

A HANDBOOK FOR FAMILIES

Information on autism and ADHD
in children

This handbook is for Kent families who would like to know more about autism and Attention Deficit Hyperactivity Disorder (ADHD) in children.

It was developed with help from parents and carers of children waiting for an assessment for autism and/or ADHD in the Canterbury area. We wanted to make sure it has information that you would find useful.

Sections include where to go for help with health, education, rights and benefits, and a listing of local and national organisations. We've also included tips that may help manage your child's behaviour and pages for you to make notes.

It is important to know that an assessment and diagnosis of autism or ADHD is not needed to access the majority of the support listed in this handbook. The only specific help that is dependent on a diagnosis is a place at a grant-maintained specialist school or an independent specialist school.

We checked all the details of organisations early in 2020 but as information in printed handbooks goes out of date we cannot guarantee it is accurate. If you find anything that needs updating, please email handbookforfamilies@nhs.net to let us know.

Please visit www.kent.gov.uk/localoffer This website is kept up to date and explains what the Local Offer is for families with children with special educational needs in Kent.

Families and Partners from the Canterbury Pilot

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We would like to acknowledge and thank SNAAP who originally developed this handbook and have supported us in updating it. This would not have been possible without their dedication in working with parents from the Canterbury District to provide an extensive range of services to children with every kind of disability.

THE LOCAL OFFER

Kent County Council provides information on their website about local support for children and young people with special educational needs and disabilities (SEND), their families and professionals.

This information is known as the Local Offer and can be found here: www.kent.gov.uk/localoffer

The Local Offer provides information about education, health and social care services available to children and young people up to the age of 25, and their families.

Knowing what is out there and having the right information in one place gives you more choice and more control over the services you use.

The Local Offer has been developed in partnership with parents, carers, young people and professionals and new information is added regularly.

The Local Offer will:

- give you information about education, health and care services, leisure activities and support groups
- hold all the information in one place
- be clear, detailed, accurate and accessible
- make it easier to find out what you need to know
- help you to find the nearest and most suitable services.

The council continually develops the Local Offer using feedback from people who use it so it will be more up to date than this printed handbook.

Go to: www.kent.gov.uk/localoffer





SOME DEFINITIONS

Special educational needs

A child or young person has special educational needs (SEN) if they have a learning difficulty or disability which calls for special educational provision to be made for him or her.

A child or a young person of compulsory school age has a learning difficulty or disability if he or she:

1. has a significantly greater difficulty in learning than the majority of others of the same age, or
2. has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.

EDUCATION

All schools are expected to meet the needs of children with special educational needs or disability (SEND). Children with SEN/SEND are entitled to attend a mainstream school if they and their parents/carers want them to, and it will not be detrimental to their education to do so. Some children and young people need more specialist provision in a special school.

All schools must publish their SEN Policy on their website. This policy sets how the school supports children and young people with SEND.



MYTHS & TRUTHS

Myth: *To get help with my child's behaviour I need a diagnosis of a special educational need like autism, Asperger's or ADHD.*

Truth: A diagnosis is not required to access support from schools, social care or other organisations. A diagnosis may help provide additional information that informs the support offered but it is important that parents/carers do not wait for a diagnosis to seek help for their child.

Special educational needs and disabilities (SEND) can affect a child or young person's ability to learn. They can affect their:

- behaviour or ability to socialise, for example they struggle to make friends
- reading and writing, for example because they have dyslexia
- ability to understand things
- concentration levels, for example because they have attention deficit hyperactivity disorder (ADHD)
- physical ability.

Here are some explanations about terms used about education:

- Code of practice

A statutory guide for parents, schools and local authorities about the help children with SEN/SEND should receive.

- Statutory needs assessment

A statutory needs assessment is a very detailed assessment of your child's needs. It involves information being gathered by Kent County Council from a range of services including education, health, an educational psychologist and medical, and social services plus any other agencies that you, the parents, wish to consult. Kent County Council will also want to know your views and concerns. Its findings will form the basis of a draft education, health and care plan (EHCP) if Kent County Council decides that one is necessary.

- Educational psychologists
Educational psychologists use a range of psychological techniques to carry out assessments of children who have learning, emotional or behavioural difficulties.

Their work includes planning intervention programmes and monitoring children's educational progress. Each school has access to the education psychology service.

- Learning support assistant

A learning support assistant (LSA) is a person, in addition to the teacher, working with a child with SEND in a school class.

- Draft education, health and care plan

A draft of the education, health and care plan (EHCP) is sent to parents for their comments, before the final EHCP is issued. Parents may request to meet or discuss the draft with an officer from Kent County Council before the draft EHCP is made final.

- Education, health and care plan

The EHCP is a legal document, issued by Kent County Council, that sets out a child's special educational needs, the outcomes the child or young person is expected to achieve, provision to meet those needs and outcomes, and the school that the child will attend.

- Special Educational Needs and Disability Tribunal

Special Educational Needs and Disability Tribunal (SENDIST) is the court which decides appeals made against decisions made by local authorities about children or young people with special educational needs. Tribunal decisions for education are legally binding on parties involved in the appeal. The tribunal can also make non-binding recommendations for issues relating to health and social care. The tribunal also hears cases of disability discrimination.

PRE-SCHOOL

If you have any concerns about your child's development before they start school you should talk to your GP, health visitor or pre-school/playgroup leader.

Getting help before starting school

Children can be referred for assessment and help by a paediatrician, health visitor, pre-school/playgroup leader or GP to a pre-school adviser. The pre-school adviser can set up further meetings with other professionals.

Some pre-school children have education, health and care plans. Help may be in the form of Portage, advice to mainstream pre-school/playgroup staff, or a place in a group meeting.

Portage

Portage is a service for children from birth to five with learning difficulties or developmental delay. Children may be referred by a GP, health visitor, speech therapist, or by their parents. Portage is delivered to parents and children in their homes by the pre-school additional educational needs (AEN) service. It is intended to help parents work with their children to manage their difficulties.

For more information about Portage, visit the National Portage Association:

www.portage.org.uk

To find out more about Portage in Kent, visit:

www.kelsi.org.uk/special-education-needs/special-educational-needs/kent-portage

If your child is attending a pre-school/playgroup they should conduct a review of your child's progress. This Early Years Foundation Stage (EYFS) progress check is carried out when your child is aged between two and three years old.

Aims of the EYFS progress check:

- review a child's development progress
- ensure that parents have a clear picture of their child's development
- enable professionals and parents to understand the child's needs and plan activities to meet them
- note areas where a child is progressing well and identify any areas where progress is less than expected
- describe actions the setting intends to take to address any

developmental concerns (including working with other professionals where appropriate).

The check should be completed by the place where the child spends the most time in. It is a statutory requirement for the provider to share the progress check with the parents. There is an expectation that the parents will share it with their health visitor.

Ambitious about Autism has a practical toolkit to guide parents and carers through their child's journey in the early years: www.ambitiousaboutautism.org.uk/right-from-the-start

Special Educational Needs Inclusion Fund

The SEN Inclusion Fund (SENIF) is a statutory requirement made available by Kent County Council to provide

funding to support pre-school children with SEN to secure better outcomes. It can provide funding when children are attending:

- pre-schooling in Kent registered to take two, three and four year old children, a registered Kent childminder, or registered Kent out of hours provider and SENIF criteria is met
- for a maximum of 30 hours per week pro rata on attendance and eligibility for the Free Early Education Entitlement (FEEE).

It is non-statutory to provide this funding for eligible two-year olds in receipt of FEEE, but Kent will continue to fund support for these children up to a maximum of 15 hours attendance.

SCHOOLS

Most children with special educational needs can be taught in mainstream schools. If your child has more severe or complex needs they may need to go to a special school or school with a special unit. Our special schools and specialist units in mainstream schools only admit children with education, health and care plans whose needs are very severe and complex.

**More information
is available online here:**
[www.kent.gov.uk/
localoffer](http://www.kent.gov.uk/localoffer)

SCHOOL SUPPORT FOR 5-19 YEAR OLDS

All schools will support children with SEN/SEND. Children whose needs cannot

be met in a mainstream school may attend a special school. Children attending special schools all have education, health and care plans.

If you have any concerns about your child's education the first thing to do is to talk to your child's class teacher. If you need more information, find out who is the school's special educational needs coordinator (SENCO) and discuss your worries with them. You may also wish to talk to the head of year, headteacher, governor with

responsibility for SEN or the chair of the governing body.

SEND Support

To meet your child's identified special educational needs and disabilities in school, the SENCO and class teacher will put together a plan and targets for your child called a provision plan.

The provision plan will identify all the support your child is being given in the school and any interventions that are needed. This will include support from agencies that



Myth: *We need a diagnosis of autism or ADHD to access support from the school.*

Truth: Every school has a duty to meet the needs of all children. Support for children is not dependent on a diagnosis for any condition. An EHCP can be offered to any child who has special educational needs whether they have a diagnosis or not.

are outside of school e.g. speech therapy should this be needed. You (and your child if appropriate) should be shown this provision plan and meet with the SENCO and class teacher to review your child's progress.

Funding for schools for pupils with SEND

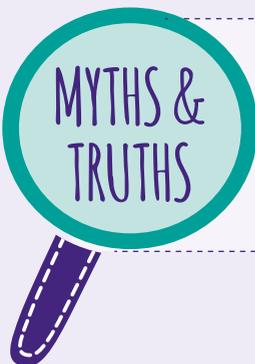
All schools are provided with money to meet the needs of pupils with SEND – you may hear this referred to as the “SEND notional budget”.

When a child needs a lot of personalised provision to be able to make progress

and be included in school life, and if the cost of this provision is greater than £6,000, schools can apply to Kent County Council for high needs funding (HNF). HNF is a contribution towards the cost of this provision. This is not dependent on a diagnosis of autism.

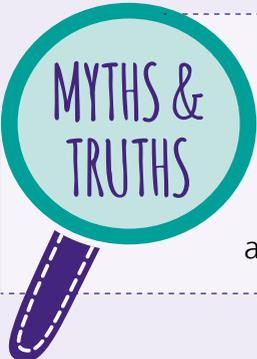
Statutory Needs Assessment – does my child need an EHCP?

If, despite the provision in place for your child being reviewed and adapted at least three times, your child is not making progress or things are getting worse, you can discuss



Myth: *My child's school has to apply for an EHCP.*

Truth: Parents/carers can make an EHCP application, not just school.



MYTHS & TRUTHS

Myth: *My child won't be given an EHCP if they're achieving academically.*

Truth: An EHCP is not based on academic performance but on meeting the needs of a child.

with the school's SENCO whether to ask Kent County Council to consider carrying out an education, health and care needs assessment.

Either you or the school can make this request by contacting the Kent SEN Assessment and Placement team. The SEN Assessment and Placement Service fulfils Kent County Council's statutory duties in relation to special educational needs and disabilities (SEND), particularly in relation to SEN assessments. The SEN Assessment and Placement Service monitors your child's

progress via annual review specialist placements. The service will:

- make decisions about whether to conduct a statutory assessment and ensure annual reviews take place
- where a statutory assessment is conducted, make a decision as to whether an EHCP is issued
- make statements of SEN and Education, Health and Care Plans (EHCPs)
- where an EHCP is issued, monitor the progress of the child or young person via annual review

Kent County Council SEN Assessment and Placement Service

These teams makes decisions about whether or not to conduct a statutory assessment, or whether an EHCP is needed.

If an EHCP is issued, they make sure that the progress of the child or young person is regularly monitored and formally reviewed annually.

Information about the statutory assessment process including timescales can be found here: www.kent.gov.uk/localoffer

NORTH KENT

**Joynes House, New Road,
Gravesend, Kent, DA11 0AT**

- 03000 41 93 45 or
- SENNorth@kent.gov.uk

SOUTH KENT

**Kroner House, Eurogate
Business Park, Ashford,
Kent, TN24 8XU**

- 03000 42 08 89 or
- SENSouth@kent.gov.uk

EAST KENT

**Brook House, Reeves Way,
Whitstable, Kent, CT5 3SS**

- 03000 42 11 60 or
- SENEast@kent.gov.uk

WEST KENT

**Worrall House, 30 Kings
Hill Avenue, West Malling,
Kent, ME19 4AE**

- 03000 42 09 97 or
- SENWest@kent.gov.uk

STAGE: POST-16 PROVISION

Post-16 educational establishments have the same duties in identifying and meeting the needs of young people with SEN as schools. Young people may

be identified as requiring SEN Support, may have an EHCP, or a request for a statutory assessment can be made at this stage of their education.



CHILDREN NOT AT SCHOOL

A child may not be in school for a number of reasons. You may choose to educate your child at home, or the school may have excluded them. Except for disciplinary reasons this is very rare, but the school may feel that inclusion is impossible without adversely affecting the education of other children. Kent County Council still has a duty to provide education unless you have elected to educate your child at home.

FINANCIAL ASSISTANCE

Transport

Kent County Council must provide free transport if it is necessary to enable the child to get to the nearest suitable school. Transport may be needed because of your child's medical condition or because you live further than walking

distance from the school. Walking distance is up to 2 miles for pupils under 8 years, and up to 3 miles for pupils from 8 to 16 years. Kent County Council may provide a free bus pass or a taxi, or if the parent provides the transport Kent County Council may give a car allowance.

Free school meals:

If your child is in Year 2 or below, they can receive free school meals.

Year 3 or above: If your child is under 19 and in full-time education, they may be eligible to receive free school meals if you receive any of the following:

- Universal Credit – if you apply on or after 1 April 2018 your household income must be less than £7,400 a year (after tax and not including any benefits you get)

- Income Support
- income-based Jobseeker's Allowance
- income-related Employment and Support Allowance
- support under Part VI of the Immigration and Asylum Act 1999
- the guaranteed element of Pension Credit
- Child Tax Credit (provided you're not also entitled to Working Tax Credit and have an annual gross income of no more than £16,190)
- Working Tax Credit run-on – paid for 4 weeks after you stop qualifying for Working Tax Credit.

The quickest and easiest way to apply for free school meals is to apply online www.gov.uk/apply-free-school-meals

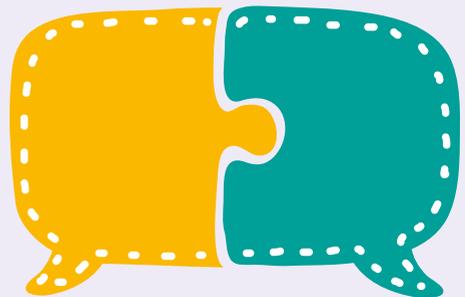
SUPPORT

Social Care Support

- 03000 411111

An autism or ADHD diagnosis is not required for social care support. Social care will undertake their own assessment to determine the level of support a child/family require following a referral.

An autism or ADHD diagnosis would be additional information that would contribute to the assessment process.



Information, Advice and Support Kent (IASK)

A helpline is open Monday to Friday, 9am – 5pm.

- 03000 41 3000
- iask@kent.gov.uk
- www.iask.org.uk

You should receive a response within two days.

IASK offers impartial support for families of children and young people (0 – 25 years) with special educational needs or disabilities. They help support children/young people and their parents to make informed choices about their children's education, other

outcomes and communicate confidently. Their advice and support is confidential and impartial. They are not on anybody's side and can:

- help you make informed decisions
- help you plan how to communicate your views or concerns in meetings or on paper
- come with you to meetings as a neutral person
- provide face to face support
- provide information about other agencies and processes
- help you prepare paperwork

- provide independent support for the statutory assessment process and at annual reviews
- offer you training and workshops.

Independent Provider of Special Education Advice (IPSEA)

IPSEA is a registered charity. It offers free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND) in England including:

- the legal duties that nurseries, schools and colleges have to support children and young people with special educational needs (including a Frequently Asked Questions section)
- school refusals (including anxiety) and exclusion
- letter templates.

You can book a helpline appointment via their website where downloadable resources are also available.

www.ipsea.org.uk

SOS!SEN

Offer a free, friendly, independent and confidential telephone helpline for parents and others looking for information and advice on Special Educational Needs and Disability (SEND) in England. They also have Walk-in Advice Clinics in north Kent.

www.sossen.org.uk

- 0300 302 3731

HEALTH

There are many health services which you and your child may need. In this section we describe the various professionals who can help, depending on the age of your child, and the way in which you can access their services.

If you have any concerns about your child's health or development, you can either contact your own GP, your health visitor (if your child is under 5), or your school nurse.

WHO CAN HELP:

General Practitioners (GPs)

Your family GP practice is staffed by qualified doctors and other health professionals. You can ask that your child sees a doctor who has had paediatric training to specialise in helping children.

Health visitors

The health visiting service is a workforce of specialist community public health nurses who provide expert advice, support and interventions for families expecting a new baby or those with children under 5 years old.

The health visiting service provides advice and support on a range of topics such as those listed below:

- growth, physical and emotional development and learning through play
- breastfeeding, introducing solid foods and healthy eating
- immunisations
- common infections, skin problems and minor illnesses in children
- challenges such as teething, temper tantrums, sleeping, eating and toilet training
- post-natal depression, bereavement and violence in the family
- reducing accidents in the home.

The health visiting service provide support in a number of places including in the home, in health visiting clinics, via programmes run

from children centres and through local phone lines.

The service is responsible for making sure that all children under 5 are offered a health review at specific times. The service has qualified staff who have skills in detecting those children who will require extra help from health services and other agencies.

In families where there is a child with special educational needs and disabilities, the health visitor will provide support in partnership with parents/ carers and in conjunction with other agencies.

You can contact the service direct or you can be referred by a GP or healthcare professional. Contact details of your local health visiting team are provided in your red book and are available at www.kentcht.nhs.uk/service/kent-baby/health-visiting-service/

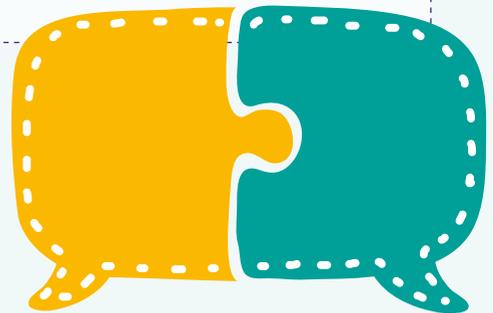
GETTING HELP WITH YOUR PRE-SCHOOL CHILD

Often, developmental issues only become apparent once a child is in a more social setting, such as a playgroup, pre-school or nursery, at which point the leader may raise concerns with you.

You can discuss your concerns with your own GP, health visitor or pre-school/playgroup workers.

The NHS Health Visiting Service will have offered you regular health and development reviews from birth. They will contact you to arrange a final check of your baby's development when they are between 24 and 30 months old. This review will cover general development, including movement, speech, social skills and behaviour, and hearing and vision.

Your health visitor will discuss any concerns you may have and suggest any actions you can take or further help you can get. You can share any concerns raised by your health visitor at this health review with your child's lead at their pre-school/playgroup, to help inform their progress review of your child.



School Nurse

The school public health service is a workforce of specialist community public health nurses who provide expert advice, support and interventions for families with a child of school age (5-19). You do not have to be in school to use this service if, for instance, your child is home schooled.

School nurses offer support for schools to develop a whole-school approach to improve the health of all children at school.

School nurses are available for individual health advice and support on a wide range of health needs including: daytime and night wetting and soiling, behaviour management, healthy eating and lifestyle, emotional health and wellbeing, puberty and growing up, stopping smoking, drug and alcohol misuse, sleep and complex health needs.

School nurses support parents and children to complete an online health assessment at key transition points. This makes sure that children receive any support they need as soon as possible.

At primary school, school nurses weigh and measure children in the Reception Year and Year 6 and undertake hearing and vision screening in Reception Year.

If you have any concerns about your child's health, development or well-being you should discuss these with your school nurse.

At secondary school the adolescent health and emotional wellbeing school health service offers health assessments, as well as a range of support for both physical and mental health, plus referral to specialist services when needed.

Each school has a named school nurse who can be contacted through the school.

More information can be found from visiting: www.kentcht.nhs.uk/service/school-health/

ACCESSING HEALTH SERVICES AND INFORMATION

Information about local services available including occupational therapy, speech and language therapy, physiotherapy and specialist nursing care can be found on the Local Offer www.kent.gov.uk/localoffer

More information about the diagnosis of ADHD can be found here: www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/diagnosis/

The Pod:

■ www.kentcht.nhs.uk/childrens-therapies-the-pod/

An online resource for children's therapies (physiotherapy, occupational therapy, speech and language therapy and care coordination).

Find out more about how you can support your child's learning and development, watch online films and resources to show you how to help your child to grow and learn. You can also make a referral to children's therapy services on the pod.

Moodspark

■ www.moodspark.org.uk/

A place where young people aged 10-16 can learn how to look after their emotional and mental health and find ways to help them bounce back when life gets tough. Provided by HeadStart Kent.

The Kent Resilience Hub

- www.kentresiliencehub.org.uk

A resource that helps young people, parents and carers and professionals to understand emotional growth and resilience. Sometimes it can be hard to know how best to support a child or young person in difficult times. HeadStart Kent have made this one place to go to increase your understanding and awareness, find approaches and tools or navigate your way to appropriate support and services. They have tried to find the best and most reliable information, articles, tools and resources relating to resilience and emotional wellbeing but would welcome suggestions and comments for other things that have helped you.

Children and Young People's Mental Health Service

- www.nelft.nhs.uk/services-kent-children-young-peoples-mental-health/

For a consultation or to make a referral call the single point of access on: **0300 123 4496**.

The Children and Young People's Mental Health Service (CYPMHS) provides emotional wellbeing and mental health advice and support for young people and their families across Kent.

This service is available to children and young people up to the age of 18 and up until the age of 25 for young people with special educational needs or as part of a wider network of support for children and young people in the care of the local authority.

CYPMHS offers advice and support for stress, low mood and depression, anxiety, self-harm or difficult to manage behaviours and assessment for neurodevelopmental difficulties such as Attention Deficit Hyperactivity Disorder (ADHD) or Autism Spectrum Disorder (ASD).

OTHER SPECIALISTS AND SERVICES THAT YOUR CHILD MAY NEED

Children's continence products service

This is a team of nurses and support workers who support children and young people assessed as needing support with continence products to help with bed and day wetting or soiling.

■ 01227 594633

Dental care clinics

Dental care can be provided for children with special needs at clinics. If you have a dentist who cannot treat your child, the dentist can refer you to the Community Dental Service. If you do not have a dentist, your GP, the school nurse or other healthcare worker can refer.

■ 0330 123 9438

Dietitian

Advice and support on food and nutritional issues may be obtained from a dietitian. When working with children with complex eating and nutritional problems, a paediatric community dietitian may work with a team of people such as doctors, psychiatrists, speech and language therapists and occupational therapists.

Anyone involved in the case of your child can refer you to the dietitian, like your GP, health visitor, specialist nurse adviser or paediatrician.

Audiology and Vision

If you have any concerns about your child's hearing or sight contact your GP or the paediatrician involved in their care. They may refer your child for further hearing and vision testing.

INFORMATION

Life Saver Pods

■ www.lifesaverpod.com

A tough, waterproof yet small enough to fit on a key

ring pod which contains 10 emergency contact numbers, all your allergy alerts and illnesses and any other emergency or health details you want to put on.

Medicalert

■ www.medicalert.org.uk

Supports people with medical conditions and allergies, keeping them safe in emergency situations, by providing the full medical ID service and custom-made medical ID jewellery.

QUERIES, CONCERNS AND COMPLAINTS

Everyone who provides an NHS service in England must have their own complaints procedure. You can often find information in waiting rooms, at reception, on the

service provider's website, or by asking a member of staff. For more information visit: www.nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs/

ACCESSING SUPPORT

EARLY HELP (SUPPORT FOR FAMILIES)

Kent County Council provide services that can be accessed locally at a time and place that suits families to help them to do well, stay safe and resolve problems at the earliest possible opportunity, before they become more serious.

Find out more by reading the Early Help leaflet for families: www.kent.gov.uk/education-and-children/early-help-support-for-families

Depending on the help that you are looking for, there are a number of ways in which you can ask for Early Help support.

Children's centres

Each centre offers different services, including:

- childcare
- early education
- training or finding a new job
- antenatal classes
- baby clinics
- support with breastfeeding
- support with parenting and speech and language
- drop-in sessions for parents and children
- services for children with special needs and disabilities
- opportunities for families to get involved with volunteering and designing services.

Please check with your local children's centre to find out what they offer. You can find more information here: www.kent.gov.uk/education-and-children/childcare-and-pre-school/childrens-centres

Youth Hubs

Kent County Council provide services which are aimed at young people and adolescents including:

- supporting the personal development of young people
- helping young people develop stronger relationships
- encouraging young people to respect and value differences
- promoting the voice of young people
- helping to set up, plan and evaluate youth club sessions
- clubs and activities for young people with additional needs.

Please check with your local youth hub to find out what they offer. You can

find more information here:

www.kent.gov.uk/education-and-children/young-people/youth-hubs

Additional Support

If you would benefit from some one-to-one support or low-level family intervention this would be classed as “Additional Support”. This support is expected on average to last 6-8 weeks. Please speak to a team member at your local children’s centre or youth hub for more information.

Disabled Children and Young People’s Teams

- 03000 41 11 11 (Monday to Friday, 9am – 5pm)
- social.services@kent.gov.uk

The team offer help to 0-25 year olds with:

- severe and profound learning disabilities

- physical and sensory disabilities
- a combination of disabilities.

A member of the Disabled Children and Young People's Team will assess your child's and family's needs. This means we will talk to you about your situation and find out what you are worried about or what changes you would like to make in your life.

After the assessment, we'll agree what kind of care and support you need. This could include:

- services that can offer you or your child support
- direct payments
- help at home
- local support groups so you have people to talk to
- short breaks, including specialised social activities, play schemes and overnight residential short breaks.

If your assessment shows you're not eligible for our specialist disability services, we will always tell you about other organisations that could help you.

LOCAL ORGANISATIONS

Kent wide:

Kent Autistic Trust – Children's Support Groups

- www.kentautistic.com

Runs groups for families, parents and carers of children and young people, to develop a community network to help each other.

If you would like more information regarding these groups, please contact: Wendy Boorman, Family Support Officer at the Kent Autistic Trust by calling **01634 405168** or emailing wendy@kentautistic.com

The Kent Parents and Children Together (PACT) Service

- www.kentpact.org.uk

Support with information and opportunities to meet with other parents/carers of children with SEN.

Headstart Kent

- www.kentresiliencehub.org.uk

Supporting 10-16 year olds to cope better with the pressures of everyday life. HeadStart Kent is part of Kent County Council's Integrated Children's Services and aims to help young people cope better when faced with difficult circumstances in their lives, preventing them from experiencing common mental health problems.

Advocacy for All

- www.advocacyforall.org.uk/self-advocacy-groups/kent-groups/

They have support groups across many areas of Kent. They help people gain confidence, meet others, join in social events and hold peer support groups. They work with over 18s who live in Kent and have a diagnosis of high functioning autism or Asperger's syndrome.

BEMIX

- www.bemix.org

An organisation of people with and without learning difficulties and/or autism who support people with learning difficulties and/or autism to speak up, make choices and become powerful by working and learning together. Most of their work is in Canterbury, Dover, Thanet, Sittingbourne and Medway but they do offer some support in other areas.

Bemix offers specific support for 16-24 year olds to find work with “Supported Internships” – a work coach helps find work in Swale, Medway, Thanet or Canterbury with support to get a paid job at the end of the placement.

So You’re Autistic?

■ www.soyoureautistic.com

This site forms part of So, You’re Autistic (SYA)? at the University of Kent, a support programme teaching those with a diagnosis, awaiting a diagnosis, or self-diagnosed HOW to be autistic – to understand what being autistic means for YOU. SYA? are also consultants delivering workshops on autistic experience, neurodiversity, & stigma-reduction.

LOCAL ORGANISATIONS

In most areas of Kent parents and families have set up

support groups to help other parents. They vary in what they offer and how they operate but most families find their services helpful.

Ashford

ASD Ashford

■ www.asdashford.com

A parent-led group which aims to support families in the Ashford area, with children and young adults on the Autistic Spectrum as well as those with ADHD.

Canterbury, Whitstable and Herne Bay

SNAAP – Special Needs Advisory & Activities Project

■ www.snaap.org.uk

■ info@snaap.org.uk

Provide an extensive range of services to children with every kind of disability, aged from 0-25 years, in partnership with parents. The focus of the services is upon all of the child’s needs including educational,

social, developmental and emotional. We focus upon the whole family and not just on the child with disabilities.

Altogether Extraordinary

- <https://www.facebook.com/pg/AltogetherExtraordinary/>

Facebook group for parents and carers of children and young people with ADHD, Autism, and/or Additional Educational Needs.

Dartford, Gravesham and Swanley

Beams

- www.wearebeams.org.uk
- admin@wearebeams.org.uk

Provide comprehensive support services to families of children and young people with any form of physical, learning or sensory impairment living in Dartford, Gravesham, Sevenoaks and the surrounding areas.

Sheppey

ADHD Sheppey

- www.adhdsheppey.com
- info@adhdsheppey.com

Helping to educate, empower and enrich the lives of people affected by ADHD and autism. There is a weekly face to face support group that meets at the Sheppey Healthy Living Centre and a closed Facebook group for parents and children.

South Kent

Includes us 2

- www.facebook.com/pg/IncludesUs2/about/
- info@includesus2.org.uk

A small, parent driven charity that provide support to disabled children, young people and their families. They operate across the districts of Ashford, Folkestone and Hythe, and Dover and support parents/carers of disabled children by providing regular, informal support groups and practical workshops.

Swale

For Us Too

- www.forustoo.org
- info@4us2.org

Based at the Orchards centre for disabled children, Sittingbourne. The charity is run by parents and carers of disabled children and young people and aims to empower families across east Kent.

The Autism Apprentice

- www.autismapprentice.co.uk

Provides information and advice and host regular information days in Sittingbourne, where parents can meet providers of services, listen to talks from experts and meet other parents who are going through similar situations.

Thanet

For Us Too

- www.forustoo.org
- info@4us2.org

Based at the Green Banks centre for disabled children, Margate. The charity is run by parents and carers of disabled children and young people and aims to empower families across east Kent.

West Kent

Space 2 Be Me

- www.space2beme.org.uk
- info@space2beme.org.uk

They work across west Kent (mainly Maidstone, Tonbridge & Malling and Tunbridge Wells) with disabled children and young people with additional needs aged from birth to 25 and their families. They work in partnership with our member families to design all our activities and services so that they support disabled children, support parents, and support the whole family.

HELP FROM NATIONAL AND INTERNATIONAL ORGANISATIONS

ADHD

The NHS provides information on ADHD here: www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/

Information from Great Ormond Street Hospital for Children about ADHD: www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/attention-deficit-hyperactivity-disorder-adhd

ADDers.org

■ www.adders.org

Set up to promote awareness of ADD (Attention Deficit Disorder) and ADHD, and to provide information and as much free practical help as it

can to those affected by the condition, both adults and children and their families.

ADDISS

■ www.addiss.co.uk

An ADHD information service that provides training and support for parents, sufferers and professionals in the fields of ADHD and related learning and behavioural difficulties.

ADDUP

■ www.addup.co.uk

Addup was set up to bring families together, to guide parents in the right direction to find the practical help they need for their children and to promote both public and professional awareness of ADHD.

ADHD Foundation

- www.adhd.foundation.org.uk

Works in partnership with individuals, families, doctors, teachers and other agencies to improve emotional wellbeing, educational attainment, behaviour and life chances through better understanding and self-management of ADHD, ASD and related learning difficulties such as dyslexia, dyspraxia, Irlen's Syndrome, dyscalculia and Tourette's Syndrome.

ADHD Kids

- www.adhdkids.org.uk

A website set up by a parent who shares her experiences of parenting her son, Daniel, who has ADHD and what she has learnt that might help other families.

Living with ADHD

- www.livingwithadhd.co.uk

Provides advice whether you are a teenager who has been diagnosed with ADHD, or you are the parent/carer or teacher of someone who has the condition.

UKAP – the UK ADHD Partnership

- www.ukadhd.com/

Established by mental health and allied professionals to improve outcomes and secure better futures for children and young people affected by Attention Deficit Hyperactivity Disorder (ADHD), together with their carers and families.

Young Minds

- www.youngminds.org.uk/find-help/conditions/adhd-and-mental-health
- www.youngminds.org.uk/find-help/for-parents/parents-guide-to-support-a-z/parents-guide-to-support-adhd/

An organisation that is there to make sure young minds get the best possible mental health support. They have an explanation of ADHD and some advice for parents on their website.

AUTISM

The NHS provides information on autism here: www.nhs.uk/conditions/autism/

Ambitious about Autism

- www.ambitiousaboutautism.org.uk

Provide services, raise awareness, offer training, support and advice for children and young people with autism and their families.

Autism Awareness Centre Inc.

- www.autismawarenesscentre.com

The Autism Awareness Centre Inc. believes that education is the key to success in assisting individuals with autism and other conditions. They are committed to ensuring their extensive autism resource selection features the newest titles available in North America.

Their blog post about Sensory Processing Disorder (SPD) contains a link to a set of checklists from infants to adulthood.

The Autism Directory Charity

- www.autismdirectorycharity.com

A directory of autism related services, products and autism friendly business in your local area and beyond. They also run a national helpline on a range of issues such as benefits, diagnosis, employment and education.

Autism links

- www.autismlinks.co.uk

Information and vital links to help you find resources, information, support groups and good ideas to support someone living with autism.

Child Autism UK

- www.childautism.org.uk

Provide services to enable children to overcome difficulties with communication, learning and life skills and give families the techniques and strategies to cope with autism through the use of Applied Behaviour Analysis (ABA).

The Curly Hair Project

- www.thegirlwiththecurlyhair.co.uk/

The Curly Hair Project is an award-winning social enterprise founded by autistic author and entrepreneur Alis Rowe. The Girl with the Curly Hair is a character created by Alis to communicate the feelings and thoughts of a person who has autism. Curly Hair Project resources are used by individuals, families and professionals worldwide.

The National Autistic Society

■ www.autism.org.uk

Offer practical help, information and advice for people with autistic spectrum disorders and their families.

GENERAL SUPPORT

AFASIC

■ www.afasic.org.uk

Helping families to understand speech, language and communication needs (SLCN) and Development Language Disorder (DLD). Provides support, information and advice.

The British Dyslexia Association

■ www.bda-dyslexia.org.uk

Confidential information, advice and signposting

dyslexia-related queries including assessment and specialist teacher-training.

Cauldwell Children

■ www.cauldwell-children.com

Provide family support services, equipment, treatment and therapies for disabled children and their families across the UK.

Changing Places toilets

■ www.changingplaces.uktoiletmap.org/

Changing Places toilets have extra features to meet the needs of people with a range of disabilities. The toilets provide enough space and the right equipment, including a hoist and height adjustable changing bench. To see where the Changing Places toilets are in Kent search by postcode on the Changing Places website.

Contact

■ www.contact.org.uk

Provide support, information, fact sheets, workshops and events to families of children with any kind of disability. They can also put families in touch with each other or local groups.

The Continance Foundation

■ www.continence-foundation.org.uk

Provide information, advice and expertise on all bladder and bowel problems.

The Disability Law Service

■ www.dls.org.uk

Provide free legal advice to people with disabilities and their carers to ensure that they have access to their rights and justice.

Epilepsy Action

■ www.epilepsy.org.uk

Offers advice, information and factsheets.

ERIC (Enuresis Resource and Information Centre)

■ www.eric.org.uk

Provides information and advice on the common condition of nocturnal enuresis or bedwetting. Also offer advice on childhood day-time wetting and soiling.

Hidden Disabilities Sunflower

■ www.hidden-disabilitiesstore.com

The Hidden Disabilities Sunflower originated in 2016 when Gatwick Airport asked 'How can we recognise that one of our passengers may have a non-obvious disability?' The answer was to create a lanyard with a simple sunflower design on a green

background as a subtle but visible sign enabling airport staff to recognise that the wearer (or someone with them) may require some extra help, time or assistance. It's starting to be recognised globally and has been adopted in the UK by all major airports, many supermarkets, railway stations, leisure facilities, in the NHS and an increasing number of small and large businesses and organisations.

Listening Books

■ www.listening-books.org.uk

Provides an audio book library for anyone who has difficulty reading the usual way. Can be downloaded to a portable player.

Mencap

■ www.mencap.org.uk

Provide information, advice and support for people with learning disabilities.

National Center for Child Anxiety Resilience Education and Support

■ www.carescenter.ucla.edu/

The UCLA Child Anxiety Resilience Education and Support (CARES) Center is an innovative American centre dedicated to supporting the development of resilient, emotionally healthy children. The centre is also focused on training, research, and community outreach to help clinicians, researchers, school staff, and parents recognize the early signs of childhood anxiety and support families in accessing resources to build family strengths and resilience.

Selective Mutism Information & Research Association (SMiRA)

- www.selectivemutism.org.uk/

SMiRA's team consists mainly of volunteers who all have knowledge of selective mutism, whether as parents, professionals or from their own personal experience. SMiRA operates a very active Facebook page, and has links to other groups and professionals throughout the world.

Sibs

- www.sibs.org.uk

Provide support and information for people who grow up with a brother or sister with a disability.

Winston's Wish

- www.winstonswish.org

Winston's Wish provides bereavement support for children after the death of a parent or sibling. Autistic people can sometimes understand death in a very concrete way and so may benefit from the resources used for younger children.

Check this information is up to date by visiting www.kent.gov.uk/localoffer – this website explains what the Local Offer is for families with children with special educational needs. As a printed document this handbook can go out of date so it is always best to check online.

RIGHTS AND BENEFITS

HELPLINES

Benefit Enquiry Line

- 0800 1690310

A free helpline for people with disabilities that provides information, advice and help with form filling.

Carers Support East Kent

- 01304 364637

Information on benefit rates and help with form-filling.

Contact

- 0808 808 3555

A charity for families with disabled children – provide factsheets, information and advice on benefits.

WEBSITES

Benefits and Work

- www.benefitsandwork.co.uk

Downloadable step-by-step guide that can help with completing DLA forms.

Carers UK

- carersuk.org/DLA

Find out more about the UK Disability benefits, how to claim, factsheets and online forum.

Department for Work and Pensions

- www.dwp.gov.uk

Government information on all benefits.

Contact

- www.contact.org.uk

A charity for families with disabled children – provide factsheets, information and advice on benefits.

BENEFITS

Carer's Allowance

- 0800 7510297
- www.direct.gov.uk/carers

An allowance for the carer of a disabled person. To qualify the carer must be aged over 16 and spend at least 35 hours per week caring for the disabled person who is getting Disability Living Allowance (DLA). It is not available to people who are full-time students (studying 21 hours or more per week) or who earn over £123 per week (current rates, net, after costs such as childcare). Carer's Allowance is

not means-tested, it is taxable and counts as income for Tax Credits and Universal Credit.

If you are paid Carer's Allowance the person you care for cannot get the Severe Disability Premium included in the award of any pre Universal Credit means-tested benefit they receive.

Disability Living Allowance (DLA)

- 08457 123 456
- www.dwp.gov.uk

This is a non-means tested benefit for children under the age of 16 years with disabilities, to help with the extra costs of bringing up a disabled child. To claim for a child, they should be one or more of the following:

- aged 3 months or over and generally needs extra help or looking after
- aged 3 or over and has severe difficulty walking

- aged 5 years or over and needs extra help getting around out of doors

Just before your child reaches their 16th birthday you will be sent an application form to fill out to claim Personal Independent Payment (PIP).

There are two components to this allowance:

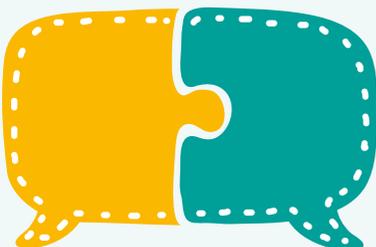
1. **Care component** which is payable at three rates depending on how much care is needed:

- **High rate** – For extra help during the day and night.
- **Middle rate** – For extra help during the day or night.
- **Low rate** – For extra help during part of the day or part of the night.

2. **Mobility component**

which is payable at two rates depending on how much help is needed.

- **High rate** – for a child who is unable to walk or has severe difficulty in walking; children who are deaf and blind; those whose health might suffer from the exertion of walking; those claiming the highest rate care component who have severe mental impairment or severe behaviour problems. This rate is payable for children 3 years and over.
- **Low rate** – for a child who can walk but may need someone to supervise or guide them. Rate payable for children 5 years and over.



You can also receive the following additional elements depending on which rate you receive.

Care component:

Low rate

- Child amount and disabled child addition (at the lower rate) on Universal Credit.
- Benefit cap exemption in Housing Benefit and Universal Credit
- Disabled child element/ disabled child rate on Child Tax Credit
- Disabled child premium on Housing Benefit

Middle or high rate:

- Carer's Allowance and Carer's Test on Universal Credit
- National Insurance Carer's Credit
- Carer's eligibility on Income Support

High rate:

In addition to the above section you can also claim:

- Enhanced Disability Premium child on Housing Benefit

Mobility component

Low rate:

- Same as low rate care component

High rate:

- Exemption from Vehicle Tax

- Eligibility for a Blue Badge
- Eligibility for the Mobility Car Scheme

Premiums for people on Income Support

If you are still receiving Income Support, you can apply for the Severe Disability Premium. Income Support is transferring to Universal Credit.

Universal Credit

Universal Credit is a means-tested benefit paid to people of working age who are on a low income. You can claim it if you're looking for work, if you are unable to work through sickness or disability, if you are a lone parent, if you are caring for someone or if you are working and your wages are low.

Universal Credit is being introduced over several years and replaces the following benefits;

- Child Tax Credit
- Housing Benefit
- income related employment and support allowances

- income based Job Seeker's Allowance
- Working Tax Credit

There is a carer amount included in your award if you have regular and substantial caring responsibilities for a severely disabled person. You do not need to have made a claim for Carer's Allowance to have the amount included in your award.

The benefit cap does not apply if you are receiving DLA or PIP for a child or young person you are responsible for.

Council Tax Reductions

Contact the council you pay your council tax to, to find out if you are entitled to a reduction.

There are 2 types of reductions you may be entitled to:

25% reduction – If you care for at least 35 hours per week for someone receiving the highest rate of the care

component of DLA, you may be classed as a 'disregarded person' and be entitled to a 25% reduction in council tax.

Reduction in band – If your home has been specifically adapted to meet the needs of a disabled resident who is substantially and permanently disabled, you may be entitled to a reduction in your council tax band. Adaptations that qualify are:

- a room (not kitchen or bathroom) mainly used by the disabled person or
- an extra kitchen or bathroom to meet their needs or
- enough floor space for a wheelchair used indoors.

NHS Low Income Scheme

- 0300 1230849
- www.nhs.uk/using-the-nhs/help-with-health-costs/nhs-low-income-scheme-lis/

If you receive benefits on low income grounds you can fill out an HC1 form to see if you are eligible for free travel to hospital, free prescriptions, free dental care and free eye tests. There are 2 certificates available, HC2 (full entitlement) HC3 (partial entitlement).

National Key Scheme (Public Toilets)

- www.radarkey.org

National Scheme run by RADAR which gives access to specially adapted public toilets in most towns and cities. Keys are available from your local council offices, and are also available to buy online.

Relief from VAT

- 0845 010 9000

Some gadgets and equipment designed solely for people with disabilities are zero rated for VAT. These include

medical and surgical appliances, specialised articles such as special beds, lifts and hoists and installation costs of special equipment. Certain building work such as improving access to a building, adaptations to a bathroom and the installation of a lift are also exempt from VAT.

Water Meter Charges

If you have metered water, are on income related benefits (such as Income Support, Housing or Council Tax benefit or Tax Credits) and use more than average, you may be able to get your bill capped. You must also have either 3 or more children under 16, or you or your child has a flaky or weeping skin disease, incontinence, Crohn's or Ulcerative Colitis abdominal stoma or renal failure requiring dialysis at home. Contact the organisation who you pay your water bill to.

HELP WITH FUNDING

There are some organisations that provide financial support and grants for children with disabilities. Each organisation will have different criteria for funding. Have a look on their websites to see if you may qualify.

Always Look on the Bright Side of Life

■ www.thebrightsideoflife.org.uk

To relieve the needs of children (under 18 year olds) by reason of finance, illness, or other disadvantage, by the provision of grants to improve their conditions of life.

Cauldwell Children

■ www.cauldwellchildren.com

Provides grants for special buggies and car seats, therapy trikes and multi-sensory equipment.

Family Fund

■ www.familyfund.org.uk

Provides grants to families who have a disabled or seriously ill child. Criteria applies, for more information visit their website.

My AFK

■ www.my-afk.org

Provides grants for equipment and mobility aids for children and young people with physical and mental disabilities.

Tree of Hope

■ www.treeofhope.org.uk

■ 01892 535525

Crowdfunding charity that helps children and young people with a disability or illness by supporting their families to raise the money they need to pay for specialist care that is not freely available through the UK healthcare system.



Check this information is up to date by visiting www.kent.gov.uk/localoffer – this website explains what the Local Offer is for families with children with special educational needs. As a printed document this handbook can go out of date so it is always best to check online.

TRANSPORT

Help with hospital fares

If you receive Income Support, income-based Job Seeker's Allowance, Universal Credit or Pension Credit, you can claim help with travel costs to and from hospital for NHS treatment when escorting your child. You can obtain a refund of your fares directly from the hospital if you produce proof that you are in receipt of benefits. Ask at the hospital for form HC1.

If you are not receiving these benefits but are on a low income (if your child is 16 years or over it is their income that counts, not yours) you may still be able to get help. Ring the hospital and ask who you need to speak to, to find out what help is available.

Blue Badge scheme

- www.kent.gov.uk/social-care-and-health/care-and-support/disability/apply-for-a-blue-badge

If you're disabled or have a health condition that affects your mobility, you can apply for a Blue Badge. You can also apply for a badge if you care for a child with a health condition that affects their mobility. Apply online through Kent County Council.

Bus pass

- www.kent.gov.uk/roads-and-travel/travelling-around-kent/bus-travel/bus-passes/bus-passes-for-older-or-disabled-people
- 03000 418383

Free off-peak travel on local bus services for a disabled person and a companion, between

9.30am and 11.00pm, Monday to Friday and all day at weekends and public holidays. An application form can be downloaded from the Kent County Council website.

Disabled Persons Railcard

- www.disabledpersons-railcard.co.uk
- 0345 605 0525

For people with a disability that makes travelling by train difficult. Get 1/3 off adult rail fares and, if you're travelling with another adult, they will also get 1/3 off their rail fare. There are no time restrictions on the Disabled Persons Railcard, so you can use it to get a discount on tickets at any time of the day and each railcard costs £20 a year.

Exemption from vehicle tax

If your child gets the higher rate DLA or PIP mobility component, you should automatically be sent a

vehicle tax exemption form (DLA 403) from the DLA unit. It is important that you complete and return the exemption form to the address stated on the letter enclosed with the form.

London congestion charges

- www.cclondon.com

Blue Badge holders are exempt from the congestion charge in central London. You need to register with Transport of London and make a one-off payment of £10.

Motability scheme

- www.motability.co.uk

The motability scheme enables disabled people to get mobile by exchanging their mobility component of their DLA or PIP to lease a new car, scooter, powered wheelchair or wheelchair accessible vehicle (WAV). You can apply after your child is three. You may have to make an advance payment.

AIDS AND EQUIPMENT

TRANSPORT

Crelling Harnesses

- www.crelling.com

Supply a large range from simple belts and adult walking reins to full harnesses including the 'Houdini Stop' strap and rear fastening harness.

McClaren Major Buggy

- www.maclarenmajor.com

Lightweight special needs buggy suitable for children up to 50kgs.

Mission Cycles

- www.missioncycles.co.uk

Range of tricycles for children and teenagers with various balance problems and disabilities.

Strider

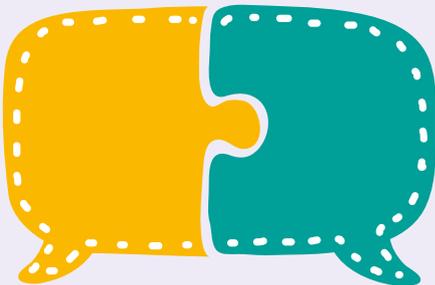
- www.striderbike.co.uk

Provide Balance Bikes to help children learn how to build their coordination and balance before moving onto a pedal bike.

In Car Safety Centre

- www.incarsafetycentre.co.uk/special-needs

Offers a range of special needs car seats, harnesses and clips and guards to adapt car seat belts.



CLOTHING

Born Anxious

- www.bornanxious.co.uk

Label free clothing range for children and adults can also be personalised with disabilities and information to help you explain your child's needs.

M&S Easy Dressing School Uniform

- www.marksandspencer.com

Uniform designed with sensory needs and fine motor skill difficulties in mind.

Rackety's

- www.disabled-clothing.co.uk

Specialist disabled clothing available in bigger sizes, washable swim pants and costumes, all in one pyjama, washable continence pads and bibs.

COMPUTERS AND IT

Abilia Ltd

- www.abilia.com

High quality assistive tools to help people live richer lives using communication aids. Also have a handy calendar app to help organise your day and clearly see what needs to be done when with simple pictures, symbols and checklists.

Inclusive Technology

- www.inclusive.co.uk

Leading supplier of software, hardware and apps for people with special needs.

SOME ADVICE ABOUT BEHAVIOUR

Some children have behaviours that parents find difficult to manage and that cause considerable stress to the whole family.

It is always useful to start by trying to identify the reason for behaviour from the child's perspective and considering what the child is trying to communicate through their behaviour.

Some behaviours are directly linked to difficulties trying to

communicate. Other triggers might be social situations which they find stressful, unstructured time, sensory difficulties or change.

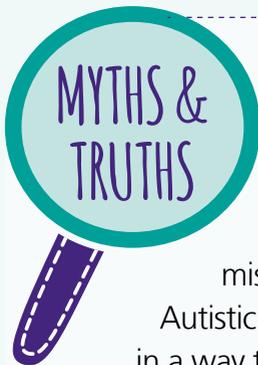
Understanding your child's difficulties can help you develop strategies to help behaviour problems.

You may find it helpful to track your child's behaviour in a diary, so you can begin to see patterns in behaviour and notice small, positive changes as you develop strategies.



Some possible underlying reasons for behaviour

- **frustration:** they can't do something or can't tell you what they want
- **fear:** they are frightened of something
- **strong feelings:** they are unhappy or angry about something
- **hyperactivity:** they have excess energy and cannot seem to burn it off
- **discomfort:** they are in pain
- **attention:** they have learnt they get your attention by behaving a certain way
- **lack of understanding:** they may need time to work out what you mean and so don't respond to an instruction when you expect them to
- **difficulty processing:** or making sense of sensory experiences in the environment.



Myth: *Children are just naughty, and if parents knew how to bring up their children they would behave like other children.*

Truth: This is probably the most hurtful myth as it shows a complete misunderstanding of what a child is feeling.

Autistic children and children with ADHD may behave in a way that is perceived by some as just naughty but no amount of good parenting can alter the fact that a child has a special educational need or disability.

SETTING THE SCENE FOR POSITIVE BEHAVIOUR

All children will communicate their needs and respond to situations differently. But there are some general rules that will help you manage your child's day to day behaviour.

■ **Establish daily routines**

- Most children will cope more easily if they know in advance what is going to happen. Visual timetables can help with this
- Routines can also be used to set up clear boundaries and acceptable behaviour, which can be reinforced with rewards.

■ **Build communication**

- It is vital to have two-way communication with your child
- If your child has limited understanding, or little or no speech, there are ways of communicating you can try. This may be using simple language (one step instructions or key words), giving children time to understand what you've said or signed and repeating key instructions
- If you're asking your child to do something, give brief instructions and be specific. Instead of asking: "Can you tidy your bedroom?" say: "Please put your toys into the box and put the books back onto the shelf." This makes it clearer what your child needs to do and creates opportunities for praise when they get it right

- Don't forget your own non-verbal language/behaviour. Your tone, warmth, posture, eye contact and facial expression will all affect how your child responds to you
- You can also communicate by using visual supports – some people will understand things better if they see it rather than hear it. Seeing it, rather than saying it, helps the person retain and process information. You can use symbols, photographs or pictures familiar to the child.

The National Autistic Society has a section on their website about behaviour www.autism.org.uk/about/behaviour.aspx

Visual Timetables

Often used with children who are on the autism spectrum and might be helpful to children with ADHD as can help them make sense of everyday life. Often used as a daily timetable, they enable children to understand what they are doing and when, give structure to the day and can reduce anxiety levels. Symbols are used to represent the tasks, activities or lessons.

Visual supports

These are usually a single symbol, picture or message used to provide structure and routine, encourage independence, build confidence, improve understanding, avoid frustration and anxiety, and provide opportunities to interact with others.

Visual supports can be used in a range of ways:

- as a single message, the child takes a yellow card



from their pocket when they need to go to the toilet, or puts purple card on the board when they're feeling stressed

- different coloured tablecloths, e.g. white for dinner time, blue for colouring time
- basic symbol to allow a person to express an opinion, e.g. by putting a thumbs down symbol next to one of today's activities, to show they didn't enjoy it
- emotion thermometer so an individual can place a marker to explain how they are feeling and learn how to recognise emotions
- time trackers to help with starting and finishing activities, and transition between activities.

More information here:

www.autism.org.uk/about/strategies/visual-supports.aspx and here: <https://autismawarenesscentre.com/5-point-scale-emotional-regulation/>

Praise and rewards

Be positive when your child behaves as you'd like. Give specific and evidence-based praise, instead of saying a general: "Thanks for doing that," you could say: "You washed the dishes really well. Thank you."

Give praise immediately and make it clear to your child that you're pleased and why.

Giving praise has so many benefits:

- helps a child's self-esteem
- shows them the difference between good and bad behaviour
- helps to set boundaries and rules, and

- reinforces the behaviours that you do want to see.

You can use a reward chart when your child needs to work on changing their behaviour. Your child collects stickers or tokens for the chart each time they behave the way you want. They then get a reward based on the number of stickers they have gathered. The stickers and the reward reinforce the praise that you give.

Alternatively, you can fill a jar with objects – glass beads, stones, and marbles. At the end of the day or week convert any objects into pocket money or small treats.

Social stories

Social stories™ were created by Carol Gray in 1991. They are short descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation

and why. The terms ‘social story’ and ‘social stories’ are trademarks originated and owned by Carol Gray.

A social story is a present tense story written about a situation which the child finds difficult to cope with. The aim is to increase their understanding and help them be more comfortable in situations.

Social stories may:

- describe a situation in terms of the relevant social clues and/or correct responses in a non-threatening format
- translate goals set into smaller understandable steps
- teach routines as well as helping to accommodate changes to routine
- address a wide variety of behaviours, including aggression, fear, obsessions and compulsions.

Social stories work especially well for autistic children because often they lack the ability to see situations from the perspective of others.

More information here: www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx

Exercise

Make sure your child gets lots of physical activity during the day. Walking, skipping and playing sport can help your child wear themselves out and improve their quality of sleep.

Living with ADHD's compact guide for parents includes 15 tips for parents: www.livingwithadhd.co.uk/files/adhd-a-compact-guide-for-parents-livingwithadhd.co.uk.pdf

NHS advice about ADHD can be found here: www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/living-with/

NHS advice about autism can be found here: <https://www.nhs.uk/conditions/autism/autism-and-everyday-life/>

"Separate the child from the behaviour"
(K, aged 13)

MANAGING DIFFICULT BEHAVIOUR

In some situations, children become anxious or distressed, which can trigger behaviour that challenges. It can take time to work out some triggers but it's important you do, so you can find ways to deal with the behaviour.

Keep social situations short and sweet. Invite friends to play, but keep playtimes short so your child doesn't lose self-control. Don't aim to do this when your child is feeling tired or hungry, such as after a day at school.

Devise strategies that remove or reduce the effect of triggers

If difficult behaviour keeps happening and you are unsure about the triggers, it can be helpful to keep a diary, or a behaviour chart, to try to learn more about it. A good example is an ABC chart:

- **A – antecedents** – the things that lead up to the behaviour
- **B – behaviour** – what the child is actually doing
- **C – consequences** – what happens in response to the child's behaviour

There is a similar model that some teachers and other professionals use called STAR – Settings, Triggers, Action, and Result. They may discuss this system with you.

Worry/Anxieties

The world can be an extremely challenging environment for an autistic child and many experience anxiety difficulties. If they do not have the tools to calm down when anxious, they may have a meltdown so developing strategies to manage anxiety and teach your child how to regulate their emotions will help.

Pick your battles carefully – when your child is autistic or has ADHD, it can seem that your entire day is spent reprimanding them. Focus on the behaviours that are the most worrying and work on those first.

Emotional recognition

Autistic people often struggle to recognise their emotional states. They can struggle to give them a label (e.g. angry, sad) and to recognise how they feel within their body and how this might make them behave.

Parents can support emotional recognition by:

- Modelling their own experience of emotions by labelling the emotion they are experiencing and talking about how it feels and how it makes them behave (e.g. “I have burnt the toast. I’m feeling angry now, it feels all hot inside.”)
- Using emotion cards and talking about how different emotions feel
- Drawing pictures of the body and talking about how different emotions affect your body (e.g. worry can make your heart go faster). There are lots of online resources to support this such as Blissful Kids’ website www.blissfulkids.com
- Accepting the emotions their child is feeling. All emotions are ok; it is the behaviour that can be difficult

- Labelling the child's emotions when you know they are experiencing them (e.g. "You seem angry now, that's ok.")
- Modelling coping strategies e.g. "When I'm angry I sometimes put on loud music."

Try to understand that there is always a reason for your child's behaviour; you may not be able to see the trigger or understand how important it is to them but just knowing there is one helps.

Here are some ways you can help your child manage anxieties and emotions:

- share different emotions together and talk about it being OK to feel worried, anxious, sad etc.
- talk about worries you have and encourage your child to tell you about the feelings they have like butterflies in their tummy
- praise your child when they tell you about worries and anxieties or use techniques they have been given
- use visual resources to teach the different feelings and emotions and talk about how to regulate emotions
- use worry monsters, worry beads, worry books, worry stones and other resources to help you child identify and manage to control their worries. Explain that once they pass the worry on it is someone else's worry to deal with and not theirs
- teach breathing techniques and introduce calm music or apps they can listen to when anxious to help them regulate themselves
- limit a child's exposure to violent, scary books, videos games and if they see anything like this that worries them talk about it and explain

- offer distractions when you see your child is becoming anxious, move their focus onto something else around them, give them a comforter, encourage them to run or jump
- make sure your child has downtime in their day to regulate themselves and manage stimulation
- introduce a calming box, punch bag or dark den which your child can use in the recovery phase.

I love chewing things.

I don't like loud noises like
are school fire alarm.

I don't like eating.

I find it hard to go to sleep.

I do not like waking up at
01:00 to 04:00 in the morning, I wake
up because I have got my self used
to it.

Please may you help me get
to sleep.



Myth: “Stimming” is strange behaviour.

Truth: The word “stimming” refers to self-stimulating behaviours, usually involving repetitive movements or sounds.

Almost everybody stims in some way such as tapping feet or chewing gum. There are various forms of behaviour that are characterised as stimming; it’s not just rocking, chewing, waving arms, or repetitive playing. It could be whistling or doing anything repetitively. The point is that a child who stims is behaving in that way as they find it comforting. It is part of a diagnosis tool for autism.

Stimming

The word ‘stimming’ refers to self-stimulating behaviours, usually involving repetitive movements or sounds. There are several reasons for stimming which include:

1. Over-stimulation:

Stimming can help block out sensory overload.

2. Under-stimulation:

Stimming helps provide extra sensory input when needed.

3. Management of emotions: Both positive and negative emotions can

trigger stimming. We’ve all seen physical reactions to joy or excitement, such as jumping or waving of hands. Frustration or anger may intensify a stim to the point of it becoming destructive.

4. Self-regulation: Some stims serve the purpose of soothing or comforting.

Meltdowns

A meltdown is an intense response to overwhelming situations. It is not a temper tantrum; it is not bad behaviour and it is not a child being naughty.

A meltdown happens when someone becomes completely overwhelmed by their current situation and temporarily loses control. This can be expressed verbally (shouting, screaming, crying), physically (kicking, lashing out, biting) or both.

Many will show signs of distress before having a meltdown, which is sometimes referred to as the “trigger” or “rumble”.

They may start to exhibit signs of anxiety such as pacing, seeking reassurance through repetitive questioning or physical signs such as rocking or becoming very still. At this stage, there may still be a chance to prevent a meltdown.

Strategies to consider include distraction, diversion, helping the person use calming strategies such as fiddle toys or listening to music, removing any potential triggers, and staying calm yourself.

Tips to help you and your child through them:

- keep calm, limit communication and stay positive
- talk to your child in a slow, calm, controlled voice
- empathise with them, reassure them you love them and are there to help them when they are ready
- if you can, safely get down to the child’s level to talk to them but give them space. If they are hitting out or shouting to be left alone give them space
- offer a hug, hold of their hands, massage their feet, rub their back etc. when they have calmed down

- create a safe place for them to feel secure and away from others, provide items they can stretch, pull, pinch, punch, squeeze and express any feelings they have bottled
- stay close but give them space to stretch out and roll if needed.

Once calm try to teach deep breathing exercises, clenching and unclenching fists, play relaxing music and reassure them again they are loved no matter what.

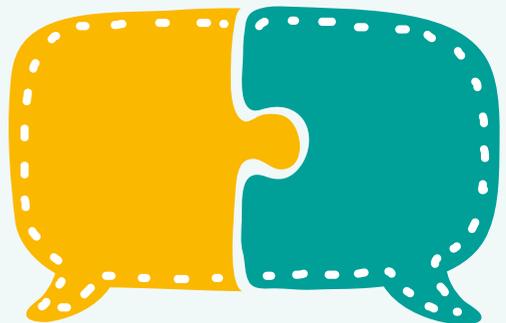
Shutdown is being frozen following a very stressful event. Some autistic people can become very quiet and self-contained or “freeze” in response to stress rather than experiencing a “meltdown”.

The Challenging Behaviour Foundation’s website has a lot of helpful information about behaviour support www.challengingbehaviour.org.uk

Self-injuring behaviours

There might be a number of factors causing a young person to self-injure which include:

- They feel they are not being listened to
- They have been told off
- They feel they have little or no choice about things
- They have been bullied
- They are feeling unwell.



The Royal College of Psychiatrists have information on their website for parents and carers: <https://www.rcpsych.ac.uk/mental-health/parents-and-young-people/information-for-parents-and-carers/self-harm-in-young-people-for-parents-and-carers>

Helpful tip: The National Autistic Society's website has a section around 'self-injury': www.autism.org.uk/about/behaviour/challenging-behaviour/self-injury.aspx.

Sleep Advice

Many people with autism or ADHD are likely to suffer from disturbed sleep patterns at some point in their lives.

Reasons for this could include:

- having difficulty settling, winding down and going to sleep
- waking repeatedly during the night, or having difficulty getting back to sleep after waking up to go to the toilet
- increased anxiety or an inability to relax causing insomnia
- social cueing problems, where an autistic person doesn't make the connection between others in the house going to bed and their own need to sleep
- irregular secretion of the sleep hormone melatonin, which regulates sleep patterns, or having atypical circadian rhythms (body clock)
- neurological conditions such as epilepsy
- sensory differences, such as increased sensitivity to blue light from smart phones, laptops and other screens, or sensitivity to certain sounds or white noise,

which may be upsetting or distracting and keep them awake

- problems caused by food allergies, which could cause gastrointestinal issues and discomfort, or increased sensitivity to caffeine or other stimulants, which can disturb sleep
- hypersomnia – sleeping too much. Increased exhaustion could be caused by the additional stress autistic people experience in social situations.

Strategies for dealing with sleep disorders

- Keep a sleep diary. This can help establish any unusual patterns of sleep and identifying factors but also be shown to professionals such as teachers, GPs etc.
- Establish a reassuring routine. Use visual timetables to make it easier to follow, limit screen time (TV, computer, tablet, smart phone) or exposure to bright lights an hour or two before bedtime, as these can inhibit the production of the sleep hormone Melatonin
- Make the bedroom more comfortable. Some children have sensory difficulties which makes it harder for them to relax, as well as stay asleep
- Block out light using dark curtains or black-out blinds
- Help reduce noise by using thick carpets, shutting doors, turning off appliances and moving your child's bed away from a wall with activity going on the other side



- Block out noises by letting the person use ear plugs or listen to music through headphones
- Remove labels from bedding and night clothes, or try bedding and nightclothes made from other materials
- Reduce smells coming into the room by closing the door fully, or by using scented oils that the person finds relaxing
- Remove distractions, such as toys on the bed and pictures on the wall (unless the person finds these relaxing), and consider a different colour on the walls
- Use relaxation techniques such as having a bath, massage, quiet time or gentle exercise such as yoga, to help the person wind down before bedtime.

TOYS AND BEHAVIOURAL AIDS

Do2Learn

- www.do2learn.com

Free printable activities and picture cards plus forms to assess behaviour and implement strategies to manage it.

Orkid Ideas

- www.orkidideas.com

Provide tools to help children develop coping strategies to manage their day. Downloadable resources for anxiety, behaviour and emotions, communication and social skills, timetable, schedule and routine.

The Play Doctors

- www.theplaydoctors.co.uk

Provide resources and visual aids to support

communication, behaviour, anxiety (worry books and toolkits), social skills including social stories and emotions.

Twinkl

■ www.twinkl.co.uk

Large range of free downloadable behaviour and reward charts.

Widgit

■ www.widgit.com

Printable symbols for use with visual timetables and visual aids/supports.

Chewigem

■ www.chewigem.co.uk

Offer a range of chewing, fidget and sensory aids.

Fledglings

■ www.fledglings.org.uk

Toys, clothes and sensory products for disabled children.

ROMPA

■ www.rompa.com

Provide specialist play, leisure, therapy and sport equipment including sensory toys and equipment.

Sense Toys

■ www.sensetoys.com

Sensory toys and educational resources for children with special needs, including autism and ADHD.

Spacecraft

■ www.spacecraft.co.uk

Supply an extensive range of multi-sensory toys and equipment.

TFH Special Needs Toys

■ www.specialneedstools.com

Wide range of robust toys and equipment including multi-sensory, soft environment equipment, toys, switches and music.

HOW AUTISM AND ADHD CAN AFFECT YOU AND YOUR FAMILY

Having an autistic child or one with ADHD can put a lot of strain on you and your family. You might need to spend a lot of time helping your child get the support they need. This can be very stressful and exhausting.

It may be hard to make time for the rest of your family and can affect your relationships with each other. If you feel you need help, you can get support from lots of places.



THINGS THAT CAN HELP YOU AND YOUR FAMILY

DO

- ask friends and family if they can help with day-to-day things or just be there to talk to
- get advice from other parents of autistic children or autistic adults
- look at websites listed elsewhere in this handbook – like www.kent.gov.uk/localoffer
- listen to other parents' stories – the charity www.healthtalk.org has stories about living with autism and ADHD or you can search online for blogs, videos and books
- ask your local council for a Carer's Assessment – you might be able to get extra support and financial benefits **(see Rights and Benefits section of this handbook, pages 49-57).**

DON'T

- feel guilty for taking time for yourself when you can – even just going for a walk on your own can help give you a break.

TALKING TO YOUR CHILD ABOUT AUTISM OR ADHD

It's your choice when you want to tell your child about their autism or ADHD but you should seek advice about it from health professionals. Some parents do it straight away, while others wait until their child's a bit older.

When you tell your child, it may help to:

- do it when they're feeling calm or relaxed
- talk to them in a place where they feel comfortable, with no distractions
- explain they do not have an illness, but they might need extra support to help them with some things

- explain they might find some things harder than other people, and some things easier
- bring them to a support group to meet other children.

The Autism Easy Read Guide from the National Autistic Society website might help you explain autism in a way your child will understand:

www.autism.org.uk/about/what-is/asd/intro-easyread

Some guidance from a parent about explaining ADHD to children can be found here:

www.adhdkids.org.uk/explain-adhd-child

"So, You're Autistic?" has a website containing resources and signposting for autistic young people.

www.SoYoureAutistic.com/young-people-portal

SUPPORTING YOUR OTHER CHILDREN

Some children can find it hard if their brother or sister is autistic or has ADHD. If you have other children, there are things you can do to help them.

DO

- make time for them whenever you can – try to do some activities with just them
- talk to them about what's going on and ask if they have any questions or worries
- let them have time on their own or with their friends – for example, sleepovers at friends' houses
- check the advice from Sibs, a charity for siblings of disabled children www.sibs.org.uk or the Kent young carers website www.imago.community/Children-and-young-people/kent-young-carers

DON'T

- exclude them in things like meetings with health professionals – it can help them understand what's going on.

AFTER YOUR CHILD'S DIAGNOSIS

An autism or ADHD diagnosis can be difficult to come to terms with at first. You might know very little about it while at the same time be trying to find new ways for everyone to live together and feel supported.

The National Autistic Society's website www.autism.org.uk has a wealth of information you may find useful, including for parents, partners and siblings, and includes real-life stories. It also provides information for grandparents, and for the children of autistic parents.

Here are some key areas of the website to look at:

- www.autism.org.uk/about/family-life
- www.autism.org.uk/about/family-life/siblings
- www.autism.org.uk/about/diagnosis/children/recently-diagnosed
- www.autism.org.uk/about/benefits-care

Living with ADHD have resources for parents and teenagers that can all be accessed here: www.livingwithadhd.co.uk/parents/resources.html

LOCAL HELP FOR CARERS

Kent: Crossroads Care Kent

- www.crossroadskent.org
- 03450 956701

East Kent – Carers Support East Kent

- www.carersek.org.uk
- 01304 364637

North Kent – Imago Community

- www.imago.community
- 01992 530330

West Kent – Involve

- www.involvekent.org.uk/carers
- 0300 0810005

West Kent ASD Carer’s Support Group

- www.westkentmind.org.uk/what-we-offer/asd-carers-support-group
- 01732 744950

A support group for parents and carers of autistic children – there is a referral procedure to join this group.

SELF-CARE

Self-care describes an activity that we do to take care of ourselves mentally, emotionally and physically. Looking after ourselves is key to improving our mental health, increasing our ability

to cope as well as maintaining positive relationships. It could be as simple as having a nice bath or going for a walk, to keeping a mood diary or finding some “me-time”.

If you don’t look after yourself you will probably find it more and more difficult to look after your child.

Talking Therapies Providers

Sometimes you may feel the need to speak to someone (who is not a member of your family or a friend) about how you are feeling. The Improving Access to Psychological Therapies (IAPT) programme is a range of NHS evidence-based interventions and treatments, such as counselling, cognitive behavioural therapy (CBT), stress management, Eye Movement Desensitisation and Reprocessing (EMDR), and sometimes group work.

Services are available for people aged 17 and upwards through your GP. You can self-refer if you want – type in IAPT and where you live into a search engine like google.

If you are worried about yourself, or finding it hard to cope, please contact your GP or, if it is an emergency and out of normal working hours, Release the Pressure.

Release the Pressure

Release the Pressure has a highly trained and experienced team available 24/7 to provide expert advice no matter what you are going through. Phone **0800 107 0160** for free confidential support at any time, or visit the website for more details. www.kent.gov.uk/social-care-and-health/health/release-the-pressure

Check this information is up to date by visiting www.kent.gov.uk/localoffer – this website explains what the Local Offer is for families with children with special educational needs. As a printed document this handbook can go out of date so it is always best to check online.

COMMON MYTHS ABOUT AUTISM AND ADHD

Here are some of the common myths we hear about autism and ADHD.



MYTHS & TRUTHS

Myth: *Autistic people and people with ADHD are stupid.*

Truth: Autism and ADHD bring with them just as many exceptional abilities as challenges. Many people with autism and ADHD have normal to high IQs and some may excel at maths, music or another pursuit. Autism is a developmental disability, not an intellectual one. It affects somebody's ability to communicate and interact with people, it can make a person rather fixed in their habits, and it can give them some sensory issues – but none of these affect intelligence. It can be hard to concentrate and pay attention with ADHD which can lower academic achievement but this is not about intelligence and can change with support and treatment.

Myth: *Autism and ADHD only affects children.*

Truth: Autistic children grow up to become adults with autism. ADHD used to be thought of as something that happened just in childhood. However, it is now recognised that ADHD can persist to adulthood for many people and can cause adults significant difficulties if not treated.

Myth: *Autism means people can't understand the emotions of others.*

Truth: Autism often affects an individual's ability to understand unspoken interpersonal communication, so somebody with autism might not detect sadness based solely on one's body language or sarcasm in one's tone of voice. But, when emotions are communicated more directly, people with autism are much more likely to feel empathy and compassion for others.

Myth: *Autism is caused by the Measles, Mumps and Rubella (MMR) vaccine.*

Truth: This idea is based on a research study published in 1998 by Dr Andrew Wakefield which has since been discredited. His study only involved 12 children, and those children weren't randomly selected – which means, in terms of method, it cannot be relied on. Two major properly run studies since have found no link.

Myth: *ADHD can be cured.*

Truth: ADHD is a behavioural disorder rather than an illness so there is no medical "cure" although it can be treated. ADHD can be treated using medication or therapy, but a combination of both is often best. No medication can be a permanent cure for ADHD but may help someone with the condition concentrate better, be less impulsive, feel calmer, and learn and practise new skills.

Myth: Autism is a mental illness.

Truth: No, it is a neurological condition that means the brain processes information differently. A mental illness is a condition that a person can experience at any time and sometimes recover from. A developmental disorder like autism, on the other hand, is something you're born with and which will be part of you for the whole of your life. Autistic people can have good mental health, or experience mental health problems, just like anyone else.

Myth: Girls don't have autism or ADHD.

Truth: Presently, more boys than girls are diagnosed with autism and ADHD. However, there's some debate as to whether this is a completely accurate reflection of the real statistics, as girls often 'present' their autism or ADHD somewhat differently from boys and may be under-diagnosed as a result.

Myth: Autistic people have mental superpowers.

Truth: This is what families often call the 'Rain Man' myth: that all children with autism have some kind of 'special ability' like brilliant mathematics or musicianship.

What this idea refers to is the phenomenon of the savant (someone with a skill that's exceptional by the standards of the general population) but the fact is that most people with autism aren't savants, and not all savants have autism.

SOME FREQUENTLY USED INITIALS

ADHD: Attention Deficit Hyperactivity Disorder

AEN: Additional Educational Needs

ASC: Autism Spectrum Condition

ASD: Autism Spectrum Disorder

CBT: Cognitive Behavioural Therapy

CYPMHS: Children and Young People's Mental Health Service

DAMP: Deficits in Attention, Motor Control and Perception

DfE: Department for Education

DLA: Disability Living Allowance

EHCP: Education, Health and Care Plan

EMDR: Eye Movement Desensitisation and Reprocessing

FE: Further Education (at a college)

FEEE: Free Early Education Entitlement

FLO: Family Liaison Officer

HE: Higher Education (at a university)

HLT: High Level Teaching Assistant

HNF: High needs funding

IAPT: Improving Access to Psychological Therapies

IEP: Individual Education Plan

KCC: Kent County Council

KEPS: Kent Educational Psychology Services

LA: Local Authority

LIFT: Local Inclusion Forum Team

LSA: Learning Support Assistant

MLD: Moderate Learning Difficulties

OFSTED: Office for Standards in Education

PDA: Pathological Demand Avoidance

PIP: Personal Independent Payment

PLP: Personal Learning Plan

PTSD: Post-Traumatic Stress Disorder

SEMH: Social, Emotional and Mental Health

SEN: Special Educational Needs

SENCO: SEN Coordinator (school)

SENDIST: SEN and Disability Tribunal

SLD: Severe Learning Difficulties

SpLD: Specific Learning Difficulties

