

MMR: marginalised, misrepresented and rejected? Autism: a focus group study

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Objective: To explore how the measles, mumps, and rubella (MMR) vaccine controversy impacted on the lives of parents caring for children with autism.

Design: Qualitative focus group study.

Setting: United Kingdom.

Patients: A purposively selected sample of 38 parents took part in 10 focus group discussions between March 2003 and May 2005.

Results: Many parents felt that the MMR vaccine could be too potent for children who are susceptible to developing autism. Of the parents whose children received the MMR vaccine, many felt guilty that they may have caused or contributed to their child's autism. Some parents felt frustrated by health professionals' lack of understanding of the negative impact the MMR controversy has had on them. Some parents were anxious about subsequent MMR decision-making for their children.

Conclusions: The controversy has had a negative impact on some parents of children with autism. This has implications for health professionals, who need to be particularly aware of the issues these parents face in future MMR decision-making for their affected child and younger siblings. It is anticipated that these findings will raise awareness among health professionals of the difficulties faced by such parents. More generally, there is a need to promote a greater awareness of the important role health visitors can play in parental decision-making and for research examining whether health professionals feel they receive sufficient training in communication skills. It is also essential that the latest scientific research findings are disseminated quickly to these parents and to those health professionals advising parents on matters of vaccine safety.

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The combined measles, mumps, and rubella (MMR) vaccine was introduced in the United Kingdom (UK) into the routine childhood immunisation programme in 1988, replacing the monocomponent measles vaccine, in order to eliminate measles, mumps and rubella and its associated congenital rubella syndrome.^{1–3} By the early 1990s, MMR coverage for 2 year old children exceeded 90% nationally.⁴ However, just as rates of measles notification were reaching an all time low, speculation about the safety of the vaccine began to emerge. In February 1998, a paper was published postulating a link between the MMR vaccine, bowel disease and autism.⁵ Wakefield and colleagues hypothesised that the vaccine caused inflammation of the gut making it more permeable, permitting peptides to leak out, which in turn were said to act as toxins on the brain causing serious developmental disorders (including autism). The paper sparked immediate criticism and concern,^{6–9} and researchers were quick to test Wakefield's hypothesis. However, subsequent scientific support has been absent,^{10–11} and further experiments designed to identify the measles virus in intestinal tissue¹² or blood¹³ have failed to find vaccine viruses. Furthermore, researchers have been unable to identify significant intestinal inflammation post-vaccination¹⁴; large epidemiological studies have found no evidence of a new form of autism associated with MMR^{15–16}; there is no evidence of an increased incidence of autism related to the uptake of the MMR or measles vaccines^{17–18}; studies investigating severe adverse reactions to the MMR vaccine conducted in Finland^{19–20} have failed to identify bowel problems or autism following vaccination; and a recent Cochrane review concluded that exposure to MMR was unlikely to be associated with autism.²¹

Despite government and public health officials acting quickly to reassure parents that the MMR vaccine was not associated

with autism, vaccine uptake dropped following the widespread media coverage of the MMR vaccine controversy (see: http://www.hpa.org.uk/infections/topics_az/vaccination/071102_MMRpreferable.htm). Recent research has investigated parents' reasons for refusing the MMR vaccine and their perceptions of the MMR controversy. Evans and colleagues suggested that for many parents it is easier to live with the risk of their child naturally contracting one of the diseases than with the risk of causing their child damage through vaccination,²² a finding reminiscent of previous work on omission bias.^{23–24} Raithatha *et al*²⁵ highlighted how parents' assessment of vaccine risk is influenced by their attitudes to the immunisation process as well as by the degree of trust they have in government and health professionals. They warned that the MMR controversy may have triggered a broader reappraisal of vaccine risk, and proposed that in order to address parents' fears about a causal link between autism and the MMR vaccine, further research into the aetiology of autism should be conducted. This was echoed in the recommendations from the Medical Research Council's (MRC) review of autism research.²⁶

Despite this growing evidence base on parental views of decision-making about MMR,^{22–24} there is a notable absence of scientific research reporting the views of one crucial group of parents, namely those caring for children with autism. To date their stories have been represented by journalists^{27–28} or through a few books in which parents offer their personal accounts.^{29–32} Horton³³ asserted that parents of children with autism: "... have become an even more marginalized group in the high-temperature debate over Wakefield's work" (p 92).

Abbreviations: MMR, measles, mumps, and rubella; MRC, Medical Research Council

Box 1 Examples of parents comparing the general health of their children with and without autism

"they're like chalk and cheese, she's a much stronger child, she, she never had a thing where he was just sickly from day one. He's always been a sickly child... he was always covered in spots, he was always on antibiotics, he always had tonsillitis, erm... he's always had bowel problems, em.... He's always had loads and loads of antibiotics. He's got asthma and eczema, erm, so he's always been on creams and lotions and potions and God knows what else. He's got food allergies.... He's very, very sensitive to whatever goes in his body. But as for our daughter she's a much stronger child." (G3: P9)

"... his immune system is shot to pieces.... He, he does seem to be one of these children who follows the, the path for antibiotics and then vaccinations and then autism. When he gets a cough or a cold he seems to have it much, much longer whereas my other son can carry on functioning and going to school. But he just gets really ill... it puts him into hospital.... I actually asked the consultant before he discharged him last time. I said 'you know, he does seem to be poorly a lot of the time, you know and he does have autism and I think there's a link between his autism and his immune system' and the consultant said 'no, that's absolutely not true, there's no correlation between autism and the immune, his immune system'. He dismissed it – so I said 'well okay' but I just felt that I had to say something." (G10: P36)

Since the putative link with autism was central to the MMR controversy, it is important to understand the views of parents of children with autism both in terms of the impact of the controversy on them, and in determining whether the controversy has given rise to particular needs for information and support. We undertook a study to elicit the views of this neglected group of parents to develop a better understanding of how the MMR controversy impacted upon their lives, and to discover whether their experience can provide lessons for future immunisation policy and practice.

METHODS

Ten focus groups were conducted in various parts of the UK with parents of children with autism. Two pilot focus groups were conducted in March 2003 as part of a larger study which looked at parental views on childhood infectious diseases,³⁴ immunisation and the MMR controversy.³⁵ These two pilot groups were of such interest that additional funding was secured from the MRC for an exploratory study with a further eight groups between April and May 2005. The focus group method was selected because it offered greater scope for the participants to set the research agenda and discuss topics of most importance to them.³⁶ The sample used purposive (maximum variation) sampling methods to ensure that the broadest possible range of experiences was included.³⁷ To recruit parents across the UK, internet searches were conducted to identify autism and carer support groups. Fifteen group leaders were contacted via email and sent information sheets to distribute to parent members; the members from 10 groups agreed to take part. Before commencing group discussions, informed consent was obtained and after completing the session any travel expenses and childcare costs were reimbursed. The final sample included parents with children with autism under 14 years old (mean age 7 years), whose autism had been diagnosed after the publication of Wakefield's paper⁵ and covered a range of severity. We also included parents with a range of different MMR vaccine decision-making outcomes for

Box 2 Example of a mother recalling an adverse reaction to MMR vaccination

"He was ill. You know, when they're really, really poorly and they've a temperature and they've just got that look of, I'm not here, that's scary as a parent, you're scared. And then when he finally kind of awoke, you know, he had the deadest eyes, it was like all the life had gone from his eyes. It was like before he was like a wee boy, twinkly eyes and after it, it was like the same eyeballs but as if, the glare had been taken out of them or something." (G1: P1)

their children in order to select the most diverse sample (table 1).

A topic guide was developed following analysis of the two pilot groups which included the following topics: experiences of getting the diagnosis; living with a child with autism; feelings about childhood immunisation and vaccine decision-making; and thoughts on the MMR controversy and its impact on their lives. Each group discussion began with parents introducing themselves and speaking about when they first suspected something was wrong with their child. All 10 groups were facilitated by SH and parents were encouraged to direct conversation between themselves with minimal interference from the facilitator. However, there were occasions when the facilitator prompted parents to explain, confirm or justify their position so that their opinions could be examined in greater depth. All groups were recorded with the respondents' permission and transcribed in full. The transcripts were checked against the recordings and imported into NVivo 2.0 (QSR International, Cardigan UK), a qualitative software programme, to facilitate systematic comparisons across the large amounts of data. Data were thematically coded. Following the principle of the constant comparative method,³⁸ each transcript was repeatedly re-examined and cross-compared to identify common themes and explore parents' underlying reasoning. Particular attention was paid to deviant or contradictory cases³⁹ and to the group dynamics.⁴⁰

Ethical approval for the study was obtained from the Faculties of Law, Financial Studies and Social Sciences Ethics Committee at the University of Glasgow. In order to ensure anonymity for the parents and their families, the groups are described only by broad regional terms, parents are identified by a number, and the names and ages of parents and children have been omitted.

RESULTS

The sample

The sample included 38 parents (34 mothers and four fathers) with 36 sons and four daughters diagnosed with autism (mean age 7 years). According to the MRC's review of autism research, autism spectrum disorders affect approximately 60 in every 10 000 children under 8 years of age in the UK²⁶ and it has been suggested that there may be as many as 15 times more males than females affected with high-functioning autism and twice as many males as females affected with lower-functioning autism.⁴¹ The gender distribution of children in this study therefore reflects the greater prevalence of autism among boys. Parents' descriptions of their child's autism ranged in severity from children who had no communication, few social skills and were totally dependent on others for basic care and safety, to children who were reasonably independent. These were often at the higher-functioning end of the autistic spectrum, with Asperger's syndrome.

Below we present the findings under the three main themes which emerged from analysis of the discussions.

Table 1 Participants in the focus groups

Group number Geographical area Pre-existing group recruited from	Participant ID and children	Brief description of autistic child (as described by parent)	Description of child with autism MMR status
G1 (pilot) Central Scotland After school club for children with autism	P1: Mother of two boys P2: Mother of two boys P3: Mother of two boys	Son with autism Son with severe autism Son with severe autism	Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR
G2 (pilot) Central Scotland National Autistic Society	P4: Mother of two boys P5: Mother of two boys P6: Mother of two boys	Son with autism Son with severe autism Son with autism	Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR
G3 North East England Autism support group	P7: Mother of one boy P8: Mother of one boy and girl P9: Mother of one boy and girl	Son with autism and ADHD Son and daughter with autism Son with severe autism	Given 1st but not 2nd dose MMR Both given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR
G4 North West England Club for children with autism	P10: Mother of one boy and girl P11: Mother of two boys P12: Mother of one boy and girl P13: Mother of two boys and two girls	Son with autism Son with severe autism Son with autism Daughter with Asperger's syndrome	Given no doses MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given both 1st and 2nd dose MMR
G5 North East Scotland Carer support group	P14: Mother of two boys and one girl P15: Mother of one boy and girl P16: Mother of one boy and girl P17: Mother of one boy and girl P18: Father of two boys	Two sons with autism Son with severe autism Daughter with autism Son with severe autism Two sons, one with severe autism and one with Asperger's syndrome	Oldest child given 1st but not 2nd dose MMR, younger child given no MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Oldest child given 1st but not 2nd dose MMR, younger child given no MMR
G6 North West Scotland National Autistic Society	P19: Mother of two boys P20: Mother of two girls and boy P21: Mother of one boy and girl P22: Mother of three boys	Son with autism Son with autism Son with autism Two sons, one with severe autism and one with a learning disability	Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Oldest child given both 1st and 2nd dose MMR, younger child 1st dose only
G7 Scottish Borders Autism support group	P:23 Mother of two boys P24: Mother of two boys P25: Mother of two boys	Son with autism Son with autism Son with autism	Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR
G8 Midlands National Autistic Society	P26: Mother of one boy and girl P27: Mother of three boys P28: Mother of one boy and girl P29: Father of one boy	Son with autism Son with autism Son with severe autism Son with autism	Given both doses MMR Given both doses MMR Given 1st but not 2nd dose MMR Given both doses MMR
G9 Central Scotland Carer support group	P30: Mother of one boy P31: Father of one boy and girl P32: Mother of three boys P33: Mother of one boy and girl	Son with Asperger's syndrome Son and daughter with autism Son with severe autism Daughter with Asperger's syndrome	Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given both doses MMR
G10 Southern England Autism support group	P34: Mother of one boy P35: Mother of one boy P36: Mother of one boy and girl P37: Mother of one boy and girl P38: Father of one boy and girl	Son with autism Son with severe autism Son with autism Daughter with autism Son with autism	Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given 1st but not 2nd dose MMR Given no doses MMR

The impact of the MMR controversy

Raised uncertainty about MMR as a cause of autism

A prominent theme of the discussions was that the MMR controversy had contributed to considerable uncertainty among the parents about the causes of autism. As a consequence, some parents blamed themselves for having unwittingly sanctioned an intervention that they now believed, with hindsight, may have contributed to their child's condition. While 10 parents were adamant that the MMR vaccine had not played any role in their child's autism, 28 parents felt it was possible that the vaccines been a contributory factor.

There were two main reasons given for this belief. In all groups parents spoke about the possibility that there may be a sub-group of autistic children who have inherently "weak" or "sensitive" immune systems which are unable to cope with vaccination. It was common, for example, for parents to speak about their autistic children having had recurrent bouts of

infection, and having been repeatedly being prescribed anti-biotics. For example, one mother said:

... if you look at my son he has all these severe allergies and he reacts to everything and I mean, we have to prepare all his food separately and all the rest of it, and he's so sensitive, and I always say his immune system is wonky... totally off kilter.... (G4: P11)

Other parents highlighted differences between their children with autism and other children in the family (see Box 1).

The second reason given for believing vaccines had played a causal role in their child's autism was that some parents believed that they had seen a significant change in their child's health or personality post-vaccination. For instance, one mother who was adamant that her son had had an immediate

Box 3 Example of mother questioning whether MMR vaccination was a cause of autism

"... I know in my, in my own mind now, that my son actually had the autism before the MMR, y'know, because, um, when I look back now, all the signs were there. But it's just, you... I didn't know how to recognise it, I mean with him it was there right from the start. But it's not as easy for other parents to say that. I mean... I've now realised that actually, he's actually had autism from the beginning.... It was there. But, you know, what did I know then?" (G8: P27)

adverse reaction to MMR remarked, "It was as if all life faded out of him" (G6: P21). Similarly, another mother stated that "after his MMR he was a completely different child, he didn't talk, he wouldn't eat, he refused to eat... ." (G3: P7). A particularly poignant story was related by a mother who described an immediate deterioration in her son after being immunised with MMR (see Box 2).

The 10 parents who did not believe that the MMR vaccine had played any role in their child's autism believed autism to be a genetic disorder, and either stated that there was a family history of autism or recalled the early signs of autism in their children pre-vaccination. One mother, reflecting on her son's autism, said that media coverage of a possible link between MMR and autism had caused her to wonder whether vaccination was a possible cause in her son's case, but she had concluded that it was not (see Box 3).

Self-blame and anger

Another important theme which arose spontaneously in all the groups was that some parents believed that they had ignored early warning signs that their child was not healthy, and had then sanctioned a vaccine that may have caused autism. This placed a significant burden of guilt upon them. Parents spoke, for example, about "feeling inadequate", a few talked almost confessionally about having "let their children down" (see Box 4) and some felt directly to blame. For example, one mother said:

I blame myself... being his mum, I had to have done something wrong for him to be like that... the majority of people need a cause... everybody needs to know why your child is the way they are. (G3: P9)

Parents often spoke angrily about how the MMR controversy had impacted on their lives. Even parents who stated that their child's autism was entirely genetic in origin felt affected by the uncertainty about the causes of autism which were heightened by the controversy. For example, one mother who thought her son had been born with autism nonetheless found the speculation surrounding MMR upsetting, and stated that:

... it makes you feel pretty damn rotten. I feel as if at the time I did the best for my boy... I wouldn't have put my child through anything that I think would harm him. (G1: P3)

Difficulties in subsequent decision-making and the role of health professionals

It was common for parents to describe how the controversy had made them anxious about subsequent MMR decision-making. Parents who considered that MMR had played a role in their child's autism were more likely to withhold the second dose

Box 4 Example of mother blaming herself

"... I feel like just I've failed my children so badly by not researching that. I feel as though I've bought organic food, I bought organic jars of food, I breastfed for as long as I could, I did everything, you know, I'd detox every f***** surface, nothing would get into them. And then I never questioned what was in the vaccine... and I know, you know everyone always says 'oh, you know, you can't blame yourself', but I do blame myself. And I should blame myself because I should have looked into that, I should have questioned that before I took my child along and got them injected." (G2: P5, tears in her eyes)

MMR, believing it might worsen their child's autism. Although many parents did decide to let subsequent siblings have the vaccine, it was often delayed until they were happy that their child was showing no sign of autism. However, this decision was described as an "agonizing decision", likened to the game of "Russian roulette". Parents commonly spoke of feeling frustrated and annoyed at health professionals' lack of appreciation of their difficult situation and some felt their concerns were dismissed or ignored by them. One mother described her reaction to receiving a routine invitation to immunise a younger sibling:

I thought... God forbid, I don't want both my children having autism; if I had a choice there's neither of them would. But after what's happened to our son there's no way on God's earth I wanted this to happen to my second one. (G3: P9)

Later she mentioned that she felt angry when her doctor dismissed her concerns and recommended giving her second child the MMR vaccination; she considered this showed a lack of understanding of how difficult this decision was for her.

When parents were encouraged to explain further why they felt angry towards health professionals, the key reason they gave was that parents thought that health visitors and general practitioners tended to underestimate the devastating impact of autism, were dismissive of their concerns about the safety of MMR vaccination and seemed to have an "inflexible approach" (see Box 5). One mother expressed this anger and frustration particularly clearly (see Box 6). Other parents in the same group went on to suggest that parents caring for autistic children need time, support and understanding from health professionals. Indeed, of the parents who had either refused their child with autism the second dose MMR or had refused to take their other children for MMR vaccination, most mentioned that they had experienced unwelcome pressure. This only served to deepen their dismay and added to their general sense of frustration and alienation towards health professionals.

However, there were a few instances where parents said that their health visitor had advised them not to have their autistic child immunised with the second dose MMR. For example, one mother said: "unofficially she [health visitor] told me, 'don't do it'. She says, 'don't do it' " (G6: P22). This mother spoke of feeling relieved and supported by this comment, but the group responded by suggesting that this is typical of the lack of consistency of care which parents experience, adding to their general sense of uncertainty.

DISCUSSION

These focus group discussions produced moving and often emotional accounts of parents trying to come to terms with their child's diagnosis of autism against a backdrop of widespread public speculation about the role of the MMR vaccine in the aetiology of autism. Although parents seemed well-

Box 5 Example of "inflexible care"

"... they like to do things a certain way and they have what, to me, appears to be a very prescribed avenue of doing things, and if you don't slot into that, if you can't comply... for instance saying 'no, he's not having his MMR and actually I'm thinking about doing this and not what you suggest', my over-riding feeling is that they don't like it. And you, you are, you are at the mercy of their beliefs, really and their ideas...." (G10: P38)

informed and were aware that the body of scientific evidence overwhelmingly supports the safety of the MMR vaccine, many remained unconvinced. The fears parents expressed in relation to their children being particularly vulnerable to immune damage were not unlike fears expressed by other parents.³⁵ Uncertainty about the origins of their child's autism was common, and the sense of self-blame that some parents felt because of their decision to vaccinate was unmistakable. The MMR controversy represented a period of continuing uncertainty about the safety of vaccines for children with, or predisposed to autism, and this impacted on some parents' later immunisation decision-making. Some opted not to immunise rather than risk exacerbating their child's condition.

The emotional impact of the uncertainty was evident. Many parents displayed frustration and anger at health professionals for failing to give them better advice for their children, for failing to recognise how damaging and undermining the debate surrounding the safety of the MMR vaccine has been, and for underestimating the impact of autism. Consistent with the findings of Raithatha *et al.*,²⁵ parents in this study took health professionals' apparent uncertainty and lack of knowledge about autism into consideration when making future decisions about vaccine risk. Like many parents in the general population,⁴² this group of parents often delayed MMR vaccination until their other children were showing no signs of autism. Although health visitors play a pivotal role in promoting childhood immunisation, little is known about how health visitors view their role in childhood immunisation and guidance on how they communicate advice to parents, particularly those with concerns, is not well defined.

This exploratory study has some limitations. The main criticism which may be levelled is that it represents a selected sample of participants and the findings may not be generalisable, a common criticism of qualitative research. However qualitative methods are essential to explore the meaning and impact of the controversy on parents, and very large sample sizes are unfeasible. Moreover, a notable feature of these focus group discussions was the high level of agreement between parents even though the sample was selected to be as diverse as possible, which suggests that the findings are robust. Nevertheless, it is possible that the more vocal parents opted into the groups and this should be borne in mind.

CONCLUSION

The fact that nearly a decade has passed since Wakefield's paper was published and so little is still known about the opinions of parents caring for children with autism, illustrates how limited the scope of the research on the autism/MMR controversy has been. This research has highlighted the considerable negative impact that the MMR controversy had had on this group of vulnerable parents. This has implications for health professionals, who need to be particularly aware of the issues these parents face in future MMR decision-making for their affected child and younger siblings. In general, these parents, perhaps more than most, face a particularly difficult decision when trying to decide whether vaccination is in their

Box 6 Anger directed at health visitor's lack of appreciation of the impact of autism

"See at the end of the day – this really f**** me off that people think that brain damage from measles and all that is worse than f***** autism – where do they get that, do you know what I mean? My child is brain damaged. He will never have the life that a normal child his age will have, right? He'll probably never leave home, the chances of him getting married are statistically... you know – off the scale. It's not going to happen. So I'm having him live with me forever as that wee boy who's, you know, and he's grown out of his peers now. They're all going ahead. He won't do that. He's never going to move further than Spiderman. Right, so... and I'm not saying – I mean I've got a very close friend whose kid died, I'm not saying that your child dying is anything less than the most horrific thing that could happen – but I think you have to see autism in the same way, as being a really tragic life-long consequence that affects family, it affects friends, it affects siblings, they want to ignore us but you have to be in their face and say don't ignore us...." (G9: P32)

child's best interests. Health professionals also need to be sensitive to the fact that some of these parents may feel in part responsible for having sanctioned an intervention that they believe may have contributed to their child's autism. More generally, there is a need to promote a greater awareness of the important role health visitors can play in parental decision-making and for research examining whether health professionals feel they receive sufficient training in communication skills.

The uncertainty and anxiety the MMR controversy has caused for these parents adds weight to the MRC's recommendations in 2001 for a comprehensive research strategy towards autism in order to confirm or refute the existence of a range of possible causal triggers for the condition. The government's pledge in February 2002 of £2.5 million towards autism research was welcomed by parents and the MRC has reported that it spends £1.3 million per year on autism research, including research on the causes of autism and autism-spectrum disorders (see: http://www.mrc.ac.uk/public-08_july_2004). Despite this considerable ongoing research effort, to our knowledge this exploratory study is the only research to date which has investigated how the MMR controversy has impacted on the lives of parents caring for children with autism. It is hoped these findings will usefully contribute to an understanding of the difficulties these parents face in making decisions about vaccination, and may sensitise practitioners, public health policy makers and autism researchers to the issues raised by the MMR debate which are most salient to this group of parents.

What is already known on this topic

- The aetiology of autism remains unclear. The suggestion that MMR vaccination may be a cause received widespread publicity, although subsequent scientific research has failed to support a link.
- Although there have been a number of studies which have examined the challenges parents face in weighing the risks and benefits of MMR vaccination, to date no research has explored these issues with parents of children with autism.

What this study adds

- This is the first research study to consider the impact the MMR controversy has had on parents of children with autism.
- There is a need for those who serve the public health interest to demonstrate a greater understanding of the negative impact this controversy had had on these parents:
- In particular, health professionals should be aware that these parents may find it difficult to weigh up the risks and benefits of subsequent vaccination for their children – including children affected, and unaffected, by autism.

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