

A Parent's Guide to  
Coping with  
Autism

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## GETTING A DIAGNOSIS

ONE OF THE CRUELLEST twists in the diagnosis that is 'autism' is that nearly all children with autism will be born without any obvious disability (the exceptions being a child born with Down's syndrome or another coexisting condition). When your baby is born, you will have absolutely no idea that he or she is anything but perfect. If you have a child with Down's syndrome, you may be aware of this pre-delivery or from birth, but you will have no indication that your child too may additionally develop or show signs of autism in a few years' time. But first, what is autism?

### A History of Autism

The diagnosis of autism was first defined by Leo Kanner in 1943. He used the word 'autism' from the Greek *auto* (meaning 'self') to describe children with certain symptoms that meant they seemed to live within themselves. His definition of autism requires that symptoms are apparent by the age of three and is also known as *classic autism*.

The other two most well-known disorders in the autistic spectrum are *Asperger's syndrome*, which is a milder form of autism in which there are no delays in language but there are significant problems with social communication, and *pervasive developmental disorder – not otherwise specified (PDD-NOS)*, which may be diagnosed when the full set of symptoms or criteria for autism or Asperger's syndrome are not met.

Very sadly, in the 1960s, Bruno Bettelheim, the director of

a home for disturbed children, had a theory that autism was caused by cold and emotionally distant mothers whom he called 'refrigerator mothers'. Bettelheim felt that these mothers were to blame for their children's development of autism. At the time this was thought to be an acceptable theory. So, for an earlier generation of families with children with autism, there was little or no help or support available and, in addition, the mothers were blamed for their children's problems. To us now, this seems inconceivably cruel and quite medieval in basis. Although his theory has been totally disproved, even now you may sometimes hear mention of it and some parents unfortunately may still feel, or be made to feel, that they are in some way to blame for their child's autism. People may ask indirectly whether you suffered from post-natal depression or something which they may feel led to you not bonding sufficiently with your child. There is another disorder – if that is the right term for these conditions – whereby a child may be diagnosed as having an attachment disorder. This is a disorder that usually affects children who have been adopted or placed in foster care at a very early age and, although some of the symptoms may be similar to those presented by a child with autism, it is indeed a very different disorder with a totally different cause.

### **Did I Cause My Child's Autism?**

Do not let anyone try to tell you that in some way you have caused your child to have autism. Because it is thought that there is a strong genetic link, some grandparents do not wish to be implicated in any way and will try to 'blame' their child's partner for any problems the grandchild may have. You may hear comments such as:

'Maybe it's because you were on the pill for a while, dear, before you had children.'

'Perhaps it's because you are a vegetarian.'

There is no substance to any of these comments as a reason why your child has autism. The thought of an inherited link is one which grandparents often do not wish to acknowledge or accept, so they may try to pin their own theories onto you. Do not take it to heart, but do not accept blame, either. *You* have done nothing wrong.

Would you get the blame if your child had diabetes or was deaf? In the same way, why should parents (very often the mothers) get the blame – if there is, indeed, any blame to apportion – for their child having autism?

Acceptance of your child's diagnosis is one of the very hardest things. Some people never really come to terms with it, but the more you are able to accept it, the better you will be equipped to deal with it and to help your child. And the first stage in this acceptance is that it is not your fault that your child has autism. 'Four children with autism? You must have done something very bad in a past life' – and this from a lady I did not even know! You will have dark days when you will allow yourself to wonder what you might have done wrong, but actually you will have done nothing wrong, so try to banish this negative thought if it pops up. Once you accept that you are absolutely not to blame for your child's condition, you will also be better equipped emotionally to deal with anyone else who comes along trying to apportion blame to you, the parent. Try not to have regrets about what you may or may not have done during pregnancy or in the first few months after your child's birth. It will not help you and it will not help your child. There are too many mothers of children with autism who still feel in some way to blame for their child's condition, so it is important to keep emphasizing this point. This unnecessary guilt will consume you and add to any other regrets you may be holding onto, and will not help you or your child.

### **Why Does Any Child Have or Develop Autism?**

Autism appears to affect children from a wide range of circumstances with no common denominator to predict its arrival. You may have conceived your baby naturally or via assisted conception (such as IVF); you may have given birth naturally or by an assisted delivery (such as a Caesarean section) – however your baby was conceived or delivered, you now have a baby with autism.

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Two of my boys were delivered naturally (albeit with a lot of additional help being twins and one of them being a breech delivery) and two were delivered via Caesarean – but all four have autism.

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Your baby may have been born early or late according to the due

date you were given and be a single child or perhaps one of twins. All sorts of theories exist about possible early signs of disability, such as a child being in the breech position (bottom or feet down) pre-delivery, but most breech babies are totally unaffected by any learning disability. *Two of my boys were breech – one being the second twin – and two were head down (cephalic delivery), but all four have autism.* There are so many variables involved in trying to determine what may or may not cause or indicate autism and many, many theories put up by parents and by professionals.

The chances are that at no time during your pregnancy will anything have been found to indicate any risk of your child developing autism. Your baby will have developed normally in the womb, nothing untoward will be detected on any scans or pre-natal tests, and at birth, any possible complications at birth will be the same, statistically, as for any newborn child.

Your little boy or girl will be cherished by you and loved from birth. He or she will probably start to achieve all the usual early milestones within the normal timescales as other babies, some earlier than average and some later.

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Of my four boys, one walked independently at ten months (which is quite early) while another of my boys seemed to 'cruise' for ever and wasn't walking independently until twenty-two months (which is quite late). Both were just within normal limits, however, and gave no indication of anything relevant, although since then both have turned out to have hypermobility (where the joints are over-flexible).

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What I am trying to convey is that the diagnosis of autism will come as a huge and devastating shock to you, as to nearly all parents. Maybe there will be a gradual realization that something is not quite right, but having looked after and loved your precious child for a few years, with no inkling of what is to come, the diagnosis will hit very hard. Overnight it seems as though your normal, healthy child has changed into a child with a lifelong disability seemingly from nowhere and for no reason. Suddenly you have no idea what the future holds for you and your child. One day they are fine, and the next they are not.

Some mothers have noted later, looking back sometime after diagnosis, that perhaps their babies were more unsettled than others

and were not good sleepers. Such babies may have cried more than some, but other babies too may be unsettled for many reasons and not then go on to develop autism. They may have developed a severe colic, which causes a tiny baby to be very unhappy, yet still there is nothing to really alert you to the fact that something serious might be happening to your child. If you are a first-time mother, you will have no real comparison of your own. Even so, all babies are different and some are easier than others, no matter what you do. So, at the time, you may think your baby is a 'difficult' baby – and, actually, they probably are – but at the time, you may not know any different. Everyone's view of what is difficult to cope with is very subjective and people's tolerance of difficulty also differs greatly, so unless you are a very experienced carer of babies, you may not have realized at the time that your baby is perhaps more unsettled than most.

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My twins were my first-born babies. Looking back, they were incredibly unsettled and I hardly ever got any sleep, but I was so proud to have had twins that I struggled through. I thought that this was just how twins were.

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### **Can Autism be Prevented or Cured?**

There is some ongoing research, which is hoping to be able to detect and predict early symptoms in young babies that might warn of the condition earlier. Much of this research is being carried out on the younger siblings of children affected by autism. But currently, there is nothing known absolutely to prevent the development of autism. However, it is agreed that an earlier diagnosis is very much more beneficial for the child as it means you can begin therapies and treatments at the youngest age possible to give your child the very best possible start in life.

### **The Wide Spectrum of Autism**

The hardest part is that no one really knows yet why or how a child develops autism. Are they born with a genetic predisposition to developing autism? Is there one trigger or many triggers and, if so, what are these? There also seem to be many types of autism within the same diagnosis: no one child is exactly the same as another and none has the same symptoms; unlike, for instance, deafness, which can be measured as the level of decibels a child can hear, or visionary

problems, which can also be similarly identified and measured. Because of the huge differences in the way in which a child may be affected, the condition is defined as Autistic Spectrum Disorder (ASD), which covers a wide range of ability and disability. This also makes any future prognosis difficult, e.g. predicting how well your child will progress and what you can hope for in the future. The definition of ASD is a very open and seemingly vague one in some ways. It means that children diagnosed on the Autistic Spectrum can be affected at very different levels, ranging from the profoundly autistic child who may not ever develop language or be able to live independently to those children at the higher functioning end of the spectrum, usually labelled as having Asperger's syndrome. Again, this makes the diagnosis hard to pin down for parents.

When you first hear the term 'autism' used about your child, what do you think of? Perhaps the stereotype of an autistic savant such as the character portrayed by Dustin Hoffman in *Rainman*? Perhaps you may have read popular novels featuring children with Asperger's syndrome? Perhaps you may already know a child with autism and may think 'but *my* child is not like *that* child'? Of course, we parents are people, too, and inevitably we will jump to conclusions and, sadly, will often assume the worst-case scenario that we can think of. Conversely, you may know someone whose child was thought to have autism but actually the diagnosis turned out to be wrong, so you will hold onto the thought that it also may not be true of your child.

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The consultant who told me that my twins had autism also told a neighbour the very same week that her son had autism. Three children in the same road in the same week? It turned out that her son was bilingual and that was the only reason for his language delay, so I clung to the hope that perhaps the consultant had also got it wrong with my boys and that maybe they had something like verbal dyspraxia (see page 69). I spent the next few weeks while we waited for a second opinion trying to convince myself that my beautiful boys had any number of issues, but not autism.

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Your reaction may also depend enormously on how the diagnosis is delivered to you. If you have a sensitive paediatrician or other professional, you may at least come away with some hope and

ideas and positive thoughts about where to go from here. If your diagnosis is given to you by someone with negative thoughts about autism, you may come back from your consultation devastated and with no proper advice for the future of your child.

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The consultant told me that my twins were autistic out of the blue during a hearing test, not a developmental assessment, and compared the condition to vegetable soup saying that 'if we all had a bowl of vegetable soup, some of us would have more carrots in theirs than others'. He then sent me away saying there was nothing I could do about it and he would see us again in six months!

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Comparing such a serious diagnosis to a bowl of soup is fairly unbelievable and to offer no advice or hope in such circumstances is appalling. However, as a parent there is much you *can* do about it, and it did not take me long to discover that.

### **Early Signs and Symptoms in Developmental Milestones**

The very earliest symptoms of autism may be noticed in a child by experts or by someone with some prior knowledge of the condition from around the age of twenty-four months. Usually it is not very apparent until between eighteen months and two years of age that there may be something developmentally delayed or different about your child. Little things like a child not waving 'bye, bye' may be put down to the child being shy or just late in developing. A typically developing child may put up their arms to you to signal that they want to be picked up and use many other non-verbal gestures like these before they start to talk. These little gestures will occur naturally and you will not necessarily be looking for them, they just happen. You probably will not even be aware of these gestures as you will just respond accordingly to your child if they indicate non-verbally that they need something.

### **Pointing**

If your child does not use physical prompts to communicate with you, you will probably not notice their absence or even be aware that they should be doing some of these things. If lots of these little gestures are missing, this may add up to a bigger picture overall, but each on its own may go unnoticed or not be seen as being significant.



One quite significant example of non-verbal communication is the act of pointing. A child should start to point at objects that they want or need or maybe just to draw your attention to something they have seen. Perhaps they will point at a dog or a car or something that catches their interest to show it and share it with you – this is called *joint attention* and is one of the first things a child should begin to do, even before they develop speech. They will point repeatedly at an object that they desire that is out of their reach in order to gain your attention so that you can get it for them. So, pointing with an index finger is an early, very important skill. But again, if your child is your first-born child, then you will not necessarily know what to expect them to be able to do and at what age.

Obvious milestones like rolling over, sitting, crawling and walking are all significant stages of development that everyone readily discusses. Indeed, the age at which a child first 'performs' each of these milestones is often a source of pride to the parents, particularly if they think that their child has achieved it earlier than others. In fact, there is not much significance at what age a child reaches a milestone as long as it falls within the quite wide age range for each activity. Less obvious developmental markers such as pointing and waving are not discussed with quite such enthusiasm and may even be performed by a child for a while before the parent actively notices.

At developmental checks, you are asked at what age your child first sat independently or walked unaided. Most parents have a clear memory of when this was and can pinpoint an exact age. When you are asked at what age your child first babbled or pointed, you may be quite vague or unsure about when or if your child babbled at all.

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Usually, parents will remember their child's first word, if they are lucky enough to hear it. For most parents, that word will just come naturally, seemingly effortlessly. For those of us with children with autism, that first word will be hard won and longed for and all the sweeter when it is finally heard. One of my boys' first words was 'juice' (or at least an attempt at that). Hearing the words 'Mummy' or 'Daddy' are a lot further down the line than for typically developing children whose first words usually include a version of 'mama' and 'dada'.

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### **Avoiding Eye Contact**

If you are asked when your child first began to point at things, you may suddenly realize that they may never have pointed at all but, until you were asked, you had not noticed or realized the significance of this. Appropriate eye contact is another function that may be impaired but which you may also have not noticed. A shy child may try to avoid direct eye contact. You may perhaps think your child is so absorbed in other activities that they do not have the time to look up or look at you. Eye contact is quite difficult to quantify or describe and some people are naturally better at it than others. A child with autism may appear to be avoiding eye contact deliberately. But, again, until this is pointed out to you, you may not have noticed it at all.

### **Speech Delay**

Of course, speech is the most obvious red flag that there may be a problem. Speech develops at different ages: often girls speak more fluently than boys at a younger age and first-born children also tend to speak earlier. Youngest children in a large family may not feel the need to use language until quite late as their siblings may be doing all the talking and interpretation for them. In twins, language can be delayed or be acquired in a slightly different way. Children who are brought up bilingual can also begin to talk markedly later than their peers. Thus, there are many variables influencing the age at which a child begins to speak. Despite this, there are ages by which certain targets of language attainment should have been reached. One of the more obvious signs that a child may have more than a straightforward language delay is that not only do they not speak, but they also appear not to understand.

You may first become concerned that perhaps your child cannot hear properly. Perhaps they do not seem to respond to their name when called or when talked about. Typically developing children will often turn when they hear their name spoken, even indirectly, in conversation. They will certainly respond when being called or talked to directly and their name used as a command to gain their attention. A child with autism might respond to their name, but not nearly as often as you would expect. Strangely, a favoured word like 'chocolate' may bring a better response than simply calling your child's name!

It was only when I asked my boys if they would like some chocolate and got no response that I realized that not only did my boys not speak, but they also did not understand language. When I produced a packet of chocolate and showed it to them, their response was, of course, immediate and they became very animated and, clearly, they did want the chocolate.

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You may have to put yourself right in front of your child to gain their attention – not because they cannot hear you, but in order to try to get any response from them at all. You may also find it hard to make eye contact with your child and may need to put your face within their range of vision instead of expecting them to look to you.

Often, delayed language is not picked up on until you start to become concerned that all the other children the same age as your child are starting to talk and your child is not. Your child may be strangely silent, or not make much noise at all; they may never have made much sound vocally, or at least nothing resembling the beginnings of speech. They may have babbled as babies, but not developed speech following on from the babbling. Or they may have begun to babble and then seem to have lost the babbling somewhere along the way.

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One of my twins made a loud continual humming noise from around the age of two which he didn't lose for years until he finally replaced it with speech. It wasn't a form of communication, just a sound that seemed to comfort him or that perhaps he just enjoyed hearing.

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Even harder for a parent in some ways is when a child has begun to talk and has the beginnings of speech but then slowly loses all their words and seems to slip into autism. This can happen quite gradually over a period of months until you realize that something is wrong or can happen almost overnight. This pattern occurs in the regressive form of autism and sadly is not uncommon.

### **Could Speech Delay be due to Problems with Hearing?**

So, your child is not talking yet and, to get to the bottom of this, you embark on a round of hearing tests and doctor's appointments. It is quite difficult to test a young child's hearing accurately as not only do they need to be able to cooperate with the testing procedure, but

they also need to understand what is being asked of them. At the same time, they need to be willing to take part and be able to pay attention for the duration of the tests. Not easy at all. Most babies will have had their hearing tested at birth so you should already know that your child is not profoundly deaf. However, it will be hard to ascertain if they have an actual hearing problem.

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Sadly, a hearing problem can often be nothing more than a big red herring at this stage. All four of my boys were diagnosed with glue ear, which took months and months of testing to prove, and then further months for treatment to be carried out in the form of the surgical insertion of grommets. Grommets will not be put in until it can be proven that your child has had a minimum of six months of glue ear – by which stage you have been following the path of hearing loss for nearly a year. You are, quite naturally, under the illusion that once the hearing issues have been rectified your child will then begin to speak. If your child continues not to talk post-operatively or post-treatment, then you start to realize that the hearing issue may not be the only problem your child has – and realize that you have been in effect been delayed by another year before the possibility of autism is suggested.

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### **How Long Will a Diagnosis Take?**

The diagnosis of autism can take a very, very long time, yet it is in your child's best interests to have a diagnosis as early as possible. There is no instant blood test or brain scan that can be carried out to confirm the condition. As yet, there is no genetic test available, although research is underway to try to prove genetic links and predisposition. You may start with taking your child for hearing tests and to see ear, nose and throat surgeons (ENTs), and then progress to seeing speech and language therapists (SLTs), educational psychologists (EPs) and paediatricians. Maybe your health visitor or nursery teacher will be the first person to pick up that your child is having some problems even before you see any of these experts. Each professional may do his or her own observations first, and it may take a while before you are referred to different specialists. All of these referrals and assessments can mean that the road to diagnosis can be a long one. Within the NHS there are, of course, waiting lists and sometimes long delays before you even manage to get an appointment with some specialists.

## Identifying the Early Signs of Autism

There is a checklist for autism in toddlers, known as CHAT, which was developed to help identify children who might be at risk of developing social communication disorders. CHAT is usually used at around eighteen months of age, or whenever there is any cause for concern. It is often carried out by health visitors or nursery staff and is intended to highlight children who might need further evaluation. It is not used to diagnose autism, but is a simple way of assessing which children need some follow-up and even perhaps a referral. If there are concerns on testing, the test should be repeated a second time a month or so later, after which the child should be referred to a specialist, often the community paediatrician. At this you will be asked questions about your child. For example:

- What are your child's play skills?
- Does your child point with an index finger?
- What early communication sounds or words has your child used?

There will also be observation questions for the person doing the assessment. It is quite a straightforward test to carry out and is basically a tick list. If there are concerns following this basic assessment, then a proper referral should be made as soon as possible.

## Criteria for Diagnosing Autism

Diagnosis these days is based on some pioneering research by Lorna Wing and Judith Gould in 1979 and is the basis for the triad of impairments upon which the diagnosis of autism is currently made. For a diagnosis to be made, your child must exhibit one or more symptoms from each of three categories. There is a wide variation in the symptoms that each child exhibits and no child will have exactly the same symptoms as another. The severity of the symptoms also varies enormously across children on the autistic spectrum. Your child may have a severe impairment in one area and only be mildly affected in another, e.g. a child with Asperger's will usually have normal language development but may suffer from anxiety or have significant problems with social interaction.

The three categories for the diagnosis of autism are:

- social impairment
- social communication and language impairment
- rigidity of thought, behaviour or play known as social understanding.

If you want to read the official list of criteria used by the medical profession, look up the diagnostic criteria for autistic disorder in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM IV), published by the American Psychiatric Association (APA).

### **Social Impairment**

Social impairment can include not responding when being talked to, as illustrated by behaviour such as:

- not turning or answering when their own name is called (even though you know they can hear you)
- seeming to be in a world of their own for a great deal of the time, which may result in the child playing alone and not being aware perhaps of other children playing around and alongside them
- appearing not to notice the presence of other people, which might result in the child actually bumping into other people or not moving out of the way as you would expect them to
- pulling you by the hand for you to reach the desired object for them, but without any eye contact or pointing to the object
- very little or poor eye contact, even to the extent that they may actively dislike being made to look someone in the eye and find it quite uncomfortable to do so
- a marked dislike of physical contact such as cuddling, which can be very distressing if a child falls over and needs physically comforting but rejects you and cries alone.

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One of the most strongly held beliefs that seems to prevail is that all children with autism show no affection and actively dislike physical contact. It will often be one of the first questions someone may ask you

on hearing that your child has autism: does your child dislike physical contact? In fact, many children with autism are more affectionate than others who don't have it, as children with autism act instinctively without worrying about what other people may think of them.

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### **Social Communication and Language Impairment**

Social communication and language impairment can vary greatly in severity. Some children may have no spoken language at all and may appear not to understand any words either. The levels of spoken (expressive) and understood (receptive) language are usually fairly equal in a child with autism. This means that a child with only a few spoken words probably only understands a few words spoken to them unlike, for example, a child who may be selectively mute and may not speak but who understands what is being spoken to them. Babies start to learn language and will cooperate and do things on command before they start to speak, which shows an understanding of language (receptively) before they begin to actually say words, e.g. asking them to clap their hands or get their shoes. A child with autism may have no understanding of language and therefore have no idea of what it is you are asking them to do, but if you physically do the action in front of them, e.g. you clap while you saying 'clap hands', then your child may cooperate and perform the same action. Your child will have understood by observing and repeating what they have seen you *doing*, not by understanding what you have *said*. Children learn naturally by imitation, but a child with autism may not pay sufficient attention and observation to others and therefore often will not imitate.

### *Echolalia*

Often without any real understanding of what is being said, your child may repeat words spoken to them: this is known as *echolalia*. If you ask a simple question, they may repeat whatever you say straight back to you. Thus the question 'Do you want juice?' comes straight back at you as 'Do you want juice?', but if your child has some language ability this can then become complicated by them getting the pronouns mixed up. So, when your child wants some juice and asks you for it, what they may actually say may be 'You want juice', as this is what they have heard said to them as opposed to realizing that the pronoun 'You' should change to make 'I want

juice'. If you ask your child directly whether they want juice, the correct response would usually be 'Yes', but you could still have the words repeated back to you – and, in fact, they may not even want any juice at all! A child may repeat the last word or two of everything you say with no real understanding and, when offered a choice, will usually appear to take the second option as they are repeating the last word they heard. For example, if you ask 'Do you want a biscuit or a piece of cake?', they may say 'cake' while grabbing the biscuit from you. In this way, language is acquired and used in a very different way by children with autism. Children with no communication difficulties will acquire language almost effortlessly whereas a child with autism finds it very difficult and will often need specialist teaching and intervention to be able to communicate at any level. Speech in a child with autism can also take the form of narrating chunks of language learned from favourite books or films, often known as 'scripting'. To an outsider this can sound as if your child has language ability but, in fact, this is not an effective form of communication. Your child may not even understand the words they are repeating, but they may like the sound the words make or perhaps the words make your child happy because they are thinking about that favourite part of a film or book. Your child may also talk nonsense jargon, which they think is speech as perhaps speech sounds like nonsense to them.

### *Does a Lack of Language Mean Low Intelligence?*

It is important to emphasize that although your child may not understand language, this does not mean that they have low intelligence. Sadly, many people assume that lacking language does indicate low intelligence.

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If you were to move to China tomorrow, would you be able to work/answer the phone/watch a film or read a book in Chinese, whether Mandarin or Cantonese? I know I wouldn't. I would find it hard to learn much more than my own name. Certainly, I would not be able to function in life in the way I do in the UK. This does not make me unintelligent; it just means I can't understand the language. It does not diminish from my own understanding of the world, or the intentions and purpose I may have. This is the closest I can come to explaining how my boys function and feel in our world without the communication skills they so badly need.

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