



"Parental Recognition of Autism – Professionals Must Listen!" © by Planet Autism

Who recognises autism in a child first?

People could be forgiven for thinking that it's usually a professional who recognises and flags up autistic traits in a child. But often it's the parents who recognise something is different with their child, even if it's their first child. It may be from noticing behaviours that seem unusual/challenging or from comparing their child with those of their peers. Sometimes however, parents don't recognise the differences and are relying on the professional, which can be even more the case in particular cultures, or if parents are worried enough to be in denial about the possibility their child has a condition such as autism.

When toddlers and young children are taken for standard health checks, if those health checks are not specifically looking for neurodevelopmental issues, there is a good chance that many children's difficulties will be missed unless they are severe. It's only usually when there is a developmental delay, such as speech or motor skills, that doctors will note this and make recommendations – and sometimes that may just mean "a period of watchful waiting". This is not good news for an autistic child as early intervention is key.

Standard health checks are rather tick-box, often not detailed or lengthy enough, and not all children with autism have noticeable developmental delays. The following article is American, but the principle remains, that if a parent doesn't realise their child has differences or issues, the doctor often won't be recognising it either and even where they do, may highlight individual difficulties without looking for the underlying cause for them:

"Doctor Visits May Be Insufficient To Spot Autism"

<http://www.disabilitycoop.com/2015/01/13/doctor-insufficient-autism/19957/>

"Routine visits to the pediatrician are often far too short to accurately identify children at risk for autism, a new study suggests.

Researchers say even trained autism experts missed 39 percent of children on the spectrum when they were asked to screen kids by observing them in 10-minute videos in a [study](#) published online Monday in the journal Pediatrics.

The finding is significant, researchers say, since pediatrician visits often last just 10 to 20 minutes."

"Accordingly, researchers are urging parents to learn the signs of autism and to act if they have concerns.

"Parents see their children at their very best and very worst," said Terisa Gabrielsen of Brigham Young University who led the study. "They're the experts for their children. They can be educated about signs and symptoms, and need to help their care providers by speaking up if there's a problem and being involved in referral decisions."

When a Parent Knows Their Child is Different

It's really important, imperative, that when parents do raise concerns, doctors and other professionals listen. The old adage of 'mother knows best', may be an adage but is not without truth. Professionals do not have enough respect for parents and mothers especially are often seen as over-anxious, neurotic and most horrifically, as having MSBP/FII for reporting concerns.

"Doctors Listen Up! Parents Can Spot Autism Long Before Diagnosis"

<https://www.autismspeaks.org/science/science-news/doctors-listen-parents-can-spot-autism-long-diagnosis>

"Lonnie Zwaigenbaum has devoted much of his career to understanding how to identify autism as early as possible. Despite his years of experience, Dr. Zwaigenbaum says physicians like himself would do well to seek the insights of a more important group of experts – parents.

"Parents are the experts when it comes to their kids and their observations are really valuable," Dr. Zwaigenbaum says. "In some respects, parents are picking up on differences at six and nine months of age that we have a much harder time seeing in the clinic."

Dr. Zwaigenbaum is the senior author of a [new study](#) showing that parents' early autism-related concerns are not only common – they're quite reliable. [The report](#) appears in the [Journal of the American Academy of Child & Adolescent Psychiatry](#).

The parents who already had one child with autism proved particularly adept at spotting the early signs of autism. Overall, their concerns at 12 months accurately predicted an eventual autism diagnosis. This was true even earlier – at 6 months – for concerns regarding sensory difficulties (unusual sensitive to sounds, light or touch). Concerns about language and sociability tended to appear later – between 12 and 15 months of age.

The researchers urge both parents and physicians to take such concerns seriously and seek further evaluations and, if needed, early intervention therapies. "Parents can play a critical role in implementing these interventions by learning how to encourage social interaction in everyday caregiving and play activities," says lead study author Lori Sacrey, also at the University of Alberta and Glenrose Rehabilitation Hospital.

"Our study argues for a renewed emphasis on parents' concerns early in life," Dr. Sacrey concludes. "Where interventions are concerned, the earlier you can start, the better ... to address early developmental difficulties that can ultimately enhance skill development and improve outcomes."

And all these articles all stress the same thing, that doctors must listen to parents because early intervention is so important!

"Listening to parents can help docs see early autism signs"

<http://sfari.org/news-and-opinion/blog/2015/listening-to-parents-can-help-docs-see-early-autism-signs>

"Children with autism are typically diagnosed at about age 4, when social deficits and other symptoms set them apart from their classmates. But some children [show subtle signs of the disorder](#) as early as 6 months of age. Recognizing these signs is important: Mounting evidence suggests that early intervention [can improve social and communication skills](#) in children with autism.

The good news is that parents often pick up on these early clues, two new studies suggest, and could help doctors spot the disorder as well. The bad news: Doctors don't always act on parents' concerns.

One study, published last month in the Journal of Pediatrics, analyzed data from a [national survey of 4,032 parents](#). Of these parents, 1,420 have a child with autism and 2,098 have a child with intellectual disability or developmental delay. The parents were asked to recall their concerns about their children's development in the months or years leading up to a diagnosis.

Parents of children with autism *tend to sound alarm bells earlier* than those whose children have other developmental problems, the study found. But for some reason doctors are more likely to dismiss a parent's worries about a child with autism than about one with intellectual disability or developmental delay. Clinicians may suggest a 'wait and see' approach, or tell the parents that their child's behaviors are nothing to worry about."

What does the Government Say About Early Intervention and Working in Partnership with Parents?

<https://www.gov.uk/government/news/new-research-shows-early-intervention-is-key-in-helping-children-with-special-needs>

"Children who have speech, language and communication needs should be helped as soon as possible, new research has concluded.

The Better Communication Research Programme, published today, recommends that there should be:

- a stronger focus on the outcomes that children and young people with speech, language and communication needs achieve
- continual services at different levels to meet children's individual needs
- professional development for all those working with children and young people with speech, language and communication needs, to recognise needs earlier and provide the right support – across education and health

The government welcomes the research and its recommendations. It supports the government's special educational needs reforms with its emphasis on early intervention, close involvement of families in decision making, and joint commissioning of services across education, health and social care."

<http://dera.ioe.ac.uk/11385/1/DCSF-00349-2010.pdf>

"The need for professionals to know how to listen and engage

4.24 It is also possible that children, young people or their families manage to locate the right professional or service to ask for help but that what they say is misunderstood or, for some other reason, not listened to or not heard.

4.25 Really listening to children, young people and families and drawing the right conclusions from what they say seems simple but is in fact a professional skill that benefits from specific training. Brief Encounters is a training programme developed by the charity One plus One and delivered now to over 3,000 practitioners, most of them staff members who work with parents of babies and young children. The programme trains professionals to listen to parents without becoming overwhelmed, to offer effective support and to make an effective referral where necessary.

5.1 Assessment is pivotal to early intervention, being positioned in the middle of the process and thus acting as the essential link between early identification of children and young people's emerging difficulties on the one hand, and the provision of support of various kinds to resolve or help manage them, on the other.

5.2 High quality assessment undoubtedly makes a huge difference to children and young people's outcomes, as well as to the effectiveness with which services are allocated in a local area. A good joint needs assessment in a locality is as important as good assessments of individual children."

http://www.ncb.org.uk/media/236258/engaging_with_families.pdf

"Although this concept of partnership has been around for many years, there is now a greater understanding that this does not mean professionals dictating the terms of the relationship but rather a more equal approach based on respect, trust, empathy and integrity.

As this booklet shows, partnership should be based on a 'principled' approach that recognises and builds on parents' expertise, where professionals and parents really listen to and learn from each other in ways that are valued and evaluated by parents themselves.

It is very easy to describe parents as their children's main educators – but do practitioners work with families in a way that connects with and honours this knowledge? Practitioners can never know children as well as those who live with them and have had loving relationships with them over time, in many cases from birth. In the words of Paulo Freire, practitioners need to 'give up the idea that we are the exclusive owners of truth and knowledge' (Freire 1970)."

So there you have it, when you face professionals who do not listen to you about your concerns, do not be fobbed off. You spend the most time with your child and you have a right to request and receive a referral for assessment for your child if you have concerns.

The NHS NICE Guidance CG128 states that children should be seen within 3 months of referral for autism assessment. See this page for more information: <http://evolutian.wix.com/planetautism>