

# AUTISM

A  
SPECIAL  
**REPORT**  
DISCUSSING THE  
CONDITION

## UNDERSTANDING THE SPECTRUM

**Early detection:** The signs to look out for and the best methods for you, your family, friends and teachers for managing autism

Research  
Why understanding  
autism will help  
those affected thrive



AUTISTICA

Stop discrimination  
Give society the  
knowledge to fight  
against stigma



NATIONAL AUTISTIC SOCIETY

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**Please support the work of the UK Autism Foundation  
we are campaigning long and hard on behalf of the poor.**

Join UKAF's World Autism Awareness Day 2011 Twitter Storm - Tweet for Autism on 2nd April using the tags #autism #worldautismawarenessday #waad - this is a worldwide event. Please place a UKAF World Autism Awareness Day twibbon on Twitter and Facebook: <http://twibbon.com/join/ukaf-backs-world-autism-day>

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*thank you*



## CHALLENGES

Autism is often heard about - but not nearly as frequently understood. With one in 100 people in the UK affected by autism, it is not rare. Yet it is hidden, and to increase understanding we need to raise awareness: the key to better lives is support and tolerance

## How to move ahead

In the UK today, it is estimated that over half a million people are affected by autism, which equates to one in every 100 people. If you include their family members, such as parents and siblings, autism touches the lives of over two million people - so it is likely that includes someone you know.

People with autism can find it very hard to make sense of the world. This can make everyday life confusing. Understanding and communicating with other people is difficult - which can leave them feeling alone and ignored.

Unfortunately we hear only too often that people with autism and their families have to deal with an overwhelming lack of understanding and support at times when they need it most.

It is for this reason that on 2nd April each year, charities across the world unite for World Autism Awareness Day.

**What is autism?**

1 Autism is a lifelong developmental disability. It is a 'spectrum' condition and includes

Asperger syndrome. The word 'spectrum' is used because, while all people with autism share three main areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively 'everyday' lives; others will require a lifetime of specialist support.

The three main areas of difficulty which all people with autism share are:

- difficulty with social communication.
- difficulty with social interaction.
- difficulty with social imagination.

**How does it affect people?**

2 Many people with autism say that the world, to them, is a mass of people, places and events which they struggle to make sense of, and which causes them considerable anxiety.

In particular, understanding and relating to other people, and taking part in everyday family and social life is hard. People who do not have autism appear to know, intuitively, how to communicate and interact with each other, and those with autism may wonder why they are 'different'.



Mark Lever  
Chief Executive,  
The National Autistic Society

'People with autism have strengths and abilities as well as challenges, just like everyone else'

**Raising awareness**

3 It can be hard to create awareness of autism as people with the condition do not necessarily 'look' disabled: parents of children with autism often say that other people simply think their child is naughty, while adults can face bullying and harassment.

**Supporting people**

4 Whilst autism is a lifelong disability, the right support at the right time can make an enormous difference to people's lives. All people with autism can benefit from a timely diagnosis and access to appropriate services and support. We would like to see a better understanding of autism and end the isolation of over two million people in the UK whose lives are touched by autism.

People with autism have strengths and abilities as well as challenges, just like everyone else, and everybody with autism deserves the chance to fulfil their potential. Greater public awareness and a willingness to accept difference can make a huge impact on the day-to-day lives of people with autism and their families.



## WE RECOMMEND



Sarah-Jane Critchley  
Project Head,  
Autism Education  
Trust

PAGE 4

'We shouldn't see autism as a problem'

**Training teachers**

p. 4

1. All teachers can expect to teach a child with autism and thus should know how to

**Government cuts**

p. 6

2. How the plans to replace the Disability Living Allowance will affect families

**MEDIA  
PLANET**

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**Managing Director:** Willem De Geer  
**Editorial Manager:** Katherine Woodley  
**Business Development Manager:**  
Christopher Emberson

**Project Manager:** Jessica Pacey  
**Phone:** 0207 665 4442  
**E-mail:** jessica.pacey@mediaplanet.com

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**Mediaplanet contact information:**  
**Phone:** 0207 665 4400  
**Fax:** 0207 665 4419  
**E-mail:** info.uk@mediaplanet.com

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For further details, visits and training dates please visit [www.priorscourt.org.uk](http://www.priorscourt.org.uk) email: [mail@priorscourt.org.uk](mailto:mail@priorscourt.org.uk)

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people with autism



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# the autism show



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The Autism Show is organised by Park View Events Ltd, 25 Park View, London, N21 1QS T: 020 8882 0629 F: 020 8338 0452 W: [www.parkviewevents.co.uk](http://www.parkviewevents.co.uk)



Sunfield is a West Midlands based residential Special School and Children's Home supporting students from across England and Wales. We are a registered charity providing year-round Education and Care for children and young people aged 6 - 19 with severe and complex learning difficulties often related to their Autism.

Sunfield believes that 'Children should be at the heart of everything we do'. Our Education, Therapy and Care departments work closely together and through a 24 hour curriculum provide the structures, environment and opportunities to enable young people to learn. We recognise and value that every child is different and build individual pathways for each student based on our thorough assessment and knowledge of the child.

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Our excellent facilities include: - a purpose built school, individualised houses, a working farm, student run shop, sensory room and our newly built sensory integration suite. There are wonderful facilities for families to help promote and support regular contact, including two very comfortable self-contained flats.



Sunfield  
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Clent  
Stourbridge  
West Midlands  
DY9 9PB

Tel: 01562 882253 Fax: 01562 883856  
[sunfield@sunfield.org.uk](mailto:sunfield@sunfield.org.uk)  
[www.sunfield.org.uk](http://www.sunfield.org.uk)

## NEWS

# PARENTS HOLD THE KEY TO UNDERSTANDING

**Question:** What's so important about education with regard to autism?

**Answer:** It's the biggest concern for parents of any child or young person with autism - appropriate education is the key to providing children on the autism spectrum with the best possible start

With current prevalence estimate for autism of one in 100 people - around one per cent of the population - every teacher should expect to teach at least one child with autism, points out Sarah-Jane Critchley, Project Head at the Autism Education Trust.

Autism is a spectrum condition and so it affects every person in slightly different ways, she says. "Therefore, while we know from recent research carried out both by The Autism Education Trust and The National Autistic Society about the number of challenges faced by children with autism in schools, we are sure that lack of awareness and understanding of autism amongst

teaching staff and peer groups is the biggest challenge facing young people on the autism spectrum today."

Sarah-Jane points out that autism, by definition, is an isolating condition and that it's essential to create tailored solutions for each individual: a one-size-fits-all approach doesn't work. It is vital, she adds, to involve their parent or carer as they are the expert on that child. Diagnosis figures continue to rise as awareness among medical professionals increases, she points out: "Our education system needs to continue to equip its teaching staff with appropriate tools and strategies to accommodate all children".

"We shouldn't see autism as a problem," says Critchley. "The sooner we accept that autism, along with a myriad of other

communication difficulties facing our young people today, is part of the norm - an expected nuance in some children - then we can begin to build appropriate teaching systems into everyday school life." Neither does it have to be expensive or time-consuming to appropriately integrate a child with autism into mainstream school life, she says.

Parents get training 'on the job' - after receiving a diagnosis of autism parents quickly become experts in the field, Sarah-Jane points out. "They hold the key to understanding their child and teachers, and the professionals who support them need to have access to that understanding. Training - at the earliest possible stage in a teacher's career - is essential. We would like to see accredited autism training modules added to teacher training programmes as well as resources within each school for regular training for all teaching staff."



**Sarah-Jane Critchley**  
Project Head,  
Autism Education  
Trust

EMILY DAVIES

info.uk@mediaplanet.com



#### THE POWER OF KNOWLEDGE

Brain scans of babies with autism in the family suggest that it may be possible to detect signs early on

PHOTO: AUTISTICA

**ceat**  
autism education and training



Early, Intensive  
intervention



Professional Training  
Services

Our consultants work in the homes of families throughout the UK to implement child-specific and evidenced-based intervention. Visit our website to view a short film, demonstrating the impact of our early intensive intervention services. Our team of Certified Behaviour Analysts provide ongoing supervision to those pursuing BACB® certification. We are an approved Type II CEU Provider, offering both training workshops and eLearning opportunities.

#### INSET TRAINING DAY SPECIALISTS Primary, Secondary and Residential Schools

Teachers and their support staff are the front-line educators who require dynamic and on-going autism-specific training. CEAT provided custom-designed training courses delivered in your school, addressing the needs of your staff and your pupils. We establish multi-agency partnerships in mainstream and special schools, and with early-years teams. Our consultants and trainers work throughout the United Kingdom to provide varied, individualized and affordable training courses. For more information about our services and to view our training prospectus, contact our Training Director, Dr Victoria Coulter on information@ceatni.net or by phone at 028 9065 9678.

[www.ceatni.net](http://www.ceatni.net)



## THE NEW SCHOOL Butterstone

An inclusive school community

The New School, founded in 1992, supports young people with a range of additional support needs who have been unable to flourish within mainstream education. Small classes, experienced teachers, care staff and therapists and a caring environment help children to learn and build self confidence. SQA qualifications from Access 2 to Higher are offered in addition to ASDAN accreditation. The school, near Dunkeld in Perthshire, is co-educational for young people aged 12 to 20. Day placements, weekly boarding and termly boarding are available.



Sir Andrew Cubie, Chair of the Board of  
Governors with students.

Further information is available at:  
[www.thenewschool.co.uk](http://www.thenewschool.co.uk)  
Or contact the Head Teacher:  
[info@thenewschool.co.uk](mailto:info@thenewschool.co.uk)

The New School  
Butterstone  
Dunkeld  
PH8 0HJ

Telephone: 01350 724216

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# Creating the future through science

**Question:** Why is making the case for autism research so important?

**Answer:** Advances have been made – but much more needs to be done and there are challenges yet to be overcome

Autism research is currently at a pivotal point, says Christine Swabey, Chief Executive of the autism research charity Autistica – with 2010 having seen significant advances in our understanding of the condition.

“For instance, research into brain scans is bringing us closer to identifying differences in the autistic brain and research studying baby siblings of children with a diagnosis of autism shows that it may be possible to detect the first signs in children as young as 1 year old”, she points out. Progress is also being made in the field of genetics and the Autism Genome Project has identified a number of autism-specific risk genes, which could

provide exciting opportunities in both assessment and treatments, Christine says.

“What’s important now is to make sure that what we learn from the research is turned, wherever possible, into practical benefits for families,” says Christine. The challenge, as ever, is funding – not just for the research itself but also to make sure the best scientists are attracted into the field of autism research. “The UK has a strong reputation in autism science but moving from the laboratory to clinical trials is a huge leap that will require drive and commitment,” says Christine.

“It’s important for all those providing services to the autism community to realise that science can support their ambitions too. We believe that science will provide the answers that families are looking for and with the cost to the UK economy of autism estimated to be around £28 billion a year, even in these challenging economic times it is surely an investment worth making. Science may not have all the answers today, but there is real hope for a better future.”



**Christine Swabey**  
Chief Executive,  
Autistica

EMILY DAVIES

info.uk@mediaplanet.com

## Autism: transition in education

**Dr Mitzi Waltz, lecturer in autism studies at the University of Birmingham**

“Although children with autism find moving between activities and spaces hard generally, the transition from primary to secondary school is especially fraught. Without careful planning, the result can be academic failure, behaviour difficulties, and all too often bullying or exclusion.

“Start with assessing the child’s strengths and difficulties to ensure that the right secondary school is chosen. This should be followed by advance visits to the new school, and identification of potential problems, such as bells used to signal class changes and navigating crowded hallways.

“Primary school staff, parents, and children with autism themselves can help by providing advance information to secondary school staff. This should include strategies that worked well in the past, what motivates the student, and which areas he or she finds challenging.

“Advance planning – and tweaking the plan as needed later on – offers the best chance for a smooth transition and good outcomes.”

**autistica**  
Science in the Service of Autism

How can research help people with autism?

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[www.autistica.org.uk](http://www.autistica.org.uk)

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## INSPIRATION



**DOWNING STREET**  
Jane Asher joins the campaign to improve education provision for children with autism  
PHOTO: NATIONAL AUTISTIC SOCIETY



## Why we should fight back

**Ivan Corea, founder of the UK Autism Foundation and whose 15-year-old son Charin who has autism, explains his concerns about how proposed Government cuts will affect people with autism**

The Coalition Government is proposing to radically reform Disability Living Allowance (DLA) and replace it with a Personal Independence Payment (PIP). In the process they plan to introduce new assessments and cut the budget and caseload by 20 per cent.

Currently, over 1.8 million working-age people receive Disability Living Allowance, Ivan points out. "The Coalition Government cuts are likely to mean over 360,000 disabled people losing DLA across the UK. But a third of disabled people live in poverty in the UK already and disabled people are twice as likely to live in poverty as other citizens."

"The disabled are bearing the brunt of the cuts," says Ivan. "Scrapping the disability living allowance will drive even more parents, carers and the autism community deeper into poverty - and it will undermine autonomy and independence. We are urging David Cameron and George Osborne to listen to the voices of parents, carers and the autism community across our land and think again before they scrap the DLA."

"Life is already a huge struggle at the moment - we are faced with increased food prices, increased utility bills, increased petrol costs. If they scrap the DLA and if councils cut public services, it will push us to the very edge. David Cameron promised that he will protect the vulnerable and we appeal to him to think again about the DLA."

EMILY DAVIES

info.uk@mediaplanet.com

## The secret of my support

**Question:** What makes Jane Asher so passionate about supporting, and campaigning for, those with autism?

**Answer:** There is always more to learn in the sometimes distressing but always fascinating world of autism, she says - along with challenges to overcome, often successfully



'Parents of newly diagnosed children are particularly vulnerable in their search for help'

**Jane Asher**  
President of the National Autistic Society,  
Patron of Autistica and Research Autism

says Jane. "At that time I was probably typical of the average person - I'd heard of it, but had no real idea what it was. I became very interested and, when the NAS asked me to open a playgroup a few weeks later, I was only too happy to help."

Jane has been President of the National Autistic Society for many years now, and is also a Patron of

Autistica, and of Research Autism, which looks into the effectiveness of various interventions. "This is an absolutely vital area: parents of newly diagnosed children are particularly vulnerable in their search for help," she says.

Awareness has improved vastly but there's a long way to go, Jane points out. As with any disability,

it's primarily lack of knowledge that leads to discrimination. Autism is of course a 'hidden' disability, which makes it particularly hard to spread understanding: the 'weird' young man with Asperger syndrome who everyone teases or the toddler who has severe classic autism throwing a tantrum in the supermarket will endure far more hardship if their behaviour is misunderstood.

"And as with every child on the planet, education is the key to opening up a fulfilled life," she points out. "For those with autism the effects of the right approach can be dramatic: when I visit adult facilities and meet those who had little or no specialised help and then see the difference in the children in our schools today, it makes everything we fight for worthwhile."

"The longer I am enmeshed in autism, the more interesting and illuminating I find it - and the more it makes me think about what the rest of us call 'normal'. Given the right support by Government and the public, I see the future for those with autism becoming increasingly bright."

EMILY DAVIES

info.uk@mediaplanet.com

## HOW I MADE IT

"I first became involved with autism in 1985 after I went to a children's tea party at the House of Commons to accept a cheque on behalf of Save the Children," explains Jane. "Children representing various charities had been invited, and I remember the room being full of the noise that one would expect. One table, though, was oddly different: the children had no obvious disability yet I could clearly see that not only were the children unusually quiet but that there was no interaction between them. They didn't even look at each other."

Later, Jane asked one of the adults accompanying them where they were from. "I learnt later that she was Lorna Wing, probably the greatest living authority on their condition, which was, of course, autism"

## FACTS

■ **The term 'autism'** is used here to describe all diagnoses on the autism spectrum including classic autism, Asperger syndrome and high-functioning autism.

■ **Autism is** much more common than many people think. There are over half a million people in the UK with autism - that's around one in 100.

■ **Autism doesn't** just affect children - children with autism grow up to be

adults with autism.

■ **Nearly two-thirds** of adults with autism in England do not have enough support to meet their needs.

■ **Autism is** a hidden disability - you can't always tell if someone has it.

■ **While autism** is incurable, the right support at the right time can make an enormous difference to people's lives

SOURCE: NATIONAL AUTISTIC SOCIETY



**NORSACA**  
quality of life for people with autism

## Supporting children and adults with autism in the East Midlands

### Services include:

- Specialist School
- Further Education College
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- Outreach Services
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- Training for Professionals and Families



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NORSACA is the working name of the Nottingham Regional Society for Adults and Children with Autism, a registered charity, no. 517954, and a Company Limited by Guarantee, registered in England, no 2053860. Registered office: Park Hall Autism Resource Centre, Park Road, Bestwood Village, Nottingham NG6 8TQ

## Infant Scientists Wanted!



Are you pregnant, or do you have a baby between the ages of 0 – 9 months who has an older brother or sister with autism?

The British Autism Study of Infant Siblings (BASIS) is a UK wide network of researchers. Our aim is to learn more about the early development of baby brothers and sisters of children with autism. We hope our studies will in the longterm help to improve early detection and diagnosis of children with autism.

If you are pregnant, or have a baby between the ages of 0 – 9 months who has a full sibling diagnosed with an autism spectrum disorder, please contact us for more details. Travel costs to central London (WC1) are reimbursed and special arrangements are made for families who live further away.

**BASIS, The Babylab, Centre for Brain and Cognitive Development. Tel: 020 7079 0761, Email: [basis@bbk.ac.uk](mailto:basis@bbk.ac.uk) or visit: [www.basisnetwork.org](http://www.basisnetwork.org)**



## Social Pedagogy in Practice

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Parent, Feb 2011

With over 70 years of experience living and working with children and young people within the autism spectrum, and those with special needs, Camphill School Aberdeen offers individualised programmes of residential and non-residential education and care.

We have a highly qualified staff team and also offer autism training to parents and professionals throughout the UK and abroad.

For more information about the school and its flexible fee structure please contact Jean Ferries, Office, Camphill School Aberdeen, Murtle House, Bielside, Aberdeen, AB15 9EP. Telephone 01224 867395 [j.ferries@crss.org.uk](mailto:j.ferries@crss.org.uk) or [www.camphillschool.org.uk](http://www.camphillschool.org.uk)



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PECS is appropriate for children and adults with a wide range of communication difficulties, including autism. Easy to access, affordable to implement and scientifically supported as one of the most effective autism interventions, PECS is an opportunity to open the door to spontaneous communication.



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# A CHOICE OF EDUCATION AND CARE FOR CHILDREN WITH SPECIAL NEEDS, THEIR FAMILIES AND LOCAL AUTHORITIES ACROSS THE UK



Nationally, Acorn Care and Education offers a broad range of education and care settings to meet the specific needs of local authorities and the children and young people they find the most difficult to place.

Every child with Autism is unique and valuable and benefits from a flexible 'personalised' solutions to their growing needs. That is why Acorn Care and Education services offer patience, respect and understanding to promote individual development through meaningful and enjoyable activities, enabling each young person to grow into happy and confident young adults.

## SOME OF OUR SCHOOLS DEDICATED TO AUTISM



**Garden School & Garden College** - Cumbria  
 - Ages 9 - 19  
 - Co-educational  
 - Residential Children's Home



**The Willows at Oakfield House School** - Lancashire  
 - Ages 5 - 12  
 - Co-educational  
 - Attached Residential Children's Home



**The Shires** - Rutland  
 - Ages 11 - 19  
 - Co-educational  
 - Residential Children's Home

### OUR RESOURCES:

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- All age day schools
- Children's Homes

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### CASE STUDY

Tom began his placement in The Willows at Oakfield House School just over two years ago when his previous placement broke down. Tom has a diagnosis of high functioning Asperger Syndrome which had previously led to him developing highly disruptive behaviours. To help Tom cope with life's difficulties he had developed many routines and compulsive behaviours; he found interacting with his peers intolerable and had very narrow interests that excluded almost all school work. Tom had some sensory issues that also made it difficult for him to tolerate eating or drinking within his previous schools.

The Willows approach to working with Tom provided him with 'Tom centred' solutions to his difficulties. By viewing the 'problem' through Tom's eyes we were able to ensure he could feel safe and secure while we removed his personal barriers to progress and learning. Tom's learning utilised his enjoyment of animals and through activities based on animal themes staff were able to begin to expand on his interests and tolerances.

The Willows nurturing approach is calm and tranquil with highly structured learning based on the NAS 'SPELL' framework to maintain an 'autistic friendly', low arousal, environment.

\*Name has been changed.

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## Helping Children with Autism



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