

# A qualitative analysis of lay beliefs about the aetiology and prevalence of autistic spectrum disorders

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Accepted for publication 12 May 2009

## Abstract

**Introduction** There has been a dramatic increase in the prevalence of autistic spectrum disorders (ASD) in the last 20 years. The reasons for this are disputed. The consensus among epidemiologists and other experts is that greater case load is due to changes in diagnostic practice rather than reflecting changing aetiological factors leading to a true increase in incidence. We set out to examine lay views concerning the aetiology and prevalence of ASD and whether they conflict with or support this consensus position.

**Methods** Over 100 unsolicited communications (letters e mails and several telephone calls) were received by a UK epidemiological study of ASD. We carried out a qualitative analysis of all correspondence in order to examine spontaneously expressed lay beliefs about the prevalence and aetiology of ASD.

**Results** The majority of correspondents suggested theories about environmental causes of ASD. This study demonstrates the strength of lay belief that the true incidence of autism is rising, and this is due to risks from modern technologies and changing lifestyles.

**Conclusion** This study based on unsolicited data highlights the contrast between lay explanations of increasing prevalence and the consensus opinion of medical experts. It also demonstrates how many people in direct contact with ASD have important information to share.

## Keywords

autism, autistic spectrum disorder, grounded theory, incidence, lay beliefs, lay understanding

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## Introduction

There have been far more diagnoses of autistic spectrum disorders (ASD) in recent years with the US Department of Education showing an astounding 556% increase in the number of children being treated between 1991 and 1997 (Stokstad 2001). In a 2005 review, Rutter writes: 'the true incidence of autism spectrum disorders is likely to be within the range of 30–60 cases per 10,000, a huge increase over the original estimate 40 years ago of 4 per 10,000' (Rutter 2005). According to Muhle and colleagues (2004), ASD now has a greater prevalence in

children than that of cancer or Downs syndrome. There is no doubt that the reported prevalence has increased spectacularly, and particularly over the last 20 years. The question is, why?

Influential work by Eric Fombonne (2001) suggested that the change is not a true reflection of more children with ASD in the population now than in the past, but is the result of the ASD diagnosis being given to more children. Three main reasons have been cited: the extension of the spectrum in recent times to include milder conditions like Aspergers syndrome, the extension of diagnosis to younger children, and increased awareness of ASD by parents and clinicians.

'Diagnostic substitution' may provide a partial explanation. Barbaresi and colleagues (2005) found that increased rates of diagnosis followed increases in funding for special educational programmes. Where resources are being directed towards ASD, greater incidence is associated with declines in other diagnostic categories indicating that clinicians prefer to label children with ASD in order to allow them access to greater resources (Shattuck 2006). If this is occurring, children who in the past would probably have been diagnosed as having a specific learning disability or a psychiatric disorder, or not diagnosed at all, are recorded as cases of ASD.

The view that the increased volume of ASD cases is due to changes in diagnostic practice has become the consensus position. As Howlin (2006) states: 'Recent increases in rates of diagnosis reflect greater awareness of autism spectrum disorders among professionals, together with widespread improvements in diagnostic practice'. We have found that this position conflicts with the opinions of many people in contact with autistic children. Individual parents, for example, have published their view that the true incidence of ASD has increased; i.e. there are actually more children now who display ASD. For example activists like Blaxill (2004) argue that large increases in numbers cannot be attributable solely to changes in diagnostic criteria or improvements in case ascertainment.

The aetiology for most cases of ASD is unknown. The idea that ASD is caused by a genetic predisposition triggered by an environmental insult is common among researchers, with proximate causes understood as risk factors making it more likely that children will develop the condition. Reviews report that many risk factors, predominantly genetic but also environmental, are associated with ASD but the effects of each are poorly established (Newschaffer *et al.* 2007). Gray suggests that uncertainty about aetiology has created a vacuum in which speculation about possible causes may flourish. Risks that have been implicated by parents include prenatal, postnatal and perinatal factors (Gray 1995). In particular, active groups have mobilized around concern over vaccines. In the UK, the measles mumps and rubella (MMR) vaccine has been a focus for activists despite clear evidence showing that the vaccine is not associated with ASD (Rutter 2005). In the USA, the use of the preservative thiomersal, which contains mercury, in many vaccines has been cited by activist groups.

In 2007 an annual review of public health concluded that the question of whether incidence of ASD really has increased remains unanswered (Newschaffer *et al.* 2007). Szpir (2006) described a 'furor' over this issue and claimed it has divided scientists and the public alike, but provided no evidence to back up this claim. Here our study seeks to examine how an unsolic-

ited sample of members of the public views the increasing prevalence of ASD, and whether their explanations differ from the consensus medical position.

## Methods

In 2004 a UK epidemiological study announced via a press release that it had been funded to examine the environmental causes of ASD. This release, describing a 'study to look at environmental causes of autism', provoked worldwide media interest with articles appearing in both the national and international press, and sparked interviews with the director of the study on national radio and local television. Some UK media outlets reinterpreted the study as focusing on MMR. For example the headline 'Funding U-turn on MMR jab study' was published by the Daily Mail (8 July 2004).

A total of 105 unsolicited letters, emails and several telephone calls were received in response to this media attention. The majority of letters and calls were from the UK with a small proportion from North America and other industrialized nations, all written between 2004 and 2006. The sample was self-selecting, from a population that had access to the Internet, television or newspapers. We analysed the content of the letters in order to examine the spontaneously expressed lay beliefs about the prevalence of the condition.

Our study had the advantage that data were neither solicited nor was data collection influenced by the presence of any researcher. This has been shown to lead participants to edit and adapt their responses (Hammersley & Atkinson 1995).

Names, locations and any other identifying features of correspondents were changed. The letters were read by two researchers, then transcribed and analysed. Significant statements and paragraphs from the letters were categorized according to themes and codes developing in the data in open coding, by the first author. A second researcher (second author) then analysed and coded a further set of letters, and the two sets of data were brought together to compare and cross code. The themes in the remaining letters were developed and codes were abstracted, linked and compared with the original categories. Thus a bottom up data-driven approach, using iterative analysis and theory building, was adopted. Theoretical saturation was reached at the 60th letter, with no new codes being identified. A third researcher (third author) reviewed the overall coding, analysis and interpretation, providing a further validity check.

## Results

The sample was a mixed group of relatives of people with autism, individuals self-described as having autism, and

professionals and clinicians with first-hand experience of ASD (Fig. 1). The overwhelming majority of the letters and telephone calls (81%) put forward the correspondents' theories and hypotheses about the causes of ASD. Of these 96% suggested potential environmental causes of the disorder. Roughly two-thirds of this correspondence (62 letters in total) put forward causes other than vaccinations; only 16 letters mentioned MMR. Over 40 different environmental factors were offered as potential causes, the majority of which (all but three) invoked modern technologies or a changing way of life (Table 1).

The vast majority of correspondents identified manmade risks; either due to medical technologies, modern lifestyles or industrial risks. Furthermore, these risks were described as associated with the latest adoption and applications of technologies so their effects are perceived as recent. This latent unease with present-day life and scientific progress was described by the sociologist Ulrich Beck (1992) as 'insecurities of the contemporary spirit' and forms a repeating theme:

Letter 60: Our body and brains are not infinitely capable of absorbing ever increasing amounts of drugs, vaccines etc.

Letter 45: I think this proves conclusively that colourings, preservatives and additives are playing a major factor on how the brain develops while in the womb between the fifteenth and seventeenth week of pregnancy.

Letter 87: I have been very concerned about the amount of foetal monitoring. The rise in hyperactivity in children and in autism goes hand in hand with the rise in foetal monitoring.

Letter 19: I hope I am barking up the wrong tree but I am still concerned at the number of children who have come to me in the past ten years with parents who are in some way associated with nuclear power stations.

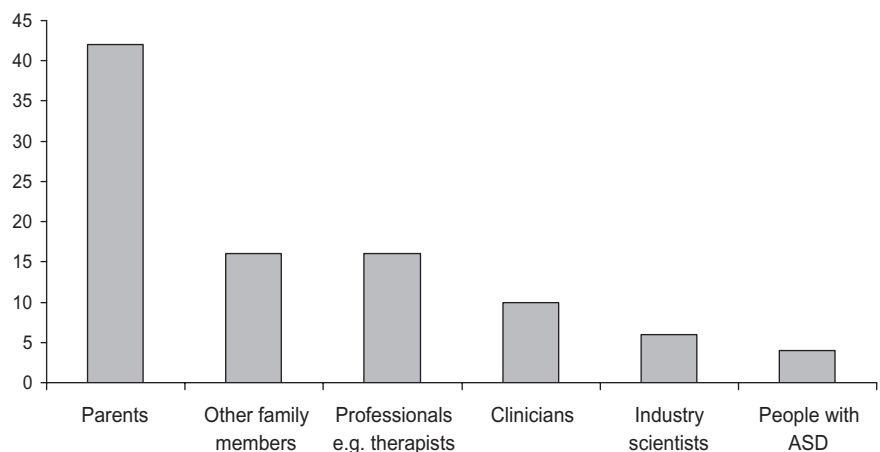
The risks of modern societies as described by Beck are frequently invisible, and are known or 'made visible' through scientific means (e.g. measurement). In this sense science can be seen to cause, identify and respond to risks. This understanding of the relationship of scientific knowledge to risks of the modern world is reflected in the correspondence. Although correspondents frequently suggested that the technological applications of modernity cause the risk of ASD (the problem), they also looked to the science of epidemiology to define and address them (the solution). Correspondents requested the epidemiological study to test or validate their theories rather than insisting that they were true, including in many cases requests to adopt specific methods:

Letter 62: We moved near a mobile phone mast and had two severely autistic children. In your research on autism will you ask people if they lived near a mast during pregnancy?

Letter 9: Even when CO is detected it is almost impossible for our victims to find someone to test the appliance and the house for CO and therefore no evidence is found of CO... However, possibly CO or suspected CO was recorded during this original research in which case it would be of great interest to us.

Letter 12: Has your longitudinal study shown up any dietary differences in the incidence and or the severity of autism? and is there any room in the new work to undertake some dietary manipulation work, and the imposition of A2 milk in situations where there are significant problems with autistic behavior?

The correspondents argued that there has been a real increase in incidence of ASD. Associated with this rise as hazards caused by modern technologies and lifestyles. The majority of the correspondence thus put forward theories and hypotheses about



**Figure 1.** Frequency of relationship to autistic spectrum disorders (ASD) where given (80% of sample).

**Table 1.** Range of environmental causes given as possible risk factors for ASD

Causes of risk		
<b>1. Medical technologies</b>		
	Ultrasound scans	
	Baby induced	
	Early cord clamping/cord wrapped around baby's neck	
	Respiratory distress	
	Caesarean section	
	Birth trauma	
	Foetal stress due to medical intervention	
Related to drugs/toxins during pregnancy	Rhogam shots	
	Contraceptive pill	
	Steroids	
	Antihistamines	
	DES (to prevent miscarriage)	
Related to vaccines	High levels of mercury due to dental mothers fillings	
	Time of day of vaccination	
	Lack of aspiration when vaccine administered	
	MMR	
	Mercury due to thiomersal	
	Vulnerability to injections when teething	
	Polio vaccine	
	Egg products in vaccines	
Pain of injection		
DPT/toxins		
<b>2. Changing lifestyle</b>		
Related to diet	Working mother leads to stress during pregnancy	
	Amount of alcohol drunk during pregnancy	
	Indoor air quality/time indoors	
	Overstimulation by cot toys	
	Too much television	
	Lack of cod liver oil	
	Food additives/aspartame	
	Disaccharides and starches	
	Food preservatives	
	Genetic origin of cows milk due to intensive animal breeding	
	Gluten in diet	
<b>3. Unavoidable technologies</b>		
	Low level radiation, from VDUs	
	Carbon monoxide exposure	
	Father works in nuclear power stations/ exposure to radioactivity	
	Exposure to chemicals	
	Living near mobile phone mast/ exposure to low level radiation	
	Moulds from indoor environments	
	Air pollution	
	Pollutants in water	
	<b>4. Biological factors</b>	
		Previous miscarriage or bleeding during pregnancy
		Dry birth (no amniotic fluid)
Child being born after twins		

ASD, autistic spectrum disorder; MMR, measles mumps and rubella; DPT, vaccines to immunize against diphtheria, pertussis (whooping cough) and tetanus; VDU, visual display unit.

environmental causes of ASD. Increasing incidence of ASD due to more contact with modern environmental triggers was a recurring topic.

Letter 52: I have been amazed at the increased incidence of autism – and pondered about the causes as have other people . . . since I left in 1995 something has happened – an explosion. The autistic did not exist in quantity pre-1995- so bearing in mind children enter schools at five years old – something changed around 1990 onwards. . . . Something definitely changed in the 1990s and which has persisted. I don't think it can all be down to better detection of autism.

Letter 64: I also believe that the increasing rates of autism in our population . . . are due to the ever increasing levels of sucrose consumption in our diet.

Letter 78: I hope that one of the factors being considered is the exposure of the foetus to ultrasound examinations in pregnancy. It does seem that the rise in incidence in autism corresponds to the rise in use of ultrasound.

Letter 74: It has recently come to my attention that there are those who believe there is a relationship between the rise in autistic spectrum disorders and the practice of early umbilical cord clamping . . . As a midwife I find this very disturbing as this has been my practice and that of my colleagues. As a precautionary measure, I now leave the cord longer before cutting it in order that the neonate might receive possible 50% more of its blood supply from the placenta.

In many cases the juxtaposition with the medical consensus is made explicit.

Letter 75: My colleagues and I were increasingly concerned about the growing number of children with autistic spectrum disorders. We did not think that the increase was solely due to improved diagnosis . . .

## Discussion

The overwhelming majority of respondents in the unsolicited sample in this study suggested that autism is caused by environmental factors. Although media reports described the epidemiological study as looking for environmental causes, the number of unsolicited letters espousing the idea of an environmental trigger demonstrates the high level of concern in this lay sample who have direct contact with ASD. Given the extent of media coverage of MMR as a potential cause of ASD it is

perhaps surprising that such an enormous range of other theories emerged. The correspondence also highlights a sharp disconnection between lay beliefs and the expert consensus explaining the increasing prevalence of ASD. The explanations given by lay correspondents focus on new hazards introduced by medical and technological advances and the lifestyles of modern society, with such hazards being responsible for the 'explosion' (Letter 52) or 'epidemic' (Letter 13) of numbers of cases of autism.

Most of the environmental risk factors proposed in the letters were already included in the scientific programme of the epidemiology autism research grant. Some other ideas were categorized as 'plausible' by the epidemiologists and indeed went on to provoke original research. Ultrasound and carbon monoxide poisoning were both examined as a direct consequence of the letters, for example. The correspondence allowed epidemiology to reap the benefit of the knowledge and experience of those with direct contact and differing relationships to autistic disorders.

Calnan (1987) highlights the logic and integrity of lay beliefs born of their social context, while Beck warns against removing the human and emotional aspects from scientific inquiry. Science should consider what is culturally significant he argues: 'Social movements raise questions that are not answered by the risk technicians at all, and the technicians answer questions which miss the point of what was really asked and what feeds public anxiety' (Beck 1992). Correspondents did not lack understanding of the 'correct' biomedical interpretation of the situation. As Greenfield and colleagues (1987) have pointed out, lay explanatory models cannot be viewed as misconceptions because they contradict current biomedical explanations. Rather, lay explanations put forward other arguments. In time these views may become more accepted, or they may not. Today, it is unclear whether true incidence has increased, and the exact aetiology of ASD remains uncertain in most cases.

Collins and Evans (2007) argue that legitimacy afforded in the western world to 'lay expertise' through consultations at policy levels has gone too far. They argue for the recognition of the elevated value of consensus medical expertise expressing a preference for norms and cultures of evidence based scientific research. Nevertheless it is important for medicine to acknowledge and be informed by the 'situated knowledge' described by Haraway (1991) as locatable critical knowledge based on the experience of actors. Perhaps a third way can be found, where lay voices neither dominate the agenda nor are ignored. Lay views can embellish paediatric expertise and provide valuable insights. In our study the correspondence contained information that epidemiologists were not aware of and upon which they were able to capitalize. Seeing through the eyes of those at

the 'coal-face' – relatives, affected individuals, a range of clinicians – also provided them with emotional and cultural perspectives on their work.

Szpir claims this issue – of increasing prevalence of ASD and the reasons behind it – has divided scientists as well as the public. It seems in the light of our study, much lay opinion lies on one side of the debate and most expert opinion on the other. This appears to be an instance where the professional consensus (or at least dominant view) is that the increased incidence is an artefact of changes in the diagnostic arena, while the correspondents' appear to take the increased incidence as a fact. The professional view here accepts that scientific understandings and opinions change – in other words, that 'facts' can be constructed and relative. The public view, as expressed here, is to argue for the 'fact' status of increasing incidence. The environmental aetiology because of modernization is also consonant with this belief in increasing incidence. Correspondents were not anti-science, however. They showed their faith in the legitimacy of science as an epistemic authority with their requests to test their ideas about the reasons for the increase. According to them modern life and medical technologies bring new risks and this is what underlies the increasing prevalence of autism.

### Key messages

- The number of children with autistic spectrum disorders worldwide has increased in absolute terms according to lay opinion.
- Many lay people believe this increasing incidence of autistic spectrum disorders is due to increased exposure to new environmental, medical and technological hazards, including vaccinations.
- The position of lay opinion contrasts with consensus expert medical opinion where changes in diagnostic practice are perceived as responsible for increases in prevalence.
- Lay opinions may become accepted in time – and cannot be dismissed as misperceptions. They may provide useful insights for researchers and paediatricians alike.

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