

HaringeyAutism

Information Pack for Parents and Carers

2011/12

Please call us **now** if you wish to be added to the Haringey Autism mailing list and to receive our free monthly newsletter.

This will keep you updated with important local and national changes that may affect you and with opportunities for respite and provision for your child. It will also link you to a large network of parents who understand your situation, invite you to our monthly meetings with speakers, library and creche.

Call Julia Wilkins on 020 8889 8422 or email juliayang2@aol.com with your contact details.

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About Haringey Autism

Have you just had a child diagnosed with an autistic spectrum disorder, (or autism, or autism spectrum condition) or Asperger Syndrome? Or do you feel that your child's social, communication or behavioural problems may point that way? You are not alone. There are now over 600 families with children like yours just in Haringey. We have put together this pack because finding the right information and help for your child can be a lonely, frustrating and bewildering task. Most of all, it can be very time-consuming, and time can be hard to find when you have a young autistic child.

Our own organisation, **Haringey Autism**, is the Haringey branch of the NAS (National Autistic Society). We are around 400 families in the borough all with children on the autistic spectrum. We send out newsletters by email to keep families in touch with a huge range of activities or services being offered to families, we run monthly support meetings for parents, have a lending library and website (<http://haringeyautism.port5.com>) where you can find this pack and also the most recent newsletter, and a refurbished computer provision service, all available free of charge. We also now run a club for adults on the autism spectrum. Call to be added to our mailing list if you wish to join or just need to talk. (Tel: Julia 020 8889 8422)

We hope this pack will help you find your way through the minefield 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. And 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. And enlighten you on ways to help with behaviour, everyday problems and communication.

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The first edition of this pack came out in 2002. This copy was updated in 2011. To keep our next version up to date, it would help greatly if you find a new or changed system, organisation, playscheme etc to let us know so that we can update the master copy. Many thanks.

Julia Wilkins/Haringey Autism. 020 8889 8422 .

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Abbreviations

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[/nas/jsp/polopoly.jsp%3Fd=140&a=5854](#) Some Abbreviations you may frequently hear and what they mean:

- ABA** - Applied Behavioural Analysis
- AEN** - Additional Educational Needs
- ASC** – Autistic Spectrum Condition
- ASD** - Autistic Spectrum Disorder
- AS** - Asperger Syndrome
- CAF** – Common Assessment Framework (form)
- CAMHS** – Child and Adolescent Mental Health Service
- CYPS** – Children and Young People's Service
- CDC** – Child Development Centre
- EP** - Educational Psychologist
- GFCF** - Gluten-free casein-free
- IEP** - Individual Education Plan
- LD** – Learning Difficulties
- LEA/LA**- Local Educational Authority/Local Authority
- LSA** - Learning Support Assistant
- MLD** - Moderate Learning Difficulties
- NAS** - National Autistic Society
- OT** - Occupational Therapy
- PCT** – Primary Care Trust(Health services)
- PDD/NOS** - Pervasive Development Disorder Not Otherwise Specified.
- SCD** - Social and communication disorder
- SEN** - Special Educational Needs
- SENCO** - Special Educational Needs Co-ordinator
- SLD** - Severe Learning Difficulties
- SALT/SLT** - Speech and Language Therapy/therapist
- SNA** - Special Needs Assistant
- TA** – Teaching Assistant
- TAC – Team around the Child
- VB** - Verbal Behaviour

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Diagnosis & what happens next

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How do I get a diagnosis for my child?

If you suspect your child has autism or Asperger Syndrome, you will need a medical diagnosis to access appropriate help. The benefits of early intervention (starting from as early as age 2) are well documented, and so an early and accurate diagnosis will be to your child's advantage. From school age onwards, much specialist educational provision is dependent upon having a 'Statement of Special Educational Needs' (see 'Education' section for more information) and this will also require a diagnosis from a multi-disciplinary team made of clinicians, psychologists and speech and language therapists.

Generally within Haringey, if an autistic spectrum disorder is suspected, your GP or community health clinic, health worker, SENCO, speech and language therapist or educational psychologist will refer you to the local Child Development Centre (CDC) at St Ann's Hospital, St Ann's Road, N15 3TH. Tel: 020 8442 6746. Here a multi-disciplinary team (usually a paediatrician and a speech and language therapist) will examine your child at either one or more often two separate HAACs (Haringey Autism Assessment Clinics) and a diagnosis will be formed at the final or Stage 2 clinic. This will all take many months from the referral. A written diagnosis with a description of your child's main areas of difficulty will follow a few weeks after the final assessment clinic. You may receive a handwritten assessment on the actual day of the clinic also depending on which doctor you see.

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 Skills 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 Intervention Panel 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 older secondary school age children, the referral may go to Haringey CAMHS rather than to the CDC.

The Child Development Centre (CDC) is based at St Ann's Hospital. Tel: 020 8442 6746. However, confusingly, the doctors who make the diagnoses are based for now at the North Middx Hospital, and are employed by Whittington Hospital. (previous to 2011, they were employed by Great Ormond ~Street Hospital). The secretaries for these doctors can be contacted on 020 8887 4374 and 4378. They are also based at North Middlesex Hospital. Any correspondence that goes to the CDC will reach the doctors as a mail bag goes daily between the sites. Sue Davies is the Specialist Health Visitor based at the CDC Tel 020 8442 6336/07989 852887.

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.

- 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 or encourage your GP to contact the society's information centre (0845 070 4004 or email info@nas.org.uk) if they have any questions about the condition.

My child has a diagnosis, now what?

There are a number of Haringey authorities who may now enter your child's life to provide support. All are over-stretched and recent 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 keep at them long and hard enough.

However – 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 the Local Authority in **the Children and Young People's service** which is made up of Education Services and Social Services and the **Health Service**

Education Services – The SEN (Special Educational Needs) department are responsible for providing for inclusion in mainstream nursery care, Under 5 centres, pre-schools, primary and secondary education, and also placements in specialist in-borough and out-of-borough schools, Earlybird programme, and supporting some home-schooling programmes. Statements of Special Educational Needs (see page 8) also fall under the umbrella of the local

authority's SEN department. Education services also fund the Educational Psychology service who assess children for statementing and annual reviews, and the 'arms length' Parent Partnership Service, an impartial service who can provide advice and support to Haringey parents having problems obtaining a statement or accessing appropriate education for their child.

Social services - The Disabled Children's team fund home-centred advice and short breaks, HINTS (Home intervention Service), CDP (Community Development Projects), FamilyLink, and 'Breathing Space' a respite service for children with autism. (see also Black and Minority Ethnic Carers' Support Service in Social Services section later on in this pack).

Health Services - provide diagnosis, on-going health care, speech and language therapy, health visitors, and occupational therapy.

The following pages will give more information on these authorities and the available provision. In addition to state provision, there are a number of local parents' support groups, all of whom may be able to help with advice and support.

Post-diagnostic support

There are a number of different official support strands:

Under 5s may be invited to join a social skills group offered by the speech and language therapy service to help assess their educational needs and select a pathway to a suitable nursery provision or reception class.

A one-off post diagnosis autism session is offered 3 or 4 times a year at the Child Development Centre to introduce parents to the autism school team, the speech and language therapy team and the specialist social worker plus a member of Haringey Autism. This is organised by Sue Davies, the specialist health visitor. 020 8442 6336.

For children under 5, there are periodic Earlybird courses run by the autism team. Sign up for this c/o Linda Nevin-Drummond or the autism team on 020 8489 5084 or email linda.nevin-drummond@haringey.gov.uk. Also from time to time, the autism team arranges a series of meetings at local schools for parents of over 5s

For parents of children aged 5 - 12 diagnosed in the past 18 months, the NAS run occasional 6 session courses called *help!* at various locations around London. Courses discuss the condition, behaviour management, communication etc but also education and transitions. The Haringey Autism newsletter will always carry details of forthcoming Help! courses so make sure you are on the mailing list. Cuts mean that the future of the NAS Help! service is unsure at the time of writing.

Join Haringey Autism – your local NAS group and link up with other parents –

always a great means of support and information sharing!

(Going private - The London Children's Practice – autism plus+ service. are a private provision offering a package of post diagnostic interventions such as speech and language therapy and report writing for tribunal. Social and communication nursery groups, sensory integration, behaviour strategies etc. Tel 020 7224 1156.

- The Hope Centre offer a range of support- see their website)

Education and Specialist help

What is a Statement?

A statement is a legal document setting out the special educational help which a child must receive by law. The legal entitlement only has worth, however, if the statement is written in accordance with the law and provides detailed information about the child's difficulties and the help provided to address those difficulties. The statement is compiled by the Local Authority's Special Educational Needs department, and takes into account the reports written by educational psychologists, speech and language therapists, clinicians, teachers, parents and any other involved professionals.

Does my child need a Statement?

Unless your child is extremely able or high-functioning and is likely to get through mainstream primary and secondary school with only the help that school can provide, then the answer for most parents will be yes, and as soon as possible.

Support for the Special Educational Needs (SEN) of children in school who do not have a statement is provided at two levels:

1. School Action (SA)

2. School Action Plus (SA+)

If your child needs help that is above and beyond what the school can reasonably provide at SA and SA+, then you should consider applying for 'Statutory Assessment' – the first step in getting a Statement (see below).

Increasingly extra help for children with high levels of SEN is given under the school stages. Local Education Authorities make no secret of the fact that they aim to restrict statements to a smaller proportion of children with SEN. If you have a child with high functioning autism or Aspergers Syndrome, it is possible you will be told that your child does not need to be assessed for a statement and that their needs can be met through the school's own funding. Be wary of this – teachers at the school are very likely to tell you that in reality

they cannot meet your child's needs at all without a statement and additional provision. Remember that education is not just about academic ability, if your child is struggling with developing socially; this is a valid part of their learning which needs to be addressed.

Stay in contact with the school – meeting with the Special Educational Needs Co-ordinator (SENCo) and class teacher can be really helpful for them as well as you. The school do have a duty to 'make reasonable adjustments' for disabled children and to differentiate the curriculum and draw up an Individual Education Plan (IEP) for children with SEN who need it. There are lots of young people with SEN whose needs can be met at the school stages and this is generally the more academically able autistic children who do not have particular behavioural problems.

When should I apply?

The process for applying for a Statement is called 'Statutory Assessment', you should ask for this if you believe:

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

You should also ask your LEA for a statutory assessment if your child is under school age, and you believe that they will need extra help when they start school.

While the school needs to make best efforts to meet your child's needs within their own budget, the school stages should not be hurdles to be jumped before you can apply for Statutory Assessment. But it can be helpful in evidencing that your child needs a Statement if you can show that despite having extra support at School Action and School Action+ your child did not make adequate progress.

How do I apply?

Obtaining one that you agree with and which will provide what you feel to be sufficient provision can be a difficult and time consuming process. The time from the first request for a Statement to the issuing of a Statement should in theory be no more than 6 months, but can be considerably longer in reality. All of this can be infuriating if you see the help your child could benefit from being withheld as a statement is required for the help to be given.. But for children fast approaching or already of primary school age, there can be a feeling of great urgency unmatched by the system.

You need to put your request in writing to the Chief Education Officer at the Local Authority, 48 Station Road, N22 7TY. The Parent Partnership Service can help you do this, they will have a model letter you can use, or you can download one from www.ipsea.org.uk. **When should I hear back?**

The Local Authority must reply within six weeks. **Remember:** Always ask in writing. Keep a copy of your letter. Make a note of the six week deadline for the LA's reply.

You may be told that a CAF (Common Assessment Framework) form needs to be filled in before you can apply for assessment. A CAF is a multi-agency referral form and can help get you support from social services and other departments. However, the CAF does not take the place of the the SEN process, and you do not need to have one filled in before you can apply.

Once issued, a Statement is reviewed annually and provision made be changed. In reality, very little changes on the Statement each year once it has been issued, so it is worth holding out for what you feel to be a Statement that will give decent provision for the next few foreseeable years.

The timetable for how long each stage of the statementing process may be dragged out for and other pointers is outlined in the booklet 'Special Educational Needs – a guide for parents and carers' published by the National Autistic Society £3. (Order number tel 0845 458 9911. NAS 664), but the local Parent Partnership Service (PPS) should be able to provide you with information on this for free.

If you wish to meet with the Special Educational Needs Dept face to face, or to better understand the assessment and statementing process, to ask questions and to set up individual appointments if necessary, call the PPS for help. Tel 020 8802 2611.

During assessment

If you feel that any of the main reports made on your child are inaccurate, or understate the problems, you can ask for changes to be made to that report because understating problems could well result in lesser provision being offered. Every borough has a legal duty to make the hours and type of provision clear on the statement and to state who is to provide it. Many if not most boroughs try to avoid doing this however. Make sure your statement is unequivocal on provision – if the report states your child has a particular need they should specify and quantify what provision your child should have to meet those needs.

If you get nowhere with changes you need to the draft statement, you might consider splashing out and having an independent evaluation made by an out of borough expert to back up your point, however private reports are expensive to obtain - expect to pay £750 for an independent educational psychologists assessment or £550 plus for a Speech and Language or

Occupational Therapy tribunal report from the London Children's Practice (tel 020 7724 1156) for instance. Again if you are on benefits, you may be able to get these reports paid for. Ask at a local Citizens Advice Bureau, or at a local solicitor who specialise in educational provision, such as Levene's near Wood Green station. You can meet with the SEN case officer to discuss your case, however remember that if you request more than one meeting, this might delay the whole process. (A private child advocate is also worth considering though, like going to a solicitor, this costs money. Try www.advocacyandmediation.co.uk .)

One of the major issues Haringey children with autism face is the total lack of occupational therapy provided by the local health authority. Even those with OT in their statements do not receive it at present and this has been the unhappy situation for many years now.

Appealing against the Local Authority's decision

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

- 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 a statement** of your child's special educational needs, after a statutory assessment.
- **Has made a statement**, or has changed a previous statement, and you disagree with part 2, 3 and or 4.

The process is explained in material that will be sent to you by the LA when they let you know their decision. www.sendist.gov.uk have a pack explaining how and when to appeal. There are strict deadlines, so if you are unhappy at any stage make sure you seek support; The PPS, NAS, Autism London, Resources for Autism, AFASIC, IPSEA and ACE helplines can all give advice, and can suggest reading material to help you through the process. Going to tribunal is sometimes inevitable, but is intensely stressful and can be very expensive, and both sides tend to do all they can to avoid it.

What specialist help is available to my pre-schooler?

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 - 8 weeks working on language, play skills, turn taking etc. Tel: 020 8442 6338.

2. Earlybird.

An NAS initiative, run in Haringey by the LEA. The first pilot scheme began in January 2001 with 6 families following a three month programme course run by the Autism team, and an Educational Psychologist. The programme brings parents together for group daytime training sessions and also visits families in their own homes. Parents/carers are helped to understand their child's autistic spectrum disorder, develop the child's communication and help find ways to manage their behaviour. To qualify for the Earlybird scheme, children must have an autism diagnosis and NOT have a full-time nursery or Under 5's placement. (Earlybird can arrange some social services respite to allow parents to attend the course). For details contact the PDC (Professional Development Centre). Tel: 020 8489 5084. Contact is Linda Nevin-Drummond or Letecia Knight. Email Linda.nevin-drummond@haringey.gov.uk or letecia.knight@haringey.gov.uk

3. 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 intervention, or may join groups at community clinics. If you wish to self-refer to the Speech and Language Therapy service, write to: G1, St Ann's Hospital, St Ann's Road, London N15 3TH. Or tel/fax: 020 8442 6866. Or contact the SLT administrator at Tynemouth Road Health Centre. Tel 020 8275 4008.

4. Haringey Early Intervention Panel/specialist pre-school nursery places.

Your child may be referred onto the Early Intervention Panel who allocate the specialist pre-school places according to need. Since March 2001, Haringey has a specialist pre-school autism unit attached to a mainstream playgroup at Woodside Children's Centre in White Hart Lane. The unit known as The Gold Room offers up to 6 morning and 6 afternoon sessions only in mixed ability and mixed age groups for pre-schoolers.

The Woodside Children's Centre Social and Communication Unit (The Gold Room) is at 59, White Hart Lane, London N22. Tel: 020 8888 4398

Other places which are allocated by the Early Intervention Panel are at Children's Centre nurseries who have considerable experience with children with special needs, and are increasingly familiar with working with autistic children. They will all have access to educational psychologists and speech and language therapists. (in ordinary mainstream nurseries, you will need to self-refer to the educational psychology service for help or the nursery may do so themselves, and speech and language therapy is usually only available in the nursery if the child is statemented)

Contact Shubi Raymond for other Early Years inclusion issues via the general council number 020 8489 0000.

The nurseries with reserved places for children with special needs include:

Plevna Children's Centre, St Ann's Road, N15.

Pembury House Children's Centre, Lansdowne Road, N17

Park Lane Children's Centre, N15

Woodlands Park Children's Centre, Woodlands Park Road, N15

Rowland Hill Children's Centre, White Hart Lane, N17.

Stonecroft Children's Centre, 100 Priory Road, N10

(Bruce Grove Primary School has a language disorder unit which some children with autism also attend though it is not primarily aimed at asd children)

5. 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 Lovaas, Verbal Behaviour and Options the better known. The majority of the children on home programmes are also combining mainstream school with their home programmes. The LEA has in the past funded a number of the home programmes but now no longer funds new programmes. You may prefer to just pay for some private additional tutoring at around £10 to £15 for a tutor and anything up to £80 an hour for occasional supervision. There are still some grants worth £2000 a year towards this available through Caudwell children – see their website online.

For more information on Lovaas/ABA contact PEACH (Parents for the Early Intervention of Autism in Children) 020 8891 0121 or see their website. Or Contact Julia at Haringey Autism for advice on local tutors or to be put in touch with other families following this route. Tel 020 8889 8422.

6. Mainstream nurseries with some extra support and speech and language therapy if you have managed to get the help detailed on a Statement of SEN in time.

Sometimes mainstream nurseries attached to schools may be a better choice than pre-school playgroups as they can be more structured, and being within

a school have a resident SENCO and school educational psychologist. If your child is in a mainstream school's nursery and is having problems, contact the SENCO and request a meeting with an educational psychologist. If your child is in a pre-school playgroup or nursery not attached to a school, you may self-refer to the Educational Psychology service or ask the head of the nursery to do so for you. You may also self-refer to the Speech and Language Therapy service for assessment though actual speech and language therapy within mainstream nurseries is presently restricted to children with statements.

7. Independent Schools

- **Kestrel House School** in Crouch Hill, Crouch End, N8 – pre-school autism/Asperger social and communication group sessions, age 2+.(These may not be running at present due to in-school changes – check directly with the school if interested) This is an option which you could pay for privately, or maybe plead for your LEA/health depts to fund. Fulltime, funded places will run from Reception class up to age 11

- **Treehouse School** in Woodside Avenue, Muswell Hill, N10. A school for children with autism aged 3 – 19 using ABA teaching principles. Places are all LEA funded and you can expect to go through the educational tribunal process and have immense difficulty to get a place here. Tel: 020 8815 5424. Headteacher Julie Sullivan.

Charity providers

Palace for All – a wonderful charity just over the Haringey border in Islington near Crouch Hill station. Based at The Old Laundry, Sparsholt Road, N19 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.

Kid City – a nursery provision and also a Wed, Thurs, Fri **drop in** provision for under 5s with special needs. 100 Tower Gardens Road, N17. see leisure section for tel number.

Challenge – a Friday morning termtime **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.

Private teaching organisations:

- **The London Children's Practice – autism plus+ service.** A private provision offering assessment, diagnosis and a full package of post diagnostic interventions such as speech and language therapy and report writing for tribunal. Social and communication nursery groups for 2 – 5 year olds, sensory integration, behaviour strategies etc. Tel 020 7224 1156.
- **The Hope Centre** – a private organisation offering speech and language

therapy, individual teaching and occupational therapy.

- **Christopher Place, The Speech Language and Learning Centre** – under 5s speech and language assessments and one to one teaching. (some bursaries available for low income families)

Haringey borough funded contact numbers for pre-school year education problems:

Haringey Autism Support Team and Earlybird scheme Tel: 020 8489 5084.
Linda Nevin-Drummond and Letecia Knight

Phil di Leo, Head of Education for Children with additional needs and disabilities, Haringey Children and Young People's Services, 40 Cumberland Road, London N22 7SG
Tel: 8489 0000/8489 3848

Sarah Parker, Operational Manager of Speech and Language Therapy Services.
Tel:8442 6866. Based at:G1, St Ann's Hospital, St Ann's Rd, N15.

Speech and Language Therapy//Asst Director of Children's Services. Tel: 8442 6877

Educational Psychology Service: Tel: 020 8489 3004. Professional Development Centre, Downhills Park Road, N15. Head of service: Yvonne Wade. Senior Educational psychologist specialising in autism, Laura Cockburn

LEA - Early Years and Play service. Tel: 020 8489 3840.

Shubi Raymond - Advisory teacher for inclusion in Early Years. (Early Years is the official term for 3,4,and 5 year olds.) Shubi is available to professionals in private, voluntary or maintained settings, where advice or support is needed in including children with SEN. Parents can also call her directly if having problems in a mainstream setting, or considering a mainstream setting. Tel: 020 8489 1497.

Haringey Parent Partnership Service, provided by Markfield exists to help parents access LEA services when you meet brick walls or need help getting through the system. They can help you with advice and support, filling in forms and attending school or LEA meetings with you to speak on your behalf. You can meet them at the Markfield Project or at the CDC weekly surgery. Book first on 020 88004134
Helpline Monday 9 – 12 or Weds 3 – 6 on 020 8802 2611.

What specialist help is available for my primary school child?

The majority of autistic primary age children in the borough go to one of the following options:

a) mainstream schools with varying levels of support from between a few hours a week extra assistance to full-time 30 plus hours support from an SNA (Special Needs Assistant); and possibly also attending a 'nurture room' in some schools that have them for a few hours;

b) to the two local special school units for learning difficulties. They are the Brook (opening in late 2011, a combination of what was previously Moselle School/William C Harvey School), based with the Willow school, previously the Broadwater Farm Primary) and the autism unit at Mulberry Primary School,

c) to the out of borough day special schools such as Woodcroft in Loughton, Radlett in Hertfordshire, Whitefields in Waltham Forest, or West Lea in Edmonton. You would only get offered a place at any of these types of school if the in borough specialist provision was unable to meet your child's needs or was full and mainstream had clearly been unable to meet your child's needs.

d) the in-borough independent special schools such as Treehouse and Kestrel School House (shortly to be changing its name as under new management!)

e) are out of school and running a home programmes or getting a few hours help via the Tuition Service in Williams Grove, Wood Green.

f) A very few needing exceptionally high levels of support and a very structured 24 hour curriculum go to out of borough residential special schools.

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

The amount of specialist help, support, and speech and language therapy your child gets in a mainstream setting is largely dependent upon the provision outlined in his/her Statement (Statement of Special Educational Needs) and the level of sympathy/understanding/tenacity displayed by the school's SENCO (Special Educational Needs Co-ordinator). For many, obtaining a statement is the only way to get help for their child - be warned

the longer you leave it, the harder it may be to obtain one as the government are trying to decrease the numbers of children who hold statements. See previous section on Statements.

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

- **The Brook School**

A new inclusive learning campus opening late 2011, to include a mainstream primary school and two special schools all on the site on Broadwater Farm.

- **Mulberry School**

Parkhurst Road, N17. Tel: 020 88082296

A mainstream primary school with an autism unit. Children will integrate into any mainstream classes their abilities allow them to access. Head of unit is Caroline Graham.

- **Radlett School for Autistic Children.**

Harper Lane, Radlett, Herts. WD7 9HW. Tel: 01923 854922.

Independent special school for pupils age 3 - 16, run by NAS. Day and boarding. Haringey pupils tend to attend daily and are transported by the borough to and from school.

- **Treehouse School**

Ages 3 – 19. Woodside Avenue, London N10.(autism)' Tel: 020 8815 5424. Independent school run on ABA lines.

- **Kestrel House School**

Age 3 – 16 provision. An independent school for children with autism on Crouch Hill, N8.

(NB under new management and due to change name shortly)

- **West Lea School**

State run school. Ages 4 -17, Hazelbury Road, Edmonton.(Aspergers, autism, complex needs) Tel:020 8807 2656 Run by Enfield LA, places generally reserved for Enfield pupils.

- **Woodcroft school**

Independent school. Ages 5-12, Loughton, Essex.(MLD autism, Aspergers)
Tel: 020 8508 1369

- **Whitefield School and Centre**

Macdonald Road (off Fulbourne Road), London E17 4AZ. Tel: 8531 3426.

State run school for children with MLD/SLD age 5 - 19 and with special classes for autistic children. Again children attend daily and are transported by special school bus from their homes. (Most places are reserved for children

from Waltham Forest)

- **Hillingdon Manor School**

Independent school for children with high functioning autism/Aspergers, age 3 – 19.

- **Holmewood School.** For children 5 – 19 with high functioning autism, Aspergers and other specific learning difficulties. The school unit is attached to an international school.

- **The Bridge School**(previously known as Harborough and Rosemary Schools) Islington.

Tel: 7272 5739. Takes 2 - 19 years.(autism). Autism units in mainstream schools.(Places generally reserved for Islington students)

The NAS, Autism London, Gabbitas and www.mugsy.org and Oasis will also have lists of special schools, including the independent ones around the country, if you want to look further afield. These schools are all expensive and LEA's can be 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 LEA as fast as possible. Parental preference is supposed to count in your choice of school for your child, but getting approval for an expensive place may not be easy as funds are very limited.

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 full or part-time, with and without extra help. 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 doggedly the parents have fought for the support.

The quality of support provided can be essential to making inclusion successful. Try to ensure that your child's learning assistant receives or has received training in autism from the autism support team (8489 5084). Check whether the support hours will include breaktimes and lunch hours – often the times that autistic children find most stressful and unmanageable but which are perversely often not included. The autism team who can go into primary schools for up to half a term and train staff in-depth on successful inclusion of children with ASD.

As more money is allocated to schools over the next few years for general use for children with special or additional educational needs, far less children will receive statements. Those with needs which are not seen as severe or complex will generally get help from these funds without the need for a statement. At present this is children needing less than 15 hours a week

support.

At mainstream school, your child will have an IEP (Individual Education Plan) which should be updated and reviewed regularly. There will also be an annual review of the child's progress and to check the Statement is still appropriate.

Concerns should be addressed first to the SENCO or the school's educational psychologist, to the Autism Team, or to the Parent Partnership Service who will help you with advice and speak on your behalf if required. (Try the NAS or Autism London if you get nowhere with the above, or private mediator Fiona Slomovitch at www.advocacyandmediation.co.uk).

Speech and Language support in schools for pupils from Year One onwards, is generally restricted to those who have statements or who are assessed at 'School Action Plus'. At Reception level, it is restricted to those who have it detailed on their statements. A recent development is the setting up of the '**Speech Language and Communication Service**' which is managed by Kirstie Watkins. This service was set up to prevent crossovers and duplications between the services. 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.

3. Home programmes

Within the borough there are also a number of children on home-based ABA programmes most of whom attend part time mainstream or special school as part of their home programme, and accompanied by their own tutors. (See 'What specialist help is available for my pre-school child?' section, or contact Julia at Haringey Autism for ideas for private home tutors tel 020 8889 8422.) Caudwell children are the only organisation we know giving grants of up to £2000 a year towards this.

(Several of our families are working with a team called the Nightingale team. see <http://abateam.co.uk>)

Within Haringey, the independent Treehouse School is run on ABA lines. (TreeHouse School. Woodside Ave, Muswell Hill, N10. Tel: 020 8815 5424)

4. Private 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.

Private speech and language therapists can be £60 to £80 an hour. You could try getting a £500 speech and language therapy voucher via an organisation called Cerebra if you are not getting one to one speech and language therapy provided.

- Palace for All in Sparsholt Road, off Crouch Hill, N19 provide very good value speech and language therapy and one to one teaching at much lower rates

- highly recommended.
- The Hope Centre is a long established centre providing teaching therapies.

Haringey borough funded contact numbers for primary age education problems:

Haringey Autism Team - Tel 020 8489 5084. contact Linda Nevin-Drummond or Letecia Knight

Phil di Leo, Head of Education for children with additional needs and disabilities, Haringey Children and Young People's Service. Tel: 8489 0000/8489 3848

Speech, Language and Communication Service. Contact:020 8442 6866. Vicki Monkmeyer.

Educational Psychology Service. Tel: 8489 3004. Yvonne Wade/Laura Cockburn

Parent Partnership Service Tel: 020 8800 4134/020 8802 2611

This body exists to help parents access LEA services when you meet brick walls or need help getting through the system. Rachel Burke/Bola Aworinde.

What specialist help is available for my secondary age child?

1.Special schools

- **Riverside. Opening late 2011.**

A large special needs provision in a mainstream secondary school based at Woodside High on White Hart Lane (Wood Green end of the road)

Ages 11- 16

- **Heartlands High – autism unit in a council run mainstream secondary school for children with autism and moderate/severe learning difficulties. Ages 11 – 16. In Wood Green. Contact Kelly McBeath.**

- **Holmewood School. An independent school, attached to an international**

mainstream school, which has provision for children with high functioning autism, aspergers and other specific learning difficulties.

- **Jewish School in Barnet, JCoss with an autism unit. See website www.jcoss.org**

- **Sybil Elgar.** NAS-run secondary school. 10 Florence Road, W5. Tel:7833 2299. WhitefieldSchool and Centre Macdonald Road (off Fulbourne Road), London E17 4AZ. Tel: 020 8531 3426. Day school with some residential boarding and respite. Ages 11 – 19

- **Whitefield School** for children with MLD/SLD age 5 - 19 and with special classes for autistic children. Again children attend daily and are transported by special school bus from their homes.

- **Treehouse School**, Woodside Avenue, Muswell Hill, N10. Independent school run on ABA lines.Tel 020 8815 5424.

- **The Bridge School** Takes ages 2 - 19 years.(Islington LEA)
Website www.thebridgelondon.co.uk

- **West Lea**, (autism and Aspergers) Haselbury Rd , Edmonton. Ages 3 - 19
Tel: 020 8807 2656 (Enfield LEA)

- **The Spa School**, Monnow Rd, Bermondsey, SE1 (must apply by October of yr 6 for entry to yr 7) Tel:020 7237 3714 (autism, Aspergers) (Southwark LEA).
Ages 11 - 19.

- **Hillingdon Manor**, 01895 813 679 (autism/aspergers)Harlington Rd, Hillingdon, Middlesex UB8 3HD (Independent school). Ages 3 - 19

- **Stormont House**, Downs Pk Rd, London E5.(Hackney LEA) Tel: 020 8985 4245

- **Oak Lodge School**, Heath View, East Finchley, N2(Barnet LEA)(autism/MLD)
Tel: 020 8444 6711.

- **Radlett Lodge**, Radlett, Herts. Day, with some boarding and overnight respite provision. An NAS school. From primary age to the age of 16. Tel: 01923 854922.

2. Residential 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 16, with additional 16 – 19 provision.

- **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. To age 19.
- **Fullerton House School**, Doncaster. A 52 week school for children with severe challenging behaviour and autism.
- **Hassocks HVS**. A residential school for children with autism/aspergers who suffer high levels of anxiety.
- **Horizon and Tadley Horizon schools**
- **Broomhayes School**, Devon. NAS run termly boarding school. To age 19. Autism and challenging behaviour.
- **Southlands School**(01590 675350)/Grately House School(01264 889751). Both schools are in Hampshire and run by the Cambian Group for children with high functioning autism/Aspergers, ages 11 -16. Fortnightly boarding. The group also run several other schools in Hampshire, Dorset and N England.
- **Doucecroft School**. Eight Ash Green, Colchester, Essex. Tel 01206 771234. Autism and aspergers age 2 – 19.
- **Potterspury Lodge School**. Towcester, Northamptonshire. Tel 01908 542912.
- **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 Somerset and Brighton. Tel 01373 814980/466222.

Details of more schools can be obtained from the National Autistic Society and from the OAAIS websites. Autism London have a good factsheet on schools in the Greater London area.

3. Inclusive secondary provision

There are no specialist units for more able autistic children attached to mainstream secondary schools within Haringey and previous plans for the one at Alexandra Park School now seem abandoned.

Haringey's very over-stretched autism team, work with children with autism in mainstream schools and their teachers and learning assistants. Tel: 020 8489 5084. The autism team together with speech and language therapy teams co-ordinate and carry out all the transition work for yr 6 primary students to adjust to secondary school, generally 5 sessions, and follow up throughout yr 7 in the new school.

If your child is out of school you may be able to access up to 10 hours a week tuition at or from the Tuition Centre or PRU (Pupil Referral Unit) for children with health needs at Williams Grove, N22 through the SEN dept at Education Services. Tel 8489 0000. 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.

4 Social Skills Youth Group

For children in years 7 and up, Run by the autism team. Tel 020 8489 5084. The group is presently known as the 'Muswell Hillbillies', and meets Thursday after school at Muswell Hill Community Centre behind Marks and Spencers.

From age 14, your child's annual review should also be attended by someone from the Transitions team at social services so that forward planning for your child's future can be started.

Post 16 education

- Haringey Sixth Form Centre –This brand new 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 is maintained by children's services. Otherise in other colleges such as CHANEL, the college itself becomes responsible for support.
- CHANEL (College of Haringey and North East London), High Road, Tottenham, N17.
- Barnet College
- City and Islington College
- Area 51 education, Coburg Road, Wood Green, N22
- Harington Scheme, Cholmeley Pk, Highgate, N6. Horticulture and life skills courses for young people and adults age 16+. 6 month or 2 year courses. 020 8341 3657.

Psychological problems =

Anxiety, stress, depression, withdrawal and refusal to go out, OCD, nervous

tics etc –

Free - Ask your GP or school to refer to CAMHS or to the Tavistock.

Paying:

The London Children's Practice – autism plus+ service. A private provision offering behavioural strategies including cognitive behavioural therapy, etc. Tel 020 7224 1156.

Private autism mentoring www.billgoodyear.org

Haringey borough funded contact numbers for secondary age education problems:

- Autism Team - Tel: 020 8489 5084
- Phil di Leo, Children and Young People's Services. Tel: 020 8489 3848.
- Social Services, Transitions 14 - 19, Gillian Rodway. 020 84890000
- Connexions North London. Faye Mahmud/Liz Osman. 020 8489 0000.
- Sarah Parker, Vicki Monkmeyer, Speech and Language Therapy Services. Tel: 8442 6866.
- Educational Psychology Service. Yvonne Wade/Laura Cockburn Tel: 020 8489 3004.
- Parent Partnership Scheme – Rachel Burke, Bola Aworinde. Tel: 020 8800 4134/020 8802 2611. This body exists to help parents access LEA services when you meet brick walls or need help getting through the system.

HARINGEY HEALTH

(see also section on Diagnosis)

Paediatricians and Clinicians

Dr Croft, Dr Banerjee and soon, Dr Kim Holt are at the CDC(Child Development Centre), St Ann's Hospital, St Ann's Road, N15 3TH. Tel 020 8442 6746. Diagnosis and follow up assessments.

Dietician

Jas Singh is the dietician based at the Child Development Centre (CDC) at St Ann's Hospital, St Ann's Road, N15.. Jas also sees children at Moselle and the White Hart Lane Nursery unit. She may be able to advise upon supplements and eating habits for children who restrict their diets, or have faddy eating habits.St Ann's Tel: 8442 6746

(useful reading matter available from NAS Publications, Amazon.co.uk or from Haringey Autism Library – Can't Eat, Won't Eat by Brenda Legge. Just Take a Bite, by Lori Ernsberger, Autism as a metabolic disorder/gluten and casein free diets for people with autism, by Paul Shattock)

Occupational therapy

Many of our children have dyspraxia, poor muscle tone or lack physical co-ordination which affects movement, handwriting, eating food and holding cutlery. They can be under or over sensitive to touch, smell, taste, sound and light and more.(known as sensory integration disorder, or sensory regulation disorder if you want to look up further information on the internet) The CDC's occupational therapy service, (based in the 'mainstream' dept) can be over-subscribed and under-manned and should in a perfect world see children with autism as a matter of course but do not have the resources to do so and at present see virtually none.. Tel: 020 8442 6137. If you feel strongly your child should be seen as he/she obviously has the need to be seen, you could threaten with a legal threat that that this is discrimination by diagnosis which is illegal but you may need to go to tribunal and have a written professional report of the child's OT needs.

(Leigh Day and Co are solicitors who are interested in this area)

In the absence of OT provision, I strongly suggest that parents educate themselves about how sensory difficulties may affect our children and learn some techniques themselves. Start with the checklist on www.sensory-processing-disorder.com

Speech and language therapy

This comes under the health department though in a way education might seem a better home for it. There is never enough of it and the children with the most severe problems in the special schools definitely get the best service. Those with speech and who are more able rarely get enough of the real benefits that a speech and language therapist could provide with social skills, auditory processing, use of language, understanding of gesture, sarcasm,

idiom etc, use of visual supports etc. They often just get a few hours a year of turn taking and game playing in a small group, and general advice given to the classroom assistant.

The Speech and language therapy department are based in numerous locations around the borough but the HQ is in building G1 at St Ann's Hospital, St Ann's Road, N15.

Ask for as much SLT (Speech and language therapy) as possible in your child's statement – make a huge fuss if it doesn't take place.

Learn what you can do yourself as a parent for your child - See the back of this pack for suggestions.

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 on the subject 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 ASD 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 special school nurse, your health centre or GP. 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 for older children especially this can be a sizeable saving. If you meet a problem getting free nappies, call the ever helpful Sue Davies, specialist health visitor at the CDC on 020 8442 6336.

Mental health

CAMHS (Child and Adolescent Mental Health Service) is based at St Ann's. Autism often co-exists alongside other disorders (co-morbidity). For additional problems associated with autism such as anxiety, depression, OCD (obsessive compulsive disorder), tourettes, tics, ADHD etc, children are seen by Dr Reenee Barton, Jessie Earle and a team of psychologists/psychiatrists. Tel 020 8442 6467. The SCAN, a joint CDC/CAMHS service is for children for severe learning difficulties who develop mental health problems – these children are often seen in their school settings.

Depending on policy at any given time, referrals can also sometimes be made to The Tavistock, Maudsley Hospital (The PDD Clinic or Psychiatry Clinic), Gt Ormond Street Hospital or to The Royal Free Hospital's Child and Adolescent Psychiatry Dept.

Sometimes a change of educational or living provision may be required, or cognitive or behavioural therapy, and sometimes drugs such as Ritalin,

Risperidone, aripiprazole, mood stabilisers and anti-depressants can do also wonders! Dr Santosh at Gt Ormond Street Hospital is highly experienced at prescribing medication for difficult cases.

(the Tavistock Clinic in North London provide a psycho-therapeutic service. The private London Children's Practice can supply cognitive behavioural therapy.tel 020 7224 1156. Private Asperger life coach Bill Goodyear at www.billgoodyear.org gets good feedback from parents)

Suggested reading, from NAS publications 'Mental health in people with autism and Asperger Syndrome: a guide for health professionals' £1.50.

Dentistry – Special needs dentist for autistic children who cannot cope with a regular dentist based at Tynemouth Road Health Centre, Tynemouth Road, N15.

Health - Going private

PRIVATE HEALTH CARE IN HARINGEY FOR SPECIAL NEEDS:

The London Children's Practice – a private service in Welbeck Street, W1 offering many health services to children with autism including a paediatric neurologist, consultant psychologist, speech and language therapists, occupational therapists, sensory integration, specialist feeding programmes for selective eaters, anger management, counselling, cognitive behavioural therapy.tel 020 7224 1156.

There is a **private dentistry** clinic at **30, Fortis Green, East Finchley**, N2 Tel: 8444 3413 where Malcolm Levenkind offers dentistry services to children with special needs.

Sensory integration - For children with sensory difficulties around sound, Auditory Integration Training, and light, contact: Pauline Allen at The Sound Learning Centre in Palmers Green. Tel: 020 8882 1060

Private occupational therapy – Try Melinda Silson at c.o.t.s Childrens Occupational Therapy Services on 020 8855 2430 based at 35 Kingsdale Road, SE18. ...or try the Hope Centre. 020 8809 8240

HARINGEY SOCIAL SERVICES/RESPITE CARE

Haringey Social Services - Disabled Children's Team – Tel: 020 8489 3671.
(New cases call mornings and Wednesday pm)

– You can self-refer here if you need help and respite, or are not coping, though most referrals come through health workers, schools, the CDC at St Ann's Hospital or the new CAF form from the educational statementing process. 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 social worker but most do not. For most children, you will just ask for the duty manager.

Social Workers (who have children allocated to them) include Pat Hampson 020 8489 3686, Zoolanda Oloka 020 8489 3415, Julie Siani 020 8489 3643 and Anita Perkins 020 8489 3677.

The Transitions team help to plan provision after school and can be involved from age 14 up.

HINTS (Home Intervention Service) can offer support and advice in the home to pre-schoolers.

CDP (Community Development Project) is mainly aimed at BME families with children under 5.

HINTS/CDP workers are Dilek McQuaid 020 8489 3463, Kujit Gautam 020 8489 3462, Eleni Manoli 020 8489 2419 and Pauletta Robinson 020 8489 3462.

What respite can they offer?

If your child is assessed for and then granted respite, it can come in a number of ways.

1. FamilyLink

- very over-stretched respite service with huge waiting list, FamilyLink workers are essentially kindly volunteers who get paid expenses and will look after your child at home or take them out for a few hours a week, or even overnight. If you can suggest someone who might with training be a suitable person to help with your child (eg a reliable neighbour), this may possibly speed things up. Tel: 8489 1466/8489 1448.

2. Breathing Space - (a respite service for children with disabilities including autism)

Respite service for parents with children with autism and other disabilities aged up to 18 years. Children can be referred by the Disabled Children's Team, HINTS or social workers. Presently serving a number of families on a regular basis offering for example 2 hours a week either in the home, or taking

the child out. The hours can be accumulated so that you could take, for example, 8 hours a month. Run by Ann Hewitt (tel 8889 5941) and Jasmine Wong (tel 8489 4569).

3. Direct Payments – You may be allocated a certain number of hours of care per week at around £9 to £10 per hour. This is then paid monthly into a bank account you set up specially for the purpose. You find and hire the worker and pay them, deducting any due taxes and national insurance contributions. Direct Payments can put you in touch with someone who can work out the deductions for you for a small fee if you wish to use this system but do not feel confident of the accounting side.

4. 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 Team Spirit at the Brook and Riverside, the Markfield Project, and Haslemere Road, and also overnight respite at Haslemere Road for over8s. Some children who are at Radlett Lodge School have in the past had occasional overnight respite at this school.

Other carers/respite possibilities:-

Voluntary help with your child at home – a couple of hours a week support from volunteer teams at Markfield, 020 8800 4134 and at Resources for Autism Tel 020 8458 3259. There are waiting lists for both.

Befrienders – Kith and Kids. There is a waiting list. (The NAS no longer run their befriending service)

Black and Minority Ethnic Carers' Support Service

Based at Selby Centre, Selby Road, London N17 8JL. Tel: 020 8808 5510.

Providing respite care to members of the black and ethnic minority communities.
8489 8980

Haringey Consortium of Disabled People and Carers(HCDC), 551b High Rd Tottenham - respite care at low cost, advice and support. 8801 5757.

For private respite care, try **Special People**, an agency supplying babysitters, teachers, childminders, etc for children with Special Needs, and run by a mother with an ASD child. Based at Palace for All, The Old Laundry, Sparsholt Rd, N19. 020 7686 0253.

(see also Leisure/respite section)

FINANCIAL HELP

On top of any normal welfare benefits, you are eligible to apply for **Disability Living Allowance** (which is paid for the child), and is divided into Care components and Mobility components (or Motability if you prefer to have a car rather than the money for mobility), and you can apply for **Carers Allowance** (which is around £50/wk and is paid to any carer who looks after a child more than 35 hours a week and earns less than approx £100 a week through other taxable payments).

Call 0845 7123456 and ask for both forms if required. Carers Allowance is easy to apply for but the DLA forms are an absolute nightmare to fill in and seem designed to put you off completing them by making them so complex and repetitive.

For under 5s, you need to fill them in each year. You can apply for the care component from birth. From age 3, you can apply for the higher rate of mobility (which you can then choose to swap for Motability - a mobility allowance which you can use to buy a car if they get high rate mobility awarded).

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.

There are a number of possibilities for getting help filling in these dreadful forms. Try:

Markfield, Markfield Rd, N15. Tel: 020 8800 4134. They hold one to one 2 hour sessions at the Markfield Project and at CDC, St Ann's Hospital to help parents with these forms. By appointment only – be warned – it takes up to weeks to get an appointment so book your appointment even if your DLA form has not yet arrived.

Haringey Carers Centre, Winkfield Resource Centre, Winkfield Rd, London N22. Contact 020 8489 8981 to book a special appointment for benefits advice, held every second Wednesday of the month.

Citizens Advice Bureaus can help when resources allow.

Specialist Health Visitor at the CDC, St Ann's Hospital Sue Davies may be able to give support or advice.

Your social worker/HINTS worker/Family Link worker/family support worker at a children's centre

Your GP/health visitor

NAS helpline

Essentially both Disability Living Allowance and Mobility Allowance are paid at

different rates depending upon the severity of the child. Do NOT understate the problems your child is faced with and can face you with, and particularly be 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 only paid for those with night-time problems, so if your nights are disturbed regularly, spell it out very clearly. **The NAS and Cerebra have extensive factsheets on their websites suggesting how to fill in these forms - www.autism.org.uk and www.cerebra.org.uk. We strongly suggest you read through these factsheets before attempting to fill in the forms.**

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 get fobbed off by the unhelpful people at the DLA who regularly tell callers with ASD children that they do not qualify for mobility payments if their children can walk – this is NOT true. You can apply under the 'refusal to walk' and severe mental impairment criteria for higher rate mobility. If getting about outside is made difficult by behaviour problems, communication and understanding problems, fears and phobias, rigid insistence on sticking to certain routes etc, dyspraxia etc, then you have a mobility problem. 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 challenge them, 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 – 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 from Julia – 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 at present. 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 on the difficulties involved).

Tax credits – Child Tax credits, Working Tax credit and Childcare Tax credits are available for those working but earning less than £16,000 per year per household. There is extra allowance made also in the Child Tax Credit for a disabled child, and more for a severely disabled child. **WHEN YOU GET YOUR DLA, TELL THE TAX CREDITS PEOPLE – YOU WILL THEN GET £200 TO £300 A MONTH MORE FROM TAX CREDITS IN ADDITION TO THE DLA!! Lots of people forget to do this step and miss out.** Tax credit helpline is 0845 3003900. If you are working less than 16 hours a week, you can still qualify for Child Tax Credits, but not Working Tax Credits.

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 Bureau Benefits Advice Line 0870 751 0925

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** to allow you to take taxis at greatly reduced rates. (eg on a fare of £11.80, you pay £1.50, the local borough pays £10.30) Tel 020 7484 2929. (note – not sure at time of writing how the recent cuts will affect this service)

Suggestions for finding additional funding.

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). There is no formal means test to obtain funds from the Family Fund, though you are less likely to obtain help if your family income is over £23,000 per year or you have savings of over £8000. They have funding for over 80,000 families, so it is well worth applying.

You can apply once a year **every year**. Things you might apply for could include:

A holiday

Outings

Fridges/freezers/ etc

Beds

Transport costs (if you are NOT already receiving higher rate DLA mobility allowance)

Driving lessons

Visiting costs if the child is in hospital

Specialist play and leisure equipment

Removal expenses

Contact them for a form - 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 reasonably fast - around 6 weeks. (The Fund can also give you leaflets on other charities who fund children with autism/special needs).

The Family Fund

PO Box 50

York

YO1 1UY

Tel: 0845 130 4542

Cerebra – 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.
Also Speech and language vouchers for £500 for children who have not received direct input from a qualified SLT for over 6 months.

Frank Buttle Trust – can supply and fit white goods for families in need. Must have application form filled in by a recognised authority. Contact Family Support team at the Markfield for help. 020 8800 4134.

Tottenham Grammar School Foundation
A local fund which 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 – 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. Or Apply to : Mr G Chappell, Tottenham Grammar School Foundation, P O Box 30498, London N13 5XU. Tel: 020 8882 2999.

Haringey Autism

Secondhand computer provision for children with autism in Haringey at use at home. A free service when we have them in stock. Contact Petra Herzig on 020 8883 0060. If you already have a computer but would like suitable software for your child to use on your own computer to help with language development, mouse skills, literacy or numeracy contact Julia 8889 8422.

DISABLED PARKING BADGES

c/o Haringey Council x Disabled Parking. Tel: 8489 0000. 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 such as your GP or health worker to obtain one. Within Haringey, you need to apply to the Disabled Parking 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 Station Road, Wood Green and get the badge in person. 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

(No congestion charge also if you have a Blue Badge! You need to register

though and there is a one off £10 charge for this. Write to Blue Badge Congestion Charge, Dept TR 121, FREEPOST, SWC 1539 PO Box 35, Leominster HR6 0ZZ, or e-mail: information@ccbluebadge.com quoting code DN08 and the serial number of your badge)

Tottenham District Community Fund – grants for carers of disabled children who have lived in Tottenham for over 3 years of up to £400 for desperately needed household items and repairs. Contact Mandy at Haringey Autism for more info. 020 8341 2633 or email her on mandy_hellawell@yahoo.co.uk

Leisure

Leisure provision for children with autism and aspergers in and around Haringey

- Kids City. Inclusive drop in play sessions welcoming under5s with disabilities and their carers. Wed 1- 2.45pm, Thursday and Fridays 10 – 1pm. 100 Tower Gardens, London N17 2QA. Call Caroline Hylton on 07960 046910.
- Markfield Project – all ages, holiday and after school playschemes for autism and Aspergers and siblings. (Long waiting lists for playschemes so sign up early!! You can always decline when a place comes up if you no longer need one) Term times second Saturday of the month adventure playground 11 - 3. Friday Parent support group, term times 10 - 12. Under 5s drop in and soft play Weds and Thurs – call for times. Individual advice. Training courses. Tel 020 8800 4134.
 - Resources for Autism , fantastic 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. Sunday morning sports group for children with autism and other disabilities run by adult volunteers. Free. Ages 5 – 14. Drop your child and any other siblings off at Ackland Burghley School and enjoy 2 guilt free hours on Parliament Hill! Keen often also run a midweek session of arts and drama, and other trips dependent on demand. NB There are WAITING LISTS here too! Sign up and expect to wait a year at least!!! Tel: 020 7250 0012 www.keenlondon.org
 - Haslemere Road, N8. Daytime activities, social skills and overnight respite for over 11s. Placement through social services only.
 - YASS! (Young Autistic Spectrum Socialising). Family activities in

holidays and half terms. Christine Marchesi. No waiting lists! Tel 020 8449 5251

- Kith and Kids – all disabilities including autism and Aspergers. 'Social Training' – 2 weeks of lifeskill development projects, for all ages from very young to very old. Also a camp week in Kent. 2-3 year waiting list. Tel 020 8801 7432
- Team Spirit at Brook/Riverside Moselle School. Ages 9 – 16 approx. After school and holiday club. Despina 07906 619319.
- Palace for All, The Old Laundry, Sparsholt Road, N8. 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.
- Haywards Adventure Playground, Market Road, Islington N7 9PL. 10.15am to 3.15pm in holidays. A special needs playscheme for over5s where you can drop off your child and siblings for the day for around £7/day/child provided they know your child in advance. Call Steve Roach on 020 7607 0033.
- Click Club – wonderful social club for 11 – 19 year olds on Wednesday evenings run by Barnet NAS. Haringey families welcome. Deborah 07950 688309.
- Muswell Hillbillies – social club for Haringey mainstream secondary school attending children with autism/aspergers. Wednesdays termtime after school. Muswell Hill Youth Centre (behind M and S car park). Run by autism team 020 8489 5084.

Autism friendly sports and activities

Football

Alexandra Palace group – termtimes Wednesday 5 – 6.30 on the cricket pitch, ages 6 – 14 approx, autism and Aspergers. Run by a football coaching group at Alexandra Palace with help from the Spurs special needs coaching team. Call Gareth or Dan at Spurs for info 020 8365 5159.

Swimming

Archway Pool, Macdonald Road, London N19. Special needs session 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 – for children with special needs – every other Sunday in Enfield. Can't find the number – try googling!

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. Call 020 8363 1711.

Tottenham Green Leisure Centre Pool – sometimes have special needs swim, and Special needs swimming lessons Call 8489 5322 for details.

Offers Club Swimming at Borehamwood on Saturdays 4:30pm-5:30pm at The Venue, Elstree Way, Borehamwood, WD6 1JY. For all the family with a member with a disability. Free. For more information contact Pat 020 8207 6521.

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 asd– 020 8216 3796/07866 198594

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.

Haringey Autism holds a number of Saturday morning sessions at Somerford Grove Adventure Playground in Tottenham spring to autumn.

Enfield NAS holds Sunday sessions every three weeks approx Spring to Autumn at Florence Hayes Adventure Playground, Angel Edmonton.

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. 020 8800 4134

Also in neighbouring boroughs

Timbuktu Playground in Hornsey, Islington has just started autism sessions.

Springfield Park in Hackney has an adventure playground.

Haywards Adventure Playground in Islington also caters for children with special needs.

Drama and Puppet making

Haringey Shed – the local branch of the Chicken Shed theatre. Inclusive drama groups for primary and secondary children run at Northumberland Park School, Highgate Primary and Crouch End library. Haringey Shed are based at the Bernie Grant Arts Centre in Tottenham on Town Hall Approach Road, N15. email info@haringeyshed.org

Turtle Key Opera – fantastic annual course held at the Royal Opera House leading to production for children age 10+ with Aspergers. Tel 020 8964 5060.

Puppet making clubs – 5 – 11 years and 11 – 16 years. Little Angel Puppuppet Theatre. Suitable for high functioning children. Contact Slavka or Sarah Schofield.

Music Therapy

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

Resources for Autism. 858 Finchley Road, NW11. Tel 8458 3259. Anne Woodward.

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

Music for under 5s children with special needs at Kid City drop ins. 100 Tower Gardens Road, N17

Dance for children with autism

I Can Dance – Dance for Special Needs ages 3 plus. Recommended by lots of parents! Call Juliet. 07931533955.

Hop Step Jump – weekly sessions every Thursday at Expressions Studio in Kentish Town for children with autism. Erin Carter. 07968 778757.

Cycling

Pedalpower - For young people and adults – cycling in the park in Finsbury Park on specially adapted trikes and recumbent cycles. Alternate Saturdays 11 – 4. See their website for dates.

Special Needs Trampolining

Sobell Centre, Islington – Wednesdays and Fridays 4.30 - 5, 5 to 5.30. Must book.

Queen Elizabeth's Girl School, High Street, Barnet. Monday evenings. Contact Ann Maria 8440 7881.

Special needs sessions also at Talacre Centre, Kentish Town)

Youth clubs

Markfield Project- a variety of clubs and activities throughout the week for all ages. 8800 4134.

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

Muswell Hillbillies. Social skills group for ASD children in mainstream secondary schools. Thursdays in term times after school at Muswell Hill Community Centre. Contact Linda Nevin-Drummond on 020 8489 5084.

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 Aspergers or high functioning autism**. The club holds workshops and discussions based on performance and visual arts and other creative disciplines. Contact 020 8964 5060.

Spectrum – a social club for girls with Aspergers – call Lesley 07714483485.(not to be confused with the other Spectrum club, run by Haringey Autism for adults)

Barnet NAS Click Club. - for children on the autistic spectrum aged 11 – 19 and their siblings of this age group which Haringey Autism members are welcome to apply to. The young people can use the extensive equipment in the gym with a qualified instructor, play table tennis or pool, use the IT suite or Art studio, and Playstation games, plus board games such as chess, scrabble, pictionary etc. Sessions for drama and using the music production studio will also be arranged, and they hope to have a film and photographic group too. Parents must attend for the first few sessions until the child feels comfortable in the club or until the facilitators are comfortable that the child no longer requires one to one supervision in the setting. The club will be held on Wednesday evenings from 6.30 to 8.30pm at Church Farm Youth Centre, Church Hill Road, EN4 8XE. Call Deborah 07950388609, or Marjorie on 07983985439, or Christine on 020 8449 5251.

Exposure – Media club – journalism, film making and desk top publishing skills (may be suitable for high functioning/Asperger secondary age children). Bigger Shoe Box, Muswell Hill Youth Club, Hillfield Park,N10.

Sailing

Sailability in Rickmansworth have one or two man sailing dinghys adapted for use by disabled children and adults. Virtually upcapsizable and operated by just one rope or tiller. Suitable for autistic people age 5 to 85 who like water! Contact Harry Codd on 01923 262528.

Riding

The Stables, Barnet Lane, Totteridge.07958 919437
Penniwells, Sewardstone Rd, Chingford, E4. 020 82074525

Cinema

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

Cineworld in Wood Green have a choice of 3 films and give out goody bags too. 10am.

East Finchley – Phoenix cinema - Kids Club – 11am, 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 12 noon which is also open to older children. Ticket £2 each or £10 for 5 – 10 people including at least 2 adults. Tel 020 8444 6789 for further information.

Get a CEA card. A nationally accepted cinema card that gives free entry to the carer. £5, lasts 3 years.tel 0845 1231295 or www.ceacard.co.uk to download an application form.

Autism friendly screenings are being held by the Picturehouse group of cinemas in Stratford, Brixton, Clapham and Greenwich. The soundtrack is turned down a little and low lights are left on the auditorium. Tickets are only £2 and current films are screened. For more info email alice.w@picturehouses.co.uk

Jewish group

Jasper Trust – is a new Jewish group for families who have a member with Aspergers. For more information email jaspertrust@hotmail.co.uk

Norwood – fantastic jewish run charity for lots of provision including under 5s special needs drop ins

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.

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 email paulmari@onetel.com

Computer clubs

SNAAP Computer/Media/Arts club. Based in Barnet's Finchley Catholic High School, this club is for children aged 3-18 and their siblings. Free to users. 3.30 - 6pm Wednesdays termtime, and sometimes in holidays. Families can stay as long as they like - children receive support from a team of trained support workers. See website www.snaaponline.co.uk The website is now saying this is a service for Barnet children but it is worth asking if your child would suit this club.

SUPPORT GROUPS AND HELPLINES

Haringey Autism (NAS Haringey)

Meets first Thursday of every month during term times at The Village Club, 27 Alexandra Gardens, London N10. (Or sometimes second Thursday if term begins in the few days after the first Thursday) For local parents of children with autism/Aspergers. Mutual support, friendship, speakers and a lot of coffee. Plus lending library. Monthly newsletter. Call for details of future meetings and to be added to mailing list. Newsletter and all events free of charge -Julia Wilkins 8889 8422. Petra Herzig 8883 0060. Website: <http://haringeyautism.port5.com> (Or go to google.com and type in the keywords 'haringey' and 'autism')

Markfield Project and Parent Partnership Scheme – Friday parents group (run by same Julia who runs Haringey Autism) 10 – 12 in term times, plus individual sessions to help parents with education and parenting advice. Call 020 8800 4134 and ask for the Family Support team. Rachel, Bola, Julia, Kate, Ruth

National Autistic Society. Huge and very good website. www.autism.org.uk

NAS Helpline with language help in 55 languages if required. 0845 070 4004

NAS Advocacy for Education Service: 0845 070 4002

NAS Parent to Parent Service: 0800 9 520 52

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. Carol and Helen. Tel: 8801 7432.

Resources for Autism

Group based in Finchley running frequent training courses for parents of children with autism, with advice on education and statementing etc. They have an extensive library of books about autism. (For the children there are art and music therapy classes. Also summer play schemes, a Saturday club for children with autism and Aspergers Syndrome aged 8 - 11, and a Wednesday youth club for teenagers on the spectrum.) They regularly run holiday playschemes in Haringey. Tel: 020 8458 3259.

YASS!

Young Autistic Spectrum Socialising. Parent run group based in Barnet who run frequent family get togethers in parks throughout the summer holidays plus other events. Call Christine Marchesi for details on 8449 5251

Haringey Dyslexia Support Group - support and reading and writing tutors for

children with dyslexia and related problems. Call Mons 5-7pm 020 8348 4292. Try also Waltham Forest Dyslexia Association for cheap dyslexia screening and classes.

Harts for Families support line 0845 303 2350. Advice for Haringey families on housing provision, benefits, special needs provision.

CARIS – Fantastic advice team based behind St Ann’s Church on 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. 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.....The amazing NAS website

you can find most things on the NAS website(www.autism.org.uk) – check out their factsheets A-Z section – great sheets on toileting problems, eating problems, sensory problems, transport, education and everything imaginable on autism and Aspergers.

How can you help your child at home?

I'm going to split this most important of all sections into the following few issues - 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 book on autism and communication and there are literally hundreds of books on behaviour by both professionals and parents. But these are the issues that I hear again and again from parents that concern them at home, and some starting ideas that I feel can help.

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?

I'm going to say he rather than he/she or it from now on, as it's easier.

Apologies if you have a girl!

What can you do?

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

1) **what the behaviour achieves for the child**, (does he 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 2) **what prompted the behaviour?** (is this an 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?)

Firstly about 1). Does he get to avoid something he fears?

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 and 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 headphones or ear defenders if they often put their fingers in 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.

My first suggestion – go to the website www.sensory-processing-difficulty.com and start with their checklist. I think you will 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.

2. 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. (A few perversely 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, or download free ones at www.do2learn.com. 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

Symbols on the move –

If you have an Iphone 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! For a great free download try www.miasapps.com

Or is it point 2?) What prompted this behaviour? Is he overloaded?

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. One step sentences. Not ` 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 'Jack, coat on.' And when he's got that part, 'Coat on, then bus' might be acceptable for a child that can cope with a 2 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. I can guarantee you will never 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 I see our 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.

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

There is a good CD-Rom called Speaking for Myself Plus. The home version is not expensive – it is very good for encouraging very early language and sentences and teaches also lots of Makaton signs. Buy online.

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! Followed by saying 'bu bu bu bu bu' or AAAAAAH! Dada is easy to teach this way, as is Mama.

Teach the word 'more', and blow some bubbles with a bubble tube (cheap to buy in any poundstore). They learn, other children can model this, that saying more means you'll blow more bubbles. Bu-bu is a good approximation of bubble too.

The word 'more' is really useful around meal times, for you to say he must eat more, or for him to say he wants more.

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 – ask Julia for some examples via email or see the NAS factsheet on social stories.

Waiting and understanding 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 **Everyday Problems**.

Toileting – a big one this for most 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, sweeties, 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.

Lots of our 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 more parents are choosing to use laxatives such as Lactulose and Movicol (on prescription only).

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 normally 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. 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 problems to the parents group, to the NAS helplines, the CDC, the autism team, your SENCO, or to the internet. 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.