

**Information for Parents  
on  
Autism Spectrum Disorders**

**South London and Maudsley**   
NHS Trust

Child and Adolescent Directorate  
National and Specialist Child and Adolescent Mental Health Service

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## Information for Parents

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### ◆ Letters from parents

A diagnosis of an autism spectrum disorder is often experienced by parents to be the end to all their normal expectations and of the hopes that they have for their child. Initially this experience can feel very much like a bereavement. The letters that follow have been written by parents who have been through the experience and understand what it feels like. They hope that you will feel encouraged and reassured by what they have to say.

## Letter from a parent

At the moment of diagnosis I think the world spun on its axis. There had been a long build up period of concerns being voiced but this was it.

Initially it didn't make much sense – I didn't know what autism was or what it meant in relation to my son. Unlike some people I have since met I hadn't 'always known' that there was a problem. Where had my son gone?...he was suddenly this diagnosis.

The next few years were turbulent to say the least. My family underwent many changes both personally and in relationship to the autism.

It was a major learning curve. I was now on my own and learnt a lot about myself, a lot about what autism was and most importantly what it meant with regard to my son. He was still my son, still my Christopher but I had to think differently to accommodate the autism.

Things move on and are constantly changing and to some degree this includes the individual who falls within the autistic spectrum. As a toddler Chris was very rigid, thrown by the smallest change to his routine. Today he is more flexible, open to trying new things yet every now and then out of nowhere comes the reminder that autism is a condition that does not totally disappear.

I can remember one day sitting on a bus with Chris watching the woman and her child sitting opposite us. The child chattered the whole time, asking questions until her mother told her to shut up. I remember looking at Chris and thinking that if he ever asked questions like that I would never tell him to shut up?! Such is life, I now have a son who relentlessly chats at me and asks questions (to which he knows the answers) and yes I do tell him to shut up!

So where are we now? Still working together to get Chris to reach his potential. Chris can still get into routines so I try never to let them establish in the first place, a fairly typical teenager obsessed with football and motor racing. Moaning about homework. Just beginning to travel independently on the bus (whilst I develop an ulcer). Chris now walks down to the shops on his own to spend his pocket money. I have just started leaving him home alone for short periods of up to 3 hours. In fact I got to go to the cinema with friends for the first time in years. It was wonderful.

Where this will end I have no idea. On a good day I can see Chris employed, living semi-independently even independently. On a not so good day he will live at home with me forever. What ever the outcome there is nothing I would change. Having Chris has brought so many positive things to our lives. Yes it is difficult, yes there are times when low is so low but it passes. I have met and made wonderful friends who really understand because a child of theirs has autism. And I have watched my son develop and grow. There is no such thing as a small development, a small achievement. Every step is a giant step forward – enjoy and celebrate.

### *Letter from a parent*

If you are anything like me, your mind will have been too numb to take in much of what the consultant said after the word 'autism'. I entered the clinic with my sweet though puzzling 3 yr-old and left holding the hand of a little stranger. It is no exaggeration to say that I felt bereaved. It was a while before I was able fully to accept that, of course, he had not changed, it was just that now I knew more about him than before. This was a helpful thought which marked the beginning of my coming to terms with the diagnosis. It also allowed me to begin finding out about the best way of helping him. What I found unhelpful and frustrating were the denials of some friends and relatives that there was a problem at all. Comments like 'lots of 3 yr-olds do that' or 'he's just shy' or 'my friend's little boy didn't speak till he was four, and he's fine', just made me angry. Though well-meaning, the effect was to trivialise the grief I felt and the very real difficulties my little boy was facing. Others, of course, were very supportive and as keen to learn more about the disorder as I was.

I began to read books and articles about autism, some of which were clinical and though very informative, rather depressing as well. I found there were lots of biographies and autobiographies about and by people with autism and these were really fascinating as well as encouraging, since I began to see that it was possible for a child with autism to make a lot of progress. I started to show my little boy how to do things that other children do instinctively, like pointing to and naming pictures and objects, and I tried to make sure I spoke to him in very simple, clear language. I had help from our local Portage worker in putting together programmes to help him learn specific tasks and skills and also from a speech therapist who specialised in autism. Gradually he made progress.

The most helpful thing, when at last I felt I could face it, was to meet other parents with similar children. The speech therapist put me in touch with another mother of a boy with autism and meeting her was a revelation! She was (still is) a warm, sensible, practical woman who met every problem with common-sense, determination and humour (the last probably being the most important!). I learnt a great deal from her, not the least being the discovery that it was possible to laugh again. After that I joined my local support group and began to realise just how many of us there are – so much for autism being a rare disorder! I felt a growing acceptance of the diagnosis and along with it, a more positive outlook and best of all, the knowledge that with such a large population of people with autism, there would always be someone to share my child's enthusiasm for classic cars, steam railways and guinea pigs.

Today, 10 years after diagnosis and now a teenager, my son is a fluent reader, enjoys the Beano and the Simpsons, greets new visitors politely and familiar visitors with enthusiasm, makes up games to play with his younger brother, fights over whose turn it is to go on the computer, enjoys eating many different kinds of food, is (slowly) learning Spanish and enjoys playing the trumpet he insisted on having for Christmas. He still has autism and his comprehension is much poorer than it appears. He would not be able to survive in a mainstream school because he would not be able to understand or return the social chat or jokes and would be very vulnerable to teasing and bullying. He has learned, one by one, the true meanings of expressions such as 'It's raining cats and dogs' and 'It's driving me round the bend'. His speech does not sound as naturally fluent as that of ordinary children and emotionally he is immature

for his age, enjoying the same jokes, for example, as his 8 yr-old brother. But it is now possible to see that, as an adult, he will be able to live happily away from home with minimum support, perhaps with one or two others with similar interests. I can also see that he will be more than capable of holding down a job which interests him – perhaps with a steam railway preservation society, or a job working with machines or engines. At school he takes pride in being helpful and I can see that he will have a lot to offer any group of which he is a member, whether at work or at home. This is not to say that I have no worries about his future – I know he will always be vulnerable and will need understanding and protection, but he is also capable, interested and full of life. There have been difficult times and I expect there will be more to come, but in my experience, nothing has been more difficult than the weeks following the diagnosis when the future looked so bleak.

I would like you to know that you are far from alone and there are good friends to be made who have also been through it and survived. Best of all, there will be moments of great satisfaction and enormous pride in your child's achievements. I felt, as I'm sure you feel at the moment, that life will never be the same again. Well, that is true, but what I couldn't know is just how interesting and rewarding it can turn out to be.

### *Letter from a parent*

When I was asked to write this letter, I promised myself I wouldn't write a sad or angry letter, but this subject can make you sad, angry, weepy, hard, emotional, determined, obstinate, persistent, amazed and dumbfounded to name but a few!

Almost seven years after "the world came crashing down around our ears" we, as a family are still here AND 'coping'. Our son was a happy little boy, a bit shy, a bit sensitive, BUT he seemed OK. He was talking very well for his age and learning to use the loo. (He was about 22 months). Then, his sister was born and his beloved Grandpop died within three weeks of each other. He started to behave strangely, tantrums, when he never had them before (I swear), he started to drop words from his large repertoire, he began to lie awake at night crying for no apparent reason. At first we put it down to sibling jealousy or upset over Grandpop (I took it very hard) BUT, when he spent a week crying and would not look at me or be comforted I knew it was more than this. Luckily, my Health Visitor was on the ball, when I told her what was happening her alarm bells started to ring! Within two weeks myself, my husband and two tiny tots in a double buggy were at an assessment clinic. Two hours later we were told (very harshly I must add) that our precious, precious boy was AUTISTIC!!! I have never before or since felt SO numb. It was the worst day of our lives. Various people have since told me it is like a bereavement, they are NOT wrong. Our boy was sent for brain scans and all sorts of tests, we even got referred to Great Ormond Street Hospital. Yes, it was confirmed he has Autism with Severe Learning Difficulties. He was just 2 ½.

When you first get this diagnosis you can easily turn into an Ostrich (bury your head in the sand). I found books and information way too depressing or scary to read or take in. I have since found out this is quite a normal reaction. Our boy slowly lost ALL his words (this took about two years). He now has none. He went back into nappies and we had a very difficult time with him, mainly due to the fact we were not sure what to do or how to 'deal' with him. We have slowly learned to cope with the 'Highs and Lows'. Life IS hard. I've often said to my husband "This is not how I planned it". We are very glad he has a sister (she's now 7), and has never known him any other way, and although she often curses him, she is brilliant with him.

He is now a beautiful, agile, sometimes graceful, bouncy, demonstrative, noisy young man of 9 years old. His teacher recently described him as a "charming child, with an impish sense of humour and a cheeky twinkle in his eye". One of the hardest lessons I feel I've had to learn is that we will never again be treated as a 'normal' family. Everything has to be planned with military precision! A friend (with her own Autistic son) told me that you do have to develop a skin like a Rhino. I don't think we'll ever get used to the stares and rude comments when we are out and about. It does make me cross when people assume that we need advice on how to raise our "Very badly behaved child"! Lots of other things are difficult to do.... We can't have a quiet family meal in a pub or restaurant, we have to plan holidays very carefully (can he 'escape'? will he break things? Will he be safe?).

It is not all 'DOOM AND GLOOM'. He is now at a wonderful special school – learning to communicate through signs, symbols and pictures, excelling at P.E. and swimming and the toilet training is going well (he still cannot be relied on not to wet

himself and won't poo in the toilet, but, one day...). Although he is a very, very noisy and demanding boy, HE is happy and getting on and maturing. Life for him is full of adventure, excitement and a lot of laughter – we are learning to laugh with him and accept him for what he is, not what one expects him to be. He can get very frustrated and angry at things we can't begin to understand, but on the whole he's a 'Happy-Chappie'.

It didn't take me too long to find and join a support group. There are many more of us out there than I thought – YOU ARE NOT ALONE! I have made some marvellous friends who accept anything I say with unfailing understanding, non-judgemental advice and a shoulder to cry on (or laugh). Our outings and parties are the easiest I know! We've been known to frighten off the locals!

Our son will probably never live independently or away from 24hr care, but as long as he is happy we will be happy too and love him for who he is...

### *Letter from a parent*

My son is just 14 as I sit to write this. He is an innocent, cheerful, sunny teenager – about whom (as yet) none of the normal teenage horrors apply – except for the monstrously untidy room. He is young for his age in many ways with his passion for Pokemon, the Beano, Lego, Nintendo and recently Asterix – at tapes of which he laughs uproariously and can recount vast amounts of: AT LENGTH! He is the family fruit bat and tries new foods almost without turning a hair (having at one stage had only one vegetable – cucumber). He loves music, especially jazz and classical, is rude to his sister and hates losing at card and board games which he loves.

Thinking back amazes me how far we have all come: in understanding autism, in learning to adjust to and live with our son's needs, in finding friends, in battling to get what we need when we need it, in being involved in the community in new ways.

The diagnosis was shattering, there is no other way to describe it – once I realised what I was facing. As with many diagnoses 10 years ago, it was a long drawn out process, which started when Fred was 3 and went on till he was four and a half and ran parallel to his assessment for special school. It started with convincing people there was a real problem; that he was not deaf – just couldn't do any of the tests; not taking in and reacting to the first official version of developmental and communication difficulties – which meant very little to me. The real breakthrough was getting an unofficial 'diagnosis' as a result of a conversation with someone who knew someone else's son – who had just had a diagnosis of autism and whose behaviour was all but identical. As we talked, the conversation became like going down a checklist of my son's behaviour and needs, to which she responded 'The other Fred does that' And that, and that..... By the end I knew: it was autism, I was convinced. I was in shock.

The official diagnosis was not for another 8 months because of all the usual problems of getting appointments and co-ordinating diaries. Even though I knew, had pushed for confirmation, was already well on with my 'grieving for the death of my son', it still hit me like a physical punch in the stomach, a roaring in the ears and little further comprehension. This time it was for real, all over again.

The 8 months between the two 'diagnoses' were hell. I have never felt so alone, so isolated, so without hope. I would sometimes cry for what seemed like hours in the evening. I found myself telling anyone I knew however slightly what had happened: I had to hear myself say it. But there was hope and more importantly, there was friendship.

I met 'the other Fred's Mum' who became a close friend and with whom I spent many an afternoon with our respective children drinking tea and wine and chatting (us not the children). I was a very early member of our local support group and other parents seemed to spring out of the woodwork like magic and various front rooms would be filled with talk and ideas, like islands of warmth in the dark, as we all found our way through this mysterious jungle of special schools, diagnosis, benefits, behaviour management, tantrums, statements, yet more strange behaviours..... But we could share our experiences, exchange tips and suggestions, be with people who 'understood' what we were saying when we were having a bad time with something,

accept our children's foibles and strange habits, have safety in numbers when we went out together. And there was laughter: often genuine at the silly situations that arise, sometimes a defence against the judgmental and unpleasant responses you get in public as your child's distress levels hit the mega decibel level with accompanying thrashing and flailing legs and arms, or are simply bizarre and 'unacceptable'.

Looking to the future is worrying for any parent: will our children be happy, will they find friends, be safe, find things to do that fulfil them. All of these worries apply as I contemplate Fred's future – only more so. He has moderate learning difficulties which will inevitably restrict his ability to learn work skills and get a job. I doubt he will ever be able to be fully independent and am concerned that his sister will feel overly responsible for him. That said, just as we have managed to find the schools he needs, made contacts who have helped him participate in clubs and be part of theatre groups, so I am sure that with persistence, fighting, struggle not to mention luck we will find somewhere where Fred and his sunny disposition will fit in; where his naïve and innocent humour and laughter will be enjoyed; where he will be able to contribute to the community and enrich the lives of others as he does ours.

At times he drives us mad, as does any child: but he also makes us very proud, teaches us to see things differently, have patience and find friends.

## **The ARD team and how a diagnosis is reached**

### *1. Who is in the team*

The Autism and Related Disorders team at the Maudsley Hospital is headed by a Professor in Child and Adolescent Psychiatry. Also on the team are a Consultant Clinical Psychologist, a Chartered Clinical Psychologist and a Clinical Psychologist in training, as well as a Specialist Registrar, a Senior House Officer, a Social Worker and a Child Mental Health Worker.

### *2. Diagnostic tools*

It is not possible to tell if a child (or adult) has autism spectrum disorder (ASD) by conducting a physical examination or by carrying out medical tests and so other methods need to be used. Here at the Maudsley, a detailed interview is conducted with parents about their son/daughter's development (this is the Autism Diagnostic Interview, or ADI). The ADI obtains information about the child's abilities in areas such as communication skills, social interaction, repetitive behaviour or rituals, imagination, concrete understanding and so on. The clinician then spends some time talking and playing with the child in order to assess their communication skills, conversational reciprocity, social understanding, imagination, empathy and so on. This is the Autism Diagnostic Observation Schedule or ADOS. Psychometric assessments of the child's intellectual strengths and weaknesses are carried out, such as the WISC - Wechsler Intelligence Scale for Children. Tests to assess use and understanding of language and other areas of functioning may also be used. A medical history and examination are also undertaken to rule out any other explanations and causes for the individual's difficulties or behaviour. This examination is also to check that growth and general health are satisfactory.

## ◆ What are Autism Spectrum Disorder and Pervasive Developmental Disorder?

### 1. General introduction

Autism was first recognised in 1943 by Leo Kanner, a clinician working in America. Hans Asperger, a clinician working in Austria in 1944, identified a group of children who showed similar characteristics to those described by Kanner, but without accompanying learning difficulties. The term 'autism' comes from the Greek *autos*, meaning 'self' and reflects a distinct quality of personality which Kanner and Asperger noticed in some of their patients. This quality might be described as being 'in a world of his own', or 'completely wrapped up in himself' with little interest in other children or in social chat or activities. Children and adults with autism can appear to be very different from one another and this raises the question as to whether autism is one disorder or several similar but separate conditions. Probably the most useful way to think of this range of difficulties is as a spectrum disorder which can be present to varying degrees in different individuals. The disorder can range from being severely disabling through to the most able individuals with autism who live and work independently.

There are different diagnoses which can be given, all of which come under the heading of 'Pervasive Developmental Disorder' (PDD) or Autism Spectrum Disorder (ASD) which is another term for the same condition. The World Health Organisation (WHO) sets out criteria which many clinicians have agreed to use to make a diagnosis of any medical condition. 'Autism' is a diagnosis given to individuals who meet all the diagnostic criteria for the disorder as described by the WHO. People with autism can have learning difficulties or be of average or above average intelligence. The term 'Asperger's syndrome' is nowadays often given to very bright people who as children developed language at the usual age yet who have social and other difficulties which are associated with autism. 'Pervasive Developmental Disorder not otherwise specified' (PDDnos) is a diagnosis which is often given when all the criteria for autism or Asperger's syndrome have not been met, but the child's difficulties are of the kind found within the spectrum of autistic disorder.

Three areas of impairment in particular are seen in autism spectrum disorder. These are in communication, social interaction and imagination. The essential diagnostic features of autism (taken from DSM-IV, a diagnostic manual issued by the World Health Organisation) include markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests. There may also be marked impairment in the use of non-verbal communication, such as eye gaze, facial expression, body postures and gestures. Younger individuals may have little or no interest in establishing friendships. Older individuals may have an interest in friendship but lack understanding of the conventions of social interaction. They may not seek to share enjoyment or interests and demonstrate a lack of social reciprocity, preferring solitary activities. There may be an impairment in awareness of others and little or no concept of the needs of others or awareness of others' distress.

Spoken language, as well as verbal and non-verbal communication skills, may be delayed or impaired and there may be stereotyped, repetitive or idiosyncratic use of language. Speech may be abnormal in pitch, intonation, rate, rhythm or stress. There may be repetitive use of words or phrases, regardless of meaning. Language comprehension may be delayed, with an inability to understand humour or non-literal aspects of speech such as irony or implied meaning. For a diagnosis of Asperger Syndrome, there will have to have been no delay in early language development, though there will be abnormalities in other aspects of communication.

There may be unusual preoccupations or stereotyped and restricted patterns of interest, abnormal either in intensity or focus. There may be an insistence on sameness and resistance or distress at minor changes in the environment (rearrangement of furniture, for example). There may be a lack of varied or spontaneous, make-believe play and fascination with movement (eg; spinning wheels) or an interest in the parts of objects.

## *2. Prevalence*

ASD is not, as was previously believed, a rare disorder. Improved diagnostic tools have enabled better recognition of ASD. Rates of diagnosis of language disorder have fallen as rates of PDDnos have risen.

Currently, it is believed that the proportion of people with an autism spectrum disorder is around 1:165 (Chakrabarti and Fombonne, 2001\*). It used to be thought that nearly all people with ASD also had learning difficulties but it now appears that this accounts for only about 25% (Chakrabarti and Fombonne, 2001). The majority of people with autism spectrum disorder fall within the average range of intelligence, some having a higher than average IQ. There are more boys than girls with ASD, with many more boys than girls at the able end of the Spectrum.

\*Chakrabarti, S Fombonne, E. Pervasive Developmental Disorders in Preschool Children. Journal American Medical Association 2001; 285: 24

## *3. Causes*

Parents often worry that vaccination, an infection during pregnancy, food or medicines taken while pregnant, or perhaps a difficult birth or injury following birth, are responsible for producing ASD in their child. The current thinking is that this is not usually the case and that the disorder has a strong genetic basis. ASD is not easy to trace through families because it does not pass down clearly from parent to child as does, for example, haemophilia. There will usually be no other member of the family on either side who has autism spectrum disorder. This suggests that autism is unlikely to be caused by a single gene, but more likely is the result of a chance coming-together of a combination of several different genes. In that respect ASD resembles many common diseases that have a strong genetic predisposition, such as heart disease and diabetes.

It can be hard to see how autism can have a genetic basis if there is no family history. However, in studies which have looked at autism in same-sex identical twins (where both twins share exactly the same genes), it is the case that if one twin has the condition, the other twin is usually also affected to some degree. Among non-identical twins, who only share, on average, half their genes, usually only one of them is affected. The rate of autism among siblings in a family where one child already has autism is about 1 in 20. Sometimes siblings may have language-related difficulties or delays but not autism.

#### *4. Prognosis*

It is not possible to predict with certainty the outcome for any child and the same is true for children with ASD. All children make progress as they grow up, and so do children with autism spectrum disorder. Usually, if a child has useful language by around 6 years, it is likely that he will be able to gain academic and life skills. The ASD will remain, but as the child grows and learns and is more able to understand what is being said to him, so the world will become a less threatening place and he may be able to respond more appropriately. Some children with ASD will be able to attend and benefit from mainstream school, others will learn better in the more structured environment of a special school where staff have a good understanding of their specific needs. There are people with ASD who live independently and are employed. There are also many who need supported employment and sheltered accommodation and there are those who are not able to live independently but need the support and understanding of well-trained staff. No matter how able the person with ASD, the ability to understand and empathise with what is going on in another person's head will remain a real difficulty for them, though, as with any skill, it can only improve with practise, training and experience.

#### *5. Relevant reading*

(All titles listed here are available from the National Autistic Society. To order, phone the Publications Department, 020 7033 9237, or fax 020 7739 0479 or order online, at [www.autism.org.uk/pub](http://www.autism.org.uk/pub) giving the relevant NAS code number.) The publications booklet is free and lists all the current titles.

#### **Asperger's Syndrome: a guide for parents and professionals**

Author: T. Attwood

Publisher: Jessica Kingsley, 1998

Code: NAS 246

#### **Autism: How to help your young child**

Authors: Leicestershire County Council and Fosse Health Trust

Publisher: The National Autistic Society, 1998

Code: NAS 247

**Freaks, geeks and Asperger syndrome**

Author: Luke Jackson

Publisher: Jessica Kingsley Publishers, 2002

Code: NAS 455

**The ages of autism** (video, running time 30 minutes)

Code: NAS 072

## ◆ What can be done

Although there is no cure for autism spectrum disorder, there are educational methods, intervention programmes, strategies and therapies which can enable the child with ASD to make best progress.

### *1. Language, communication and behaviour*

Simplifying language so that it is clear, unambiguous and concrete is the best first step in making the world a less confusing place for the child with ASD. It is helpful to avoid language that does not literally mean what it says, such as ‘It brought the house down’ or ‘I cried my eyes out’. Such expressions can cause anxiety in a child who has only a concrete understanding of language. Even common expressions like ‘drawing the curtains’ can be misunderstood and lead to bewilderment in the child’s mind. An ordinary child loves to be chatted to just for the sake of it. For the child with ASD, the social purpose of communication is difficult to understand, so that social chat is confusing and even disturbing. As a result, some children with ASD react with alarm if too much language is addressed to them and may show this by behaving in disruptive ways. These communication difficulties are found in children with ASD regardless of the child’s IQ.

#### Speech therapy

Speech therapists who are familiar with the communication problems of people with ASD may work in mainstream or specialist schools and also in a clinical setting. Programmes to meet the needs of the individual can be set up as part of their schooling and adapted for use both at school and at home. Specialist speech therapists working with children with ASD focus on improving the child’s social communication, using, for example, turn-taking games or setting up circle-time groups which encourage the child to learn the to-and-fro nature of communication. The speech therapist may also introduce a signing system, such as Makaton, to help the child who has little or no spoken language to communicate, or PECS (Picture Exchange Communication System, see p.18). Teaching a child to use signing or a visual method of communicating when they have little or no language does not discourage the development of speech – on the contrary, it helps the child learn that communication is useful and encourages the development of spoken language.

#### Behaviour management

Behaviour management mainly deals either with decreasing an inappropriate or dangerous behaviour or with increasing suitable behaviours via skills training. You may be able to get help from the clinical psychologist at your local child development centre. They advise on strategies for managing behaviour problems such as tolerating toe and fingernail cutting, or teaching skills such as potty training, or sitting calmly at a table to be able to eat dinner or concentrate on a lesson, etc. Clinical psychologists work either with the child or individual with ASD or with the whole family. They also offer behaviour management advice to people working with those with ASD, such as school staff.

### Skills Teaching

Some local councils provide a Portage scheme. A Portage worker can enable you help your pre-school-age child to acquire skills or improve abilities in areas such as dressing, playing, eating, physical co-ordination, sleeping, and so on. (See p.23 for phone number.)

### *2. Education and statementing*

To date, the most effective way of helping a child with ASD is through appropriate education. Although ASD is an organic disorder, it is appropriate education rather than medicine which will help the child reach their potential. What kind of education is best depends on the individual child, their level of general intelligence and their level of language and behaviour. For a child with ASD but without learning difficulties and with few behaviour problems, mainstream school with support may be the most suitable. The emphasis here should be on 'support'. It is essential that the support worker understands what the child needs to help them with both social (playground) and class situations. It is important that the help is appropriate and enables the child to retain and foster a sense of self-esteem. Parents can play a major role in educating their child's helper as to their needs and the kinds of strategies which are effective.

It is likely that a child with ASD and learning/communication difficulties would find it difficult and stressful to try to cope with the demands of mainstream school. Instead, the structured day of a special school geared to the needs of children with ASD would provide an environment more likely to enable the child to reach their potential. Such schools use social skills and language/communication programmes tailored to the individual needs of each child.

Whether in mainstream or special school, the child with ASD will usually need a Statement of Special Educational Need in order to obtain the kind of support they need. The statement allows the funding of the type of educational placement or support considered appropriate to allow the child to access the national curriculum and benefit from a school education. The Code of Practice, available free from DfEE (see p.20 for phone number) explains what a statement is, what qualifies a child to obtain a statement, how to go about getting a statement and the duties of the local education authority.

### *3. Therapies and intervention programmes*

The PDD team at the Maudsley does not support or recommend any particular therapy. Most have not been clinically assessed and cannot therefore be recommended. It is important that parents make judgements based on their knowledge of their own children and on information that can be obtained from sources such as the National Autistic Society (see p.21 for phone number) or their local clinical services.

Shortage of space here allows for only a short description of the most well known of the therapies which are popular at the moment. **For more detailed information it is**

**recommended that parents contact the National Autistic Society for their fact sheets on individual therapies and treatments (see p.21 for details).**

### TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children)

A highly structured visual teaching method which can be adapted to meet the individual needs of children with ASD. In schools, it uses visual cues so that both the day's programme and work is clear and predictable for the pupils. It prepares pupils for the workplace in providing each student with a workstation designed to minimise distractions. A typical example might be that a tray containing work is placed to the left of the pupil and an empty tray to the right. Visual instructions show what work is to be done and as each piece of work is completed, the student places it in the tray to his right. It is clear to the student when they have finished and they then refer to the day's programme to see what to do next, whether another task or a break for a drink or a rest.

### Picture Exchange Communication System (PECS)

'PECS uses a behaviourally based programme to teach the child to exchange a picture card for something the child likes and wants. Objects, pictures or symbols may be used, according to the child's developmental level...PECS helps pre-verbal children with autism learn how to express their needs, about how communication works. Children who can already speak may also benefit from the use of picture symbols to help them understand the sequence of daily routines...Symbols can also be used to help the child understand available choices, or to reinforce the concept that something is 'finished' and show the child what will happen next. This use of 'visual structure' is part of the TEACCH approach and can be used at home, as well as at school.'

*(Taken from The autism handbook, published by the National Autistic Society)*

### NAS EarlyBird Programme

The EarlyBird Project was set up by The National Autistic Society in 1997 to develop and evaluate an autism-specific model of early intervention using a parent programme. It is a three-month programme which combines group training sessions for parents with individual home visits when video feedback is used to help parents apply what they learn, whilst working with their child. The programme aims:

- a. to support parents in the period between diagnosis and school placement.
- b. to empower parents and help them facilitate their child's social communication and appropriate behaviour within the child's natural environment.
- c. to help parents establish good practice in handling their child at an early age so as to pre-empt the development of inappropriate behaviours.

*(Information taken from NAS news sheet.)*

### The Lovaas Method

Is a behaviour therapy based on Learning Theory, whereby desired behaviour is rewarded and reinforced, and undesirable behaviour is ignored. It is an intensive, 40-hour-a-week therapy and requires a team of trained helpers if the required input is to be achieved. As with many therapies, claims have been made for its success in

enabling children with ASD to become indistinguishable from their peers in regard to social, intellectual and emotional functioning. Evaluation studies have not shown these claims to be altogether justified, although behavioural intervention (in which desired behaviour is reinforced through reward and undesired behaviour ignored) is largely felt to be a useful tool. In particular it can be effective in enabling children to sit quietly and focus on the task in hand and for encouraging compliance generally.

#### *4. Relevant reading*

##### **It can get better...Dealing with common behaviour problems in young autistic children**

Authors: P. Dickinson and L. Hannah

Publisher: The National Autistic Society, 1998

Code: NAS 284

##### **Why does Chris do that?**

Author: T. Attwood

Publisher: The National Autistic Society, 1993, revised and reprinted 2002

Code: NAS 066

**Fact sheets** from The National Autistic Society (NAS) on therapies and treatments, available from: NAS, Publications Dept, tel: 020 7903 3595

##### **Special Educational Needs – Code of Practice**

Available from the Dept. for Education and Employment (DfEE), tel: 0845 602 2260 (Free)

##### **The Gabbitas Guide to Schools for Special Needs**

Gabbitas Educational Consultants

126-130 Regent Street, London W1R 6EE

Tel: 020 7734 0161

Fax: 020 7437 1764

e-mail: [admin@gabbitas.co.uk](mailto:admin@gabbitas.co.uk)

website: [www.gabbitas.co.uk](http://www.gabbitas.co.uk)

*Gabbitas advertise expert, one-to-one guidance on all stages of education from 5-25.*

*NOTE: this is not a free service and is not a recommendation from the Maudsley Hospital, but a note for your information.*

◆ **Support, benefits and information locally and nationally**

*1. Disability Living Allowance*

Information and advice on this and other welfare benefits can be obtained from The National Autistic Society and Contact a Family (see p.22).

Disability Living Allowance is a benefit available to children and adults with a disability who are under 65 years old. There are two components, one for help with personal care, which is payable at three different rates, and one for help with mobility, which is payable at two different rates.

Complete the DLA Claim Pack (DLA1), or for children DLA1 Child, available from your local DSS (Department of Social Security) office or by ringing the Benefit Agency Enquiry Line on 0800 882200.

A free fact sheet entitled *Claiming Disability Living Allowance* is available from the NAS Autism Helpline. Send an SAE marked 'Claiming Disability Living Allowance' to NAS Autism Helpline, The National Autistic Society, 393 City Road, London EC1V 1NG.

Other benefits are:

Invalid Care Allowance (ICA), Severe Disablement Allowance (SDA), Disability Working Allowance (DWA).

*(Information taken from The autism handbook, published by The National Autistic Society)*

**Advice lines:**

The Benefit Enquiry Line  
Freephone 0800 882200

The Disability Alliance Rights Advice Line  
Tel: 020 7247 8763 (Minicom available)  
*(Information taken from Contact a Family leaflet.)*

## 2. National agencies, charities, newsletters and website addresses

### **The National Autistic Society**

393 City Road, London EC1V 1NG, Tel: Switchboard – 020 7833 2299

Autism information, advice, support: 0845 070 4004.

e-mail: [nas@nas.org.uk](mailto:nas@nas.org.uk)

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

Runs education and adult centres, publishes books and leaflets, has a library available to parents and researchers, runs an autism helpline for parents, carers and those with autism spectrum disorders, organises conference and training programmes, offers specialist diagnosis and assessment services, encourages research, supports local groups and families, runs Prospects – a supported employment service for adults with autism spectrum disorders.

Parent to parent telephone support: **0800 9 520520**. Parents can call at any time and leave a message on the freephone number and a parent volunteer will call them back. Because volunteers are all parents themselves, they are able to talk at various times, including evenings and weekends.

*(Information taken from NAS leaflet.)*

### **OAASIS**

Office for Advice, Assistance, Support and Information on Special Needs

(Set up by the Hesley Group)

Hesley Group Head Office, The Coach House, Hesley Hall, Tickhill, Doncaster DN11 9HH. Tel: 01302 866906

Hesley Group Southern Office, Brock House, Grigg Lane, Brockenhurst, Hampshire, SO42 7RE. Tel: 09068 633201.

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

Email: [oaasis@hesleygroup.co.uk](mailto:oaasis@hesleygroup.co.uk)

OAASIS offers information on various learning difficulties, advice on assessment and statementing, prospectuses of all 9 Hesley Group special schools, college and adult provision, publications – quick, easy reference guides to many learning disorders, advisory days for parents. *(Information taken from OAASIS leaflet.)*

### **Contact a Family**

170 Tottenham Court Road, London W1P 0HA

Tel: 020 7383 3555

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

Support for families who care for children with disabilities and special needs – can advise on statementing, leisure activities, holiday schemes, playgroups, benefits, etc.

### **MENCAP**

123 Golden Lane, London EC1Y 0RT

Tel: 020 7454 0454

### **The National Portage Association**

Tel: 01935 471 641

Practical step-by-step programmes and support for parents to help children achieve specific tasks/overcome specific problems (eg; toilet training, feeding, dressing, etc).

NB – Not every area in the UK will have Portage. You will need to contact the National Portage Association to find out if a Portage scheme operates in your area.

### **Afasic**

2<sup>nd</sup> Floor

50 – 52 Great Sutton Street

London EC1V 0DJ

Tel: (Helpline) 0845 355 5577

Fax: 020 7841 8901

Email: [info@afasic.org.uk](mailto:info@afasic.org.uk)

Website: [www.afasic.org.uk](http://www.afasic.org.uk)

A UK charity representing children and young adults with communication impairments, working for their inclusion in society and supporting their parents and carers. Afasic offers advice, support, information, publications, activity holidays, training.

### **Handicapped Adventure Playground Association Ltd (HAPA)**

Hapa runs five adventure playgrounds in London for children and young people with disabilities and special educational needs. All are open during school holidays for individual children/groups and for siblings and friends. Various after-school schemes/clubs are offered and playgrounds also open on Saturdays.

Hapa, Pryor's Bank,

Bishop's Park

London SW6 3LA

National Information Line: 020 7731 1435

*(Information taken from NAS Resource List)*

### **Holiday Care Service**

Provides free information on holidays for people with special needs. The Service also produces a booklet on holiday and short break accommodation, suitable for carers, either travelling alone or with a person with a disability.

Holiday Care Service

2<sup>nd</sup> Floor, Imperial Buildings,

Victoria Road, Horley,

Surrey RH6 7PZ

Tel: 01293 774535

Fax: 01293 784647

*(Information taken from NAS Resource List)*

**Riding for the Disabled Association**

Has many groups throughout the country. RDA produces a list of National Holidays annually in February.

RDA,  
Avenue 'R', National Agricultural Centre,  
Kenilworth,  
Warwickshire CV8 2LY  
Tel: 01203 696510  
*(Information taken from NAS Resource List)*

**IPSEA (Independent Panel for Special Educational Advice)**

A registered charity providing advice on LEA's legal duties towards children with special educational needs, free second professional opinions for parents who disagree with an LEA's assessment of their child's special educational needs, and free representation at the Special Needs tribunal when parents want to appeal against an LEA decision.

Advice line: 0800 0184016  
Website: [www.ipsea.org.uk](http://www.ipsea.org.uk)  
*(Information taken from OASIS information sheet)*

**ACE (Advisory Centre for Education)**

Offers advice and publishes handbooks including the ACE Special Educational Handbook; Tribunal Toolkit: Going to the SEN Tribunal; Appealing for a School, and various summaries of the law.

Tel: 0808 800 5793  
*(Information taken from OASIS information sheet)*

**Asperger United**

Published four times a year – a newsletter written by and for people with Asperger Syndrome. The newsletter is suitable for adolescents and adults with autism and Asperger syndrome. Parents and professionals are, however, welcome to subscribe. For further details contact the Publications Dept of The National Autistic Society, tel: 020 7903 3595.

*(Information taken from NAS Resource List)*

**Our Voice**

The newsletter of Autism Network International which is a self-help and advocacy organisation run for and by people with autism. Membership costs \$20 US dollars a year and includes a subscription to Our Voice. Cheques/money orders should be made payable to ANI, P.O.Box 448 Syracuse, New York 13210, U.S.A.

*(Information taken from NAS Resource List)*

**On-line Asperger Syndrome Information Service** (OASIS – an American organisation) website. A great deal of useful information can be found from this site, much of it for teachers.

<http://www.udel.edu/bkirby/asperger/>

*(Information taken from OASIS information sheet)*

The **TEACCH** website is worth visiting and in particular its article Structured Teaching.

<http://www.unc.edu/depts/teacch/structur.htm>.

*(Information taken from OASIS information sheet)*

**The Center for the Study of Autism** has several good papers on childhood autism, theory of mind.

<http://www.autism.org/contents.html>

*(Information taken from OASIS information sheet)*

A site based in America for the **families** (including the partners) of people with Asperger Syndrome is at:

<http://www.faaas.org>.

*(Information taken from OASIS information sheet)*

**Team Asperger** in America have produced a CD Rom for teaching people with AS about facial expressions and what they mean. You can download a demo version from their site:

<http://www.ccoder.com/GainingFace>.

*(Information taken from OASIS information sheet)*

### **Siblings:**

try <http://www.autism.org/siblings/sibneeds.html>.

<http://www.chmc.org/departmt/sibsupp>.

<http://www.chmc.org/departmt/sibsupp/sibnet.htm> (sibnet direct link)

<http://www.chmc.org/departmt/sibsupp/sibkids1.htm> (sibkids direct link)

*(Information taken from OASIS information sheet)*

### **Autism-UK**

<http://www.autism-uk.ed.ac.uk/advice.html>.

*(Information taken from OASIS information sheet)*

## ◆ Adulthood

We believe strongly that it is important for the individual with autism spectrum disorder to live as normal a life as possible. This includes the expectation that they will live independently of their parents as an adult, be appropriately employed if possible and enjoy leisure activities. To parents who have just received a diagnosis of ASD for their young child, it might seem unimaginable that this could be either achievable or desirable. However, as understanding and knowledge about ASD increases, so too do the opportunities and support networks for those with the disorder. There are many adults who work and live independently with varying degrees of support. This support may be provided by a variety of agencies such as social services or organisations for supported employment, for example.

Everybody with ASD is different and individual and will have different strengths and weaknesses, different aspirations and needs, different likes and dislikes. It would be impossible to set out a formula for adult living which would suit everyone. Parents usually have the best understanding of their child's needs and skills and are often best placed, perhaps working together with outside agencies, to help find an appropriate and satisfying way of life for their son or daughter.

### *1. Further Education and Training*

Transition planning review at 14yrs for students with a statement of special educational needs:

A transition plan should be made at this time by parents and the school so that the student can plan for future education, training and employment. The local Careers Service can be contacted and asked to send a careers officer who will be able to advise and help make appropriate choices for further education, courses and qualifications. A careers officer can also help in liaising between the different agencies involved in funding courses of further education.

If the school provides education beyond the age of 16yrs a student may prefer to stay rather than move to a new establishment. The statement of special educational needs continues to be in effect for as long as the student remains at school, whether it is the same school or a different one. Once the student moves on to further education and leaves school, the statement ceases to be in effect, but entitlement to disability support continues. (Note that some 6<sup>th</sup> form provision is considered to be further education, so that the statement would cease even though the student remains in the same establishment.)

The Local Education Authority is obliged to liaise with social services about the student's needs, both at the time of making the transition plan and when the student is due to leave school, so that the student's needs are fully known to the local social services team and suitable support can continue. It is advisable to contact the LEA beforehand to ensure that they are aware and able to send an officer to attend the transition plan meeting.

*(Information adapted from The Gabbittas Guide to Schools for Special Needs.)*

## 2. Employment

The **Disability Employment Advisor (DEA)** at your local employment service/Job Centre should be a useful starting point for finding out about local opportunities for employment. DEAs should also be able to advise on training courses and other local organisations which can provide support when starting a job or work experience. DEAs can also arrange for a PACT assessment, which is a series of tests designed to clarify areas of skill and identify the kinds of jobs at which the applicant would do well. **The Association for Supported Employment**, Pennine View, Gamblesby, Penrith CA10 1HR, Tel: 01768 881225, can also advise on other help/organisations which may be available.

*(The above information taken from the National Autistic Society leaflet 'What Next? Moving on from Diagnosis'.)*

**Horizon** is a joint UK/European employment initiative supporting training, vocational guidance, counselling and job creation schemes for people with a learning disability. More information from the DfEE Support Unit (Tel: 0121 616 3660 or 3661).

Website: <http://www.employment.ecotec.co.uk>

**Prospects** is a supported employment scheme for people with autism/Asperger syndrome set up by the National Autistic Society, 393 City Road, London EC1V 1NE, Tel: 020 7704 7450

Email: [prospects@nas.org.uk](mailto:prospects@nas.org.uk)

**Workwise** – Supported Employment Offices, run by most Social Services, help people with learning difficulties find suitable work. Contact your local social services and ask for the Supported Employment Officer.

**SKILL** – the National Bureau for Students with Disabilities, helps with further and higher education and employment throughout the UK. 336 Brixton Road, London SW9 7AA, Tel: 0207 274 0565

*(The above information taken from OASIS information sheet 'Adults with autistic spectrum disorders')*

## 3. Living

As mentioned in the introduction to this section, adults with ASD will vary widely in their abilities and needs. Some will be able to live independently with a minimum of support, only needing, for example, help to organise cleaning or domestic routines. Local adult services may need to be involved in liaising between agencies or providing services. Housing associations may be able to help in finding suitable accommodation for the more independent individual. Other ASD adults will need a little more support and may benefit from living in shared accommodation with two or three others and a visiting or resident helper. Not only can domestic routines then be well-organised and implemented, but there is someone on hand to help sort out any other problems which may arise either for an individual or within the group. For the

less able adult with ASD there are many state-run, privately run or charitable homes and communities where individuals receive a high level of support and helpers and residents live and work together.

For detailed information contact your local autism society or the National Autistic Society (information, advice, support, Tel: 0845 070 4004) or local Social Services for a list of registered homes. The NAS can also provide:

- A list of their own and affiliated centres for adolescents and adults with autism. Ask for the information sheet entitled '**ESTABLISHMENTS FOR ADULTS**'.
- A list of NAS residential, day, vocational and further educational opportunities. Ask for the information sheet entitled '**THE NATIONAL AUTISTIC SOCIETY SERVICES FOR ADULTS**'.

Housing:

### **Notting Hill Home Ownership (NHHO)**

Tel: 020 8357 4475

'...a scheme aimed at people with a whole range of disabilities.....Shared ownership is a scheme funded by the government and local authorities to help people who can't afford to buy outright. It's run by experts in low cost housing – in this case Notting Hill Home Ownership (NHHO) – a registered social landlord.'

*(Information taken from NHHO leaflet.)*

### **Golden Lane Housing**

(Registered charity established by The Royal Society Mencap in 1998)

Run **Shared Ownership** scheme and **Secure Futures Scheme**. Golden Lane

Housing, Mencap, London EC1B 1AA

Website: [www.glh.org.uk](http://www.glh.org.uk)

For information about the **Camphill Communities**, contact:

The Association of Camphill Communities

Gawain House, 56 Welham Road, Norton Malton,

North Yorkshire YO17 9DP

Tel: 01653 694 197

Fax: 01653 600 001

e-mail: [info@camphill.org.uk](mailto:info@camphill.org.uk)

website: [www.camphill.org.uk](http://www.camphill.org.uk)

#### 4. *Relevant reading*

The **Gabbitas** Guide to Schools for Special Needs (see p.20) also list colleges of further education throughout the UK.

**COPE** – Compendium of Post-16 Residential Education and Training for young people with special needs, 7<sup>th</sup> edition. 1998, Lifetime Careers, Wiltshire Ltd, ISBN 1-873408-587. Tel: 01225 716024.

The National Autistic Society (NAS) produce a sheet '**Details of Colleges that Accept People with Autism and Asperger Syndrome**'.

**'The Association of National Specialist Colleges Directory 1997 and 1998 and 1999'** a directory of colleges with specialist provision for disabled students. Available from Olive Ralphes, Trevor Villa School Lane, St Martins, Oswestry SY11 3BX.

**'Planning for the future – The transition from child based services to adult services'**. Leaflet available from Contact a Family, 170 Tottenham Court Road, London W1P 0HA. Tel: 020 7383 3555.

**'After age 16 – what's new? Choices and Challenges for young disabled people'**. Published by and available from the Family Fund Trust, PO Box 50, York, YO1 2ZX  
*(Information taken from Contact a Family leaflet.)*

**'A guide to getting what you need from your Local Authority at 19 plus. An information pack for disabled people, their advocates and carers'**. Action 19+ Campaign, c/o SCOPE, Campaigns Department, 6-10 Market Road, London N7 9PW. Tel: 020 7619 7100.  
*(Information taken from Contact a Family leaflet.)*

#### **Special Educational Needs – Code of Practice.**

Available free from the Dept. for Education and Employment (DfEE), Tel: 0845 602 2260

#### **A Guide to Successful Employment for People with Autism**

Authors: Marcia Dartlow Smith, Ronald G Beicher, Patricia D Juhrs. 1996, ISBN 1 55766 171 5. Publishers: Jessica Kingsley Publishers, 116 Pentonville Road, London N1 9JB. Tel: 0207 833 2307.

**A supported employment scheme for able adults with autism or Asperger syndrome**

(About 'Prospects', the supported employment scheme.)

Authors: L Mawhood and P Howlin

Publishers: The National Autistic Society, 1997. ISBN 1-899280-55-3.

**Autism preparing for adulthood**

Author: Patricia Howlin

Publishers: Routledge

ISBN: 0-415-11532-9

**Community Care: Your Rights to Housing and Support**

Author: J Morris

Publishers: Pavilion Publishing (Brighton)/ Joseph Rowntree Foundation 1997

Available from the Mencap Bookshop. Mencap tel: 020 7454 0454.

*(Information taken from mencap public liaison unit resource list)*

**Front Door Keys: Housing Opportunities For People With Learning Disabilities**

Publishers: Pavilion Publishing (Brighton)/ New Era Housing 1997

Available from the Mencap Bookshop. Mencap tel: 020 7454 0454

*(Information taken from mencap public liaison unit resource list)*

**COPING a survival guide for people with Asperger syndrome**

Author: Marc Segar

Publishers: Information Service

Early Years Diagnostic Centre

272 Longdale Lane, Ravenshead, Notts. NG15 9AH

Tel: 01623 490879