

Child Autism UK

releasing potential



**Autism: Information for Parents
- including 10 key tips for families**

www.childautism.org.uk

Autism: Information for parents, including 10 Key tips for families



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What is Autism?

A Brief Overview

Autism is a complex developmental disability that affects the way a child communicates and relates to the world around them. The underlying causes of autism are still uncertain. It appears likely from ongoing research that chemical imbalances in the brain, genetic factors and bio-medical disturbances may be factors.

Autism is described as a spectrum disorder, which means that children can be affected to different degrees, some severely and others in more subtle ways. All children with the condition will be affected by a range of impairments, which includes all or some of the following:

- **Difficulty with social interaction** (problems with social relationships, often appearing inappropriate or paying little attention to others, often finding the actions and emotions of others confusing).
- **Difficulty with developing imagination** (problems in developing imaginative play or having a limited range of repetitive and rigid play, difficulties with planning and problem solving).
- **Difficulty with social communication** (problems in developing speech or meaningful communication, difficulties using or understanding gestures or facial expression).

In addition, children with autism may (to a greater or lesser extent) have difficulties with:

- **Self Help Skills** (such as washing, toileting, feeding and dressing)
- **Physical Skills** (such as catching a ball, balancing, opening packets, holding a crayon)
- **Language Skills** (such as using and understanding the various components of language e.g. distinctions between 'he' or 'she', 'what' or 'where', 'on' or 'under' and so on, and such as following instructions)
- **Academic Skills** (although this is often due to issues of language difficulties and issues with group learning)
- **Attention** (when not on the child's terms)
- **Inconsistent Sensory Input** (such as being under or over sensitive to touch, textures, sights, sounds, tastes and smells)
- **Sleeping Patterns**



How does Autism manifest itself?

While the range of resulting scenarios and behaviours is vast, here are some examples.

Some children may:

- Use a variety of non-verbal ways of getting items they want, such as pulling mum to the food cupboard, climbing up to the top toy shelf, crying and so on.
- Avoid eye contact
- Show aggression
- Have prolonged or unpredictable tantrums and appear frustrated
- Develop obsessional interests eg. Thomas the Tank Engine, dinosaurs, insects.
- Play with toys in unconventional ways eg. Preferring to line them up or concentrate on a particular part eg. A wheel on a car, or repeat the same scenarios over and over.
- Show anxiety when there is a change in routine eg. A different route to school, different helper at nursery and so on.
- Be in nappies and show no awareness of wetting or soiling
- Show strong likes or dislikes to: the texture of clothes, foods, noises, spinning or flashing objects, certain places such as the supermarket and so on
- Have actions they like to do over and over, such as flapping hands, jumping on the spot, flicking fingers, chewing sleeves, walking on toes and so on.
- Find it difficult to fall asleep without help and may sleep at erratic hours

Children on the Autistic spectrum may have difficulties in common areas, but within each area, the extent of the difficulties can differ greatly. ***As a result, each child has very different needs and therefore well planned, individualised treatment suited to those specific needs is vital.***

“ Child Autism UK has been a lifeline for me and my family since my son got his diagnosis ”

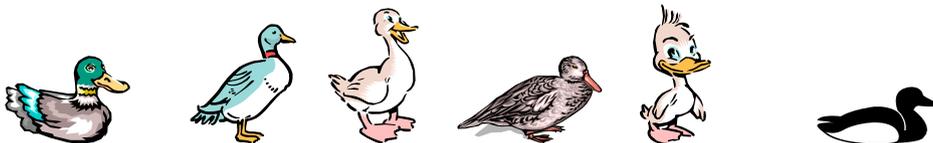
Survey of Parents

Autism - A Parent's Experience

Everybody was telling me what a good job I was doing because my nine month old son was so quiet and self-contained. He was not demanding, needy, clingy or any of the things his peers were. I can't remember ever feeling that his passivity was down to my parenting I always thought it was something in him. He didn't reach out to be picked up, point or wave bye-bye. For a long time though, I was able to tell myself I was being neurotic. People around me also shied away from any suggestion that there might be "something wrong." They'd say, "he's just in a world of his own", which I now know is an observation heard by lots of parents of children later diagnosed as autistic.



He was nine months old and happy to flip through his books on his own for up to an hour. He would listen to his music, transfixed and unmoving for long stretches. This was so unnerving that a friend once asked me to turn the music off, he was so disturbed by the sight of such a deeply transported child. When my son walked he walked on tiptoes. He would eat a whole tube of toothpaste if I let him and when we visited other people's houses he would often be found downing a tube of toothpaste in the bathroom. He flapped his hands for no reason and lined up his toys rather than played with them. I remember taking him to a friend's house and he went around the house collecting up about 30 ornamental ducks of all different sizes and types and lining them up. My friend thought he was a genius to do that.



Lots of things he did in his first two years convinced everyone around us that he was a genius, which it turns out rather cruelly, is a common early "amateur" diagnosis for an autistic child.

He did begin to talk but he labelled everything, he never requested things verbally, so although he could say "biscuit" he wouldn't say it to get a biscuit, he'd pull me across the room by my finger toward the biscuit tin, screeching. At about two years 90% of his speech was echolalia: recitations of books he'd memorised or songs he knew – over and over and over. Proof that speech is not communication.

When his younger brother was born he didn't notice him at all. The difference between a child actively ignoring someone and a child who doesn't even know someone is there is difficult to understand until you see it in your own child.

When we finally began to explore obtaining a diagnosis he was two. I was so frightened of mentioning 'the a-word' to my health visitor that my husband ended up having to take him. My son was finally diagnosed at just three by which time I knew he was autistic; I just needed the piece of paper that confirmed it in order to ensure we could get the most appropriate provision in place for him. There's nothing so angering and heartbreaking as having to push to get a doctor to tell you news you do not want to hear.

Federay Holmes

“ It's fantastic support for our son and the whole family ”

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Ten Key Facts About Autism

Scale of the Problem

- One in a hundred children born are diagnosed as being on the autistic spectrum.
- A survey of 200 LEAs revealed 87% of respondents perceived an increase in children diagnosed with autistic spectrum disorder (ASD) over last five years.

Getting a Diagnosis & Obtaining Support

- Getting your child diagnosed and therefore obtaining access to support is often incredibly difficult and most children are not picked up at an early stage when their brain is most receptive to help.
- The average age of diagnosis for a child with autism is 6 years, while for a child with Aspergers Syndrome the average age is 11 years. Most parents notice something is wrong at 15 months old.
- Over 50% of the parents with children with autism reported difficulty getting LEA funding for their child's education, 33% of Under 5's and 20% of Over 5's received no funding at all.

Cost Financial & Personal

- The annual total cost of autistic spectrum disorder in the UK is at least £1 billion. Evidence suggests that even a moderate increase in education provision could potentially result in major savings in later living costs.
- The economic consequences to parents of having an autistic child living at home include an annual loss of earnings estimated as at least one-sixth of average disposable income.
- Stress levels in ~50% of the mothers of autistic children were assessed to be very severe in the 'critical' range with mothers experiencing more symptoms of stress than parents did with children with other disabilities.
- 60% of children with typical autism will grow up to be dependent on adults in all aspects of life.

Behavioural Intervention

- In a significant study 47% of children treated with intensive behavioural intervention achieved "normal" functioning.



What is Applied Behaviour Analysis (ABA)?

An Overview

Behaviour Analysis is the study of environmental events that change behaviour. ABA is the application of this science and has been used to help many areas of society, from traffic safety to the treatment of eating disorders. The education of children with autism is one area in which these principles are successfully applied. It is an area which is supported and validated by a wealth of scientific research.

The Use of ABA In the Education of children with autism

ABA programmes for children with autism typically have two main components:

1. Skill-building: teaching the deficit behaviours (social interaction, communication, play skills etc)
2. Behaviour Management: decreasing behavioural excesses (self-stimulatory behaviours, non-compliance, aggression, rigidity etc).

The programmes usually have the following key characteristics:

Strategies Based On Applied Behavioural Analysis

- Strategies of Reinforcement are used to develop new skills.
- Targeted skills are broken down into small, attainable steps and built upon.
- Prompting and Shaping strategies are used to help the child learn quickly and easily.
- The functions of challenging behaviours (such as aggression or self-injury) are ascertained in order to reduce them and teach appropriate replacement behaviours.
- Collection and analysis of data is used to inform the development of the programme

One-to-One Instruction

Initially, instruction is provided in a one-to-one setting (with one tutor and one student). This arrangement promotes attending skills and decreases the likelihood of the child becoming distracted.

It should be emphasized that the longer-term goal of any ABA programme is to prepare the child for naturally existing distractions (e.g. the presence of other students in a classroom) and to shift from the one-to-one model to group instructions.

“ expertise and a tailored approach to the individual child and family, flexibility and dynamic thinking ”

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Intensity

Success in an ABA programme is generally considered to depend on the intensity of the programme, (Dr Lovaas - 1987).

Early Intervention

Another important variable in predicting success with ABA is the age of the child at the start. Research indicates that children who start treatment before the age of 42 months are likely to make the most gains.

However, children at any age can benefit from ABA and recent studies have also demonstrated its effectiveness for school-age-children. (Eikeseth, et al, 2002)

Family Involvement

For maximum success to be achieved, family participation is critical. Programmes typically start at home until the child is able to successfully interact socially with his/her peers.



The Child Autism UK Model

Child Autism UK is committed to providing 'best practice' services within a behavioural framework. The extensive curriculum is taught using a positive and child-centred approach.

A Positive Approach

- Motivation and positive relationships are key, children learn best when they are having fun and this is always a priority.
- The team ensure (through prompting and shaping procedures) that the child is successful at least 80% of the time.
- Emphasis is on teaching as naturally as possible across all environments (Natural Environment Teaching – NET), and on rapid generalisation of functional skills to new situations. This ensures the child experiences maximum success.
- Child Autism UK Case Managers work with parents, siblings and extended family members to include them. Parents are encouraged to become active members and managers of the team and to facilitate the generalisation of new skills.
- Child Autism UK takes a positive approach to Behaviour Management. Challenging behaviours are carefully analysed and wherever possible more appropriate replacement behaviours are taught.

A Comprehensive Curriculum

- The curriculum covers all aspects of the child's life with particular emphasis on communication, language, play and social skills. However, all areas of the child's strengths and needs are addressed including self-care skills, independence and behaviour management.
- Patterns of typical development and links to the National Curriculum are used as a basis for the curriculum. However Case Managers are trained to use flexible programming in response to the child's individual needs.
- Skills taught are always functional for the child, the child will not be taught a curriculum item unless they are able to build on it or make immediate use of it.

“ Professional effective service, without Child Autism UK I hate to think what my child's capabilities would be now ”

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An Individualised Approach

Child Autism UK appreciates that every child is unique and that autism can have a wide range of symptoms. This necessitates a flexible and child-centred approach. Therefore clinical staff have a wide range of strategies at their disposal such as:

- Discrete Trial Training (see Glossary)
- Verbal Behaviour Strategies (e.g. language development based on the work of Skinner (1957), teaching to fluency, errorless learning).
- Augmentative Communication Systems (e.g. such PECS (Picture Exchange Communication System) or sign language)
- Visual Support Strategies (e.g. Social Stories, picture schedules)

Instruction is highly personalised and delivered by a team of tutors supervised and trained by the Case Manager.

Child Autism UK clinical staff assess the individual needs of each child and make recommendations of intensity according to these needs. For most clients, Child Autism UK recommend that programmes run from 30-40 hours a week

“ Our child has achieved so much that would not have happened without the support of Child Autism UK ”

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Top Ten Tips for Families

There are many strategies that can help support children with autism. We've pulled together some of our favourites which we hope you find helpful.

1. Catch them being good.

This is fundamental for increasing your child's self-esteem and improving behaviour. It's so easy to notice when things are wrong but frequent use of this one tip can transform your relationship with your child and help them understand what's expected of them. In ABA speak, this is 'reinforcement'. It can be tiny actions at first e.g. 'Fantastic, you tidied your bricks', or 'Thanks for turning off the iPad'. For younger children non vocal reinforcement may work better e.g. a tickle, a hug, or a turn with a favourite toy

2. Find out what interests your child

This could be anything from nice smells, sounds, squidgy toys to fun computer games. The specific ABA strategy for this called 'reinforcement sampling'. These reinforcers can be used to increase useful behaviours such as communication. For example, a child can be encouraged to ask for bubbles only when you're sure they really want the bubbles. Items can only act as effective reinforcers if the child is still motivated by them. Favourites may change regularly, so try new things each time along with previous favourites.

3. Make time for quality time

Spend time with your child doing the things they enjoy so they associate you with good things. This is called 'pairing with reinforcement'. These slots may need to be very short at first, but with time will become longer and more interactive.

4. When your child needs to do something they don't want to, make sure you follow the activity with something they enjoy.

This is called the Premack principle and will increase the chances of them doing the first activity next time you ask. You can use a visual support with pictures of the First activity and the Next activity, or use 'First' 'Then' language depending on what works best for your child.

5. Keep language short and simple

Children with autism often have difficulty processing lots of words, particularly if they're upset. Using short phrases such as 'time to get your shoes' or 'shoes on' will be a lot more effective than 'ok you need to finish what you're doing, go and find your shoes, put them on and then get your coat and bag'.

“ Wonderful support at the end of the phone when you really need it ”

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6. Have high expectations

Parents who have high expectations usually help their children more than those who don't. For example, if your child is shy, still expect them to say 'hello' to you and others. If your child is non-verbal and pointing at something they want, name the item and look at them expectantly. If they make even a slight sound, give them the item straight away. Over time increase your expectations e.g. from 'u' to 'up', this is what we call a shaping procedure

7. Help more often than you think you should

Parents sometimes don't help because they think the child already knows what to do. Whether you think it's a 'can't' or a 'won't' situation, help anyway. There may be some other factors at play that you don't know about, for example social situations can create the same pressures that make public speakers forget what they were going to say. Even helping the child do something they've been able to do for a long time is better than them not doing it all. Provide a higher reward when they do the activity without help. This is called 'differential reinforcement'.

8. Help less often than you want to

Many children are held back from independence because their parents automatically help them without giving them a gentle nudge to do it themselves. With the ABA approach we use task analysis to break down a complex skill like handwashing into small steps. Most children can be taught by starting with small easy targets such as drying their hands and then chaining the steps together.

9. Be Consistent

It is often stressful for people with autism who aren't able to predict what's going to happen next. For some, visual timetables have a calming effect. For all children though, research has shown that parents who are consistent in their expectations and responses are more emotionally stable.

10. Observe, don't mentalise

If your child is not able to tell you why they do certain things, it is dangerous to guess. For example, if you think they're flapping because they're bored but actually they're over-stimulated and trying to calm down, then Introducing an exciting trip out could be harmful. Make lots of observations about when and where the behaviour occurs, what happened immediately before and afterward. This will help you build up a more informative and objective picture.



These tips are based on the science of ABA (applied behaviour analysis) but can be used by any parent not just those wanting to do full-time ABA programmes. These strategies can be built upon and tailored to each individual child. If you would like more help, or to apply for a more comprehensive package of support, please call the Child Autism UK helpline on 01344882248

Please also call this number for a fuller version of this pack or email your request to info@childautism.org.uk



About Child Autism UK

Child Autism UK is a national charity which supports children with autism and their families. A leading provider of Applied Behaviour Analysis (ABA) services, Child Autism UK is positive about the potential of every child and works to enable children with autism to realise that potential.

Mission Statement

Child Autism UK promotes Early Intensive Behavioural Intervention (EIBI) and helps parents of children with autism by providing support, information and choice.

Vision

Child Autism UK wants a world where the parents of children with autism get superior professional advice in a timely manner and, feel empowered to make informed decisions and appropriate choices. Child Autism UK wants to broaden the reach of ABA and ensure high quality provision is accessible to all.

Positive About Potential

Child Autism UK is positive about potential. We are passionate about releasing the innate potential of each individual child that we work with. We are also concerned about the future potential of ABA in the UK; the future potential of the parents we support, our volunteers, our staff and the potential of our own organisation to make a difference.

Positive About Potential underpins all our work.

Parent to Parent Helpline

Child Autism UK has a register of parents who have volunteered to offer their support to other parents. If you would like to speak to a parent in your immediate area who is running a programme we can try to arrange this for Child Autism UK members.

How can I contact Child Autism UK?

Our enquiry line is open during normal working hours. You can also fax or e-mail us and get information from our Website, as follows:

Child Autism UK, 3-5 Forest House, Horndean Road, Bracknell, Berkshire. RG12 0XQ

Tel: 01344 882248

Fax: 01344 882391

Web: childautism.org.uk

E-mail : info@childautism.org.uk

“ You have been a life saver. We as a family are so grateful. We would have been lost in a very deep, dark hole without you ”

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