiting your GP, who may recommend a blood test to determine whether iron deficiency may be a factor.

Bacterial infection Chronic bacterial infection can lead to 'infectious anaemia'. When the body is fighting a bacterial infection, it sequesters iron from the blood into storage tissues, including the bones, spleen, liver and lymphatic tissue. This is a protective strategy: it renders iron unavailable to bacteria, as bacteria can use iron to grow and proliferate. While it is an effective defence against acute infections, if infection becomes chronic, iron is locked away long-term and is not available to be integrated into red blood cells, so anaemia develops. In this circumstance, simply supplementing iron will be ineffective at addressing anaemia. The key is to resolve the infection.

Gut health is key A healthy gut is essential for optimising iron absorption and regulating iron levels. Chronic bleeding or inflammation in the gastrointestinal tract can lead to reduced iron absorption and increased iron loss. Examples of conditions that might cause gastrointestinal tract inflammation are bowel diseases such as Crohn's, ulcerative colitis and coeliac. The gastrointestinal tract may also become chronically inflamed through poor diet, a parasitic infection or food allergies and intolerances.

Dietary iron You can help your child or teen to maintain optimal iron levels by incorporating iron-rich foods into their diet. The most readily absorbable form of iron for the body is haem iron, found in animal protein. Red meats and organ meats are particularly rich sources of haem iron. Offer one or two portions a week of these foods. You can incorporate organ meats into bolognese sauce or shepherd's pie to disguise the taste if needed. Non-haem iron is found in

Common symptoms of iron deficiency anaemia include:
Extreme fatigue
Weakness
Pale skin
Chest pain, fast heartbeat or shortness of breath
Headache, dizziness or light-headedness
Cold hands and feet
Inflammation or soreness of the tongue
Brittle nails
Poor appetite, especially in infants and children with iron deficiency anaemia

vegetables (especially green, leafy vegetables such as spinach and kale), grains, pulses, nuts and seeds. But non-haem iron is not easily absorbed if consumed alone. Including Vitamin C-rich foods, such as bell peppers, tomatoes and citrus fruit, and cruciferous vegetables such as broccoli, cauliflower and cabbage in meals enhances the absorption of non-haem iron from food by up to 300 per cent. Tea, coffee and dairy products all inhibit the absorption of iron, so try to avoid consuming these at the same time as iron-rich foods. Iron absorption is dependent on a sufficiently acidic environment in the stomach. Where stomach acid production is insufficient, or when an individual is on long-term medication that suppresses stomach acid production, iron absorption can be significantly reduced. **Identifying the cause of iron deficiency** Simply giving an iron supplement is not always the right strategy to correct an iron deficiency. Alongside assessing a patient's clinical presentation, medical and functional tests can shed light on the cause of the iron deficiency. A reputable functional medicine practitioner or nutritional therapist can guide you on which tests are most appropriate to help establish the cause(s) of the iron deficiency and the most appropriate interventions to redress it.

LIBRARY CORNER

Our pick of new and useful books



Autism and Us: Old as Time



Autism, says author Eustacia Cutler, who is the mother of Dr Temple Grandin, has been part of us since we first left handprints on cave walls 40,000 years ago. This book takes an in-depth look at its

neurological history and how society has viewed it. It quotes from medical records, folk tales, beliefs and Victorian literature and explores the 19th century mix of ignorance, cruelty, fumbling knowledge and surprising love that led to the first medical recognition of autism. Cutler gives a unique perspective on the past century of growth in our understanding of the condition.

● Future Horizons, \$19.95/available in the UK from Eurospan Bookstore, £21.95

What Works for Autistic Children



Imagine a world where your autistic child is included, engaged and cherished for how they are; a world that changes for autistic children, rather than changing the child. *What Works for Autistic Children* brings

the conversation about inclusivity to the forefront and turns it on its head. Instead of modifying the autistic child and making exceptions or special circumstances, author Dr Luke Beardon shows parents how the world must change to accommodate your child.

He identifies the aspects that impact on your child's life most – family, school, their friends, their environment – and outlines the steps that should be taken by everyone involved to improve their outcome and create an autism-friendly landscape. From early communication, through pre-school, primary school,

secondary school – on holidays, school trips and with friends – Beardon's message is that your child should not have to struggle to exist within the parameters of a world they don't understand. This book presents the dialogue, tools and starting points to involve every professional and family member as advocates for a world where an autistic child can flourish.

● Sheldon Press, £12.99/around \$16.99 online

The Autism Full Employment Act



This book is aimed at adults who would like to advance in the world of work and who are autistic, have attention-deficit hyperactivity disorder (ADHD) and learning and mental health

differences. It's an American book that sets out to rebuild and improve autism employment programmes in the United States, but it includes ideas that transcend international borders on how to build an inclusive society for the autism and neurodivergent community.

During the pandemic of 2020, authors Michael Bernick and Dr Lou Vismara, along with autistic adults, practitioners and advocates, set out to create and develop an Autism Full Employment Act. The Act is an attempt to rebuild autism employment programmes decimated by the Covid pandemic, and to address problems with the current system.

The Autism Full Employment Act shows how the world of work can be a success for many who are not employed today. The authors review the autism employment initiatives in recent years among major employers, state and local governments, autism-focused businesses and autism transition programmes and present strategies to build on these initiatives.

● Skyhorse Publishing, \$22.99/around £20.77 online

“It explores the 19th century mix of ignorance, cruelty, fumbling knowledge and surprising love”

Women with Autism



This is a useful book for any female who suspects they might be autistic, or has been recently diagnosed. Dr Claire Jack takes readers through the journey of autism diagnosis, explaining

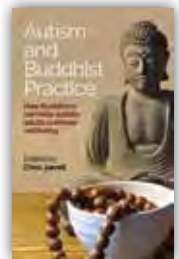
what to expect when coming to terms with the condition and how you can move beyond feeling fearful, unsure and confused to feeling confident in yourself.

She explains the issue of masking, which many autistic women have spoken of, explaining how they masked their condition to the outside world. Based on her experience of coaching autistic women throughout the world, and of being a woman on the autism spectrum, Dr Jack helps readers move beyond their diagnosis towards accepting and embracing themselves and the condition.

There is a useful checklist of women's symptoms and the stages to expect in seeking a diagnosis. Whatever stage autistic women are on their journey, this book will help establish where they may want to be and how to get there.

● Casacat Press, £12.99/around \$21 online

Autism and Buddhist Practice: How Buddhism can help autistic adults cultivate wellbeing



This series of reflective accounts explores the benefits that Buddhist practice can bring for autistic individuals, and outlines how Dharma teachers, centre directors and meditation group leaders can help

ensure sessions are truly autism sensitive. It includes a wide range of international contributors, who discuss aspects of their autistic experience and the impact of Buddhism on their lives. This is a thought-provoking and often moving portrayal of the intersect between the lived experience of autistic people and spiritual practice.

There are personal accounts of the positive impact Buddhist practices have had on relationships, social interactions, sensory overload, mental health and wellbeing. These reveal more about Buddhism and the support that it can offer to the autistic community through, for example, personal practice, parenting and special educational provision.

● Jessica Kingsley, £16.99/\$24.95

the autism show

in association with  National Autistic Society

The National Event for Autism

London

9-10 June 2023 | ExCeL

Birmingham

23-24 June 2023 | NEC

Manchester

7-8 July 2023 | Manchester Central



GATHER INFORMATION & PRACTICAL ADVICE



HEAR THE UK'S LEADING AUTISM PROFESSIONALS



INTERACT WITH INNOVATIVE FEATURES



ACCESS ONE TO ONE SPECIALIST SUPPORT



LEARN FROM ADULTS ON THE SPECTRUM



DISCOVER 100s OF HELPFUL PRODUCTS & SERVICES

Book your tickets now and save 20%

Follow us on



www.autismshow.co.uk

Educational support when you need it most.

TCES provides independent specialist education to neurodiverse pupils aged 7-19 in and around London.

Pupils will have complex needs typically with autism and associated conditions and SEMH (social, emotional and mental health).

OUR SCHOOLS AND SERVICES OFFER:

- A therapeutic approach to education,
- A broad and differentiated curriculum,
- Unique and award-winning LIFE leadership programmes,
- Universal, group and targeted therapy,
- Post-16 programmes.

Our TCES Home Learning service offers home-based and virtual support to pupils who are out of education and struggling to be in school.

We do not exclude pupils.
We never give up!

Contact us to find out more about the services we offer and our open days.

Email: Feedback@TCES.org.uk

Call: 020 8543 7878

Visit: www.TCES.org.uk



TCES THE COMPLETE
EDUCATION SOLUTION
CREATING UNIQUE JOURNEYS FOR LIFE AND LEARNING

TCES is committed to safeguarding vulnerable children and safeguarding is the responsibility of us all.

