



# Autism Information Pack for Parents and Carers in Haringey

April 2023

# Introduction

***If you don't have time to read through this booklet right now, just start with these four things:***

- 1) Apply for the DLA (Disability Living Allowance) – you can download and print the form from <https://www.gov.uk/disability-living-allowance-children> or telephone: 0800 121 4600 and ask for a form to be sent to you
- 2) Get an appointment at Markfield to help you complete the DLA form - call the Family Support Team Administrator on 0203 667 5233 or email: [familyadmin@markfield.org.uk](mailto:familyadmin@markfield.org.uk) Also ask for a Markfield welcome pack – which has details of the family play sessions, parents support groups, training courses and other services offered by this Tottenham-based charity
- 3) Visit the Haringey SEND Local Offer website and bookmark it <https://www.haringey.gov.uk/children-and-families/local-offer> This site has lots of information about local services for children with special needs
- 4) Then read the very last section of this booklet from page 59 onwards – *How you can help your child at home*

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Every care is taken to ensure that this Autism Information Pack is accurate. If you find any information which you believe to be inaccurate, please let us know – see page 4. The listed services and links to websites of organisations and service providers are published in good faith. Their inclusion in this pack does not imply that Markfield endorses or supports them, nor does the absence of a service from the pack imply that Markfield does not support them.

## About this pack

This pack has been designed for Haringey parents and carers of children and young people with a diagnosis of Autism Spectrum Condition (ASC) or who suspect their child/young person may be autistic.

Have you just had a child diagnosed with an autistic spectrum condition (ASC)? Or is your child on the waiting list for an autism assessment? Autism is a lifelong condition that affects how a person communicates and interacts with other people. People with autism may also experience a need for sameness or familiarity that leads to them having, for example, unusually strong interests and/or rigid behaviour. Autism can also be referred to as Autistic Spectrum Disorder (ASD) – it's the same thing. Autism has had various different names in the past (e.g., Asperger's Syndrome, classic autism). It is estimated that approximately one in 100 children in the UK are autistic.

An autism diagnosis can be difficult to come to terms with. You may be coping with a condition you know very little about and trying to find new ways for everyone to live well together and feel supported.

Many parents feel there is not enough support for those on the waiting list for assessment, or guidance on what to do next after diagnosis. We hope this pack will help you find your way through the maze of local health, education, social services, and respite care, and so be able to better access what help is there for you. We hope it will help you to meet other parents who have the same concerns as you, understand your situation and can offer their valuable experience to you. Lastly, we hope it will open up to you some fun ideas of where to go and what to do with your child in and around Haringey, to enlighten you on ways to help with behaviour, everyday problems and communication.

The first edition of this pack was created in 2002, by parent volunteers in the local branch of the National Autistic Society (NAS). The pack is now published by Markfield – a charity in Tottenham which provides a range of services for disabled children and their families, including the SENDIASS information service. For more information about Markfield visit: [www.markfield.org.uk](http://www.markfield.org.uk)

To help us keep the pack up to date it would help greatly if you let us know if you find a new or changed system, phone number or website, etc.

The Markfield team: email: [familyadmin@markfield.org.uk](mailto:familyadmin@markfield.org.uk) Tel: 0203 667 5233

## Abbreviations

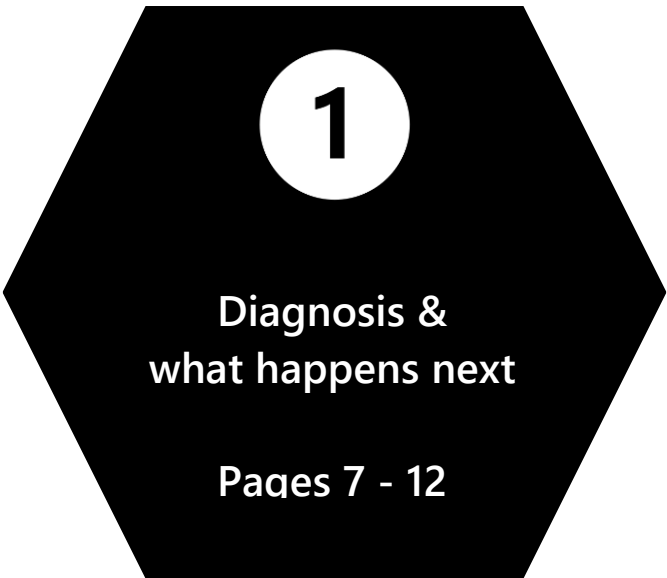
Some Abbreviations you may hear and what they mean:

<b>AEN</b>	Additional Educational Needs
<b>ASC</b>	Autistic Spectrum Condition
<b>ASD</b>	Autistic Spectrum Disorder
<b>AS</b>	Aspergers Syndrome
<b>CAMHS</b>	Child and Adolescent Mental Health Service
<b>CDC</b>	Child Development Centre
<b>CIN</b>	Child in Need
<b>CP</b>	Child Protection
<b>CYPS</b>	Children and Young People's Service
<b>DLA</b>	Disability Living Allowance
<b>EHCP</b>	Education Health and Care Plan
<b>EP</b>	Educational Psychologist
<b>EY</b>	Early Years
<b>GFCF</b>	Gluten-Free Casein-Free
<b>HFA</b>	High functioning autism
<b>IASS</b>	Information, Advice and Support Service
<b>IEP</b>	Individual Education Plan
<b>LAC</b>	Looked After Child
<b>LD</b>	Learning Disabilities
<b>LDA</b>	Learning Disability Assessment
<b>LA</b>	Local Authority
<b>LSA</b>	Learning Support Assistant
<b>MLD</b>	Moderate Learning Difficulties
<b>NAS</b>	National Autistic Society
<b>OT</b>	Occupational Therapy
<b>PDA</b>	Pathological Demand Avoidance
<b>PIP</b>	Personal Independence Payment
<b>RAS</b>	Resources Allocation System (form)
<b>SENDIASS</b>	Special Educational Needs and Disabilities Information Advice and Support Service
<b>SCD</b>	Social and communication disorder
<b>SEN</b>	Special Educational Needs
<b>SEND</b>	Special Educational Needs and Disabilities
<b>SENCO / SENDCO</b>	Special Educational Needs Co-ordinator
<b>SLD</b>	Severe Learning Difficulties
<b>SALT/SLT</b>	Speech and Language Therapy/therapist
<b>SNA</b>	Special Needs Assistant
<b>SPOE</b>	Single Point of Entry
<b>TA</b>	Teaching Assistant

TAC	Team around the Child
TAF	Team around the Family

## How to use this booklet

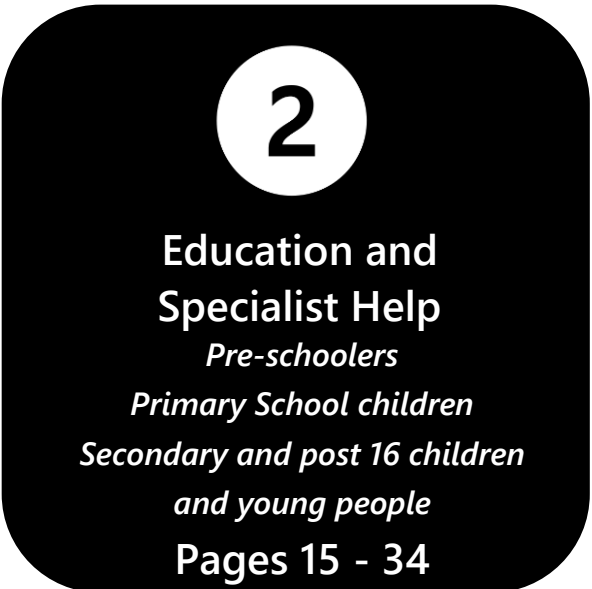
This booklet is divided into four sections to help you to find the relevant information. Please note the number within the geometrical shape on the right of the page; this will be the section you are currently reading



**1**

**Diagnosis & what happens next**

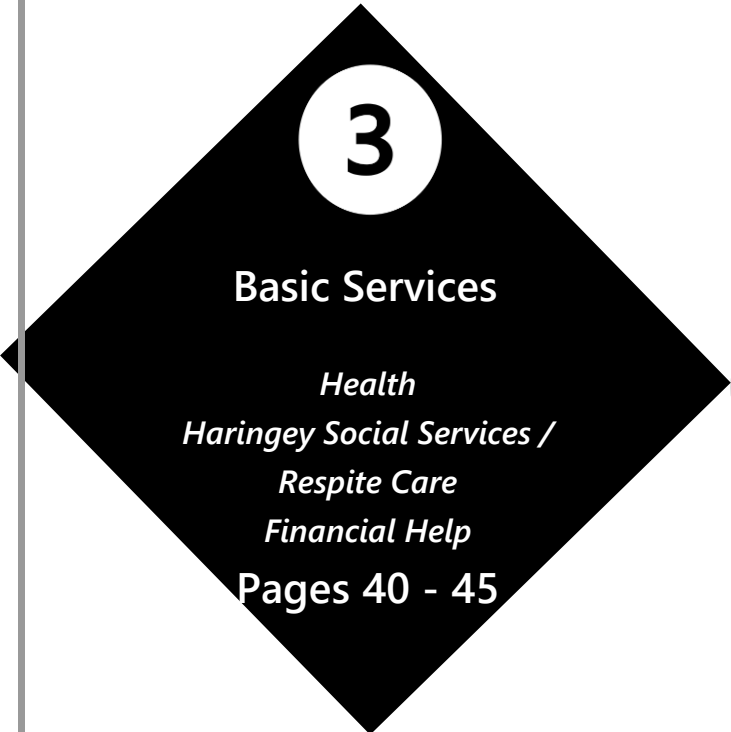
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**2**

**Education and Specialist Help**  
*Pre-schoolers*  
*Primary School children*  
*Secondary and post 16 children and young people*

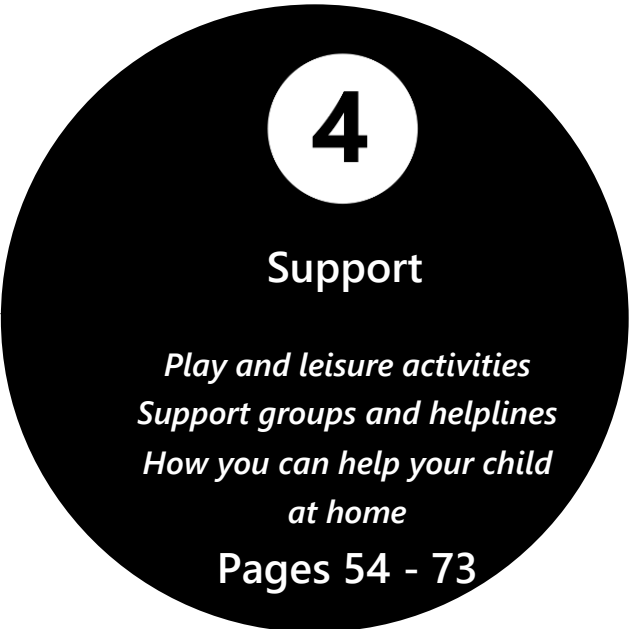
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**3**

**Basic Services**  
*Health*  
*Haringey Social Services /*  
*Respite Care*  
*Financial Help*

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**4**

**Support**  
*Play and leisure activities*  
*Support groups and helplines*  
*How you can help your child at home*

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## Diagnosis & what happens next

1

### How do I get an autism assessment for my child?

The characteristics and severity of autism varies from one person to another, this is why autism is referred to as a 'spectrum' condition. In order for a diagnosis to be made, a person will usually be assessed as having significant difficulties with social communication and social interaction and will have one or more of the following characteristics:

- *Be resistant to change or doing things differently*
- *Have restricted, repetitive patterns of behavior, interests, or activities - for example always playing the same game in the same way or repeatedly lining toys up in a particular order*
- *Many autistic people will also have problems with 'executive functioning' – they have significant difficulties with planning, organizing, and regulating their behaviour.*
- *Strong sensory preferences and/or sensitivities are also very commonly seen in autistic children.*
- *Have great difficulties communicating what they need or want because of their difficulties with verbal and non-verbal communication.*
- *Struggle to do 'chit-chat' or to have reciprocal (2-way) conversations (they may not know how to start or keep a conversation going and/or like to focus on things that interest them/they know about).*
- *Find it hard to understand other people's non-verbal communication (facial expressions, gestures) and tone of voice.*
- *Have a very literal understanding of language and find metaphors and idioms confusing.*
- *Don't know and/or understand the unwritten social rules around what is ok and what is not ok to say (and may, therefore, make insensitive or insulting comments) and do not understand how to behave in social situations (and may, therefore, for example, stand too close to another person).*
- *Struggle to understand and interpret other people's thoughts, feelings and actions.*
- *Have difficulties predicting what will happen next in social situations.*
- *Develop complex rules and systems to manage social interactions.*
- *Have behaviours such as biting, pinching, kicking, pica (putting inedible items in the mouth), or self-injurious behaviour.*

If you suspect your child is autistic, you will need a medical diagnosis to access appropriate help. The benefits of early help (starting from as early as age 2) are well documented, and so an early and accurate diagnosis will be to your child's advantage.

Generally, within Haringey, if an autistic spectrum condition is suspected, your GP or community health visitor, health worker, SENCO, Occupational Therapist, Speech and Language Therapist or educational psychologist will refer you to the local **Child Development Centre (CDC)** for Haringey, which is based at

Tynemouth Health Centre, Tynemouth Road, N15 4RH  
Tel: 020 3224 4655 or 020 3224 4726

Your child will be assessed at one, or more often two, meetings.

A written diagnosis with a description of your child's main areas of strengths and difficulties will follow in due course after the final assessment clinic.

For all children, the diagnosis will mean that your child will be added to the autism register held by the autism team, and their diagnosis made known to Children's Services. For under 5s, it may lead to you being offered a place on the 'Social Communication Group' run by the Speech and Language Therapy department for autistic children or children with a social-communication disorder, and it may propel you more quickly towards the Early Years Panel check, who allocate specialist pre-school places, and also get you a place on an Earlybird scheme run by the autism team which will teach you more about how to understand and manage your under-5 child.

For secondary school age children aged 12 and over, the referral will go to Haringey CAMHS rather than to the CDC or direct to Tavistock and Portland.

For under 12s, if the diagnosis is not straightforward and a second diagnostic opinion is needed, the child will be seen at Great Ormond Street Hospital.



## **I'm struggling to get a referral – what now?**

If you're finding it difficult to get a referral for your child, being assertive and persistent can help. You might also find the following tips useful.

It is often easier to get referrals from your child's preschool/nursery/school as they can provide better evidence based on their observations and interactions with your child.



- Before your appointment, prepare notes on what you want to say to your GP.
- Keep a diary to record any unusual behaviour by your child and how often it happens.
- Give your GP some information on autism from The National Autistic Society (see above section on Diagnosis) or encourage your GP to contact them on email [nas@nas.org.uk](mailto:nas@nas.org.uk) if they have any questions about the condition.

## Pre-diagnosis support

All of the Haringey children's centres offer SEND stay and play sessions where you can get advice and support – see page 25 for more details.

Markfield offers specific services to parents of children who are on the waiting list for an autism assessment, and also for young people aged 12 to 17 – see box below.

These services are also available post –diagnosis – for for parents whose child has been diagnosed with autism within the last three years.

### Support for parents of children recently diagnosed with autism, or on the waiting list for an autism assessment

- **One-to-one advice** about how to navigate the autism assessment process, and NHS, education and social care services to help your child
- Help to apply for **Disability Living Allowance (DLA)**
- **Parents support groups** – in person and online – to meet other local parents of children with autism and hear from relevant professionals.
- Parent **training sessions on autism awareness**
- A 13-week parenting programme:  
**Strengthening Families Strengthening Communities** specially tailored for parents of autistic children

#### Direct support for young people:

Markfield runs a **monthly social club** for autistic young people aged 12 to 17

#### For more information:

**Telephone:** 020 3667 5233

07762106044

**Email:** [familyadmin@markfield.org.uk](mailto:familyadmin@markfield.org.uk)

These services are free for Haringey residents. Provided by Markfield, and commissioned by North Central London Integrated Care Board (ICB)

## My child has a diagnosis, now what?



There are a number of Haringey services who may now enter your child's life to provide support. All are over-stretched and government cuts have done nothing to improve the situation, and you may at times feel like you need to become a lobbyist more than a parent to get the right help, but don't give up, you are your child's main advocate, and the help can be there if you inform yourself and are persistent.

There is also a lot you can – and will have to - do yourselves. Please educate yourself about your child's autism, extraordinary abilities and extraordinary difficulties. The more you learn about autism, the more fascinating you will find your child. Learn about the causes of behavioural problems, common everyday problems and how to improve communication. You can make life so much easier for your family and for your autistic child if you do. See the back of this pack for some starting ideas.

The main areas of state-funded provision and responsibility are divided between educational settings, the Local Authority including the Special Educational Needs Service- and Social Services provided by Haringey Council, and the Health Services, provided by NHS Whittington Health.

Education Services – Each school and nursery is responsible for ensuring children with special educational needs and/or a disability are fully included in the setting and their needs are met. The local authority inclusion team and educational psychology service can support them with specialist advice if they need it. Some children require more support than what is ordinarily available in a mainstream setting, and this can be accessed through Early Years Inclusion Funding or Education, Health Care Plans which are administered by the local authority.

The Local Authority also funds SENDIASS (the Information, Advice and Support Service) based at Markfield, which is an independent service providing free impartial advice and support to Haringey parents about navigating the systems to access appropriate support for their child.

Early Help service – the Haringey Early Help Team offers support for families with children aged 0 to 19 who are affected by multiple issues including housing, domestic abuse, mental health, substance misuse.

<https://www.haringey.gov.uk/children-and-families/early-help>

Cygnets parenting programme – the Haringey Early Help Team is offering a specialist 6-week parenting programme, which is specifically for parents of children aged between 6 and 18 years old who have a diagnosis of autism.

Contact Elena Carballal for details: [elena.carballal@haringey.gov.uk](mailto:elena.carballal@haringey.gov.uk)

Social services – The Disabled Children's Team (DCT) supports children with severe or complex needs (not all those with an autism diagnosis will qualify for DCT help). They fund some home-centred advice, and specialist short breaks activities such as clubs and playschemes through an assessment called RAS (Resource Allocation System form), to assess what your level of need is. If you qualify you are awarded a Personal Budget to fund activities. The DCT also oversees Child-in-Need (CIN) meetings, when families with disabled children are really struggling to cope.

Health Services - provide diagnosis, on-going health care, speech and language therapy, health visitors, occupational therapy and mental health services such as CAMHS.

Contact the Haringey Council SEND Team:

The team that administers EHC assessments and EHC Plans

Phone: 020 8489 1913

- early years and up to year 6 [SENDETeam1@haringey.gov.uk](mailto:SENDETeam1@haringey.gov.uk) Manager: Abeke Phillips
- years 7 to 11 [SENDETeam2@haringey.gov.uk](mailto:SENDETeam2@haringey.gov.uk) Manager: Traci Pope
- year 12 onwards [SENDETeam3@haringey.gov.uk](mailto:SENDETeam3@haringey.gov.uk) Manager: Lisa Novelli

For other Haringey specialist teams, please see below:

- Language and Autism Support Team (LAST) - 020 8489 3466
- Educational Psychology Service - 020 8489 3004
- The Education Inclusion Team, including Area Senco's, Portage and Sensory Support - 020 8489 5090

The Local Offer website

Local authorities are required to publish a SEND Local Offer which gives information on the provision for children and young people with special educational needs or disabilities (SEND) both in and outside the local area. The Haringey Local offer has a huge amount of information about services in the borough.

See: <https://www.haringey.gov.uk/children-and-families/local-offer>

## Post-diagnostic support

1

- CAMHS offers post diagnostic support for the young person/family dependent upon need. A referral is needed to access CAMHS. Usually children are seen for challenging behaviours or severe mental health needs.
- The Language and Autism Support Team (LAST) offers termly sessions for parents/carers and families of autistic children. Together with the Child Development Centre and other professionals they offer parents/carers of children aged 5 and under with a recent diagnosis an 'Autism Family Seminar' using resources developed by the National Autistic Society. <https://www.haringey.gov.uk/children-and-families/local-offer/health-services/language-and-autism-support-team>  
Contact: Telephone: 020 8489 3466 Email: [LAST@haringey.gov.uk](mailto:LAST@haringey.gov.uk)

## Charities and parent groups that might be helpful

1

### LOCAL CHARITIES

Markfield: a community hub in Markfield Park, South Tottenham  
Tel: 0203 667 5233 / 0208 800 4134  
Email: [familyadmin@markfield.org.uk](mailto:familyadmin@markfield.org.uk)

Markfield runs a range of services for families including:

- One-to-one advice surgeries for help with navigating services – for parents of children on the waiting list for assessment and diagnosed with autism
- a parent support drop-in on Fridays in school term-time from 10 am to 12 pm  
Markfield Park, Markfield Road, London N15 4RB
- A volunteer befriending scheme – matching families with trained volunteers. Run by Riccarda Courtney - email: [familyadmin@markfield.org.uk](mailto:familyadmin@markfield.org.uk)
- A range of free courses on all aspects of the SEND system parenting a SEN child,
- A 10-week course for under 5s and parents ('Stepping Stones') to learn play activities to support communication skills development. Email [familyadmin@markfield.org.uk](mailto:familyadmin@markfield.org.uk)

SENDIASS at Markfield: <https://markfield.org.uk/haringeys-send-information-advice-support-service/> Haringey's Special Educational Needs Independent Advice and Support Service for help with educational issues, as well as navigating health and social care systems. SENDIASS helpline: 020 8802 2611 Email: [sendiass@markfield.org.uk](mailto:sendiass@markfield.org.uk)

The National Autistic Society (NAS) is the main charity for autistic people and their families. NAS offers information, advice and support. They can be contacted via their online forms <https://www.autism.org.uk/enquiry>

There is not currently a Haringey NAS branch, however there are active NAS branches in neighbouring boroughs. For details of NAS branches visit:

<https://www.autism.org.uk/what-we-do/branches?page=2>

Kith and Kids: an organisation with a lot of activities specific for autistic people, severe learning difficulties, their families and siblings. Based in Tottenham at The Irish Centre.

Tel: 0208 801 7432 <https://clarahost.clara.net/www.kithandkids.org.uk/>

Caris: offers holistic support and advice to families with children in the borough..

CARIS Haringey, St Philip's Church, Philip Lane, N15 4HJ. Play sessions, holiday schemes, food bank, clothing, help with housing advice for those in temporary housing

Tel: 020 8801 3004 Email: [info@carisharingey.org.uk](mailto:info@carisharingey.org.uk)

Mums in Mainstream: a group for Mums and female carers of kids with Autism diagnosis. It is not restricted to Haringey locals but most are based within the borough. *We hold regular meetings in Haringey and operate via our Facebook page. We are neuro-affirmative and offer peer to peer support. Our kids attend the full span of educational settings and are all ages, abilities, and backgrounds. We are unfunded, independent, and welcoming. Any questions should be directed to us via the message function on our MumsInMainstream Facebook page.*

[https://www.facebook.com/MumsInMainstream/?ref=page\\_internal&paipv=0&eav=AfZKjSIFEd9uTTdfApFpWCWU533BkS9NMm0QJMI\\_8\\_2t0O6NMtb3m5F6yi9TIEB5sS4&rd=1](https://www.facebook.com/MumsInMainstream/?ref=page_internal&paipv=0&eav=AfZKjSIFEd9uTTdfApFpWCWU533BkS9NMm0QJMI_8_2t0O6NMtb3m5F6yi9TIEB5sS4&rd=1)

ABC Autism BAME Community: A Haringey group for BAME children with autism.

Facebook: ABC Autism Bame Community email: [abamecproject@gmail.com](mailto:abamecproject@gmail.com)

The Challenge Group: an under 5's playgroup for families with babies and children with additional needs. Based at St James Church, Muswell Hill Road, N10. Term times, Fridays 10 to 11.30am.

Tel 020 8883 6277 – Celia Webster, Hannah Whitehead..

AFK: a charity supporting disabled young people with after school and holiday schemes, and employment skills training. Based in Hornsey.

<https://www.afkcharity.org/>



## NATIONAL CHARITIES

National Autistic Society. A helpline and huge range of online information about autism.  
[www.autism.org.uk](http://www.autism.org.uk)

Family Fund: A national charity providing grants for a wide range of items, such as washing machines, fridges, computers, holiday vouchers.

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

Email: [info@familyfund.org.uk](mailto:info@familyfund.org.uk) Tel: 01904 550055

Caudwell Childrens Charity: a national charity, Caudwell Children helps disabled children across the UK. They act as a safety net for families who are unable to gain the help they need with grants and sensory packs and advice.

Tel: 0345 300 1348 Email: [charity@caudwellchildren.com](mailto:charity@caudwellchildren.com)

<https://www.caudwellchildren.com>

Contact: a national charity with a wealth of information on disability and benefits and your rights and a helpline

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

Email: [info@contact.org.uk](mailto:info@contact.org.uk) Tel: 0808808 3555

Challenging Behaviour Foundation: a national charity focussed specifically on children, young people and adults with severe learning disabilities whose behaviour is described as challenging. Making a difference to the lives of children, young people and adults across the UK by providing information and support, running workshops and speaking up for families on a national level.

General Enquiries: 01634 838739 Family Support Line: 0300 666 0126

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

Email: [support@theCBF.org.uk](mailto:support@theCBF.org.uk)

ACE: ACE Education, 72 Durnsford Road, London N11 2EJ

Tel: 0300 0115 142 <http://www.ace-ed.org.uk/>

Independent advice and information on state education in England

Email: [enquiries@ace-ed.org.uk](mailto:enquiries@ace-ed.org.uk)

**IPSEA** - Independent Provider of Special Educational Advice offers free and independent legally based information, advice and support to help get the right education for children and young people with special educational needs and disabilities (SEND).

<https://www.ipsea.org.uk/>

## Education and specialist help

2

Autistic children and young people may have difficulties in one or more of these areas of need which impact on their education:

Communication and interaction – difficulties with speech, language and [communication](#). Children and young people may have difficulty taking part in conversations, either because they find it hard to understand what others are saying or meaning, or because they have problems with fluency of speech and sound production. Children and young people on the spectrum have difficulty making sense of the world and may be easily distracted by certain stimuli, such as noise, bright lights or strong smells. They will often have problems with [changes](#) to their routine.

Cognition and learning – difficulties in gaining basic literacy and numeracy skills or understanding concepts. Children and young people may need more practical activities, tasks set out in smaller steps, or specific programmes to support development of literacy and numeracy skills.

Social, emotional and mental health – difficulties with emotional and social development, immature [social skills](#) and difficulty making and sustaining good relationships. Children and young people may become withdrawn and isolated, or display challenging, disruptive behaviour or have [meltdowns](#). Some children on the spectrum may have additional diagnoses of Attention Deficit Disorder (ADD) or [Attention Deficit Hyperactivity Disorder](#) (ADHD).

Sensory and/or physical needs – these needs can be wide ranging and may require adaptations to the curriculum, study programme or physical environment. Many children and young people on the spectrum may also have [sensory](#) and/or physical needs. For example, they may be hypo- (under) or hyper- (over) sensitive to noise, sight, smell and touch. They may also have fine and/or gross motor skill difficulties, such as difficulties with pencil grip, balance and awareness of personal space.

## The school-based stages of support

2

### SEN Support in mainstream education

You don't need to wait for a diagnosis to get support for your child, and not all autistic children will need extra support in school. Getting the right support in education is

important and your child/young person may be entitled to extra help in school (via SEN Support) if they have severe difficulties in one or more of the above areas of need.

It is a legal requirement for nurseries and schools to comply with their 'best endeavours' duty to make sure that the necessary provision is made for any pupil on roll who has SEN. (Section 66 of the Children and Families Act 2014).

This legal duty applies to:

- all nurseries which provide free state-funded 15 / 30 hour places
- maintained, mainstream schools and academies
- free schools which are not special schools
- Pupil Referral Units
- 16-19 & alternative provision academies
- further education settings



The SEND Code of Practice

The Special Educational Needs and Disability (SEND) Code of Practice (2015) explains how schools, local authorities and NHS bodies should identify, assess and provide for children and young people with SEND.

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/398815/SEND Code of Practice January 2015.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf)

The SEND code of practice describes the level of support offered to children with SEN. In your child's classroom, all work should be differentiated (set at an appropriate level for each child) but if an early education setting, school or college believes that a child has SEN, they will need to put in place extra support. This is called SEN Support and may include obtaining specialist advice from professional services from outside the early years setting, school or college, such as an Educational Psychologist.

Haringey guidance on SEND support

Haringey has published on the Local Offer a guide which sets out in detail the types of support which mainstream schools are expected to provide

[https://www.haringey.gov.uk/sites/haringeygovuk/files/send\\_support\\_guidance.pdf](https://www.haringey.gov.uk/sites/haringeygovuk/files/send_support_guidance.pdf)

Haringey Council's guidance to schools is to include all children with a formal diagnosis of autism on the school's SEND register even if they are managing well without extra support - as this will ensure teachers are alerted to their neurodiverse profile and additional support may be needed at transitions.



To request SEN Support for your child in school, request a meeting with the SENCO (The SENCO is the teacher in your child's school or nursery with day-to-day responsibility for SEN) and the class teacher.

You may find it helpful to ask if a friend or advisor from SENDIASS (Markfield) can come to the meeting with you.

This draft letter may help. It's a good idea to keep a copy of your letter to take with you to the meeting as a reminder of the concerns you've listed.

---

Dear [insert head teacher's name],

Child's name and date of birth I am concerned that [insert child's name] is not making adequate progress in school and may have special educational needs. In particular I am worried about:

[list your concerns , for example:

- slow rate of progress in reading
- difficulty in relating to others
- possibility of being bullied
- poor communication skills]

I would like to meet with you to discuss my concerns and what the school can do to help.

I would also like to bring my friend/advisor [insert their name]. The questions I would like to discuss are:

[list questions]

I would like a copy of my child's school records and a copy of the school's SEN policy.

I hope that we can work in partnership, so that [child's name] can do as well as possible.

I look forward to hearing from you.

Yours sincerely,

[Your name]

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Before the meeting:

It's useful to do some preparation before meeting school staff. The following questions may help you:

- *What extra help has your child received and how effective has it been?*
- *Is your child's progress reviewed regularly? Have you had the opportunity to comment on their progress?*
- *Have any professionals, such as an educational psychologist, seen your child and suggested ways to help?*
- *Does your child have a diagnosis of an autism spectrum condition? If so, does the school have details of it? Are your child's difficulties getting worse? What changes would you like to see?*

At the meeting:

Discuss your child's needs,

The SENCO must make an analysis of their needs, using the teacher's assessment and experience and evidence of their progress, attainment and behaviour.

The SENCO must agree if Special Educational Needs (SEN) support is required and draw up an SEN Support Plan (sometimes called an Individual Education Plan (IEP).

Your views and your child's views should also be taken into account. You should always be consulted and kept informed of any action taken to help your child and of the outcome of this.

Once your child has been identified as having SEN, the school should take action to put effective support in place. You must be told about any special educational provision put in place for your child and the four main steps of implementing the SEN support which form part of the graduated approach must be adhered to.

Ensure that his/her pupil profile is shared with the staff working with your child

SEN Support should be reviewed regularly – usually once a term.



**Schools should follow the cycle of: Assess, Plan, Do and Review**

**Step 1 – Assess**

There should be a clear analysis of your child's needs based on the teacher's assessment and experience of your child as well as information about their progress, attainment and behaviour. The assessment should be regularly reviewed. In some cases, outside professionals who may already know your child will liaise with the school to help inform the assessments.

## Step 2 – Plan

You must be notified if it is decided that your child needs SEN support. You should also be consulted about the interventions and support to be put into place for your child, as well as the expected impact on their progress and when this will be reviewed.

All staff working with your child should be aware of the approach and teaching strategies being used and of any additional support being provided. This should be recorded on the school's information system.

## Step 3 – Do

The class or subject teacher remains responsible for your child's progress on a daily basis, working closely with any teaching assistants or specialist staff involved to plan and continually assess the impact of the support/interventions being put into place. In turn, the SENCO should support the class or subject teacher in further assessments, problem solving and advising on effective implementation of the support.

## Step 4 - Review

There should be a clear agreed date to review the effectiveness of the interventions and support put into place and the impact it has had on your child's progress. You and your child (where appropriate) should be given the opportunity to present your views. The class, or subject teacher, working with the SENCO and any external professionals involved with your child, should revise the support in the light of your child's development and progress made.

## Involving specialists

If your child makes little or no progress following interventions and support put into place, they should consider involving specialists from outside agencies. This might be, for example, an educational psychologist, an autism outreach specialist or a speech and language therapist, who can give advice and provide more specialist assessments.

You should be consulted if a professional from outside the school is to be involved with your child's education. Any involvement of outside specialists should be discussed and agreed with you and the support your child will receive should be recorded and shared with you. A date should be set for when progress will be reviewed.



## **What is an EHC plan and does my child need one?**

For children or young people who have special educational needs that are more significant, complex and that can't be met through school resources, the local authority

will need to make an assessment of their education, health and care needs (an EHC needs assessment) and may then decide on the basis of the reports to draw up an Education, Health and Care Plan (often referred to simply as 'a plan') which must be reviewed annually.

The EHC Plan is compiled by the Local Authority's Special Educational Needs department and takes into account the reports written by the school SENCO, educational psychologists, speech and language therapists, clinicians, teachers, parents and other involved professionals from health and social care.

As well as special educational provision an EHC plan would have details of any social care provision such as a personal budget / direct payment

Children will generally be given support through school resources (called (SEN Support) before they are offered an assessment for an EHC plan. Others may be offered an EHC needs assessment straight away, depending on their level of need.

The process for applying yourself for an EHC plan is called 'EHC needs assessment', you should ask for this if you believe:

- *that your child may have a learning difficulty or a disability which is holding them back at school; and*
- *that the school is not able to provide all the help your child needs.*

You should also ask your LA for an EHC needs assessment if your child is under school age, and you believe that they will need extra help when they start school.



## **How to apply for an EHC Plan**

The SENCO at nursery or school can make the application for an EHC needs assessment. Parents/carers can also do this independently - see below

The time from the first request for an EHC needs assessment to the issuing of an EHC Plan should be no more than 20 weeks, by law.

To make the request as a parent you need to put your request in writing to the Local Authority. There is a parental request form on the Local Offer website which you can use – although you are not obliged to use this format. The SENDIASS service can help with this (tel 020 8802 2611)

<https://www.haringey.gov.uk/children-and-families/local-offer/education-health-and-care-plans-ehcps/request-ehc-needs-assessment>

## **When should I hear back from the Local Authority?**

The Local authority must reply within 6 weeks to let you know if they agree or not to go ahead with an EHC needs assessment.

If the LA refuses to assess they must inform you in writing of your right of appeal to the Special Educational Needs and Disability Tribunal. The LA will also offer a 'next steps' meeting with you and your child's school/nursery to discuss how your child's needs can be met under SEN Support. If you appeal to Tribunal this must be lodged within two months of receiving the refusal letter.

If the LA agrees to assess, they then have 14 weeks to carry out the assessment, and at that point the Local Authority will decide based on the evidence from the assessment whether an EHC Plan is needed.

If the Local Authority decides to issue an EHC plan, a draft plan will be written and sent to the parents who are given 15 days to suggest any changes. In total, the finalised EHC plan should be issued not later than 20 weeks from the initial request. Once issued, an EHC plan is reviewed annually and provision can be changed. In reality it can be difficult to get major changes made to the EHC plan once it has been finalised, so it is worth holding out for what you feel to be a plan that will give decent provision for the next few years.

## **What if I disagree about provision in my child's EHC Plan**

Your SEN Team caseworker will offer a 'co-production meeting' with you to discuss the draft EHC Plan before it is finalised. This is your opportunity to raise any questions or disagreements with the wording.

The recommendations in the professional reports are used to draw up the EHC Plan. If you feel that any of the professional reports made on your child for an EHC needs assessment are inaccurate, or understate or overstate the problems, you can ask for changes to be made to that report, because an inaccurate description of needs could well result in the wrong level/type provision being offered. Make sure your child's EHC plan is also clear about the special educational provision – for each need identified in section B of the Plan there should be specified and quantified provision in section F of the EHCP to meet that need. If the wording in section F is vague and unquantified ask your SEN Team case officer for clarification, if necessary they should refer back to the relevant professional to ask for this.

Independent professional reports

Some parents may choose to pay for have a private evaluation by an independent expert, however private reports are expensive - expect to pay £1000 for an independent educational psychologists assessment or £650 plus for a Speech and Language or Occupational Therapy tribunal report from the London Children's Practice (tel 020 7724 1156) for instance. Independent reports tend to be not as highly regarded by local authorities who believe they are not as objective as those from NHS and LA in-house teams.

Support with resolving disagreements with the Local Authority

Any Haringey parent can use the free SENDIASS service at Markfield to advise and support them to help resolve disagreements with the Local Authority over EHC Plans, and help write any necessary letters. Tel 020 8802 2611.

**Ace Education:** <http://www.ace-ed.org.uk>

**IPSEA:** <https://www.ipsea.org.uk>

Independent Provider of Special Education Advice (known as IPSEA) is a registered charity (number 327691) operating in England. IPSEA 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). They also provide training on the SEND legal framework to parents and carers, professionals and other organisations.

Private advocacy: A private child advocate is something parents may wish to consider although, like going to a solicitor, this costs money.

## **Appealing against a Local Authority decision**

2

There are several points at which you can appeal to the SEND tribunal if you cannot agree with the Local Authority, including if the LA::

- *Will not carry out a statutory assessment of your child's special educational needs, following a request by you or by your child's school.*
- *Refuses to make an EHC plan of your child's special educational needs, after a statutory assessment.*
- *Has made an EHC plan, or has changed a previous EHC plan, and you disagree with the content.*

The process to lodge an appeal is explained in the letter that will be sent to you by the LA when they let you know their decision.

The Tribunal website has a pack explaining how and when you can appeal <https://www.gov.uk/courts-tribunals/first-tier-tribunal-special-educational-needs-and-disability>

Parents are obliged to consider mediation before lodging a Tribunal appeal.

There are strict deadlines for making appeals to Tribunal, so if you are unhappy at any stage make sure you seek support.

The IPSEA.org.uk website is also very good on this appeal/tribunal process. Helplines can all give advice: SENDIASS, NAS, AFASIC, Contact-a-family, IPSEA, ACE, and can suggest reading material to help you through the process.

Going to tribunal is sometimes inevitable, but it is a long-winded and bureaucratic process and can be intensely stressful, and both sides tend to do all they can to avoid it.

### **Transport advice and help**

If your child has to travel more than 3 miles to get to their educational provision and there is no suitable alternative school closer to your home you may be entitled to school travel assistance from LA. Speak with your SEN case worker, and/or seek advice from SENDIASS.

If you have any difficulties securing SEN transport for your child you could contact SENTAS – the special educational needs transport advocacy service

<https://sentas.co.uk> email: [info@sentas.co.uk](mailto:info@sentas.co.uk)

## **What specialist help is available to my pre-school child?**



Early education is part of the foundation stage of education. Early years practitioners must review the progress of all children between the ages of two and three. If your child is identified as having SEN, a graduated approach of assessment, planning and reviewing their progress should be adopted. All early education settings must have regard to the SEND Code of Practice, have a written SEN policy and nominate a member of staff to act as their SENCO.

In Haringey, there are many early years nursery education options that can support children with special educational needs. These include children's centres, nurseries, childminders, nursery classes in primary schools, playgroups and pre-schools.

You may hear these called 'early years settings'. You can find out more about early years settings and childcare in Haringey on the [childcare and early years pages](#). Some settings

will publish an 'SEN Information Offer' describing their experience with and provision for children with Special Educational Needs and Disabilities.

If you need support finding Early Years provision for your child with SEND contact the Childcare Brokerage Service: 0208 489 1000 Email: [earlyeducation@haringey.gov.uk](mailto:earlyeducation@haringey.gov.uk)  
<https://www.haringey.gov.uk/children-and-families/childcare-and-early-years/childcare-options/childcare-brokerage-service-2-and-3-year-olds>

For further information visit the Family Information Service Directory:

<https://fisd.haringey.gov.uk/> and carry out a search for 'children with disabilities' or 'SEN' or call Haringey's Disabled Children's Team on 020 8489 3671.

All early years settings must make reasonable adjustments for children with special education needs and must follow the Special Educational Needs (SEND) Code of Practice ([https://www.haringey.gov.uk/sites/haringeygovuk/files/send\\_code\\_of\\_practice\\_approved\\_by\\_parliament\\_29.07.14.pdf](https://www.haringey.gov.uk/sites/haringeygovuk/files/send_code_of_practice_approved_by_parliament_29.07.14.pdf))

### **Area SEN Coordinators (SENCOs)**

The Area SENCOs are a team of qualified early years professionals who all have extensive experience of working with children with a range of additional needs, including Autism, Downs Syndrome, Cerebral Palsy, Global development delay, and speech language and communication difficulties. They offer support and advice to private, voluntary and independent early years settings to help develop inclusive practice and plan for children with additional needs, and training and workshops for early years practitioners and SENCOs to cover a range of SEND issues. .

Settings should complete the Request for Area SENCO form, on Haringey website, to refer your child to the Area SENCOs. Email: [areasenco@haringey.gov.uk](mailto:areasenco@haringey.gov.uk)

### **The Huddle**

A free drop-in play group for parents of preschool children with additional needs run by the specialist health visiting team and Haringey Portage service. Here you can access informal support from the professionals running the group and your child will be able to access a range of play materials. Get practical tips on supporting your child's early play and communication development, and information about services in the borough. The Huddle meets every Tuesday 10am-12noon at the Pembury Children's Centre.

For enquiries about this services contact.

Sue Davies - [susan.davies29@nhs.net](mailto:susan.davies29@nhs.net)





Sarah Geismar - sarah.geismar@nhs.net

<b>Haringey Children's Centres</b>		
<b>Children Centres</b>	<b>Address</b>	<b>Phone number</b>
Broadwaters	Adams Road N17 6HE	020 8885 8801
Park Lane	139 Park Lane N17 0HB	020 802 8782
Pembury House	Lansdowne Road N17 9XE	020 8801 9914 07790 114 982
Rowland Hill	315 White Hart Lane N17 7LT	020 8808 6089 07870 157 955
Triangle Children, Young People and Community Centre	91-93 St Ann's Road N15 6NU	020 8802 8782
Welbourne	Stainby Road N15 4EA	020 8493 1197
West Children's Centre Team	Not centre based	07970 242 803 <a href="mailto:childrencentrewest@haringey.gov.uk">childrencentrewest@haringey.gov.uk</a>
Woodlands Park	Woodlands Park Road, N15 3SD	020 8802 0041
Woodside	59 White Hart Lane N22 5SJ	020 8888 4398

[https://www.haringey.gov.uk/children-and-families/childcare-and-early-years/childrens-centres#haringey children's centres](https://www.haringey.gov.uk/children-and-families/childcare-and-early-years/childrens-centres#haringey%20children's%20centres)

### **Pre-school education issues - Haringey Council support teams/contacts:**

**Early Years Brokerage** Team – support to find childcare for children with SEND.

0208 489 1000 Email: [earlyeducation@haringey.gov.uk](mailto:earlyeducation@haringey.gov.uk)

Haringey SEN Team



- Statutory Assessment Team - which administers EHC needs assessments and plans. There are 3 teams within the SEN Team, based on the school year group ( see page 11) Tel 0208 489 1913
- Educational Psychology Service - 020 8489 3004
- Language and Autism Support Team - 020 8489 3466

- The Education Inclusion Team, including Portage, Area Senco', LAST and Sensory Support- 020 8489 5039

Mary Jarrett,

Head of Service for Integrated Service for Children with Special Educational Needs and Disabilities

Sarah Lewis : Principal Educational Psychologist

[educationalpsychology@haringey.gov.uk](mailto:educationalpsychology@haringey.gov.uk)

Early Years Inclusion Team: Tel: 020 8489 3498

### **Haringey Portage Service**

Portage workers visit children at home with their families and help children to develop their skills through supporting parents in play based activities with their child. The Portage workers will visit families until your child starts in an Early Years Setting, advising and supporting parents in all areas of the child's development. They will also work closely with the professionals working with your child. The aim is to help parents/carers to identify what is important to them and their child and plan goals for learning and participation.

Main contact: Irene Malone - Education Inclusion Team Administrator

Telephone number: 0208 489 5039 Email: : [portage@haringey.gov.uk](mailto:portage@haringey.gov.uk)

**Early Years Inclusion Funding** – also known as top up funding – this has led to significant changes in the Early Years landscape with increased choice for parents and developing skills for playgroups etc through more experience of children with additional needs.

If a child receives Disability Living Allowance (DLA), this entitles nurseries to additional funding and also parents with access to a free 15 hours a week place for 2 year olds. See page 45 for where to get help to fill in DLA applications.

For help with issues relating to therapies (speech therapy, occupational therapy)

Borough Lead for Therapies and Specialist Nursing Whittington Health.. tel: 0208 442 5731 or leave a message with the Therapies Secretary Marion Picknell tel: 0208 442 6040

Liz Alsford, Lead for Additional Therapies (SLT): 020 3224 4399  
email [Liz.Alsford@nhs.net](mailto:Liz.Alsford@nhs.net)Haringey

## **Independent advice**

**Haringey SENDIASS** (Information Advice and Support Service), provided by Markfield provides free independent impartial advice to parents about SEND law and policies, and information on accessing services. They can help you with accessing information,, filling in forms and attending school or LA meetings with you. You can meet SENDIASS Advisers at the Markfield centre and at outreach surgeries.

Email [sendiass@markfield.org.uk](mailto:sendiass@markfield.org.uk) Helpline 020 8802 2611.



### **1. Social Communication Group.**

Run by Speech and Language Therapists at one of the local health centres as part of the referral pathway for pre-school children with autism or a social-communication disorder, the social communication group runs for 6 to 8 weeks working on language, play skills, turn taking etc.

Tel: 020 8489 5039

### **2. Haringey Speech and Language Therapy**

Other than the Social Skills Group, some children may also receive one to one speech and language therapy in short bursts of weekly or monthly interventions in school, or may join groups at community clinics. The Speech and Language Therapists may also visit you at home. If you wish to self-refer to the Speech and Language Therapy service, contact the SLT advice line: 0203 224 4399 or the SLT administrator at Tynemouth Road Health Centre. Tel 020 8275 4008.

### **3. Children's Community Occupational Therapy Team**

There is a Early Years specialist autism OT team who can offer sensory assessment and advice to under 5s and help with practical difficulties with dressing, feeding, handwriting etc. They are based at the Child Development Centre. Tel: 0203 224 4655.

### **4. Home programmes**

There are a number of children in the borough still following part-time home-based behavioural intervention programmes developed in the United States, also known as ABA or Applied Behavioural Analysis. There are a number of models with ABA, Verbal

Behaviour and Options the better known. The majority of the children on home programmes are just doing it part time at home alongside normal attendance at special or mainstream school. The Local Authority does not fund ABA programmes. Some parents choose to pay for some private additional tutoring at around £20/hr for a tutor and anything from £35 to £80 an hour for occasional supervision.

For more information on ABA contact a reputable national provider such as The UK Society for Behaviour Analysis (<https://uk-sba.org>) or Autism Partnership. Tutors can be found on [www.ABA tutor.co.uk](http://www.ABA tutor.co.uk)

***5. Mainstream nurseries with some extra support and speech and language therapy, or more help if you have managed to get the help detailed on an EHC plan.***

## **Under 5 parents groups and play sessions**

Haringey Childrens centres offer specialist SEND stay and play sessions

The Haringey Local Offer website also lists other groups and sessions:

[https://www.haringey.gov.uk/children-and-families/local-offer/support/leisure-activities#children\\_under\\_five](https://www.haringey.gov.uk/children-and-families/local-offer/support/leisure-activities#children_under_five)

Markfield under 5s stay and play - Thursdays 12 to 2.30pm in school term-times. An inclusive drop in stay and play at the Markfield centre in Markfield Park, South Tottenham, N15 4RB. 020 8800 4134 or 0203 667 5233.

Markfield Stepping Stones programme – a free 10 week language and play programme for under 5s and their parents. 0203 667 5233. Plus free training and courses on autism, managing behaviour, Makaton, and much more at Markfield – see their website.

Palace for All – a charity just over the Haringey border in Islington near Crouch Hill station. Based at Brickworks, 42 Crouch Hill, Finsbury Park, London N4 4BY, tel 020 7561 1689, this organisation offers numerous treatments and also small group and 1 to 1 speech and language therapy and teaching. There is a termly charge but it is very reasonable. They also have lots of drop in play sessions.

Challenge Group – a Friday morning termtime, 10 to 11.30am drop in for under 5s with special needs at St James Church Hall, Muswell Hill Road, N10. The parents organising this group include a child psychologist and a physiotherapist.

Email: [cebwebster@gmail.com](mailto:cebwebster@gmail.com) or [churchoffice@st-james.org.uk](mailto:churchoffice@st-james.org.uk)

## What specialist help is available for my primary school aged child?

2

The majority of autistic children in the borough fall into one of the following groups:

- attend a local mainstream primary school, with additional help ranging from zero to full-time one-to-one support.
- attend a local special school or specialist unit in a mainstream school run by the council, or a local independently run special school.
- are out of school and follow a home programmes or get tuition from the Haringey Learning Partnership (HLP)
- a very few children needing exceptionally high levels of support and a very structured 24-hour curriculum go to out of borough residential special schools.

Most autistic children in the borough attend mainstream schools. There are also several special schools for children with more severe or complex needs – see below.

The Local Authority's policy is to increase in-borough provision for autistic children, particularly by increasing the number of children in supported mainstream settings and to oppose parents' requests for out of borough and independent school placements except in extreme circumstances where needs very clearly cannot be met in borough.

If your child needs more help than can be provided from the school's own resources they will need an Education Health and Care Plan (EHCP).

### **Autism advisory service in schools**

The Advisory Teachers in the Language and Autism Support Team (LAST) support staff working with autistic children from Reception age up to the age of 19. They work in close partnership with therapies such as Speech and Language Therapy and Occupational Therapy services to improve outcomes for autistic children. Haringey schools/colleges can request additional support and training from LAST.

Also see the [Language and Autism Support Team page](#) on the Local offer website or contact [last@haringey.gov.uk](mailto:last@haringey.gov.uk) 0208 489 3466 for more information.

Schools can also make referrals to and request support from to following teams, whether or not your child has an EHC Plan:

- Haringey Speech and Language Therapy Team
- Haringey Educational Psychology Service
- Haringey Occupational Therapy Service

Ask your child's school or educational setting regarding this.

## Special schools and units for autistic primary age children, attended by Haringey pupils

- *The Brook School – Adams Road, N17. A special school with amazing facilities on a shared site with a mainstream primary school (Willow) on Broadwater Farm. For children with autism and/or complex needs. Tel: 020 8808 7120. [admin@thebrook.haringey.sch.uk](mailto:admin@thebrook.haringey.sch.uk)  
Headteacher Maureen Duncan*
- *Mulberry School Parkhurst Road, N17 9RB. Tel: 020 8801 0189. [office@mulberry.haringey.sch.uk](mailto:office@mulberry.haringey.sch.uk)  
A mainstream primary school with an autism unit. Children will integrate into any mainstream classes their abilities allow them to access.*
- *The Grove School – ages 5 – 19, exclusively for children with autism, based in Haringey on Downhills Park Road, N17.  
Lucia Santi, Headteacher. Tel: 020 3876 6555 website: <https://thegroveschool.co.uk>*
- *Vale at Lancasterian Primary School special educational needs including physical disabilities, sensory impairments, medical conditions, developmental delay, learning or communication difficulties and social, emotional needs. King's Road, N17 8NN Tel: 020 8801 2299*
- *Holmewood School. An independent school For children 5 – 19 with high functioning autism, Aspergers and other specific learning difficulties. Has lower school in Woodside Park 020 8920 0660 and upper school in Muswell Hill Tel: 020 3908 8991*
- *Treehouse School – Ages 4 – 19. Woodside Avenue, London N10. Tel: 020 8815 5424. Independent school run on ABA principles.*
- *Kestrel House School – Ages 5 – 16 . An independent school for children with autism at 104, Crouch Hill, N8 9EA. Tel: 020 8348 8500*

Some out of borough specialist schools:

2

- *The Bridge School Has several sites see website for details <https://thebridgetrust.academy/>  
Takes 3 - 19 years.(autism). Autism units in mainstream schools. (Places generally reserved for Islington students)*
- *West Lea School State run school. Ages 4 -17, Has two sites one for primary Meridian Campus and one for secondary Haselbury Camous. (autism, complex needs) Tel: 020 8807 2656 Run by Enfield LA, places generally reserved for Enfield pupils.*
- *Woodcroft school – Tiny independent school. Ages 5-12, Loughton, Essex. (MLD autism, Aspergers) Tel: 020 8508 1369*

- *Hillingdon Manor School* Independent school for children with high functioning autism/Aspergers, age 3 – 19. Primary ages tel 01895 420315. Secondary ages Tel 01895 813679

Directories listing schools:

- The NAS <https://www.autism.org.uk/our-schools>,
- John Catt's directory on <https://www.specialneedsguide.co.uk/>
- <https://www.goodschoolsguide.co.uk/school-search>
- Autism London, Gabbitas <https://gabbitas.com/school-search>
- and <https://schoolguide.co.uk>

Independent schools are expensive, and LA's can be very reluctant to fund places at them, preferring to provide in-borough for their autistic children. Whichever route you take, contact the schools early, take a look around and if you decide you would like a place there, register your interest with the school and the LA as fast as possible. The LA must consider parental preference over choice of school, but getting approval for an expensive independent school will not be easy as funds are very limited and tend only to be allocated when in-borough placements have been demonstrated to be unable to meet the child's needs, or all places are full.

## **2. Mainstream primary school with varying levels of support**

There are many children on the more able end of the autistic spectrum attending mainstream school with support from a LSA (Learning Support Assistant) or TA (Teaching Assistant). Hours of support provided vary from none to full-time one to one support, depending partly on the needs of the child and partly on how effectively the parents have engaged the system to get support.

The quality of support provided can be essential to making inclusion successful. Try to ensure that your child's TA or LSA receives training in autism from the LAST team (020 8489 3466) who go into schools and train staff in-depth on successful inclusion of children with ASC (page 29). Check whether the support hours will include breaktimes and lunch hours – often it is the unstructured times that autistic children find most stressful and un-manageable, but which are often not included.

The Local Authority policy is to direct more funds to schools for general use for children with special educational needs, so that fewer children will need EHC plans. Those with needs which are not seen as severe or complex will generally get help at school level

through the system known as SEN Support without the need for an EHCP. At present this is children who need extra help that costs up to £6,000 a year.

At mainstream school, your child will have an SEN Support Plan (sometimes called an Individual Educational Plan or IEP) which should be updated and reviewed regularly. If they have an EHC Plan there will also be an annual review of the child's progress and to review and update the EHC Plan.

If you have concerns about the support your child is getting at school these should be addressed first to the school SENCO. Parents can also contact the Language and Autism Support Team, SENDIASS Information Advice and Support Service (see next page) can advise you how to raise concerns

The Educational Psychology Service offers free 40-minute consultations for parents of children without EHCPs. This is arranged through SENDIASS – see above

Speech and Language Therapy in schools for pupils from Year Three onwards, is currently restricted to those who have EHCPs. Parents may self-refer to the service, or schools can refer children to the service with parents' consent. Contacts are listed on the next page.

Palace for All (charity)

A charity that provides very good value speech and language therapy and one to one teaching at much lower rates. Tel: 020 7561 1689 <http://palaceforall.org.uk> Based at the Brickworks, 42 Crouch Hill, London N4 4BY

### **Help with Primary age education issues – contact numbers/emails:**



Language and Autism Support Team. Manager: Esther Joseph 020 8489 3466

Email: [last@haringey.gov.uk](mailto:last@haringey.gov.uk)

- Alena Lerari, Statutory Assessment Team Manager, Haringey SEN Dept, Children and Young People's Services. Tel: 020 8489 3877
- Mary Jarrett, Head of Service for Integrated Service for Children with Special Educational Needs and Disabilities [mary.jarrett@haringey.gov.uk](mailto:mary.jarrett@haringey.gov.uk)



- Educational Psychology Service. Tel: 020 8489 3004
- Liz Alsford, Head of Additional Therapies (Whittington Health): 0208 442 5731.  
Email: [liz.alsford@nhs.net](mailto:liz.alsford@nhs.net)

SENDIASS (Information Advice and Support Service) - based at Markfield  
– Tel: 0208 802 2611  
Email [sendiass@markfield.org.uk](mailto:sendiass@markfield.org.uk).

This independent advice service helps parents access LA and NHS services when you get stuck or need help getting through the system.

## **What specialist help is available for my secondary age child?**

### **Mainstream secondary provision**

A very large number of children on the autistic spectrum attend all of the secondary mainstream schools in Haringey with support varying from none, to full time one to one classroom support provided via an EHC plan.

There are no specialist units for more able autistic children attached to mainstream secondary schools within Haringey but there is The Grove School, which is under The Heartlands Community Trust - for pupils aged 5-19 with primary diagnosis of Autism (see next page), you must have an EHC Plan to get a place – apply through Haringey LA.

Haringey's Language and Autism Support Team (LAST) work with staff supporting Autistic children in mainstream schools and their teachers and learning assistants. Tel: 0208 489 3466 email: [LAST@haringey.gov.uk](mailto:LAST@haringey.gov.uk)

LAST offer support from year 5 with sharing the diagnosis, with parental consent. The team also offer support around the transition from year 6 to year 7.

If your child is out of school, you may be able to access up to 10 hours a week tuition through the Haringey Learning Partnership – which oversees a range of alternative educational provisions, including one for children with health needs at Pulford House, 4 Pulford Road, London N15 6SP Tel: 020 8489 4459.

The Tuition Centre can teach up to 5 hours a week in the pupils' own home if they are too fragile to cope with attending classes at the Tuition Centre building. Contact Donna Lockett. This service is considered a short term gap to prepare for a move to a longer term placement. Pulford House, 4 Pulford Road, London N15 6SP Tel: 020 8489 4459

## Special schools in Haringey:

- **Riverside** – a large special needs provision in a mainstream secondary school based at Woodside High on White Hart Lane (Wood Green end of the road) For children with autism and/or complex needs. Ages 11- 16. Contact Martin Doyle (head). Tel 020 8889 7814  
Email: [admin@riverside.haringey.sch.uk](mailto:admin@riverside.haringey.sch.uk)
- **The Grove** – ages 4 – 19, school run by the Heartlands Community Trust for children with autism, and for those with high functioning autism/Aspergers whose needs cannot be met in mainstream school. [www.thegroveschool.co.uk](http://www.thegroveschool.co.uk)  
The Grove School, Downhills Park Road, Tottenham, London, N17 6AR. T: 020 3876 6555  
E: [office@thegroveschool.co.uk](mailto:office@thegroveschool.co.uk)
- **Vale at Northumberland Park School** – Northumberland Park School, Trulock Road, London, N17 0PG. Tel: 0208 801 6111
- **Holmewood School.** - an independent school, attached to an international mainstream school in Woodside Park and Muswell Hill, which has provision for children with high functioning autism, aspergers and other specific learning difficulties. Tel 020 8920 0669/0
- **Treehouse School,** Woodside Avenue, Muswell Hill, N10. – an independent school run on ABA principles. (Autism, severe learning difficulties) .Tel 020 8815 5424.

## Special schools outside Haringey

- **JCoss** – Jewish School in Barnet, with an autism unit. See website [www.jcoss.org](http://www.jcoss.org) 020 8344 2220
- **The Southover Partnership** - very small autism and behavioural support school based in Southgate and Finchley. The Southover Partnership School provides a holistic education for children and young people with autism, behaviour, emotional and associated learning and social difficulties, and those at risk of exclusion. 1<sup>st</sup> Floor, 322 Ballards Lane, London, N12 0EY. T: 020 8446 0300 [www.southoverpartnership.com](http://www.southoverpartnership.com)
- **Hillingdon Manor** - (autism/aspergers)Harlington Rd, Hillingdon, Middlesex UB8 3HD (Independent school). [www.hillingdonmanorschool.org.uk](http://www.hillingdonmanorschool.org.uk) Ages 3 – 19yrs. Tel: 1901895 813 679
- **Odyssey House School** - 2c Northwood Road, London, N6 5TN, Tel: 020 8348 8009 [info@odysseyeducation.org.uk](mailto:info@odysseyeducation.org.uk)
- **The Bridge School** - Takes ages 2 - 19 years.(Islington LA) Website [www.thebridgelondon.co.uk](http://www.thebridgelondon.co.uk) Takes mainly Islington pupils.
- **West Lea** - (autism and Aspergers) Haselbury Rd , Edmonton. Ages 3 - 19 Tel: 020 8807 2656 (Enfield LA) Takes mainly Enfield pupils
- **Stormont House** - Downs Pk Rd, London E5.(Hackney LA) Tel: 020 8985 4245. Takes mainly Hackney pupils, but has pupils from othe boroughs. High functioning autism and Aspergers catered for.
- **Oak Lodge School** - Heath View, East Finchley, N2(Barnet LA)(learnig difficulties and autism) Tel: 020 8444 6711

- **Sybil Elgar School** – Havelock Road, Southall, Middlesex UB2 4NY. NAS school
- **Hendon School.** The **HARP** unit - an autism resource provision within this mainstream school in the borough of Barnet. (Autism/Aspergers) 020 8202 9004
- **Edith Kay Independent School** – 32 Crouch Road, Brent, NW10 8HR  
Tel: 020 8961 4204 or 07983 934 923



### Residential special schools include:

- **Helen Allison School** - an NAS run school in Meopham, Kent, approximately 75 minutes drive from Haringey. Offers daytime or weekly boarding or overnight respite provision for children with autism/Aspergers. Tel 01474 814878. Head is Jacqui Ashton Smith. Ages to 5-19. Tel 01474 814878
- **West Heath** - Ashgrove Road, Sevenoaks, Kent TN13 1SR. tel: 01732 460553 fax: 01732 456734. <https://www.westheathschool.com/form/?pid=21&form=16>
- **St Johns School and College** - in Brighton, Tel: 01323 872940
- **Cotswold Chine school** - Telephone: ([01453 837550](tel:01453837550)) Fax: (+44) 01453 837555  
E-mail: [info@cotswold-chine.org.uk](mailto:info@cotswold-chine.org.uk)  
Address: Cotswold Chine, Box nr Stroud, Gloucestershire, GL6 9AG, United Kingdom
- **The Sheiling school** - Horton Road, Ashley, Ringwood BH24 2EB 01425 477488
- **Acorn Lodge School** - Residential school in Norfolk Tel: 01953 888 656
- **Prior's Court School** - Thatcham, Berkshire. Tel: 01635 247202. 38 week or 44 week weekly boarding for children with autism and challenging behaviour/complex learning. Ages 5 - 25
- **Fullerton House School** - Doncaster. A 52 week school for children with severe challenging behaviour and autism. 0800 0556789.
- **Hassocks HVS** - A residential school for children with autism/aspergers who suffer high levels of anxiety. West Sussex. 01273 832901
- **Tadley Horizon school.** - Ages 5-19. Tadley, Hampshire. 01189817720
- **Broomhayes School** - Devon. NAS run termly boarding school. To age 19. Autism and challenging behaviour.
- **Cambian group** - Many residential school UK wide Tel: 0161 507 3723
- **Doucecroft School** - Eight Ash Green, Colchester, Essex. Tel 01206 771234. Autism and aspergers age 2 – 19.
- **Eagle House School** - Banham, Norwich, Norfolk. Tel 01953 888656. Residential 38 and 52 week school for children with autism and moderate to severe learning difficulties.
- **Heathermount School** - Ascot. Run by Disabilities Trust. Tel 01223 265567
- **Priory Group Schools** – the group run several schools specialising in high functioning children – in Surrey, Hampshire, Somerset and Brighton. Tel 01373 814980/466222.

Details of more schools can be obtained from the National Autistic Society and from the OAASIS websites. Autism London has a good factsheet on schools in the Greater London area. Haringey SENDIASS has a list of maintained and independent special schools in North & east London.

## Autistic Youth Group

For Autistic young people in mainstream schools aged 11-16., Run by LAST . Tel 020 8489 3466. The group will be moving to Rising Green in April 2023, for more information contact: [last@haringey.gov.uk](mailto:last@haringey.gov.uk)

The LAST team also run a weekly online youth 'gaming' club that provides opportunities for Autistic youth 14-19 to meet online with some structured content that is adapted to suit their interests. This group is for 14-19 year old Autistic young people. Please email [last@haringey.gov.uk](mailto:last@haringey.gov.uk) for more information. .

## Post 16 education and employment skills



Post 16 colleges:

- **Haringey Sixth Form Centre** – This sixth form close to White Hart Lane station, has a special needs section, opened in Sept 2007. (If your child goes to this sixth form centre as opposed to a college, then the statement/EHC plan is maintained by children's services. Otherwise in other colleges such as CONEL, the college itself becomes responsible for support.
- **Ambitious College** – Pears Campus at CONEL, Head of College: Linda Looney, Address: Clyde Road, South Tottenham, London, N15 4FY. Telephone: 020 3870 8775  
Email: [admin@ambitiousaboutautism.org.uk](mailto:admin@ambitiousaboutautism.org.uk) (address to Nkiruka Egwuonwu)
- **CONEL** (College of Haringey and North East London), High Road, Tottenham, N17. (Autism provision) <https://www.conel.ac.uk>
- **Riverside** – A large special needs provision in a mainstream secondary school based at Woodside High on White Hart Lane (Wood Green end of the road) For children with autism and/or complex needs. Ages 16- 19. Contact Martin Doyle (head). Tel 020 8889 7814
- **Barnet Southgate College** (Autism provisions at Hendon and Southgate sites) Tel: 020 8266 4000 <https://www.barnetsouthgate.ac.uk/contact-us> or email: [info@barnetsouthgate.ac.uk](mailto:info@barnetsouthgate.ac.uk)
- **City and Islington College** Several sites in Islington. <https://www.candi.ac.uk> Tel: 0207 700 9200
- **Area 51 education**, Coburg Road, Wood Green, N22 (For autism, severe learning difficulties and PMLD) 020 8881 7739
- **DALO** – Daytime education service for young people with autism and learning difficulties. Collects in Haringey, based in New Southgate. 020 8368 0943
- **Harrington Scheme Cholmeley Pk**, Highgate, N6. Horticulture and life skills courses for young people and adults age 16+. 6 month or 2 year courses.
- **Ada** – Ada National College for Digital Skills, Broad Lane, London N15 4AG Tel: 0203 1050 125  
[info@ada.ac.uk](mailto:info@ada.ac.uk) or [sixthform@ada.ac.uk](mailto:sixthform@ada.ac.uk)
- **Capel Manor College** various campuses in and around London, courses from post 16 to apprenticeships. <https://www.capel.ac.uk/campuses-and-facilities/>
- **Ellingham Employment Project** Ellingham Project work to enable people with disabilities to fulfil their potential, specifically with regard to the following areas of speciality: Employment

*Programmes, transition to employment and supported internships for 16-25 year olds.*  
<https://www.ellingham.org.uk/overview>

## Employment skills

For autistic young people needing help with finding work and becoming more employable, try also

- CareTrade for apprenticeships
- My AFK (Action for Kids) for training for basic workskills and work placements
- Pathways to Employment at Tottenham Hotspur  
<https://www.tottenhamhotspur.com/the-club/foundation/community-outreach/equalities-and-inclusion/#Pathways>
- Kith and Kids ELSEP lifeskills and employment project
- Job Centres



## **Contact numbers for help with secondary age and post-16 education issues:**

- Language and Autism Support Team. Manager: Esther Joseph 020 8489 3466  
[last@haringey.gov.uk](mailto:last@haringey.gov.uk)
- Alena Lerari, Statutory Assessment Team Manager, Haringey SEN Dept, Children and Young People's Services.
- Mary Jarrett, Head of Service for Integrated Service for Children with Special Educational Needs and Disabilities [mary.jarrett@haringey.gov.uk](mailto:mary.jarrett@haringey.gov.uk)
- Educational Psychology Service. Sarah Lewis Tel: 020 8489 3004.
- Mainstream Speech and Language Therapy service tel: 0203 224 4399
- Occupational Therapy Service (OT) Te: 0203 224 4655

### Independent advice

SENDIASS (Information Advice and Support Service at Markfield) Tel: 020 8 802 2611.  
email [sendiass@markfield.org.uk](mailto:sendiass@markfield.org.uk)

For help to access services when you get stuck or need help getting through the system.

# HARINGEY HEALTH

(see also section on Diagnosis)

3

The following services are based at the Child Development Centre (CDC) as well as mainstream and special educational settings in the borough. These services may or may not be relevant to your child at some point either before or during their time in education. Further information about these services can be found on the Whittington health website. <https://www.whittington.nhs.uk/mini-apps/service/>

## **Paediatricians and Clinicians**

The paediatricians are at the CDC (Child Development Centre), Tynemouth Health Centre, N15 4RH. Tel 020 3224 4655. Diagnosis and follow up assessments.

## **Speech and language therapy**

You may receive speech and language therapy to a greater or lesser extent at school, but if you want/need more you may consider getting some private help.

Use <https://www.asltip.com/find-a-speech-therapist/>

Make sure the therapist includes autism in their list of special needs covered and is registered with The Health and Care Professions Council (HCPC) by doing a search here: <https://www.hcpc-uk.org/>

## **Palace for All (charity)**

Brickworks, 42 Crouch Hill, London N4 4BY

An Islington centre that provides very good value speech and language therapy and one to one teaching at much lower rates. Tel: 020 7561 1689 <http://palaceforall.org.uk>

## **Haringey Children's Community Occupational Therapy (OT) Service**

The Children's Community Occupational Therapy (OT) Service in Haringey provides assessment, advice and intervention for babies, children and young people with a range of difficulties or complex special needs. The team of OT's work to support children and young people develop their independence in performing activities of daily living where there is a clinical need. Referrals can be made by any health professional involved with your child or your school's Special Educational Needs Coordinator (SENCO).

Tel: 0203 224 4655.

For more information on this service visit the Haringey Children's Occupational Therapy team page on the Whittington Health website.

Where the parent/ carer feels the need to instruct an independent OT they can search for one at the <https://www.rcot.co.uk/about-occupational-therapy/find-occupational-therapist>

Ensure they are registered with The Health and Care Professions Council (HCPC) on: <https://www.hcpc-uk.org/check-the-register/>

**Caudwell Children have a wonderful autism sensory pack/equipment which you can apply for online, ask for help at the Friday Parents Group at Markfield.**

### **Parent information session – sensory differences:**



The Haringey children's Occupational Therapy team offers a free online information session) for parents and carers of children who exhibit sensory differences where they discuss with attendees' sensory differences in children, why it occurs and what can be done to help a child with sensory differences. Your child does not need a referral to our service for you to access this parent information session.

### **Specialist health visiting team**

The Specialist Health Visiting team provide a wide range of support to families of children who have a child with identified additional needs that may or may not have a diagnosis. They can help with onward referrals to relevant services that can provide support to meet a child's needs. They also provide the following:

#### **Bladder and Bowel assessment**

Many autistic children find the transition from nappies to toilet training difficult and require considerably more time than typically developing children to learn this essential skill. If your child is over the age of four years old, has an ASC diagnosis, and still needs nappies for day and/or night-times, you can request an assessment to access nappies free through your specialist health visitor, your special school nurse, health centre or GP.

You can contact the specialist health visiting team on 020 3224 4655.

### **Haringey Children's Speech and Language Therapy Service**

The Haringey Speech and Language Therapy (SLT) service provides and assessment and intervention for a wide range of children across early years, mainstream and special school settings with language and communication needs. Depending on the level of need this service provides assessment and where needed group and/ or one to one therapy.

This team runs an open referral service with an advice line where a message can be left and a SLT will then contact you.

SLT advice Line: 020 3224 4399

### **Haringey Social Communication Team**



The Haringey Social Communication Team (SCT) are made up of Paediatricians, Speech and Language Therapists (SLT) and an Occupational Therapist (OT). The SCT works very closely with the Haringey Language and Autism service and the Child and Adolescent Mental Health Service in the borough.

### **Parent seminars after autism diagnosis – for parents/carers of children aged 5 and under**

After your child receives diagnosis, parents/carers of children 5 and under are invited to attend seminars held with the Haringey Language and Autism Team and the Haringey Speech and Language Communication Team. . These seminars are held 3-4 times per year, they provide a space where parents can talk about the recent diagnosis, learn about autism and receive practical advice from parents and professionals running the seminar. For more information about when the seminars are running you can contact the Haringey Language and Autism Team - [last@haringey.gov.uk](mailto:last@haringey.gov.uk)

### **Functional skills workshops**



The Haringey SCT offers specialist workshops for parents of autistic children during term time. These are delivered over two mornings for parents of autistic children who would like to support their child in learning how to develop their self-care skills.

These workshops are designed to provide you with an opportunity to share your skills and knowledge with other parents and equally gain advice and practical tips from their experiences as well as from our team.



Your child must be known to the Haringey SCT or OT teams to access this workshop.

### **Specialist children's dentistry**

The specialist children's dental service is based at the Tynemouth Road Health Centre. This service provides dental check-ups for children with additional needs that will not comply with a traditional dentist. You can request that your child is referred to this service from your own dentist, GP or any other health care professional involved with your child.

You can contact the specialist dentist service via the Whittington Health website or telephone 020 3316 8353.

### **Dietician**

Dieticians are based at the Child Development Centre and also see children at the special schools and units and may be able to advise upon supplements and eating habits for children who restrict their diets or have faddy eating habits. You can ask any health professional working with your child to make a referral to the dietetics service if you are worried about your child's eating.

Your paediatrician or dietician may suggest softening medications such as Lactulose or medications to encourage bowel contractions such as Movicol.

### **Child and Adolescent Mental Health Service**

The Haringey Child and Adolescent Mental Health Service (CAMHS) is based at the St Ann's Hospital, Tel: 020 8702 3400.

The CAMHS LD team at St Ann's Hospital provides assessments and treatments for children and young people aged 0-17 who are experiencing serious mental health problems or marked emotional and behavioural problems which are complex and enduring and have a significant impact on the child or young person's functioning. Depending on your child's need Haringey CAMHS offer a post autism .diagnosis support service for the young person/family dependent upon their needs.

More information about the Haringey CAMHS team can be found on their [web page](#)

<https://www.haringey.gov.uk/children-and-families/local-offer/health-services/children-and-adolescent-mental-health-service-camhs>

The Tavistock Centre in North London provide a psycho-therapeutic service.  
Tavistock Centre,120 Belsize Lane, London, NW3 5BA. Tel: 020 7435 7111

The NHS CHOICES team offer support to children and young people in Haringey who are facing issues that can impact them emotionally. This may include bullying, anxiety or family problems. For the full list of conditions, the team is able to assist with see web page: <http://www.beh-mht.nhs.uk/services/choices/172> Tel: 020 8702 3405

Open Door – a local charity providing talking therapies for 12 to 25 year olds and parents of teenagers. tel: 020 8348 5947 or email [appointments@opendooronline.org](mailto:appointments@opendooronline.org) or <https://opendooronline.org>

## Free nappies

Your health visitor should be your first port of call re toilet training. However, this is no easy area for many autistic children and the NAS produce some good books and a free online factsheet filled with ideas that have worked for different families. If your child is over the age of three (this may soon change to four), has an autism diagnosis, and still needs nappies for day or night-times, (and for the majority will for some years still, at least at nights), you can get them free through your specialist health visitor. Generally, you are given nappies, but request pull-ups if your child is averse to nappies. Nappies and pull-ups become very expensive in the larger sizes, so this can be a sizeable saving. If you meet a problem getting free nappies, call **Sue Davies** or **Sarah Geismar** specialist health visitor & nurse at the CDC on **0203 224 4776**.

## Health - going private

### Private health care in haringey for special needs:

Sensory integration therapy

- Maximum Potential – 020 7486 4747 <http://www.maximumpotential.eu>

- Hopscotch childrens therapy centre 0207 486 8168.

<http://www.hopscotchtherapy.co.uk>



## Haringey Social Services/Respite Care

Haringey Social Services - Disabled Children's Team (DCT) – duty line - Tel: 020 8489 3671 or 0208 489 3672 (New cases call mornings and Wednesday pm) Email: [dctduty@haringey.gov.uk](mailto:dctduty@haringey.gov.uk)

You can self-refer to the DCT if you need help and respite, or are not coping, though most referrals come through health workers, schools, the CDC at Tynemouth Road or Early Help. The team will meet the family and child, make an assessment, discuss needs, offer advice and in some cases offer residential provision or after-school, holiday or home-based respite care.

Some children get an allocated disability social worker, but most do not. For most children, you will just ask for the duty social worker.

### **What respite can they offer?**

If your child is assessed for and then granted respite it is known as Short Breaks, For details of the eligibility criteria for a short breaks budget visit <https://www.haringey.gov.uk/children-and-families/local-offer/support/short-breaks-and-respite>

The Short Breaks can be provided in a number of ways:

#### **1. Direct Payments or Short Breaks and Respite**

Children and their families may be eligible for funded short breaks - including direct payments

You may be allocated a certain amount per week. This is then paid every 4 weeks into a bank account you set up specially for the purpose. You can then either

- Find your own playscheme and book the times you want and pay them directly, keeping all receipts.
- find and hire a support worker yourself and Direct Payments can put you in touch with someone who can do the payroll service side of things for you for a small fee.
- Book a support worker via an independent agency and pay the agency directly, keeping all receipts.

## 2. After school, holiday or weekend/overnight respite

You may find it easier to have respite in the form of a regular after school or holiday playscheme with transport provided. The Disabled Children's Team uses after school provision with the Brook, Team Spirit at Riverside, and the Markfield Project.

### Other carers/respice possibilities:-



**FREE** Voluntary befriending help with your child at home – a couple of hours a week support from volunteer befriending teams at:

- Markfield. 0203 667 5233
- Resources for Autism Tel 020 8458 3259
- Kith and Kids. Tel 020 8801 7432.

There is a waiting list for all of these. It is worth signing up though as your name will come to the top of the lists eventually!

And also free for Under 5s – Homestart volunteers. A volunteer to help with your child for a few hours a week for 6 months or more. You could self refer or ask a professional who knows your child to refer you to this service. Tel 020 8352 4151. [www.home-start-haringey.org](http://www.home-start-haringey.org). Based at 100 Tower Gardens Road, N17 7QA

**For a Fee:** Some special needs care agencies provide trained support workers for a few hours per week (usually between 3 and 15 hours per week) on a regular basis. We can't recommend any at present, but know of Dimensions, Resources for Autism, Rocksolid247 and Special People.

## Financial Help

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On top of any normal welfare benefits, you may be eligible for Disability Living Allowance (DLA) for under 16s (which is paid for the child), and is divided into Care components and Mobility components (if your child receives the Higher Rate Mobility award, you can use this to obtain a motor vehicle instead of receiving the money). DLA is non means tested and does not count towards your taxable income.

<https://www.gov.uk/disability-living-allowance-children>

You can also apply for Carers Allowance <https://www.gov.uk/carers-allowance> (which is around £76.75/wk and is paid to any carer who looks after a child more than 35 hours a week and earns less than approximately £132 a week through other taxable payments. Carers Allowance does count towards your income and so if you receive this, you will receive less Universal Credit if you are claiming UC).

Call 0800 121 4600 and ask for both forms if required. They will come quickly in the post. You have six weeks to fill in the DLA form from the day you order one.

Help to fill in application forms

The Carers Allowance form is fairly simple to fill in. However The DLA forms are long and seem designed to put you off completing them, so do not underestimate the benefit of getting free professional help to complete your form. You do not have to pay anyone to help you fill in a DLA form – as there are a number of organisations in Haringey where you can get free help:

- Markfield: call 020 3 667 5233 or 020 8800 4134 , or email [familyadmin@markfield.org.uk](mailto:familyadmin@markfield.org.uk) and ask for a DLA appointment. There can be several weeks wait for a DLA appointment at Markfield, so ask for one as soon as you can

Other options for free help to complete your DLA form:

- Haringey Connected Communities service 020 8489 4431  
<https://www.haringey.gov.uk/community/financial-support-team>
- Haringey Citizens Advice (CAB). <http://www.haringeycabx.org.uk/> or email: [admin@haringeycabx.org.uk](mailto:admin@haringeycabx.org.uk)  
Adviceline: 0300 330 1187 (Weekdays 10am-1pm & 2pm-4pm)  
Office: 020 3872 5840 (General enquiries only. No advice given on this number)
- Disability Action Haringey - a Deaf and Disabled peoples' organisation which offers help with benefit applications Tel: 0203 555 0071 email: [info@d-a-h.org](mailto:info@d-a-h.org)

### More about Disability Living Allowance (DLA)

For under 5s, you may need to fill the DLA in each year. You can apply for the care component from birth. From age 3, you can apply for the higher rate of mobility though it is extremely difficult to get for autistic children as it relies upon claiming 'severe mental impairment' and the necessary amounts of paperwork are not often available until the child is some years older.

When the child approaches 5, you have to re-fill in your Disability Living Allowance form and you can then apply for the lower rate of mobility if you were not awarded the higher rate of mobility. But once they grant you an allowance you agree with, this should then remain unchanged for the next 5 or 6 years.

Essentially both Disability Living Allowance and Mobility Allowance are paid at different rates depending upon the severity of the child's needs. Documenting (in detail) your child's every daytime and night-time problem, and every issue you face getting your child about outside the home is a fairly depressing task. Do NOT understate the problems your child is faced with and you endure, be particularly very clear about night-time problems - incontinence, difficulty going to sleep, many awakenings, tantrums, fits, lack of sleep (needed by child) etc. etc. Higher benefit rates for Disability Living Allowance is normally only paid for those with night-time problems, so if your nights are disturbed regularly, spell it out very clearly. The NAS and Contact a Family have extensive factsheets on their websites suggesting how to fill in these forms - [www.autism.org.uk](http://www.autism.org.uk) and [www.contact.org.uk](http://www.contact.org.uk). If your child has sleep issues, try to get professionals to write this in their reports as this helps with the DLA enormously.

We strongly suggest you read through these factsheets before attempting to fill in the forms if you are determined to tackle them yourself (but please don't!!!).

Most autistic children will qualify for low rate mobility DLA, but you can apply under the 'severe mental impairment' criteria for higher rate mobility if you qualify for high rate care and can prove severe learning difficulties, and severe behavioural problems requiring frequent physical restraint.

Make sure you photocopy the forms before sending them off, so that you are clear about what you wrote. If they do not award you the level you expect, you can then appeal, and also it will help you fill the forms in the following year - much of it will be the same. Do not be afraid to challenge them via a mandatory reconsideration then a

tribunal hearing – they will warn you that you may be offered less if you challenge to put you off – this is extremely unlikely (and in our experience) many if not most challenges, backed up by a letter from a GP or a professional who knows your child are successful.

(Note – we are finding that generally most families with a child with autism who has night-time sleep problems are getting high rate care and low rate mobility DLA awards. If (as your child gets older) you have huge difficulties getting about with them, don't be scared to go back and contest the mobility part – you may want to get professionals to back you up in writing a report to describe your child's difficulties).

### **Benefits helplines**

Benefits Advice Line – 0800 882200

Contact-a-Family and Citizens Advice Bureau specialist money advice project – face to face or in the home for families with disabled children – 0808 808 3555

Citizens Advice (CAB) Benefits Advice Line 0300 330 1187

### **Getting about by taxi**

If you have a disabled child whose disability or challenging behaviour makes taking public transport difficult, you can apply for a Taxicard [www.taxicard.org.uk](http://www.taxicard.org.uk) to allow you to take taxis at greatly reduced rates. Tel 0207 934 9791. (note – not sure at time of writing how the recent cuts will affect this service) See the Haringey website [www.haringey.gov.uk](http://www.haringey.gov.uk) and search Taxicard for latest info. Many families now find Uber cheaper and easier to use.

### **Suggestions for additional sources of financial help**



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#### **The Family Fund**

Financed by government and administered by the Rowntree Memorial Trust for children with a severe handicap (and they include autism in this category). Grants are for families receiving benefits or on a low income. You can apply once a year every year. Things you might apply for could include:

- *A holiday*
- *Clothing and bedding*
- *Fridges/freezers/ washing machines etc*
- *Beds*
- *Computers, laptops, ipads*
- *Specialist play and leisure equipment*

Contact them for a form, or ask Markfield for one (at the Friday morning parent drop-in) - they will require your name and address and the child's GP. Someone from the Fund will visit to follow their guidelines. From application for funding to a decision is now around 3 – 4 months.

### **The Family Fund**

**PO Box 50**

**York**

**YO1 1UY**

**Tel: 0845 130 4542**



**Cerebra** – [www.cerebra.org.uk](http://www.cerebra.org.uk). Tel 01267 244216. This is a small grant scheme offering practical assistance to improve the quality of life of children and young people to age 16 affected by neurological conditions. Examples of grants made are: touch screen computers/holidays (up to £500)/specialist car seats/approved therapies/trampoline/sensory toys/specialist cycles.

**CARIS Haringey**, Helps with Clothing, food parcels, play schemes, housing crisis (ie temp accommodation) St Philip's Church, Philip Lane, N15 4HJ  
Tel: +44 020 8801 3004 Email: [info@carisharingey.org.uk](mailto:info@carisharingey.org.uk)

**Frank Buttle** <https://www.buttleuk.org>

**Turn2us** is online grant search, you can apply through the website.

The website can also help with what benefits you are entitled to.

<https://www.turn2us.org.uk>

### **Tottenham Grammar School Foundation**

A local fund which can help with anything educational provided the school/group or individual lives in the Haringey area. Things you might apply for could be:-

A computer , Play equipment, Toys, a laptop, classes, (or even maybe an Ipad with special software such as Proloquo2go or TapSpeak.)

You can download a Special Somerset Award form from the Tottenham Grammar School Foundation website or get a form from Markfield – you will need to get your school to sign it and a health professional to agree in writing that your child would benefit from the equipment. You will also need someone at the school to fill in other form showing that the child has used and is seen to benefit from the equipment and



software. This is a new part of the form and a tricky one as schools often do not have the time to do this, or are mystified as to what is needed, check with your school SENCO or Speech and language therapist first? After signing the for, the school will need to send it directly to: Mr G Chappell, Tottenham Grammar School Foundation, P O Box 30498, London N13 5XU. Tel: 020 8 882 2999.

### **Disabled Parking – Blue Badges**

To apply for a Blue Badge visit the Haringey Council website, go to [www.Haringey.gov.uk/blue-badge-sms](http://www.Haringey.gov.uk/blue-badge-sms)

These are a godsend to many parents of autistic children with severe behavioural problems, allowing them to park closer to shopping, schools, doctors, etc.

You will need to fill in a Blue Badge application form. For children above 5, you automatically qualify if you receive Disability Living Allowance Mobility Allowance at the highest level. For those at lower levels of Mobility Allowance, you will need a letter of support from a professional (Haringey website says they wont accept a letter from GP) Within Haringey, you need to apply to the Disabled Parking/Blue Badge dept and send off your documents. They will then send a letter of approval for the badge which you have to take to a Customer Service centre such as the one in Wood Green library.

The NAS provide a detailed factsheet on 'Blue Badges' telling you how to apply for one which is available on their website [www.autism.org.uk](http://www.autism.org.uk) ([I could not find this](#))

You can also apply for a resident Blue Badge holder permit, introduced to stop the theft of Blue Badges from vehicles. The permit is issued online and you don't need to display anything in your vehicle. Go to the Haringey website and search 'Resident Blue Badge Holder.'

If you have a Blue Badge you are exempt from the congestion charge! You need to register though and there is a one off £10 charge for this. For more information call 0343 222 222

Also, there is no road tax if you get the higher rate DLA or enhanced rate PIP mobility component (you can get the form at the post office) if you have a Blue Badge – check online!

Drop into Markfield Parents Group on Friday mornings , 10am – 12, in school termtimes, if you need further information or help applying for Family Fund grants or a Blue Badge.

## Play and leisure activities

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### Leisure provision for autistic children in and around Haringey.

**Bridge Renewal Trust** - The Community Hut offers a wide range of activities from group gardening sessions, healthy cooking and eating, Saturday cafe, social events, language classes and a wide range of other activities. Laurels Healthy Living Centre, 256 St Ann's Road, London N15 5AZ. Telephone: 020 8442 7640

**The Challenge Group** – under 5s special needs drop in play in termtimes on Friday mornings at St James church, Muswell Hill. [www.wave-for-change.org.uk](http://www.wave-for-change.org.uk)

The Challenge group is a Christian organisation that welcomes those of all faiths and none.

WAVE CHURCH - 2nd Sunday of the month at The Methodist Church, North Bank, Pages Lane

THE WAVE CAFE - a pop up cafe currently running art workshops 7:30pm on Thursdays at The Birchwood Centre, N10 3BG.

**Markfield Project** – all ages, a big building in the middle of Markfield park, adventure play, soft play and a great play space, meeting rooms for parents and a family support team. A welcoming centre for families with autism.

– Holiday and after school playschemes for disabled children and siblings for which there is a fee and places must be booked in advance. They are usually funded through Short Breaks Personal Budgets from the Disabled Children's Team

– Family Club - Termtimes second Saturday of the month adventure playground 11.30am to 2.30pm. Voluntary donation £3 per family

– Open Access to adventure playground on most Saturdays, 11am to 3pm. Voluntary donation £3 per family

– Under 5s – stay and play - Thursdays 12 to 2.30pm. Voluntary donation £3 per family

– Free - Friday Parent support group, in school termtimes 10am to 12,

Free Individual advice sessions for parents. Book these in advance

Free training courses for parents. Tel: 020 8800 4134 or 0203 667 5233

**Resources for Autism** autism specific holiday playschemes and after school clubs.

Ages 8 – 19. (in Temple Fortune.), There is a charge and yes, you guessed it, a waiting list.

Tel 020 8458 3259

**Keen London** – All their sessions are free of charge. They take place during term-time on Saturdays in Dalston, East London and Vauxhall, South London, and on Sundays in Finsbury Park, North London. They also run residential trips. Get on their waiting list – well worth it!

Tel: 020 7686 3172 [www.keenlondon.org](http://www.keenlondon.org)

**Team Spirit** – at Riverside School. Ages 11 – 16 approx. After school and holiday club. Natalie Stoakley 07950 930708

**Palace for All**, Drop in days in holidays and half terms, term time youth club and activities and therapies for young children with disabilities. Tel: 020 7561 1689. Brickworks, 42 Crouch Hill, Finsbury Park, London N4 4BY.

**Enfield NAS** Run SEN trampoline sessions every Sunday 9am-10am at Jump In, Enfield. They also run adult social group. Natasha Rajamahendra, Co-Branch Officer. 07757 120777 email: [branchofficer@enfieldnas.org.uk](mailto:branchofficer@enfieldnas.org.uk)

**Autistic Youth Club 11-16 year olds**

**Autistic online gaming club 14-19 year olds.**

Run by Haringey LAST team (see page 12) For information on either of these youth clubs contact: [last@haringey.gov.uk](mailto:last@haringey.gov.uk)

**AFK (formally Action for Kids)** – a centre close to Hornsey overground station providing short breaks, holiday programmes and more for children with physical disabilities, learning difficulties and autism ages 14 – 25. Cost around £96 per day including transport. My AFK also run independent living skills and employability skills courses. Tel: 020 8347 8111.

**Kith and Kids** – Kith & Kids supports families who have a son or daughter with autism or a learning disability (many also have a physical or sensory disability) to overcome their social isolation. Tel: 0208 801 7432. Email: [projects@kithandkids.org.uk](mailto:projects@kithandkids.org.uk)

## **Autism friendly sports and activities**



### **Football**

Special needs football group run with the Tottenham Hotspur inclusion team. Venues and times vary.

## **Swimming**

Archway Pool, Macdonald Road, London N19. Special needs session Thursday, 5-6pm and Saturdays 4.30 - 6pm, fun pool with waves, flume, etc. Loads of children with autism having a lot of fun. Carer free, children £1.50 each, or get an lzz card at reception and then get in for £1.

Gateway seekers swimming club – a fun session for children with special needs and their parents/carers – every other Sunday at Albany Pool, Hertford Road in Enfield.

Halliwick Penguins – Swimming club for people with disabilities with volunteer helpers. Good at helping children learn to swim in an informal way. Southgate Leisure Centre. Saturdays. Website for more info: <http://www.halliwickpenguins.org/contact-us/4570332192>

Tottenham Green Leisure Centre Pool – sometimes have special needs swim, and special needs swimming lessons. At present, their disabled swim appears to be on Sundays 12 to 1. Call 020 8885 7300. for details.

Park Road Pools and Fitness Park Road Leisure Centre, Park Road, N8  
9am to 10am - £2.40 per child Email: [haringey-scd@fusion-lifestyle.com](mailto:haringey-scd@fusion-lifestyle.com) - Tel: 020 8341 3567

Kentish Town's pool also runs special needs swims with lessons. Sorry – no details.

Enfield Academy of Swimming – holiday swimming courses suitable for children with autism

## **Adventure Playgrounds**

Several playgrounds have sessions for children with autism – best way to find out when these are on is to make sure you are getting the Haringey Autism newsletter which always lists the dates.

Markfield has an adventure playground often with open access on Saturdays, and with a family club for disabled children and their families on the second Saturday of the month term times. Markfield, Markfield Park, reached via Markfield Road or Crowland Road, N15 4RB. Tel: 020 8800 4134

Somerford Grove Adventure Playground is tucked behind the Spurs football ground and reached via Park Lane Close, off Park Lane, N17. Enfield NAS sometimes have sessions here.

### **Drama**

Haringey Shed – the local branch of the Chicken Shed theatre. Very successful and Inclusive drama groups for primary and secondary children age 7 – 16. run at Haringey Sixth Form College. Haringey Shed are based at the Haringey Irish Centre, Pretoria Road, N17. email [info@haringeyshed.org](mailto:info@haringeyshed.org) Call 020 8801 7209/0208 243 8743/07850 617 169

Turtle Key Arts – run Turtle Key Opera, Key Club and Musical portraits courses held at the Royal Opera House children and adults age 10 to 30 with Autism. tel 020 8964 5060. <https://www.turtlekeyarts.org.uk/projects>

Little Angel Theatre run Spectrum Youth Theatre for 11 to 18 year olds see website: <https://littleangeltheatre.com> and search "Spectrum Youth Theatre."

### **Art:**

ActionSpace run Art Award through their Young Peoples Programme <https://actionspace.org>

Turtle Key Arts run art course aimed at 16 + <https://www.turtlekeyarts.org.uk/projects>

Artbox in Islington. For young adults. Visit [www.artboxlondon.org](http://www.artboxlondon.org)

Art classes and art therapy at Resources for Autism.

### **Music Therapy**

Nordoff Robbins Music Therapy Centre, 2 Lissenden Gardens, NW5. Tel: 7267 4496

Music therapy one to one at Resources for Autism. Tel: 020 8458 3259

### **Dance for children with autism**

I Can Dance – Dance for Special Needs ages 3 plus. Recommended by lots of parents! Call Juliet: 020 8444 1707 [www.icandance.org.uk](http://www.icandance.org.uk)

### **Cycling**

Pedal Power - Cycling for adults and teenagers with learning disabilities, Finsbury Park, N4 (by the basketball courts) Emirates Stadium, Hornsey Road, N7 7AJ

Every two weeks on Saturdays from 10am to 4pm

Contact: Jo Roach - Email: [info@pedalpowercc.org](mailto:info@pedalpowercc.org) | Tel: 020 8809 7718

### **Special Needs Trampolining**

Enfield NAS Branch run every Sunday morning 9 – 10 am Venue: Jump In, 22, Lumina Park, Lumina Way, Enfield, EN1 1FS

Cost £9.95 per child (siblings welcome at same price) plus £1 Transaction fee. Carers go free.

You must pre-book your place. Book at [www.gojumpin.com](http://www.gojumpin.com) – go to 'Book Now' and select 'Enfield' and 'Relaxed SEN session'

### **Soft play**

Kidz Adventure Zone Unit C, 2 Coburg Road, Wood Green, 0208 8819737

Clowntown - Behind Tesco on Colney Hatch Lane, N10

Markfield – at under 5s stay and play on Thursdays 12 – 2.30, or at the Family Club, second Saturday of the month, 11.30 – 2.30. Markfield Park, N15 4RB. 020 8800 4134

Park Road Leisure centre – for 0 – 6 years Mon to Fri 9 – 11am, 11.30 – to 1.30pm, 2-4pm, and 4.30 – 6.30pm, Sat and sun 9 – 11am, 11.30 – 1.30pm and 2 – 4pm. Contact to book at busy times and check a private party hasn't booked the space Tel: 020 8341 3567

Tottenham Green leisure centre – Multi storey soft play. 0 – 4years in baby and toddler area, and 4 – 12 years in junior area. Call to check the soft play is not booked first by a private party.

Tel: 020 8885 7300

### **Youth clubs**

Markfield Project- a variety of clubs and activities for all ages. Places are funded through Short Breaks Personal Budgets (see page 43). 020 8800 4134.

Team Spirit. After school activities for children at Riverside School.

### **Autistic Youth Club 11-16 year olds**

### **Autistic online gaming club 14-19 year olds.**

For information on either of these youth clubs contact: [last@haringey.gov.uk](mailto:last@haringey.gov.uk)

Resources for Autism. 858 Finchley Rd, NW11. Sat am and pm. 8 - 12 year olds. Wednesday eve - 13 plus. For details, tel: 020 8458 3259.

Turtle Key Arts also run The Key Club, held on Saturday mornings monthly 10 to 1, from September to June, for anyone over 16 with autism. The club holds workshops and discussions based on performance and visual arts and other creative disciplines. Contact 020 8964 5060.

Actually Haringey – An autism specific hub offering a range of activities and support for autistic people aged 16 and over

Email: [autismhub@haringey.gov.uk](mailto:autismhub@haringey.gov.uk). Or call/text: Cyril – 07773628429/ Alex 07964973255/ Jason 07980 316571

Cool Cats Club, for 18+ with learning difficulties – run 5 times a year at St Joseph's Pastoral centre, St Josephs Grove, The burroughs, hendon NW4 4TY. Call 07843253599 email [thecoolcatsclub@live.co.uk](mailto:thecoolcatsclub@live.co.uk)

### **Martial arts – Sanjuro**

At Bruce Grove Community Centre. Alan 07870 157613 or Glenn Delikan Sanjuro's Chief Instructor m. 07779 249 469 e. [glenn@sanjuromartialarts.com](mailto:glenn@sanjuromartialarts.com)  
[www.sanjuromartialarts.com](http://www.sanjuromartialarts.com)

### **Skiing & Snowboarding**

**Snowability** – Snowbility is the brainchild of Ski Development Coach, Richard Fetherston, who discovered the incredible benefits that could be achieved for people with additional needs and mental health challenges through ski and snowboard coaching. Snowbility, The Snow Centre, St Albans Hill, Hemel Hempstead, Hertfordshire, HP3 9NH Tel: 01442 773 007 or Email: [kathy@snowbility.co.uk](mailto:kathy@snowbility.co.uk)

You can get funding to pay for lessons from the Snow Sports Foundation  
<https://www.snowsportsfoundation.org.uk> Tel: 07980 014 134

### **Sailing/Canoeing**

**Sailability** <https://www.sailability.org/?p=19>

Saturdays Canoeing at West Reservoir at the Castle Climbing centre at Manor House. Amazing place which may suit some children.

For over 18s, try the Castle canoeing club on Sundays 10 – 1. Amazing bargain!

### **Riding**

- The Stables Horse Activity Centre, Barnet Lane, Totteridge. 07958 919437  
email: [info@thestableshorseactivitycentre.org.uk](mailto:info@thestableshorseactivitycentre.org.uk)
- Penniwells RDA Centre, Edgwarebury Lane, Elstree, Herts. WD6 3RG Tel: 020 8207 4525
- Chigwell Riding Trust Group Tel: 020 8500 6051
- Kentish Town City Farm Tel: 020 7916 5421

### **Cinema**

Lots of cinemas hold Saturday or Sunday morning showings of non-current films for around £1 to £2, often called Movies for Juniors. Get to see old favourites again and not have lost lots of money if it didn't work out!

Also, lots of cinemas have monthly autism friendly screenings, usually without adverts and trailers, with lights still on and less sound, and you can bring your own food and drinks in – all helpful for children with autism who can find cinemas an overwhelming experience at first. Both Wood Green cinemas, and the Phoenix in East Finchley have autism screenings.

East Finchley – Phoenix cinema - Kids Club – 10am, starts with an Activity Workshop on a first come first served basis for a maximum of 30 children aged 5 – 8 and must be pre-booked, followed by the film at 11am which is also open to older children. Ticket £3 each. Tel 020 8444 6789 for further information.

Get a **CEA card**. A nationally accepted cinema card that gives free entry to the carer. £6, lasts 1 year. tel 0845 1231295 or [www.ceacard.co.uk](http://www.ceacard.co.uk) to download an application form.

### **Religious groups**

Jewish Autism Trust – is a Jewish group for families who have a member with autism or Aspergers. For more information email [info@jewishautism.org](mailto:info@jewishautism.org) Tel: 0845 385 0300

Norwood – jewish run charity for lots of provision including under 5s special needs drop ins. <https://www.norwood.org.uk> Tel: 020 8809 8809

Catholic pastoral care for children with Special Needs who find it difficult to attend church – A range of pastoral services for people with all forms of SEN and their families available at St Joseph's Pastoral Centre in Hendon, north London. 020 8202 3999.



C of E – try St James Church in Muswell Hill who at time of writing are offering help for children with special needs to be able to attend Sunday school.

Contact Celia at Wave, [info@wave-for-change.org.uk](mailto:info@wave-for-change.org.uk)

Wave run Wave Church, The Challenge Group and Wave Café see website: <https://www.wave-for-change.org.uk>

SEEDs at St. Peter-in-Chains Parish 12 Womersley Road, London, N8 9AE  
(next door to the church) tel: 020 8340 3394

**Cubs and Scouts** – Special Needs cubs/scout group meets on Tuesday evenings at the Scout Park in Gordon Road, Bounds Green, N11(amazing venue of 11 acres of green space with lakes, climbing wall, archery, greenhouses, etc). Contact via website: <https://www.scouts.org.uk/groups/>

### **Drumming art and performance group**

Bright star, Saturdays 11 – 1. Middle lane Methodist church N8. For young people and adults with autism and learning disabilities ages 11 – 50. Carer stays. Contact Vida Black 07999 592 580.

## **Parent Support Organisations**

4

### **Markfield Project**

Friday parents drop in group 10 – 12 in termtimes, plus booked individual advice sessions to help parents with navigating services, education and parenting advice. Call 0203 667 5233 Or email [familyadmin@markfield.org.uk](mailto:familyadmin@markfield.org.uk)

**SENDIASS helpline:** 0208802 2611 – Free help to navigate the education, health and care services

### **Haringey SEND Parent Carer Forum: SEND Power**

The SEND Parent Carer Forum is free to join for any parent who lives or receives services in Haringey. They have regular meetings and events, and work to improve services in the borough for children with SEND. in Haringey.

Email: [sendpcf@bridgerenewaltrust.org.uk](mailto:sendpcf@bridgerenewaltrust.org.uk) or [hello@sendpowerinharingey.org](mailto:hello@sendpowerinharingey.org)

### **Autism BAME Community**

Stella Sutherland 07534 723969. Email [abamecproject@gmail.com](mailto:abamecproject@gmail.com)

### **Ambitious About Autism**

The charity Ambitious about Autism have developed a parent toolkit called 'Right from the start'. This practical toolkit contains a wealth of straightforward information in one place to guide parents and carers through their child's journey in the early years.

From the autism assessment process to the first day of school, this toolkit is packed with practical tips and checklists to support parents during the earliest years of their child's life. It also provides signposts to sources of support or additional information. If you have a pre-school child, you can download the free toolkit by visiting the 'Ambitious about autism' website - <https://www.ambitiousaboutautism.org.uk/information-about-autism/early-years/parent-toolkit>

### **Kith and Kids**

For families with a member with a physical or learning disability. Family support, information on educational, medical and social issues, weekend and evening activities and holiday projects for members, development of 'friendship' schemes, supporting of members' social integration. (presently Kith and Kids autistic members are aged 8 - 35 years). There is a waiting list to join. Tel: 020 8801 7432.

### **Resources for Autism**

Based in Finchley running frequent training courses for parents of children with autism, with advice on education and EHCPlans etc. They have extensive library of books about autism. They have behavioural advice and support in the home. Plus 3 adult evening groups. (For the children there are art and music therapy classes, summer play schemes, a Saturday club for children aged 8 - 11, and a Wednesday youth club for teenagers on the spectrum). They also run holiday playschemes. Tel: 020 8458 3259.

### **CARIS**

Fantastic advice team based behind St Philips Church near St Ann's Road.N15. Housing advice and help for families who are in temporary accommodation. They also run summer play schemes for children and their parents, special needs children welcome. Food bank and free clothing also. Gloria Saffey on Tel 020 8800 5300

**Contact-a-Family.** 0808 808 3555. General special needs legal and education advice.

**IPSEA** – (education advice) – 0800 018 4016

**ACE** – (Advisory Centre for Education) – 0808 800 5793

And last but not least.....

**National Autistic Society** Huge and very good website. [www.autism.org.uk](http://www.autism.org.uk)

## How you can help your child at home

4

This most important of all sections covers: Behaviour, Sensory Difficulties and Communication, and Everyday problems.

A whole book could be written on each of them, and as you will find out if you haven't already, whole books already have! You could fill libraries with books on autism and communication and there are literally hundreds of books on behaviour by both professionals and parents. In this chapter are some starting ideas that we feel can help with some of the the issues that we hear again and again from parents that concern them at home.

### Behaviour, Sensory Difficulties and Communication

#### Firstly 'behaviour'

By this we mean behaviour by the autistic child that is angry, upset, aggressive or 'challenging' to others in some way. This can include meltdowns, shouting, crying, cursing, hitting, pushing, biting, throwing objects, deliberately breaking things, running away, refusing to walk, lying down in the middle of shops and UTTERLY refusing to move on, insisting on watching the same film endlessly, loathing having to play with other children except close family members...any of this sound familiar?

*Note: when talking about a child in this section we will refer to 'he' for simplicity rather than he/she. Apologies if you have a girl!*

#### What can you do?

Inevitably this is much too simple, but try to work out:

##### **1) Has the child learned that the behaviour will achieve something for him?**

That is, does he either **get to avoid something** he does not like eg. noise/smell/crowd/touch/ demands to do something he fears, as he knows from experience he will be removed from the situation, or does he know he will get something he wants eg a drink or sweet, a hug, extra attention. Either outcome could cause more of that particular behaviour and you may want to change your own response to his behaviour to see if it lessens the tantrums. For a few weeks, try to be absolutely consistent and not rewarding the tantrum with hugs or sweets or foods, or not allowing the tantrum to result in the removal from a situation to see if the child then finds a better way to cope.

## 2) Did something cause the behaviour?

Is this an inevitable overload from too much sensory or information overload? Is he too stressed by too many demands and too much language that he does not understand? Is he in pain? Could he be constipated? Or is he so hyperactive and short of sleep and overloaded that he is completely worn out?

**a. Educate yourself about common sensory problems** for children with autism. If you start to understand how they are experiencing the world, often experiencing everyday sounds, even light touch or a kiss, flickering light, the feel of clothes and especially socks and seams and labels as sheer pain, then you may feel less exasperated at their fearful reaction to some of these things. If you knew how distressing a drop of water on their clothes feels, you would be less surprised that they may try to remove them several times a day... If you knew how unbalanced their world felt and how spinning and rocking and jumping made it feel less so, you might invest in a mini-trampoline rather than getting furious that they keep breaking the sofa and the beds... Make their lives easier – soft clothes, easy to remove, if you find something they like to wear - buy a whole load in one go! Invest in a good set of headphone or ear defenders if they often put their hands over their ears – it may make going outside much more bearable for them, do you have fluorescent lighting that flickers and affects him? Recognise that heavy pressure, big slow hugs, rolling up tightly in a duvet, etc may be hugely relaxing for your child. Weighted blankets can calm hyperactive systems and induce better sleep.

You can visit the website [www.sensory-processing-difficulty.com](http://www.sensory-processing-difficulty.com) and start with their checklist. You will probably immediately recognise many sensory difficulties you had no idea that your child suffered from.

Sometimes you can distract them slightly from their discomfort with food, music or a game on your mobile phone for example on a noisy bus, but very often knowing what to avoid is just as important.

Investigate the amazing autism sensory pack which you apply for online from Caudwell children.

**b. Understand that anxiety is a huge factor** for our children and not knowing what is going to happen is the worst thing for most, but not all, of our children (perversely a few get more anxious if they know what is going to happen).

Make life predictable and easier to understand with the use of visual supports. You can find examples of visual symbols on websites about PECS. You can use a digital camera and print off real pictures of his school, pool, playground, home etc. Google Image is a great source of symbols nowadays. If you want flexible systems, then a strip of Velcro

on the fridge and laminated and velcro'd symbols that you can put up in various orders are very helpful.

If you have a visual schedule on your wall or fridge that shows what will happen that day in a row of easy to understand pictures or signs, he will feel much better.

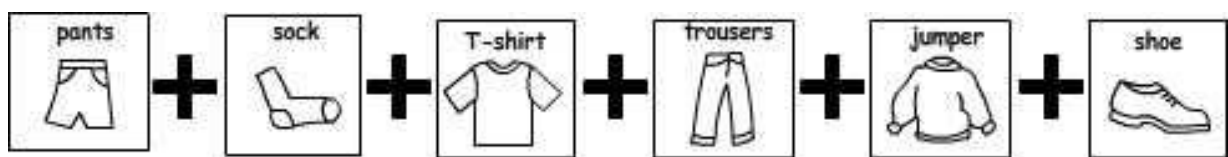
For example, your signs might read from left to right:

Clothes on, Breakfast, Bus stop, School, Swimming, Home.

In the bedroom, you could have a row of signs that show how to get dressed:

Old clothes off

Then pants – socks – T-shirt – trousers – jumper – shoes



You could lay the clothes out in this same order, left to right, on the bed so that he knows what is happening, and can eventually get the hang of it himself.

In the bathroom, you could have a set of visual signs that show for example:

Seat up, trousers and pants down, pee in toilet, pants and trousers up, flush toilet, wash hands. (you may then need a set of signs to show how to wash hands above the basin)

You can use visual symbols to explain situations where he is going to have to wait a bit.

For example

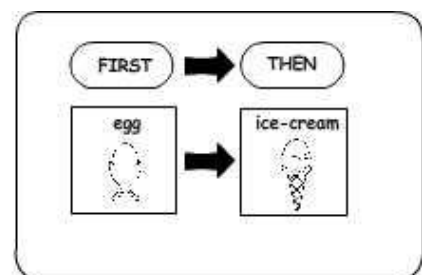
First Egg Then Ice cream

Or

First Bath Then Storytime

Or

First Shopping Then Playground slide



**If you have a smart phone or an ipad, these are great devices for having stored pictures or symbols that you can use either to show your child what you are planning, or for child to indicate to you if he is non-verbal, what he has in mind! There are lots of apps available for this.**

## Sensory overload and the final straw

We've talked already about sensory overload so you will understand this one by now. But remember a child might be able to tolerate a few minutes of a noise they detest but not half an hour. They may be able to stand water one day but not the next. Coping with having to touch something sticky might be just tolerable when calm but utterly impossible after being in a room with a flickering light for 20 minutes. Standing in a bus queue with other people bumping into him may be an overload of unthinkable levels.

The other massive overload – and this is the big one – is language and communication.

Our children find it extremely hard to decipher language. When they are stressed, they find even the simplest language hard to follow, **so make your language SIMPLE!**

Use one step sentences.

Don't say: *'Come on hurry up we're going to be late you need to put you coat on right now or we'll miss that bus won't we, and you don't want that do you?'*

Just say *'Jack, coat on.'*

When he's got that part, *'Coat on, then bus'* might be acceptable for a child that can cope with a two-part instruction. But keep it simple - it makes an amazing difference.

Keep your tone of voice light, encouraging and never blaming or exasperated (well, not never, you're not a saint, but as little as you can, it makes life so much worse for your child). Try to remove all sentences that start with 'Why do you.....?' It's not helpful, he has no way of knowing or explaining just will feel vastly discouraged and upset by your disapproval. Remember - You are the calm sea that makes your child's life safe and tolerable – if your anxiety levels are out of control, he will not be able to progress. Someone has to appear to be completely calm and unfazed by what is happening and giving off the air of being able to cheerfully make it all fine again. Find a mantra that works for you 'I am the calm sea'... or counting calmly in your head (not aloud!) up to five, rather than snapping out some irritated comment at a bad moment. Make sure you as the parent are the parent who de-escalates situations, not the one who escalates them out of your own frustration. You only get to pay the price later and you're not the only one.

Do not punish your child by smacking, shouting or violence. It does not work well with any child but especially not with children with autism and is incredibly unfair on a child who is generally behaving in a certain way because they do not understand, or because they have through no fault of their own, been overloaded.

Don't meet your autistic child from his stressful day at school or nursery with a long list of questions 'How was your day?' 'What did you do today?' 'Who did you play with?' 'Was it fun?' These are baffling and stressful questions for a child with autism, even the very most able ones detest this sort of questioning. You are unlikely to get a satisfactory or honest reply to this sort of question. Most will ignore you, get very angry or learn to grunt OK to get you to back off. Instead, just meet them calmly, with very little but reassuring language, just for example *'Hi there. Let's go home now'*

School is hugely stressful for many autistic children and they generally need downtime afterwards – time alone with a computer or a favourite pet for example. They do not need playdates that they have not asked for or having to play with siblings forced upon them immediately after school. **Make sure they have time to calm down at intervals in the day so they can try to manage their stress loads.**

**Keep the environment quiet and orderly.** Do not tolerate your other children teasing and provoking your autistic child at home. They need a room or a space where they can get away completely (if possible) when they need quiet and no people.

**Keep your rules and daily habits simple and consistent.** Many tantrums are because something that was allowed one day by one person is now apparently not OK on another day with a different person. Autistic children put huge importance upon tiny details and changes in small things are vastly upsetting to them. If relatives undermine you all the time and constantly upset your child, or try to change your rules, try to explain his disability to them and why he needs certain things in a certain way. If they cannot respect this, you may have to consider how much they are needed in your life at this point, or how often they can be around. A supportive extended family is the best thing you and your child can have, but one that makes progress impossible can be unbearable and this is a decision we see families having to make all the time.

**Help your child with their language development.** They are not interacting with other children much of the time – they are often actively avoiding being around any language. If they do not speak, people often do not speak to them much and then the language they could be understanding falls further and further behind. So even if they do not speak, make sure you are spending lots of time with them looking at picture books, saying the names of things out loud, making sure they know the names too 'Touch the book' allows them to show you that they know the word even if they cannot

say it. Books are expensive – get them from the library if your child is not going to rip them to bits.

LetMeTalk is a very useful free app you can download onto your android phones, ipads and iphone which has over 9000 images which you or the child can line up into short sentences.

*I want a juice/ I don't like ham* etc. the phone can then speak out the sentence.

Try watching BBC TV and website 'Something Special' which is fun and also teaches basic Makaton signs. You and your child, if nonverbal, could learn simple Makaton signs such as home, pee, drink, eat, sleep, more, etc.

Another excellent but much more expensive piece of speech and language therapy software is a programme called 'Lexion' which you could use for years at home to really develop language and listening skills. Buy online.

Singing and music are great ways to develop language too.

If your child is at a very early stage of learning and you cannot get his attention at all for learning, try a very simple technique. Teach the words 'Do this!' Get someone to sit or stand behind the child. You say, 'Do this!' and then make one clear action such as clapping your hands or patting your head. The the person behind the child holds his hands and make him do the same action. You then act completely delighted and gives him tons of praise. Yes! You clever boy! Wow! Fantastic!

Then another 'Do this!', and the same action a couple of times until he's got it, lots of praise each time. If he doesn't do it, then the person behind gets to hold his hands and clap them again, lots of praise again etc. Most children get this fairly quickly and are delighted to have found they've done something successfully. If it's not working, leave it cheerfully and try again another day.

Once the child has understood the Do This! Instruction, you can use it for lots of new copying skills and even for language eg. Do This!

### **Eye contact – Autistic children and adults can find eye contact highly stressful.**

Do not obsess over making your child look at you while you are talking to them. For many children with autism, they can look, or they can listen but not both at the same time. Your efforts to make them look at you may be making it impossible for the communication you are seeking to take place. Over emphasis on looking at you can cause a child to develop the habit of staring at people which can cause lots of issues later in life for them.



Try also to ask their teachers to call their name before talking to them but not to insist on eye contact.

For more able children, it is the **social situations** that they are unable to understand, the reading of other people's emotions and points of view, the point behind traffic lights that turn red, the need to share or wait, the coping with anger, the irritation of homework that should have stayed at school, etc.

Social stories can be a good way of tackling these issues – see the NAS factsheet on social stories.

**Waiting and understanding about time** are also difficult areas – teaching a child as early as possible to read a watch, understand a calendar etc are valuable tools in helping them understand when something will happen, when words like 'in a few days' or in a 'while' or 'in a minute' are driving them crazy.

For less able children, tools such as large sand timers can be helpful to indicate a 5 minute or 1 minute wait etc. (See how sensory difficulties and communication all got swallowed up in the behaviour section there?)

So now straight onto **common everyday problems**

## Toileting

4

This is a big issue for many parents of young children with autism.

Generally, our children are in nappies longer than most children – don't stress too much, they generally get there in the end, often around 4 or 5 years. If they're not ready for potty training, leave it for another few months and try again. They'll probably be in night-time nappies for some years longer than day-time nappies. The NAS has a good factsheet on this that you may want to read.

Lots of boys don't want to pee standing up – they see their mums sitting on the toilet so that's what they think they should do. Brothers, dads and uncles need to be prepared to be seen peeing to get the message through sometimes! A bit of floating breakfast cereal like a cheerio in the loo becomes a good game. If you pee on it standing up, it goes jumpy jumpy etc. Make it fun. If the noise of the toilet flushing is off-putting and scares him, then leave the flush for another month. One skill at a time.

For potty training, the trick is just lots of repetition. These are children who don't like any change much and having always pee'd and poo'd in a nappy, they aren't going to choose to do it another way happily. You may have to pick a warm day, remove the nappy for the whole day and take the child to sit on the potty for a minute every 30 minutes and hope to catch all the pees and poos. Explain that the pees and poos like to go in the potty. Lots of praise, or whatever works any time a pee successfully ends up in the potty. Lots and lots of repetition. You may basically find it easier to put aside a couple of days just to do this if you can. Or if you are really busy, you'll just put the nappy on to go out and that's where all the pee will go immediately, and you'll be feeling you're back to square one. If they are really reluctant, you could try getting them to go and choose the potty in the shop with you or choose a special child's seat to go on the toilet instead.

**Reluctant poo-ers** – Many autistic children suffer from chronic constipation and gut issues. Look up autism and gut disorders on the internet to learn more. A chronically constipated child is a child in pain who will really fear passing a bowel movement and the pain it will cause. If your child appears to sit awkwardly or strain abnormally or not poo for days at a time, or conversely only appear to have diarrhoea (this can be a sign of constipation where only the diarrhoea can get past the blockage), then you really should insist this is investigated by your GP/paediatrician. Some parents choose to remove gluten and milk protein (casein) from their child's diet and there is a lot of anecdotal evidence that this can help. Nowadays though, more parents are choosing to use laxatives such as Lactulose and Movicol (on prescription only) which make it easier to give a regular diet than removing gluten and casein.

### **Faddy and restricted diets**

Autistic children rarely eat a wide range of foods and some of them severely limit themselves to just three or four foods. This causes enormous anxiety in families. Why will he not eat except in that room, on that seat, with that particular plate, with foods not touching and not mixed up? Why are no 'bits' ever OK? Why does he only eat yoghurt, milk and white pasta? Why will he only eat chips and nothing else in a restaurant? Why does he only eat Kentucky Fried Chicken and nothing else ever – it's been four months now? And so on. I rarely ever meet a parent of an autistic child without fairly dramatic food likes and dislikes. The fact that many have difficulties holding cutlery and so are being spoon fed only makes their refusal to eat most foods all the more painfully noticeable.

There is no easy answer to this. Some children will eat more foods in a different setting particularly if they see other children eat them and school lunches can be a great help

with widening their food tolerances. But for many the opposite is true – they would appear to far rather starve than try something new when it comes to food. Most children still look strangely healthy on the daftest of diets, but it is worth having a chat with a dietician and checking on whether a supplement might be needed.

Try to introduce new foods, if not to be eaten for some days, weeks or months, then at least to be touched, sniffed and licked. Gradually the tolerance does tend to increase. But it is really really gradual. Mostly I would say food fussiness to an extreme degree is pretty much part and parcel of having an autistic child. The person who suffers most is the stressing parent, so make a decision not to let it stress you. It is what it is.

And last, because this is really the hard one at the end of the day...



### **My child doesn't sleep**

Some of our children really do only sleep 3 or 4 hours a day and this is utterly exhausting for a parent who has already chased them all day. You can do all the things you'd do for typically-developing children – a fixed bedtime, a calming routine – bath, story time, bed, no excitement or games at this time, a clear message that getting up will not work etc etc. but it still has no effect – their system is in overdrive. Partly doing all the things above in the behaviour and communication sections will help by making them less anxious and hyper. Watch very carefully what they are eating and drinking – they can be hugely oversensitive to artificial colours, flavours and sweeteners. Cut processed foods out for a while, remove all fizzy drinks and squashes and Ribenas. See if there is a difference. Make sure they have a lot of exercise in the daytime but not in the evening – swimming, running, trampolining, can all wear them out. If nothing works, make another appointment with your GP or with your doctor at the CDC and ask whether a medication such as melatonin might be appropriate to help them fall asleep. Being chronically short of sleep is very bad for your child's health and being short of sleep makes it impossible for you to parent well, so don't tolerate it year after year.

Well, that's it. You got to the end of the pack. Must be time for bed!

Bring your remaining issues and challenges to the parents' support groups, to the NAS website, the Child Development Centre, the autism team, your SENCO, or to the internet. Seek out courses at Markfield or help from Resoures for Autism or your specialist health visitors and therapists. Keep searching for solutions. Love, enjoy and be endlessly fascinated by your amazing child.

**Remember always, you are the calm sea.  
Your calm keeps your child afloat.**

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