

Autism: Advice and Information for parents and carers of children with a diagnosis or suspected diagnosis in Dacorum



DSPL | Delivering Special
Provision Locally
Achieving quality outcomes

Who is this leaflet for?

This leaflet has been written for parents and carers of children and young people living in the Dacorum district of Hertfordshire, who have or may have autism. It has been written by local parents, autism specialists, SENCos and head teachers, working with the Dacorum Delivering Special Provision Locally (DSPL) Board. For more information on DSPL, see page 6.



This page: The word wall is used in schools to enable children to communicate their needs and thoughts by pointing or getting the visual prompt.

Front cover: This young person comes to school earlier when it is quiet. The handover helps to prepare for the transition from home to school.

What is autism?

Autism is a difference, not a disability. Autism is defined as a “developmental disorder” which affects the way in which people perceive others and the world around them. All people on the autistic spectrum share certain characteristics.

These are defined within two areas: firstly, social communication and interaction, and secondly restrictive or repetitive patterns of behaviour, passions and interests together with sensory processing.

Difficulties with social communication and interaction can mean that people on the autistic spectrum find it hard to understand social expectations; they can lack a social instinct that tells them what to say and do in given situations. There can be difficulties with expressing or recognising feelings and emotions as well as confusion over rules of friendship.

The patterns of behaviour see people adopt routines that help them to feel comfortable – preferring to take a particular route or insisting on something being done in a specific way. People on the autistic spectrum often have a passion for a subject – it might be Minecraft, Lego, modes of transport or a TV programme/ film franchise.

Sensory processing difficulties cover not only the five senses we are all familiar with (too bright/loud or not bright/ loud enough) but also the vestibular sense which helps us balance, and the proprioceptive sense that helps us know where we are in relation to other objects or people.

What is the difference between Autism Spectrum Disorder (ASD), Autism Spectrum Condition (ASC), being ‘on the spectrum’ and autism?

You may hear any of these terms used, and there is no difference between them. ASD is the term used for the actual medical diagnosis, but some people with autism don’t like being described as having a disorder so they prefer the term ASC.

What should I do if I think my child has autism?

If your child is in an early years setting or school, you should ask to speak to their key worker, class teacher, Special Educational Needs Co-ordinator (SENCo), Inclusion Co-ordinator (INCo) or head teacher to talk about how they can best be supported. You can also ask if the school has an Autism Lead member of staff.

Do I have to take my child to see my doctor?

If you are concerned about your child's difficulties, then you should make an appointment with your GP, who may then recommend an appointment with a paediatrician.

Your GP will then make a referral to a child development clinic such as the Pat Lewis Centre in Hemel Hempstead. There could be a wait of a year or more before a formal diagnosis can be made, during which time your child's school or setting will work with you to make sure your child is getting the support they need.

Your school can start putting support in place without a formal diagnosis. This might include providing a safe space for your child to go to when they're feeling overwhelmed, using a visual timetable, or allowing them to arrive or leave school slightly before or after the other children to help with their anxiety. These can be helpful strategies for your child even if it turns out that they do not have autism.

Does my child need an Education and Health Care Plan (EHCP)?

An EHCP is "a plan of care for children and young people aged up to 25 who have more complex needs". Not every child who has autism needs an EHCP to get the support they need in mainstream school. Your SENCo will talk to you about different strategies that can be tried first. However, in order to attend a special school, your child will need an EHCP.

Find out more at www.gov.uk/children-with-special-educational-needs/overview

Will my child have to change school?

The majority of children and young people with autism can have their needs met in a mainstream setting. Mainstream schools in Hertfordshire are being encouraged to send their staff on training courses about autism, and teachers will know about reasonable adjustments that can be made for your child. Schools are also being asked to assess how well they think they support their children with autism.

You can find out more about your school or setting's commitment to supporting children with autism by asking to see their Local Offer, which sets out the support they offer for children with Special Educational Needs and Disabilities (SEND). This should be easy to find on their website, but if it isn't they will be able to provide you with a copy.

In a small number of cases, it is felt that a child's needs are best met at a special school. You'll be able to discuss with the SENCo or Autism Lead at your child's current school whether this is the best solution for your child.

What extra support might my child need in school?

Sometimes children who have autism benefit from one-to-one support from a teaching assistant. This is not appropriate for all children with autism and is not automatically available. Schools have additional funding in their budgets to pay for one-to-one support, but if this has already been allocated to other children, they may need to apply for Exceptional Needs Funding from Hertfordshire County Council. To bid successfully, they need to prove that your child's needs are exceptional, and include evidence from all the professionals who have worked with your child.

The Autism Education Trust has put together guidance on working with your child's school which can be downloaded here: www.aetraininghubs.org.uk/parent-guide

Developmental changes and transitions

Parents and carers of children with autism face a variety of challenges. One of these is that your child's needs will change as they develop and mature. Strategies and support mechanisms that work for your child at one stage in their life may become ineffective at a later stage, as different needs develop. Be prepared to have a dialogue with your child's school about what is working and what else could be tried.

This school uses a "jig" as a means of presenting a task in a step by step fashion.

Stay Healthy

1 Rinse hands with water



2 Apply plenty of soap



3 Rub your hands together



4 Rinse your hands



5 Dry your hands



Where else can I get support?

Financial Support

Some families may be eligible for Disability Living Allowance (DLA) and/or Carer's Allowance. Find out more by following the links below. You can get advice on applying for these allowances from the Citizens Advice Bureau and/or your local School Family Service (listed below).

Disability Living Allowance: www.gov.uk/disability-living-allowance-children

Carer's Allowance: www.gov.uk/carers-allowance/overview

Advice and peer support

Finding out that your child has a diagnosis of autism can result in a complex mix of emotions, for example relief that you have a diagnosis for your child, along with a period of adjustment to a different way of being. You may experience feelings of grief or loss, however although your child now has a diagnosis, they are no different from before. The following organisations will be able to offer you advice and support so that you don't feel you are alone.

LOCAL ORGANISATIONS

Dacorum Delivering Special Provision Locally (Dacorum DSPL) – Schools and families in Dacorum have access to funding, advice and training through Dacorum DSPL www.dacorumdspl.org.uk or phone 07809 240858.

Every area of Hertfordshire has its own DSPL Board and runs its own activities. Visit www.hertfordshire.gov.uk/dspl to find out more.

School Family Workers – Dacorum has three services, offering support for families of children attending Dacorum schools.

Schools in Tring, Berkhamsted, and some parts of Hemel Hempstead are covered by Dacorum Family Services: www.dacorumfamilyservices.org.uk or phone 01442 401222.

Schools in Apsley, Boxmoor, Chaulden, Gadebridge and Hammerfield are covered by Gade Family Services: www.gadeschoolsfamilysupport.co.uk or phone 01442 278793.

This page: The calm room provides a valuable tool in helping young people to learn self-regulation skills.

Next page: Another example of a calm room.



Schools in Kings Langley and surrounding villages are covered by the Kings Langley Partnership of Schools: www.kls.herts.sch.uk/parents-information/extended-services or phone 01923 264504.

SENDIASS – Independent Supporters within Hertfordshire who work directly with families and young people (0-25), to find their way through the changes to the Special Educational Needs and Disabilities (SEND) system. Phone 01992 555847 or visit www.hertfordshire.gov.uk and enter 'SENDIASS' in the search box.

ADD-Vance – A Hertfordshire based charity providing specialist information, training and advice for professionals, as well as support for children, adults and families on issues relating to Autism, Attention Deficit Hyperactivity Disorder (ADHD) and related conditions. Visit www.add-vance.org or phone 01727 833963.

Hope for Autism in West Herts – Support group for parents, carers and teachers of children with autism, with or without a diagnosis. Regular meetings in St Albans. For more information go to www.hopeforautism.org or phone 01442 219981 (during school hours).

Herts Autism Resource Centre (HARC)

is the Hertfordshire branch of the National Autistic Society. Contact via nasherts.org.uk or 07836 667394.

Families in Focus CIC provide free courses for parents of children with additional needs in Hertfordshire, and free parent networks to offer emotional, practical support, share experiences and reduce isolation. Visit www.familiesinfocus.co.uk or phone 01442 219 720.

KIDS HUB - The KIDS East and West HUBs offer information and support for parents and carers of disabled children and young people aged 0-19 in Hertfordshire. Any parent or carer of a child aged 0-19 with any impairment can access the HUBs without a referral: www.kids.org.uk/hub or phone 01923 676 549.

Herts Parent Carers Involvement (HPCI) – Part of a national network of parent carer forums, HPCI is an independent parent carer led organisation with a network of parent carers from all over Hertfordshire. They aim to improve services for their families by working alongside those providing services for children and young people with SEND (Special educational needs and disabilities). Parents or carers of children and young people with SEND aged 0-25 are encouraged to join. Visit www.hertsparentcarers.org.uk or phone 07840 360245.

Herts Additional Needs Database (HAND)

– If you are the parent or carer of a child or young person with an additional need or disability aged 0-25 you can join HAND. To join HAND the child or young person's special needs will have a substantial impact on their everyday life. They are likely to need additional support, adjustments and/or aid and adaptations to help them at school and at home. Phone 07840 360245 or visit <http://handnews.hertsc.gov.uk>

NATIONAL ORGANISATIONS

The National Autistic Society (NAS)

is the leading UK charity for autistic people and their families. Visit www.autism.org.uk for information. **Autism Helpline:** 0808 800 4104

The Autism Education Trust (AET)

has put together resources for parents: www.aetraininghubs.org.uk/parent-guide or 020 7903 3650.

NHS Choices: information about autism, getting a diagnosis for your child and how to talk to them about their condition. Visit www.nhs.uk and enter 'Autism' into the search box for a list of useful pages.

The Curly Hair Project is a social enterprise dedicated to supporting females with Asperger's Syndrome. For more information please go to <http://thegirlwiththecurlyhair.co.uk>

What advice and support does my school get?

These services are free of charge to the school as they are funded through the Local Authority or the local DSPL:

Training on Autism

from Hertfordshire County Council or through the local DSPL group.

Special School Outreach Service

Mainstream schools can receive a visit from a teacher from one of Hertfordshire's special schools to give advice on a particular child or group of children.

Communication and Autism Team

A team of Autism Specialist/Advisory Teachers and Early Years Autism Specialists working directly for Hertfordshire County Council. This is a needs led team who will support young people who have difficulties with communication and social interaction.

Can a change in diet help?

There has been very little research done on the effects of following a special diet, but some parents of children with autism say that cutting out certain foods has helped their child. If you want to put your child on a food elimination diet, please discuss this with your GP first.

It is wise to try cutting out one food group at a time. This is because:

1. You don't want to risk your child losing out on essential nutrients
2. If you notice any changes, you will need to know which food is responsible.

Eliminating certain food groups is not effective for every child with autism, but it may be worth trying for a week or two and keeping a diary. For more information, visit www.webmd.com and search for 'gluten free casein free diets for autism'. Some GPs also recommend an Omega 3 supplement.

Other terms used to describe autism

The diagnostic criteria for autism have recently been changed. All people with autism now have a single diagnosis of autism. Until recently, it was considered that there were different types of autism within the spectrum, so you may still hear the following terms or phases:

Asperger's Syndrome

Those diagnosed with Asperger's Syndrome are of average or above average intelligence.

Pathological Demand Avoidance (PDA)

People with PDA have anxieties about being in control and are driven to avoiding demands and expectations. While it is still recognised that strategies for children with autism do not necessarily work for children with PDA, the actual medical diagnosis is more likely to be "Autism with demand avoidance traits".

High Functioning

Those with high functioning autism have an IQ higher than 70.



The student prefers to be in the corner of a classroom away from the noise. Sensory equipment is provided for when he/she feels anxious.

Other resources

Search YouTube (www.youtube.com) and Ted Talks (www.ted.com) for;

Sarah Hendrickx

Motivational speaker, writer and trainer who speaks about her experience of having autism, gender, relationships, employment and alcohol.

Dr Wen Lawson

researcher, psychologist, writer and poet with high functioning autism.

Rosie King

Young woman with autism who has appeared on BBC documentaries and Ted Talks.

Examples of word and choice books, to enable children to articulate their needs.



USEFUL BOOKS

Fiction

The Curious Incident of the Dog in the Night Time by Mark Haddon

Asperger's Syndrome

Complete Guide to Asperger's Syndrome by Tony Attwood

Asperger's and Girls by Tony Attwood and Temple Grandin

The Girl with the Curly Hair series of books by Alis Rowe

Books by writers who are on the spectrum

Temple Talks... About Autism and Sensory Issues by Temple Grandin

The Reason I Jump by Naoki Higashida

Books for parents and professionals

It's Raining Cats and Dogs: An Autism Spectrum Guide to the Confusing World of Idioms, Metaphors and Everyday Expressions by Michael and Delia Barton

The Autistic Spectrum: A Guide for Parents and Professionals by Lorna Wing

Strategies for dealing with Anxiety and Emotions

When my worries get too big by Kari Dunn Buron

The Incredible 5 Point Scale by Kari Dunn Buron

Starving the Anxiety Gremlin by Kate Collins-Donnelly

The New Social Story Book by Carol Gray


FACEBOOK GROUPS

Autism Discussion Page: Bill Mason posts bite-size extracts from his books
ADD-Vance: Moderated discussion group

Blog

Steph's Two Girls (www.stephstwogirls.co.uk)

St Albans based mother of two girls, one of whom is diagnosed with PDA.

A photograph showing two children, a boy and a girl, in school uniforms (blue sweaters and grey trousers) sitting on a gravel path. They are looking at a small stone fountain with a statue of a child. The fountain is surrounded by various colored stones and is set against a backdrop of green foliage. The scene is outdoors, likely in a school garden.

This school has a sensory garden, which provides another safe and calm space to prevent sensory overload.

All information is correct at the time of printing. Thanks to all Dacorum DSPL Board members, Autism Working Group members, schools, parents and young people who have worked with us to produce this leaflet.
www.dacorumspl.org.uk