

This leaflet was created by the Bexley Autism Advisory Service in collaboration with Oxleas NHS, Bexley NHS Commissioning Group and Bexley NAS.



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# AUTISM SPECTRUM DISORDER INFORMATION FOR FAMILIES IN BEXLEY



A collaboration between:



*“We know what we are, but not what we  
may be.”*

*William Shakespeare*



## Notes



## Notes

## Introduction

Autism Spectrum Disorder (ASD) describes a complex range of developmental disorders which affect around 1 in every 100 children. Children with an ASD all have difficulties in three main areas of social development:

- **Social interaction** - how they approach or receive approaches from others, working cooperatively
- **Language and communication** - processing or retaining verbal information, regardless of whether they are non-verbal, verbal or highly articulate
- **Imagination and Flexible thought** - ability to predict or anticipate; track others' thoughts, actions or intentions; cope with change

And many will also have difficulties with:

- **Sensory processing** – unusual reactions to sights, sounds etc, integrating information from different sources at the same time, for example, listening and doing

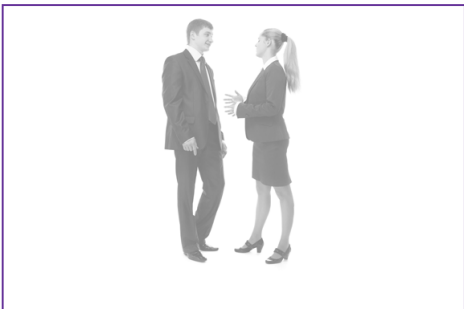
Children with these difficulties are often said to have an *autism spectrum disorder*. This is because there is a wide spectrum of ability; the effect will vary according to the individual. Many children with ASD have additional or profound special educational needs but many are of average or above average ability and successfully attend mainstream schools alongside their peers.

Children often have excellent mechanical skills such as reading or numeracy, but may need to be directly taught how to apply their knowledge in practical, problem solving situations.

However they are affected, the autism will always influence the way an individual thinks, learns and relates to the world. The unique way in which autism affects each child means that they, as well as their families, have needs requiring understanding and / or support.

In line with national guidelines (NICE clinical guideline 128, September 2011, [www.nice.org.uk/cg128](http://www.nice.org.uk/cg128)), the term *Autism Spectrum Disorder* is now used by UK diagnostic teams to describe all conditions on the autism spectrum including terms previously used such as, Asperger Syndrome and High Functioning Autism.

Although ASD is a lifelong condition, and is unlikely to be 'cured', there are strategies that can manage difficult behaviours and help the child to socialise, communicate and learn. This booklet contains information for parents on some of the services which are currently available. It is not meant to replace personal contact. If you would like to talk to someone, please contact the parent support organisations, Bexley SNAP or Bexley NAS (see list of local organisations on page 14) who can link you to other professionals or other local parents if you would find that helpful.



## Notes

## Useful Contacts

Residents with an 'eligible' disability can apply for a **Freedom Pass** which offers free travel on London's public transport. For further information go to - [www.inspirecommunitytrust.org/inspire-services/transport](http://www.inspirecommunitytrust.org/inspire-services/transport) or apply at [www.tfl.gov.uk/tickets](http://www.tfl.gov.uk/tickets)

**NAS** help on how to apply to Social Services for support, what you're entitled to, how to get an assessment and how to complain: [communitycare@nas.org.uk](mailto:communitycare@nas.org.uk)

**iPhone and iPad** apps for communication [www.mashley.net](http://www.mashley.net)

**IPSEA** is an organisation that gives independent advice on special educational matters, law, appeals and so on. [www.ipsea.org.uk/](http://www.ipsea.org.uk/)

### Dentist (SEN Specialist) in Bexley

Bexley and Greenwich Primary Dental Care Service  
Head Office ☎: 020 8331 3950

**Bexley Beavers Swimming Club** has swimming every Friday at Crook Log and are currently applying to become a registered charity. Find them on **Facebook**

**Cinema card** (carers go free) [www.ceacard.co.uk/](http://www.ceacard.co.uk/)

**Merlin's Magic Wand** [www.merlinsmagicwand.org/](http://www.merlinsmagicwand.org/)

**Family fund** 📄: [www.familyfund.org.uk/grants/how-to-apply](http://www.familyfund.org.uk/grants/how-to-apply)

And finally, to get you in the festive mood ...

### Churchill Theatre - Cinderella – Relaxed Panto

Wednesday 4 December 2013 @ 1.30pm  
To book tickets or discuss further, contact:  
**Jackie Vaughan, Churchill Theatre Bromley**  
Monday am, all day Tuesday and Thursday

☎: 020 8290 8225

✉: [jackievaughan@theambassadors.com](mailto:jackievaughan@theambassadors.com)

📄: [www.atgtickets.com/bromley](http://www.atgtickets.com/bromley)



## Some typical traits of children with ASD

- Does not respond, or responds inappropriately to approaches from others
- Stands too close/far
- Difficulty reading facial expression, body language
- Takes you literally, has difficulty understanding jokes or sarcasm, 'I could eat a horse'; 'That was clever, wasn't it?'
- Can appear rude, 'Would you like to get on now?' - 'No!'
- Says the wrong thing at the wrong time, speaks to strangers on intimate terms
- Laughs inappropriately for no apparent reason
- Speaks oddly or sounds pedantic
- Has difficulty initiating conversation or knowing when to stop
- Mismatch between content and tone, eg talking cheerfully about a sad event
- Asks the same questions over and over
- Upset by change
- Difficulty expressing or managing emotions or responding appropriately to emotional states of others
- Talks to you as if you know things you don't, such as people or places
- Has difficulty with comprehension that goes beyond the literal eg, 'Why did X do that?' 'How did X feel about....?'
- Has special, obsessional ways of doing things, getting upset if they can't do things in a certain way
- Seems socially naive, easily led, vulnerable to teasing
- Focuses on detail, not seeing the big picture or rule that links parts together
- May be sensitive to smells, sights or sounds not noticed by others
- Has poor co-ordination disliking physical activities, such as games and P.E.
- Lacks common sense, poor sense of danger
- Has problems knowing what is fact or fiction, real or pretend

## Assessment and Diagnosis

ASD is a complex disorder and is not always easy to diagnose. People close to a child may be aware something is subtly different about the child's social and communication development, particularly in terms of behaviour or delayed speech but it can be some time before the process of assessment is begun. In most cases, this will happen either pre-school or in the early years of primary. For some, especially girls, the difficulties the child presents are on the margins of the condition and a diagnosis may not be sought till much later.

With parental permission, a child may be referred for assessment by the family doctor, health visitor, a speech therapist or other health or education professional.

### What is the Role of the Autism Assessment Service?

The diagnosis is made by a multi-agency team, supported by information drawn from all those involved with the child, such as parents, speech and language therapists, teachers, specialist teachers and educational psychologists. In this way every aspect of the child's strengths and difficulties is taken into account in making a diagnosis.

In Bexley, following national guidelines, there is a multi-agency assessment service (A.A.S.) headed by a consultant paediatrician experienced in diagnosing Autism. A diagnosis may also be made by an alternative, recognised centre of expertise such as Bexley CAMHS. (See page 13 for details).



Parents have found the following books helpful:

**The Complete Guide to Asperger's Syndrome:** a guide for parents and professionals. ISBN 1 978 1 84310 669 2 – Tony Attwood

### Autism: The Facts

(Oxford University Press 1993 reprinted 1998) ISBN 0 192623 27 3  
- P Bolton and Simon Baron-Cohen

**The Autistic Spectrum:** a guide for parents and professionals  
ISBN 0 094751 60 9 – Lorna Wing.

**I am Special:** (Introducing Children and Young People to their Autistic Spectrum Disorder) ISBN 1 85302 916 5.

There are many books written by people with ASD describing their experiences which give insight into how it feels for them including

### A Real Person – Life on the Outside

ISBN 978-0285636620 - Gunilla Guerland

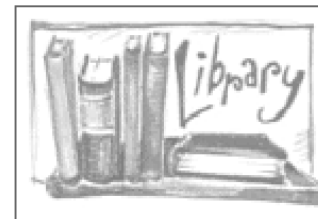
### Pretending to be Normal—Living with Aspergers

ISBN 1 85302 749 9 - Lianne Holliday Willey

**The Reason I Jump: One Boy's Voice from the Silence of Autism** ISBN 978144776751- Naoki Higashida

**Curious Incident of the Dog in the Night Time** ISBN: 0099450259  
- Mark Haddon

Bexley SNAP have a lending library of books about ASD to borrow free of charge. (see page 14 for contact details)



# Useful Books

A wide range of books on ASD and Asperger Syndrome are available from:

**National Autistic Society** Publications Lists:  
020 7903 3595 – see website on Page 17

## **Jessica Kingsley Publishers**

☎: : 020 7833 2307 Fax: 020 7837 2917  
Website: [www.KP.com](http://www.KP.com)

These books are suitable for children around 10 years and above, available from this publisher:

### **Blue Bottle Mystery**

ISBN 1 85302 987 5 - Kathy Hoopman

### **Of Mice and Aliens – An Asperger Adventure**

ISBN 1 84310 007 X - Kathy Hoopman

### **All Cats Have Asperger Syndrome**

ISBN 978 1 84310 481 0 - Kathy Hoopman

### **Freaks, Geeks and Asperger Syndrome**

A user guide to adolescence

ISBN 978 1 84310 098 – Luke Jackson

### **Survival Guide for Girls and Women with Asperger Syndrome**

ISBN 9781849058360 - Lianne Holliday Willey

**My Brother is Different:** (Barbara J. Morvey) and other books for parents and young children who have a sibling with Autism. [www.nas.org.uk/pubs](http://www.nas.org.uk/pubs)



## **The core members of the A.A.S. include:**

- Consultant Community Paediatrician
- Specialist Speech and Language Therapists
- Specialist Educational Psychologists

**At the pre-school stage**, those involved in identification and referral for diagnosis are likely to be: professionals working closely with parents, eg health visitors and / or general practitioners; pre-school or nursery staff.

**At the school stage**, those involved may include: teachers; members of the educational support services; educational psychologists working with the pupil in school; and community doctors working within the health service.

## **What happens if a child is referred to the A.A.S?**

A brief overview of Bexley Autism Assessment Service - referral to final assessment. Further information is available from the A.A.S. Team secretary. (See page 12 for details)

When a child is referred for investigations into a possible Autism Spectrum Disorder, with your agreement, questionnaires are sent to parents/carers and to your child's school/nursery to ensure they have the most comprehensive picture about your child's social functioning in a range of settings.

When all the necessary information is received, your child will be seen within 12 weeks for an initial appointment by one of the medical team (paediatrician). Further information will be gathered around your child's medical and developmental history, from birth to the present day. Your child will also be examined and developmentally assessed. Blood tests may be ordered, if

thought appropriate, so that other conditions can be considered / ruled out. From this appointment, referral to appropriate support services can be made, if not already in place. The information gathered will then be discussed at the A.A.S. monthly team meeting, with doctors, speech and language therapists, educational psychologists and team secretary present. At this meeting, an appropriate plan will be made in order to conclude the diagnostic assessment process.

### What happens next?

A concluding assessment session will take place at the Children's Development Centre, Queen Mary's Hospital, with the core team members present along with parents/carers. A representative from school is also invited to attend. Your child will undergo the 'Autism Diagnostic Observation Schedule' (ADOS), a widely-used semi-structured, standardised assessment of communication, social interaction, play / imaginative uses of materials, and restricted and repetitive behaviours. Then all the information gathered from parents/carers and school, as well as your child's strengths and needs will be discussed, and, if appropriate, a diagnosis of Autism Spectrum Disorder will be given. (Other conditions, such as Attention Deficit Hyperactivity Disorder, motor coordination difficulties, may also be discussed during this meeting).

Within 4 weeks you will receive a full report of the assessment. With your permission, a copy will also be sent to your GP, school and any other relevant professional.

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## Useful Websites

### The National Autistic Society (NAS)

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

For information sheets:

[www.nas.org.uk/infosheets](http://www.nas.org.uk/infosheets)

For publications:

[www.nas.org.uk/pubs](http://www.nas.org.uk/pubs)

### OAASIS Information Sheet

Autism Spectrum Disorder and motivation for Advice, Assistance, Support and Information on Special needs

[www.oaasis.co.uk](http://www.oaasis.co.uk)

### ACE – Advisory Centre for Education

[www.ace-ed-org.uk](http://www.ace-ed-org.uk)

☎: 0808 800 5793

### Autism Independent UK

[www.autismuk.com](http://www.autismuk.com)

☎: 01536 523274

[www.info.autism.org.uk](http://www.info.autism.org.uk)

Useful daily tips for parents

### Facebook 'Autism Sparks'

### One parent's view

[www.mysonsnotrainman.com/blog.html](http://www.mysonsnotrainman.com/blog.html)

### Websites for resources and strategies

For educational toys, games and resources for emotional awareness, traffic light timers, and motor skills etc  
[www.learningresources.co.uk](http://www.learningresources.co.uk)

[www.kansasasd.org](http://www.kansasasd.org)

[www.do2learn.com](http://www.do2learn.com)

[www.thegraycentre.com](http://www.thegraycentre.com)

Emotional understanding, anxiety and self regulation

[www.amazingawarenessbands.co.uk](http://www.amazingawarenessbands.co.uk)

[www.5pointscale.com/](http://www.5pointscale.com/)

[www.kidscandream.webs.com/page12.htm](http://www.kidscandream.webs.com/page12.htm)

### eBay shop 'extra-special-friends'

Free social story templates, printable home visual supports, home routines, emotion flash cards etc. Ready laminated social stories, reward charts, PECs support

### Fiddle toys and Chewables

[www.amazon.co.uk/chewelry](http://www.amazon.co.uk/chewelry)

# Other Useful information

## MEDIC ALERT

Autism wristbands have been designed by people affected by autism. They provide vital personal and medical details in an emergency or if a person with Autism wanders off or goes missing.

[www.medicalert.org.uk](http://www.medicalert.org.uk) ☎: 0800 58420

## ACCESS TO PUBLIC TOILETS

A personal RADAR key for access to a toilet for the disabled can be purchased for a small charge. You will need proof of disability. RADAR keys can be obtained from the management and security offices at the Broadway Shopping Centre, Bexleyheath on the first floor.

RADAR National Key Scheme: ☎: 020 7250 3222

## DISABILITY LIVING ALLOWANCE

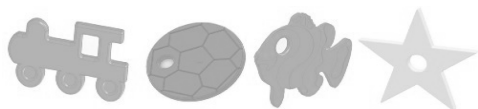
This is a non means tested benefit for adults or children with an illness or disability who need:

- Help with getting around
- Help with personal care, or
- Help with both of these

Many children with ASD are entitled to Disability Living Allowance

For more information contact: The Benefit Enquiry Line 0800 882200

Personal Independence Payment (PIP) Information for those over 16: [www.gov.uk/pip](http://www.gov.uk/pip) ☎: 0845 850 3322



# What if the Child does have an ASD?

The assessment team will:

- Discuss a management plan for the child with the parents and other relevant professional, for example, the teacher
- Provide information on the condition and signpost parents/carers to relevant support agencies and organisations
- Give parents the opportunity to raise immediate questions
- The paediatrician will liaise with other health professionals, education and social services where necessary and advise on any specific referrals that have been agreed to, for example, to the Educational Psychology Service or Positive Steps. (See page 13 for details of these services).
- They will forward a copy of their findings to the Bexley Advisory Team for ASD for information. (See page 12 for notes on how a child is referred to this team)

While all children with autism will benefit from an informed and supportive educational environment, not all will need specific intervention or additional support.



# Post Diagnosis

Follow-up after diagnosis may be offered by a range of professionals.

## Pre-School Children

Services available are:

- **Children's Centres** may be able to offer advice and information about your local support. (See Page 12 for contact details)
- **Positive Steps** is an 8 week parenting programme offered by a multi agency team, which aims to help parents where their child presents with challenging behaviours. (See page 13 for details)
- **Bexley Early Autism Service (BEAS)** part of the Specialist Teaching Service, can visit you and your child to offer support. This service is accessed via the Educational Psychology Service (See page 12 for details)
- **NAS EarlyBird Programme**, a 12 week course for parents of pre-school children with autism, devised by the National Autistic Society. Further information can be obtained via local co-ordinator (See page 12 for details)
- If appropriate, a **Specialist Nursery** placement may be sought via the Educational Psychology Service



# National Organisations/Contacts

**The Family Fund** - For grants to help with expenses incurred as a result of caring for a disabled child. For further information go to [www.familyfund.org.uk](http://www.familyfund.org.uk) or [info@familyfund.org.uk](mailto:info@familyfund.org.uk)

☎: 0845 130 4542/ 08449 744099

**The National Autistic Society** - A U.K. charity which provides education, treatment, welfare and care to people with autism.

[www.nas.org.uk](http://www.nas.org.uk) ☎: 020 7833 229

All 0808 numbers are free from landlines and most mobiles

Autism Helpline: 0808 800 4104

Education Rights: 0808 800 4102

Parent to Parent: 0808 800 4106 (Confidential listening service provided by parent volunteers)

Information Centre: 0207903 3599

**Contact a Family (CAF)** - Gives advice, support and information to local parents' groups and to individual parents anywhere in the UK

☎: [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk) ☎: Freephone: 0808 808 3555



## Independent/Local Support and Information

**Bexley Parent Partnership Service** For independent advice and support regarding your child's education,

✉: [Mary.howard@bexley.gov.uk](mailto:Mary.howard@bexley.gov.uk) ☎: 0203 045 8407

**Bexley NAS** (Bexley Branch of the National Autistic Society) - a parent led group, offering support to parents/carers and a programme of activities for families living with ASD.

✉: [Bexley@nas.org.uk](mailto:Bexley@nas.org.uk) ☎: 07826 950 496

**Bexley SNAP** is a support agency for families of disabled children and young people in Bexley, and provides a wide range of services to both children and their parents / carers.

✉: [info@bexleysnap.org.uk](mailto:info@bexleysnap.org.uk) ☎: 020 8320 1488

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

Find them on **Facebook! Bexley SNAP**

**Bexley Voice** – a voluntary group of Bexley Borough parents of children with special or additional needs supporting parents and acting as a voice to ensure the rights and needs of our children are met.

✉: [bexleyvoice@hotmail.co.uk](mailto:bexleyvoice@hotmail.co.uk) ☎: 07512 409 936

**Bridging the Gap (SE)** – For adults with ASD and their carers

✉: [info@btgse.co.uk](mailto:info@btgse.co.uk) ☎: 020 8300 5444

**Carers' Support (Bexley)**

✉: [info@carerssupport.org](mailto:info@carerssupport.org)

☎: 020 8302 8011



## School age Children

Services available are:

- The **Special Educational Needs Co-ordinator** (SENCo) at your child's school will be able to work with parents to devise an individual programme (IEP) for your child based on advice from professionals involved and their own knowledge of the child in school. If your child requires further help in school, an individual assessment of need may be requested by school or parents, which could include assessment by an Educational Psychologist.
- Schools can refer to the **Autism Advisory Service** who will arrange to observe and / or meet with your child in school, depending on need. The SENCo can arrange for parents to meet with a member of the Advisory Team in school. Parents can access this service by appointment at the monthly 'Drop-ins' arranged by Bexley SNAP. (See page 14 for details of how to contact this Service).
- There is a range of educational provisions in both mainstream and special schools. Further information can be obtained from the school SENCo or Bexley Special Educational Needs (SEN) department. (☎: 0203 045 4451)
- **'Living with Autism'** is a programme of 6 weekly sessions designed to meet the needs of families whose child has received a later diagnosis of autism and is in school. (Access to this course is via Bexley SNAP.)



# Support and Information

**Advisory Service for Autism** - This service comprises of two advisory teachers and a small team of specialist support who work alongside them to deliver support / implement advice in schools. Referral to this Service is made by the school SENCo. Contact: Joan Ratcliff, Advisory Teacher for ASD for primary / Tracy McDonald, Advisory Teacher for secondary

☎: 0203 045 5003 / 5019 ✉: [Joan.ratcliff@bexley.gov.uk](mailto:Joan.ratcliff@bexley.gov.uk)  
✉: [tracy.mcdonald@bexley.gov.uk](mailto:tracy.mcdonald@bexley.gov.uk)

**Bexley's Children's' Centres** - A children's centre provides a one-stop shop within the community for parents and providers of childcare and family support, bringing together a wide range of services. Details of Children's Centres can be found at: [www.bexley.gov.uk/index.aspx?articleid=3241](http://www.bexley.gov.uk/index.aspx?articleid=3241)

## Bexley Early Autism Service

Can support pre-school children with autism and their families at home and school. (Referral to this service is via educational psychologist)

Contact: Joan Ratcliff, ☎: 0203 045 5003  
✉: [joan.ratcliff@bexley.gov.uk](mailto:joan.ratcliff@bexley.gov.uk)

**Children's Development Centre** - Queen Mary's Hospital, Sidcup. For enquiries about referral contact: Vicki Lupton, AAS Team Administrator, Bexley Community Paediatrics, ☎: 0208 302 2678 x 4748 ✉: [vicki.lupton@nhs.net](mailto:vicki.lupton@nhs.net)

## Early Bird Coordinator in Bexley

(EarlyBird is for parents / carers of pre-school children)

Contact: Joan Ratcliff, Advisory Teacher for Autism  
☎: 0203 045 5003 ✉: [joan.ratcliff@bexley.gov.uk](mailto:joan.ratcliff@bexley.gov.uk)

## Educational Psychology Service

Contact: Early Intervention Team Managers  
Ferwa Jaffery / Mike Johnson

☎: 0203 045 3107 / 4469 ✉: [ferwa.jaffery@bexley.gov.uk](mailto:ferwa.jaffery@bexley.gov.uk) /  
✉: [michael.johnson@bexley.gov.uk](mailto:michael.johnson@bexley.gov.uk)

**Positive Steps** - This programme is offered following initial advice and support from your health visiting team, educational setting, GP, speech and language therapist or paediatrician, should you continue to find managing your child's behaviours difficult.

For further details please contact the services above.

## Social Services

An individual assessment of need can be asked for, which may lead to a package of support, according to need and eligibility for services.

Contact: ☎: 0208 303 7777 and ask for 'Social Services' or 'Children with Disabilities Team'  
✉: [customerservices@bexley.gov.uk](mailto:customerservices@bexley.gov.uk)

## Speech and Language Therapist

Following referral, the speech & language therapist may offer advice regarding your child's communication level, appropriate strategies, programmes and workshops (for parent of pre-school Children).

Contact: Woodside Clinic ☎: 01322 521330  
✉: [SLH-TR.slt-admin@nhs.net](mailto:SLH-TR.slt-admin@nhs.net)

**CAMHS (Bexley)** - 'Child and Adolescent Mental Health Services' provide mental health treatment and services to children, young people and their families/carers. Access to this service is through referral by GP or any other professional involved in the child's network e.g. health, social care and education.

Contact: ☎: 0203 260 5200 [www.camhscares.nhs.uk](http://www.camhscares.nhs.uk)

