



Published in final edited form as:

Nat Rev Neurosci. 2007 February ; 8(2): 153–160.

Interacting and paradoxical forces in neuroscience and society

Jennifer Singh,

Stanford Center for Biomedical Ethics, Center for Integration of Research on Genetics and Ethics, 701 Welch Road, Building A, Suite 1105, Palo Alto, California 94304-5748, USA.

Joachim Hallmayer, and

Department of Psychiatry and Behavioural Sciences, 1201 Welch Road, MSLS Building, Room P112, Stanford, California 94304, USA.

Judy Illes

Program in Neuroethics, Stanford Center for Biomedical Ethics and Department of Radiology, 701 Welch Road, Building A, Suite 1105, Palo Alto, California 94304-5748, USA.

Abstract

Discoveries in the field of neuroscience are a natural source of discourse among scientists and have long been disseminated to the public. Historically, as news of findings has travelled between communities, it has elicited both expected and unusual reactions. What scientific landmarks promote discourse within the professional community? Do the same findings achieve a place in the public eye? How does the media choose what is newsworthy, and why does the public react the way it does? Drawing on examples of past challenges at the crossroads of neuroscience and society and on a case study of trends in one neurogenetic disease, autism, we explore the dialectical forces interacting in scientific and public discourse.

The reactions of the public to scientific discovery are often not subtle, and can elicit mass, migratory-type social behaviours. This migration can take the form of public acceptance or rejection of certain scientific discoveries, which in turn leads to other behaviours that could result in further actions or beliefs. Such behaviours can be described metaphorically as 'flocking'^{1–4}. The phenomenon of flocking occurs not only in the public sphere; in science, individuals and professional organizations naturally migrate to new ideas, new investigational tools⁵, new discoveries involving drugs or genes, and targeted funding opportunities. Overall, such flocking behaviours are influenced by opportunity, emotional triggers⁶, the societal value attached to knowledge to be gained and the potential impact of that knowledge.

The net effect of these interactions within the scientific sector and between scientific discovery and public discourse is a highly complex movement among communities of people. It is a movement that clearly underscores, as Rose suggested in 2003, the need both for increased science literacy among non-scientists and for a literacy of public understanding and action

Correspondence to J.I. e-mail: illes@stanford.edu

Competing interests statement

The authors declare no competing financial interests.

DATABASES

The following terms in this article are linked online to: OMIM: <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM>

Asperger's syndrome autism

FURTHER INFORMATION

Center for Integration of Research on Genetics and Ethics: <http://cirge.stanford.edu>

Program in Neuroethics — Stanford Center for Biomedical

Ethics: <http://neuroethics.stanford.edu>

Access to this links box is available online.

among scientists⁷. Here, we explore this proposal further by considering past examples of flocking events in neuroscience and an in-depth analysis of the public response to research on one specific neurogenetic disease, autism. Our discussion of autism takes a detailed look at trends in research, scientific discourse and media coverage, the divergence of these trends and the ensuing public distrust of the well-established measles, mumps and rubella (MMR) vaccine, and the impact on public health and policy.

Neuroscience and flocking

The ways in which the media and society respond to scientific discoveries and either accept or challenge reported scientific findings can be illustrated by a number of significant events in the history of neuroscience. Here, we briefly sample four of these events: lobotomy 'mad cow disease', the 'Mozart effect' and 'geno-hype.' These events all involved shifts in social behaviour brought about by the interaction between scientific discovery and its dissemination. The contributions of different stakeholders are central to such interactions, as are the potential for new knowledge, health and medical implications, and any ethical or moral challenges that might accompany them. The overall social, political and cultural climate — the *Zeitgeist* — in which a discovery is made can influence the science itself, how it is disseminated and certainly how it becomes embodied in the public mind.

Lobotomy

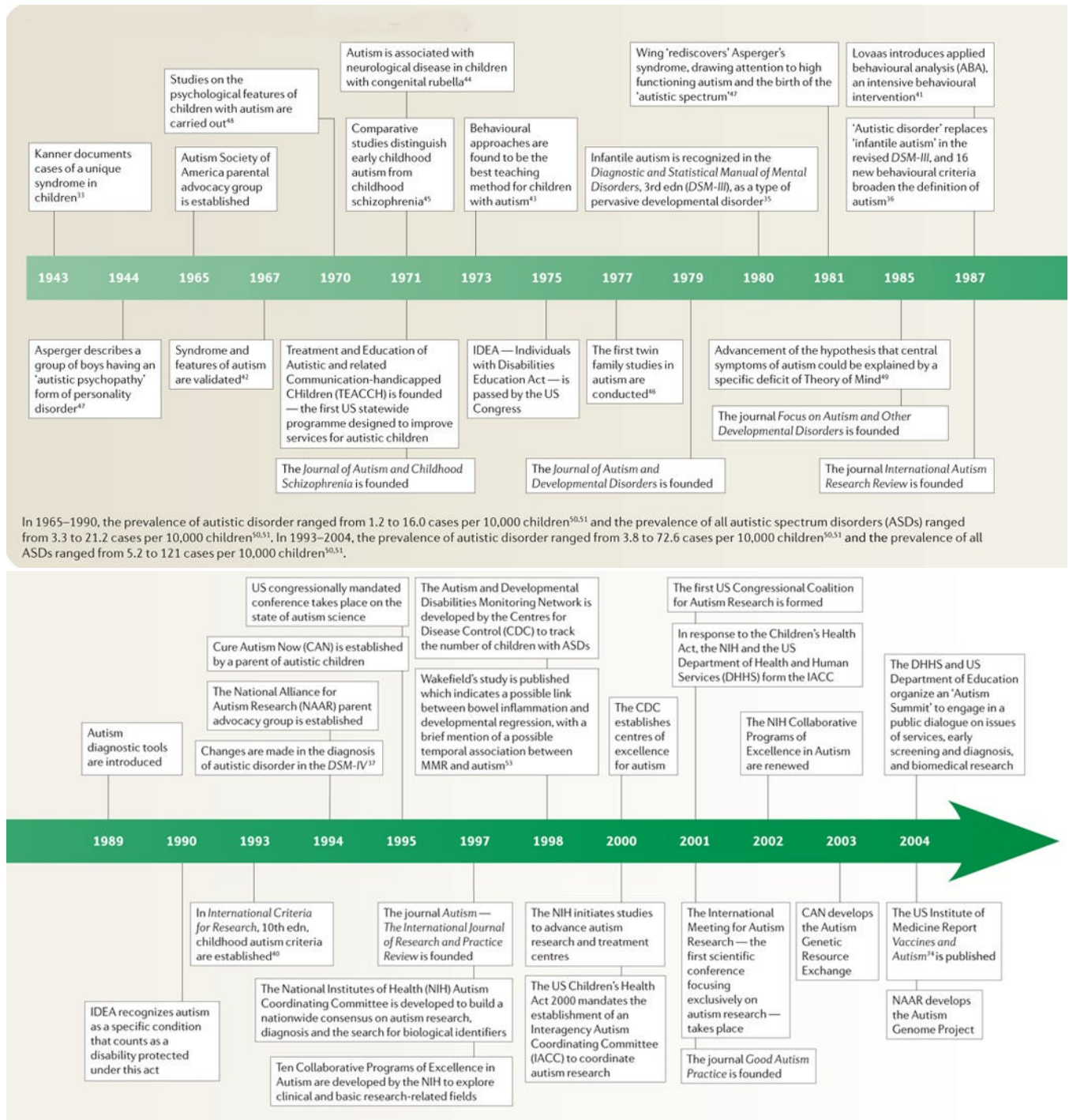
One of the earliest and perhaps darkest events in the history of neuroscience and society was the popularization of psychosurgery for the treatment of mentally ill patients^{8,9}. During the late nineteenth century, the clinicopathological correlations between brain, thought and behaviour became apparent and, through much of the first half of the twentieth century, surgeries involving the prefrontal lobes were reported to bring relief to patients with treatment-resistant disease¹⁰. These procedures, however, also dramatically changed the personalities of patients¹¹. Despite concerns raised by many in the medical community about these side effects¹², the promotion of prefrontal lobotomy by one neuroscientist through his relationship with prominent newspapers and magazines nevertheless brought about early public acceptance of this procedure¹⁰. The 1949 Nobel Prize provided additional medical legitimization of the technique. Alternative and less traumatic procedures such as 'transorbital lobotomy' might have been additional contributing factors to the widespread use of neurosurgical procedures for the treatment of the mentally ill before such methods were more closely scrutinized^{10,13}. Even today, psychosurgery is proposed as an effective treatment for drug refractory cases of schizophrenia and other psychiatric disorders^{9,14}.

The enthusiasm with which the public first greeted lobotomy mirrored the initial positive response of the press; the eventual reversal in the press to scepticism, if not out-right criticism, predicted a similar shift of the public view¹³. The outcry of those opposed ultimately raised awareness of the potential for misuse, indeed abusive use, of initially misrepresented and sensationalized methods to address social problems with complex causes¹¹.

Mad cow disease

The bovine spongi-form encephalopathy (BSE) epidemic, popularly known as mad cow disease, had a similar professional-public profile to that of lobotomy. One study in the United Kingdom sampled three different time periods of the media coverage of BSE, from the first indication of this disease in cattle in 1986, to reports that BSE could jump from species to species, and then to the time when variant Creutzfeldt-Jacob disease (vCJD) was linked to BSE¹⁵. The shift in the media coverage of BSE as a minimal threat to the economic impact on the cattle industry, and finally to the threat posed to human health, created legitimate uncertainty on the part of the public about the assurances offered by government and health

officials. The coverage of government misjudgements and their disastrous consequences, both scientifically and economically, were fuelled by public reaction and forced the banning of British meat from menus¹⁵. Only recently, in March 2006, the European Union voted to lift the ban on beef from the United Kingdom. Restrictions still remain for beef containing vertebral material and for beef sold on-the-bone today.



Timeline

Selected milestones in autism spectrum disorder

Mozart effect

The history of the Mozart effect, a positive effect of listening to classical music on spatial reasoning skills, further elucidates the powerful interaction of science and media on shared beliefs in society¹⁶. This event was characterized by the flocking of parents towards a method believed to improve brain development in early childhood. Although the 1993 hypothesis that listening to classical music (Mozart in particular) before a spatial skills test could improve performance was ultimately rejected¹⁷, the public's interest in the proposed effect was resilient. The attraction of this easy-to-adopt approach to potentially improve brain development even transferred from the laboratory and the home to public policy: in 1998, legislature in the US state of Georgia mandated the distribution of a recording of classical music to all newborn infants¹⁸. The flocking of industry (toy manufacturers in particular) to this phenomenon, which existed more in the news than in scientific reality, marks another dimension of the complexity of interactions between science and society^{19,20}.

Geno-hype

Discoveries in genetics have operated fundamentally at the intersection between science and society and provide further examples of shifts in behaviour due to, or at least correlated with, how such findings were reported. The media has accurately emphasized the medical benefits of genetics research^{21,22} and, in many cases, disseminated important core messages about health²³. Reporting by the press has also been variously deterministic and enthusiastic, justifying accusations about geno-hype and the overinflation of the effect of genetics on complex human traits^{24,25}. More recently, empirical research has shown that, even as discourse in the press regarding medical genetics moves away from the notion of biological determinism²⁶, optimism for certain neurogenetic disorders such as schizophrenia and Alzheimer's disease remains an overriding theme. This framing is one of empowerment²⁷: if a gene for a disorder exists, then the disorder is tangible; if a gene has not yet been identified, it will be; and gene discovery will bring cures to people who suffer from neurogenetic disorders and hope to them, their families and society²⁸.

Public reaction to discoveries in genetics — the 'buy in' to the hope or hype — is highly dependent on the context in which the information is received, if and how it can ultimately be applied, and the extent to which new possibilities interact with different cultural norms and values in a society. In the 1990s, for example, Hamer and colleagues published evidence for a genetic marker on the X chromosome that was shared more often in brothers who were homosexual than heterosexual²⁹. This study implicated neurogenetics in the value-laden question about the origins, expression and societal acceptability of homosexuality, and it received widespread media attention on the discourse of heritability. Although nowhere in the original article or in press releases were there claims of an actual gene discovery, the idea of a 'gay gene' emerged from the extensive media coverage.

Although the media widely publicized the idea of a gene for homosexuality, it did so in different ways on the international scene. As Conrad has described²⁸, the press in the United States viewed the discovery as good science, and treated it with cautious optimism by considering the discovery as significant scientific work but one that would still require replication. While recognizing the possibility of adverse effects such as stigma, the US press also saw a possibility for reducing discrimination through the 'naturalization' of homosexuality. In the United Kingdom, the press reported the study in terms of perils, including a future in which predictive genetic testing for homosexuality could be possible. The rhetoric of great promise represented

in the US media and the rhetoric of concern represented in the British press might have been due to differences in cultural and religious values about personal identity and privacy but also, as Conrad suggests, to structural factors such as the close alignment of UK newspapers with specific political views or parties, the vicissitudes of the media's relationship with scientists, and the impact of gay activists and organizations on journalistic perceptions.

Each of these four examples highlights various layers of group behaviour in the support or rejection of science by different stakeholders among the public, scientists, the medical profession, policy makers and advocacy groups. They are only a select group of events, and our review of them has been deliberately brief to lay the groundwork for a discussion of interactions of science and society in greater depth. To this end, we turn next to a detailed analysis of one case study in neuroscience and neurogenetics discovery — autism — that has had a relatively long history and that is marked by both well-defined milestones and rapid change.

A case study

We embarked on the study of autism in the context of science and society by exploring the historical interplay between research on autism, discourse among scientists who conduct autism research and the dissemination of autism studies through the media. The purpose of this study was to identify the main forces that influence professional, personal and public understanding of autism³⁰. Through a retrospective analysis, we sought to identify important themes in relevant research over time in funded projects and programmes³¹, peer-reviewed literature and the print press, and to investigate how they reflect each other. The data were interrogated using methods commonly used in content analysis³² by coding — identifying and quantifying — the themes of brain and behaviour, genetics (both discovery of susceptibility genes and gene expression studies), environmental causes, treatment, epidemiology, diagnosis, and family and services.

Evolving an understanding of autism

We began by identifying selected milestones in the history of autism to frame the analysis (TIMELINE). These events were chosen based on early contributions of individual clinicians and researchers, changes in the diagnosis of the disorder over the years, political shifts affecting research and treatment, and the rise of US federally funded research programmes. The first milestone was the initial identification of autism as a complex developmental disability appearing during the first three years of life³³. Although unusual language and emotional behaviours have endured as the prevailing neurocognitive characteristics of autism, different sets of diagnostic criteria quickly developed over time^{34–40}. The term 'autism spectrum disorder' (ASD) is frequently used to include those with autism, Asperger's syndrome and pervasive developmental disorder — not otherwise specified (PDD-NOS). Different categories evolved not only through medical research but also from observations by complementary and sometimes competing stakeholders, including paediatricians, psychiatrists, psychologists, teachers, speech therapists, social workers and parents of children with autism.

The TIMELINE shows the emergence of multiple US advocacy groups, the different US educational and treatment programmes such as Treatment and Education of Autistic and related Communication-handicapped CHildren (TEACCH) and Applied Behaviour Analysis (ABA)⁴¹, as well as the various contributions from different disciplines of psychiatry^{33, 42–46}, paediatrics⁴⁷ and psychology^{48, 49}. In parallel with these events, there was a marked increase in the prevalence of autism and ASDs^{50, 51}, which was surely a contributing factor to the attention this group of disorders garnered over time. In the United States, monitoring systems were set in place to track the number of children with autism (such as the Centers for Autism

and Developmental Disabilities Research and Epidemiology Network (CADDRE) at the Center for Disease Control (CDC)), and free educational services became mandatory through the Individuals with Disabilities Education Act (IDEA).

Strong political momentum on behalf of people with autism rose in the mid-1990s, effectively promoting public research programmes, interagency committees and the establishment of the first US congressional coalition on autism research. These events included the congressionally mandated meeting on the state of autism research in 1995 and the Children's Health Act of 2000. As a result, both the number and type of small- and large-scale research studies increased, including the establishment of Collaborative Programs of Excellence in Autism (CPEA) developed by the National Institutes of Health (NIH), Studies to Advance Autism Research and Treatment Centers (STAART) and regional centres of excellence for autism and other developmental disabilities launched by the CDC. These US research initiatives were significant given the impact on national resources and the breadth of agendas ranging from basic research and epidemiology to treatment and services.

The work of important US advocacy groups, notably the National Alliance for Autism Research (NAAR, now Autism Speaks) and Cure Autism Now (CAN), has been instrumental for funding research into the causes and treatment of ASDs. NAAR was established in 1994; CAN was founded in 1995. Both were direct results of the dissatisfaction with the quantity and nature of research programmes obtaining government funding. In 2006, NAAR merged with Autism Speaks to better serve its constituents. CAN has announced that it will follow suit in 2007. These groups collectively made contributions of US\$80 million towards autism research as of 2006. They also initiated their own genetics research programmes and established numerous outreach and awareness activities aimed at families, physicians, governmental officials and the general public. Coincident with these events, five peer review journals devoted to autism⁵² were established to provide investigators with a dedicated home for reporting their discoveries.

Trends in research

With the goal of understanding the interaction of history with trends in science and with society's understanding of those trends via the media, we conducted a retrospective analysis of three sets of government funding data: newly funded autism research projects between 1973 and 2004 by the NIH in the United States, the National Research Register in the United Kingdom, and the Canadian Institute of Health Research. These are major databases in countries in which autism has become a focus of scientific, political and social awareness. Two raters (J.S. and J.I. or the research intern) coded all the data with good inter-rater reliability between pairs of raters on random sub-samples of research projects. Some results total more than 100% because our coding scheme allowed for multiple codes for each of the abstracts and articles retrieved.

Our results for the NIH database revealed an overall broadening of research themes (FIG. 1), with a surge in 1997 that coincided with the new CPEA established in the United States. The trend was driven primarily by new research on brain and behaviour, and on genetics. Psychoeducational and psychopharmacological treatment studies followed similar trends to genetic studies, especially in 2000 and 2002. The study of the environmental causes of autism was not a principal focus of autism research at the US national level. Funding trends for new autism projects funded in Canada and the United Kingdom paralleled those of the United States.

Trends in science discourse and reporting

With an understanding of primary funding and research themes in hand, we next examined the peer-reviewed literature on autism research and main themes in a sample of articles from the

international press. To capture one aspect of scientific discourse, we identified and coded the top 5% of cited peer-reviewed literature on autism from 1994 to 2004 (Science Citation Index, May 2006, using the keyword phrases 'autism or autistic'). This search yielded a total of 229 original research abstracts from 10 unique journals. Most of the papers were in the *Journal of Child Psychology and Psychiatry and Allied Disciplines*, the *American Journal of Human Genetics* and the *Journal of Autism and Developmental Disorders*. For coverage of autism research reported in the international press, we coded news articles from the Lexis Nexis Academic database of General News (major newspapers such as The New York Times (United States), The Guardian (United Kingdom) and the Toronto Star (Canada) from 1994 to 2004). Using the keyword phrases 'autism or autistic' and 'research', we retrieved 33 independent newspapers (United States, $n = 21$; United Kingdom, $n = 7$; other, $n = 5$) that yielded 437 articles. There were a total of 183 articles from the American press and 221 articles from the British press. This is clearly not a comprehensive press sample but a representative and manageable entry point through which to capture the science of autism conveyed through the "filter of journalistic language and imagery"²⁴.

Our coding method was identical to that used for newly funded research projects to enable direct comparisons. We found that the focus of scientific, peer-reviewed literature closely mimicked that of newly funded autism projects. Media reports on autism research, however, did not. Disconnections and paradoxical relationships between the focus of autism research internal to the scientific community and the focus external to it in society were evident.

The first paradox we identified was that brain and behaviour research was a focus of funded research and scientific discourse but was not the focus of the media. Brain and behaviour was a main focus of new grants in autism research in all of our samples from the United States, Canada and the United Kingdom (42% of the total). It was also the most prevalent theme in the scientific discourse we identified in the peer-reviewed literature (41% of papers). By contrast, merely 11% of articles in the major international print press from these countries and others focused on brain and behaviour. Another paradox is that genetics research was a focus of funded research and scientific discourse, but not the focus of the media. Second to brain and behaviour, genetics was the next most frequently identified category of autism research. Among scientific discourse, genetics represented 34% of our sample of the peer-reviewed literature. This is almost five times higher than genetics research reported in the media (7%).

Environmental causes and epidemiology research were the foci of the media but not of newly funded research projects or discourse among scientists. This was the greatest paradox observed, with other contrasts embedded in it. Studies on the environmental causes of autism reported in the media (48%) far exceeded research (7%) or related discourse (13%) (FIG. 2). This disproportionate reporting of environmental causes in the media is correlated with the controversial Wakefield study⁵³, in which data from 12 children indicated a possible temporal association between the MMR vaccine and autism. Among all the media articles with an environmental focus, 70% in our sample were about the MMR vaccine and 40% referred to the Wakefield study. Among the articles on the MMR vaccine, 75% were published in the United Kingdom, 22% in the United States, and the remaining 3% from other regions of the world. For the most part, the tone was critical of the link between MMR vaccination and autism. TABLE 1 shows the range and frequency of environmental causes of autism reported in the print media from 1994 to 2004 compared to those reported in the newly funded research projects and journal articles that we examined.

To place these findings in the context of history, consideration of vaccination campaigns in the United Kingdom in particular is helpful. The development and compulsory use of the smallpox vaccine in the nineteenth century⁵⁴, for example, and the anti-pertussis vaccine

movement in the mid-1970s^{55, 56} created a generalized public scepticism about the naturalness (or unnaturalness) of vaccinating children against childhood disease and a mistrust of vaccinations. As discussed earlier, false assurances by the British government during the BSE controversy caused journalists and the public alike to become suspicious of government and health officials. The controversy of the Wakefield study and the link between autism and the MMR vaccine occurred in the wake of this history of mistrust. The combination created a template for journalists to question government officials⁵⁷, and one through which the public would now also view similar controversy. MMR vaccination rates dropped in 2003 and 2004 to a record low in the United Kingdom. Similar patterns were reported, although not to the same extent, for the United States, Australia and New Zealand⁵⁸.

Public concerns about the vaccine also prompted a flow of research funds to new studies designed to test the claims of the Wakefield study. Several were launched in the United Kingdom^{59–63}, the United States⁶⁴, Finland⁶⁵ and Denmark⁶⁶. All of the studies ultimately disproved the hypothesis of a link between autism and the MMR vaccine. Despite this evidence, many parents today continue to be sceptical of the safety of the vaccine. In December 2006, the US Congress approved a \$1 billion five-year bill called the Combating Autism Act. It will provide funding for new NIH Centers of Excellence on autism, including those potentially focused on environmental factors.

The take-home message from these analyses is that despite a relatively long and intricate history of autism, millions of dollars of funding and thousands of papers in the peer-reviewed literature to explore causes, symptoms and possibilities for intervention, the selective reporting of the press was in sharp contrast to the focus of research and funding. Perhaps, as Nelkin suggests: “In an age where communication among scientists is specialized and obscure, simplification is an essential if not a controversial part of making science palatable to the public”²⁴. In the case of autism, the press provided information to the public that was straightforward to understand and to which the public could then respond actively or, indeed, reactively. That response, controversial for both its ethics and its wisdom, had some negative consequences for public health and policy, as we discuss next.

Controversy, complexity and community

Each of the cases we have presented illustrates the complex exchange between stakeholders that creates situations which stimulate affinity for and distancing from research and scientific information. The nature of this behaviour depends on many contextual variables, including the utility of the scientific information and the political, cultural and social context in which information is generated and received. In the case of autism, society experienced a sense of urgency about an effect that had uncertain and controversial scientific legitimacy. The intensity and volume of coverage in the press itself overrode the critical content overtly contained therein, creating the possibility of a measles epidemic and a potential health crisis^{67–70}. The weight of press coverage and public response was carried by the United Kingdom, the country in which the Wakefield study was conducted and also the country in which the prime minister himself would not publicly disclose whether his child had received the MMR vaccine⁵⁷.

The advancement of the controversial link between MMR and autism is partly reminiscent of the notion of ‘neuro-policy’ we have described elsewhere⁷¹. Actions in the political arena that led to the dissemination of information rejecting the causal link were in the interest of public health policy and allayed the fear of parents preparing to forgo the triple vaccine. Actions by advocacy groups such as Justice, Awareness, Basic Support (JABS) in the United Kingdom, advocated for parents to have the option to choose single rather than multiple vaccines and for

continued research on the proposed link between MMR and autism. Personal convictions from researchers who supported this approach also called for a rethinking of the vaccination policy.

Given the history of anti-vaccination campaigns and the steady increase in the prevalence of autism, our findings are not surprising. Different interpretations of them are worthy of consideration, however. Note, for example, that environmental themes were reported more often because they were more newsworthy than the dominant brain and genetics research themes. Such a disparity in reporting might have prevented the wider community from entering into an unbiased and informed discussion of the scientific enterprise, led to misunderstandings and, as the other examples have also shown, resulted in sometimes irrational and potentially harmful decision-making. By contrast, we note that a recent blog report at *Slate.com* on a possible link between television and autism⁷² stirred widespread coverage by US and UK press, radio and television while attracting substantial derision from the professional community and parental groups alike.

The media coverage of MMR can be also viewed as a reasonable reflection of the issues deemed most important by the public. In this regard, it could be argued that it is the official funding agencies that are out of step: media coverage of autism based on the controversy of MMR not only stimulated awareness of autism but also highlighted the need for additional research in the causes and treatment of this disorder⁷³. In the United States, for example, congressional hearings held from 1999 to 2000 on childhood immunization prompted an investigation by the Institutes of Medicine (IOM) to review immunization safety^{74,75}. Although the reports showed no apparent increase in the rates of autism associated with the MMR vaccine, the focus on autism had the benefit of bringing attention to autism research in other areas, including causes and treatment.

Each of the cases we have featured in this paper also highlights the diversity and complexity of issues that arise in the face of scientific discovery and public dissemination. No two cases are the same, yet they raise similar important questions about the responsibilities that scientists bear for societal behaviours that their results might elicit, and the responsibilities of journalists who report scientific discoveries. In a comprehensive study of genetics researchers and science writers, Gardner *et al.* identified social responsibilities valued by each profession²⁷. Scientists expressed a commitment to report all the news necessary for open, free and well-informed debates, a trend that parallels globalization and mobility. Journalists expressed a commitment to balance accuracy against the need-for-speed in an era of increasingly complex information. Complexity increases when technological breakthroughs lead to new forms of social organization and even to changes in the mental representations of human experience²⁷.

There is no magic formula to predict the societal responses to advances in science, and whether these responses will have unintended consequences. A cycle of knowledge that draws on dynamic interactions among stakeholders rather than on relatively confined peaks of information dissemination would be one positive response to mitigating these unknowns. Interdisciplinary efforts that are embraced by all aspects of academia, citizen forums and innovative art and technology education would serve to achieve stronger partnerships among these groups. There is ample evidence for the need, precedent and effectiveness of such innovations on a global scale^{7,11}. As Gaskell *et al.* wrote in *Science* in 2005, “The public expect and want science and technology to solve problems, but they also want a say in deciding which problems are worth solving. [It is a matter] of seeing the public as participants in science policy with whom a shared vision of socially viable science and technological innovation can be achieved.”⁷⁶

Like the rise of advocacy and dedicated research centres for autism in the 1990s, many for-profit biotechnology companies have surfaced to capitalize on cutting edge genetics research.

Other new institutions arose in response to associated ethical concerns. For example, the council for Responsible Genetics, based in Cambridge, Massachusetts, USA, currently commissions studies of controversial issues and reports its findings in accessible publications. Among the topics it has investigated are genetically modified foods, the risks of gene therapy and designer genes and the controversial status of cloning. The recently established Gene-media Forum promotes public dialogue about genomics research and its implications for society. The Forum promises “a diversity of views” and “the fullest coverage of the social and political issues, as well as the science of the genetic revolution”²⁷.

No doubt the present perspective is limited by the examples selected, by the data sampled, by limitations inherent to the Lexis Nexis database and search engines, and by the specific definitions we have attributed to discourse for the peer-reviewed literature and for society through the press analyses. The views of children and adults with autism and other disorders of the CNS — for example, advocacy groups, educators and policy-makers — are also clearly vital to illuminating the true impact of the interacting forces of scientific discovery, dialogue and dissemination on the conceptualization of brain health and disease. Our own work continues in these areas.

Conclusions

We conclude by thinking about the very public nature of scientific discoveries. As Gross⁷⁷ wrote, “Science is public: it demands rational, critical debate; it involves observation, description, and measurement.” Communities that produce science and communities that respond to science are profoundly shaped by the ways in which that science is communicated. Each operates guided by its own needs, motivations and constraints, and responds with varying degrees of cooperation and conflict, whether that response is to views on cognitive well-being or causes of mental illness, neuro degenerative disease and genetics, sexual preference and genetics, music and neuro development, or the safety of certain foods. Some reactions are sweeping, such as the distancing (or flocking) of the public from the MMR vaccine and to a lesser extent a shift in portfolio for some basic neuroscience and clinical research; other reactions are more limited. As our analysis of autism research demonstrates, priorities can be divergent and leave the scientific community and government agencies ill-prepared to lead the public perception to a more balanced outlook based on scientific data. Neither community represents a force that evolves or acts alone, however: each is driven by individuals who share common interests and history that can cross geographical, cultural, ethnic, behavioural and health status boundaries⁷⁸. Opening up conceptual borders between these communities is key to achieving mutual understanding, to the translation of constructive responses in society, and to a future of continued discovery and increasingly effective disease interventions.

Acknowledgements

Supported by grants from the US National Institutes of Health (National Human Genome Research Institute, National Institute of General Medical Sciences, National Institute of Mental Health and National Institute of Neurological Disorders and Stroke). The authors extend their thanks to R. Briere (Canadian Institutes of Health Research, Institute of Neurosciences, Mental Health and Addiction), E. Racine, N. Guido-Estrada, S. Waldman, M. Devasher and R. Murugesan. The authors also thank reviewers for extremely helpful comments on this manuscript. Parts of the data were presented at the *Society for Neuroscience*, Annual Meeting, October 13–18, 2006, Atlanta, Georgia.

References

1. Mader TF. Appeal of words: a commercial venture. *Et Cetra* 1978;35:136–144.
2. Dobrev SD. Career mobility and job flocking. *Soc Sci Res* 2005;34:800–820.
3. Reynolds RC, Peng B. Knowledge, learning and swarms in cultural systems. *J Math Sociol* 2005;29:115–132.

4. Ip GW, Chiu CY, Wan C. Birds of a feather and birds flocking together: physical versus behavioral cues may lead to trait- versus goal-based group perception. *J Pers Soc Psychol* 2006;90:368–381. [PubMed: 16594825]
5. Illes J, Kirschen MP, Gabrieli JDE. From neuroimaging to neuroethics. *Nature Neurosci* 2003;6:205. [PubMed: 12601375]
6. Delgado-Mata C, Ibanez J, Aylett R. Let's run for it! Conspecific emotional flocking triggered via virtual pheromones. *Lect Notes Comp Sci* 2003;2733:131–140.
7. Rose SPR. How to (or not to) communicate science. *Biochem Soc Trans* 2003;31:307–312. [PubMed: 12653626]
8. Valenstein, ES. *Great and Desperate Cures: The Rise and Decline of Psychosurgery and Other Radical Treatments for Mental Illness*. Basic Books; New York: 1986.
9. Mashour CA, et al. Psychosurgery: past, present, and future. *Brain Res Rev* 2005;48:409–419. [PubMed: 15914249]
10. Valenstein ES. The history of lobotomy: a cautionary tale. *Mich Q Rev* 1988;27:417–437.
11. Illes J, Bird SJ. Neuroethics: a modern context for ethics in neuroscience. *Trends Neurosci* 2006;29:511–517. [PubMed: 16859760]
12. Freeman W, et al. Neurosurgical treatment of certain abnormal mental states (panel discussion). *J Am Med Assoc* 1941;117:517–527.
13. Diefenbach CJ, et al. Portrayal of lobotomy in the popular press: 1935–1960. *J Hist Neurosci* 1999;8:60–69. [PubMed: 11624138]
14. da Costa DA. The role of psychosurgery in the treatment of selected cases of refractory schizophrenia: a reappraisal. *Schizophr Res* 1997;28:223–230. [PubMed: 9468356]
15. Washer P. Representations of mad cow disease. *Soc Sci Med* 2006;62:457–466. [PubMed: 16046039]
16. Bangerter A, Heath C. The Mozart effect: tracking the evolution of a scientific legend. *Br J Soc Psychol* 2004;43:605–623. [PubMed: 15601511]
17. Rauscher FH, Shaw CL, Ky KN. Music and spatial task performance. *Nature* 1993;365:611. [PubMed: 8413624]
18. DiPietro JA. Baby and the brain: advances in child development. *Anna Rev Public Health* 2000;21:455–471. [PubMed: 10884961]
19. Genius Products, Inc. 2006. [online] <<http://www.geniusproducts.com>>
20. Baby Einstein Co. 2006. [online] <<http://www.babyeinstein.com>>
21. Petersen A. Biofantasies: genetics and medicine in the print news media. *Soc Sci Med* 2001;52:1255–1268. [PubMed: 11281408]
22. Bubela TM, Caulfield TA. Do the print media 'hype' genetic research? A comparison of newspaper stories and peer-reviewed research papers. *Can Med Assoc J* 2004;170:1399–1407. [PubMed: 15111473]
23. Caulfield T. Biotechnology and the popular press: hype and the selling of science. *Trends Biotechnol* 2004;22:337–339. [PubMed: 15245905]
24. Nelkin, D. *Selling Science: How the Press Covers Science and Technology*. W. H. Freeman & Co.; New York: 1995.
25. Lippman A. Led (astray) by genetic maps: the cartography of the human genome and health care. *Soc Sci Med* 1992;35:1469–1476. [PubMed: 1485194]
26. Condit CM, Ofulue N, Sheedy KM. Determinism and mass-media portrayals of genetics. *Am J Hum Genet* 1998;62:979–984. [PubMed: 9529342]
27. Gardner, H.; Csikszentmihalyi, M.; Williams, D. *Good Work: When Excellence and Ethics Meet*. Basic Books; New York: 2001.
28. Conrad P. Genetic optimism: framing genes and mental illness in the news. *Cult Med Psychiatry* 2001;25:225–247. [PubMed: 11453260]
29. Hamer D, et al. A linkage between DNA markers on the X-chromosome and male sexual orientation. *Science* 1993;261:321–327. [PubMed: 8332896]
30. Singh J, Hallmayer J, Illes J. The paradoxical relationship of scientific and public discourse in autism research. *Soc Neurosci Abstr* 2006;692:21–68.

31. Charman, T.; Clare, P. Mapping Autism Research: Identifying UK Priorities for Autism. National Autistic Society; London: 2004.
32. Neuendorf, KA. The Content Analysis Guidebook. Sage Publications; Thousand Oaks, California: 2002.
33. Kanner L. Autistic disturbances of affective contact. *Nervous Child* 1943;2:217–250.
34. Rutter M. Diagnosis and definition of childhood autism. *J Autism Child Schizophr* 1978;8:139–361. [PubMed: 670129]
35. APA. Diagnostic and Statistical Manual of Mental Disorders. 3. American Psychiatric Association; Washington DC: 1980.
36. APA. Diagnostic and Statistical Manual of Mental Disorders. 3. American Psychiatric Association; Washington DC: 1987. Revised
37. APA. Diagnostic and Statistical Manual of Mental Disorders. 4. American Psychiatric Association; Washington DC: 1994.
38. Volkmar FR. Categorical approaches to the diagnosis of autism: an overview of DSM-IV and ICD-10. *Autism* 1998;2:45–59.
39. Tidmarsh L, Volkmar FR. Diagnosis and epidemiology of autism spectrum disorders. *Can J Psychiatry* 2003;48:517–525. [PubMed: 14574827]
40. WHO. International Classification of Diseases: Diagnostic Criteria for Research. 10. World Health Organization; Geneva: 1993.
41. Lovaas OI. Behavioral treatment and normal educational and intellectual-functioning in young autistic-children. *J Consult Clin Psychol* 1987;55:3–9. [PubMed: 3571656]
42. Rutter M, Lockyer L. A five to fifteen year follow-up study of infantile psychosis. I Description of sample. *Br J Psychiatry* 1967;113:1169–1182. [PubMed: 6075451]
43. Rutter M, Bartack L. Special education treatment of autistic children: a comparative study. II Follow-up findings and implications for services. *J Child Psychol Psychiatry* 1973;14:241–270. [PubMed: 4767020]
44. Chess S. Autism in children with congenital rubella. *J Autism Child Schizophr* 1971;1:33–47. [PubMed: 5172438]
45. Kolvin, I. Infantile Autism Concepts, Characteristics and Treatment. Rutter, ML., editor. Churchill Livingstone; Edinburgh: 1971. p. 7-26.
46. Folstein S, Rutter M. Infantile autism: a genetic study of 21 twin pairs. *J Child Psychol Psychiatry* 1977;18:297–321. [PubMed: 562353]
47. Wing L. Asperger's syndrome: a clinical account. *Psychol Med* 1981;11:115–129. [PubMed: 7208735]
48. Hermelin, B.; O'Connor, N. Psychological Experiments with Autistic Children. Pergamon Press; New York: 1970.
49. Baron-Cohen S, Leslie A, Frith U. Does the autistic child have a 'theory of mind'? . *Cognition* 1985;21:37–46. [PubMed: 2934210]
50. Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *J Autism Dev Disord* 2003;33:365–381. [PubMed: 12959416]
51. Williams JG, Higgins JPT, Brayne CEG. Systematic review of prevalence studies of autism spectrum disorders. *Arch Dis Child* 2006;91:8–15. [PubMed: 15863467]
52. Wolff S. The history of autism. *Eur Child Adolesc Psychiatry* 2004;13:201–208. [PubMed: 15365889]
53. Wakefield AJ, et al. Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *Lancet* 1998;351:637–641. [PubMed: 9500320]
54. Fenner, F., et al. Smallpox and its Eradication: The Pathogenesis, Immunology, and Pathology of Smallpox and Vaccinia. World Health Organization; Geneva: 1988.
55. Cangarosa E, et al. Impact of anti-vaccine movements on pertussis control: the untold story. *Lancet* 1998;351:356–361. [PubMed: 9652634]
56. Baker JP. The pertussis vaccine controversy in Great Britain. *Vaccine* 2003;21:4004–4010.
57. Lewis J, Speers T. Misleading media reporting? The MMR story. *Nature Rev Immunol* 2003;3:913–918. [PubMed: 14608376]

58. Burgess DC, Burgess MA, Leask J. The MMR vaccination and autism controversy in United Kingdom 1998–2005: inevitable community outrage or a failure of risk communication? *Vaccine* 2006;24:3921–3928. [PubMed: 16564116]
59. Taylor B, et al. Autism and measles, mumps, and rubella vaccine: no epidemiologic evidence for a causal association. *Lancet* 1999;353:2026–2029. [PubMed: 10376617]
60. Taylor B, et al. Measles, mumps, and rubella vaccination and bowel problems or developmental regression in children with autism: population study. *Br Med J* 2002;324:393–396. [PubMed: 11850369]
61. Farrington CP, Miller E, Taylor B. MMR and autism: further evidence against a causal association. *Vaccine* 2001;2001:3632–3635. [PubMed: 11395196]
62. Kaye JA, Melero-Montes M, Jick H. Mumps, measles, and rubella vaccine and the incidence of autism recorded by general practitioners: a time trend analysis. *Br Med J* 2001;322:460–463. [PubMed: 11222420]
63. Fombonne F, Chakrabarti S. No evidence for a new variant of measles-mumps-rubella induced autism. *Pediatrics* 2001;108:e58. [PubMed: 11581466]
64. Dales L, Hammer SJ, Smith NJ. Time trends in autism and in MMR immunization coverage in California. *JAMA* 2001;285:1183–1185. [PubMed: 11231748]
65. Makela A, Nuorti JP, Peltola H. Neurologic disorders after measles-mumps-rubella vaccination. *Pediatrics* 2002;110:957–963. [PubMed: 12415036]
66. Madsen KM, et al. A population-based study of measles, mumps, and rubella vaccination and autism. *N Engl J Med* 2002;2002:1477–1482. [PubMed: 12421889]
67. Jansen VA, et al. Measles outbreaks in a population with declining vaccine uptake. *Science* 2003;301:804. [PubMed: 12907792]
68. Kidd M, et al. Measles-associated encephalitis in children with renal transplants: a predictable effect of waning herd immunity? *Lancet* 2003;362:832. [PubMed: 13678885]
69. Murch S. Separating inflammation from speculation in autism. *Lancet* 2003;362:1498–1499. [PubMed: 14602448]
70. Mayor S. Researcher from study alleging link between MMR and autism warns of measles epidemic. *Br Med J* 2003;327:1069.
71. Racine E, Bar-Ilan O, Illes J. fMRI in the public eye. *Nature Reviews Neurosci* 2005;6:159–184.
72. Wallis, C. Blame it on Teletubbies. *Time Magazine*. 22 October 2006 [accessed 2 December 2006]. [online], <<http://www.time.com/time/magazine/article/0,9171,1549331,00.htm>>
73. Shirley DS. Challenges to autism research. *J R Soc Med* 2005;98:523–525. [PubMed: 16260809]
74. IOM. Immunization Safety Review: Measles-Mumps-Rubella Vaccine and Autism. Washington National Academies Press; Washington DC: 2001.
75. IOM. Vaccines and Autism. Washington National Academies Press; Washington DC: 2004.
76. Gaskell G, et al. Communication, social values and the governance of science. *Science* 2005;310:1908–1909. [PubMed: 16373561]
77. Gross, CG. *Brain, Vision, Memory: Tales in the History of Neuroscience*. MIT Press; Cambridge, Massachusetts: 1998.
78. Marshall PA, Berg JW. Protecting communities in biomedical research. *Am J Bioeth* 2006;6:28–30. [PubMed: 16754445]

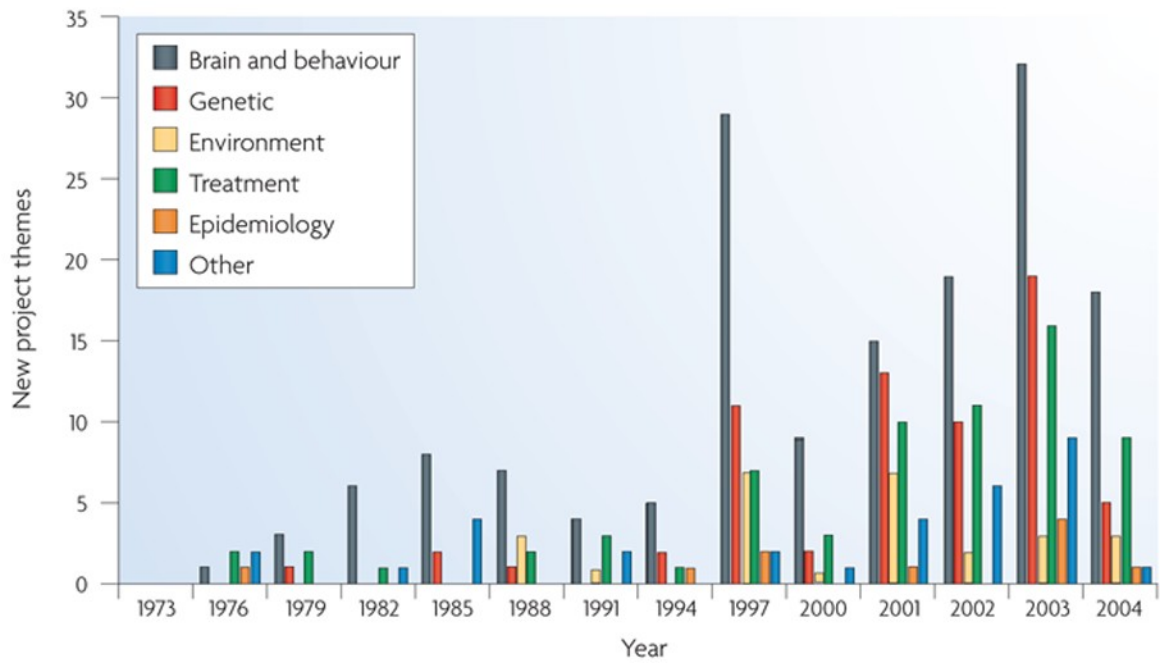


Figure 1. Themes of newly funded research projects (1973–2004)

Newly funded research projects were focused on brain and behaviour, and on genetics. These trends were mirrored in scientific discourse occurring in top-cited peer-reviewed journal articles from 1994 to 2004.

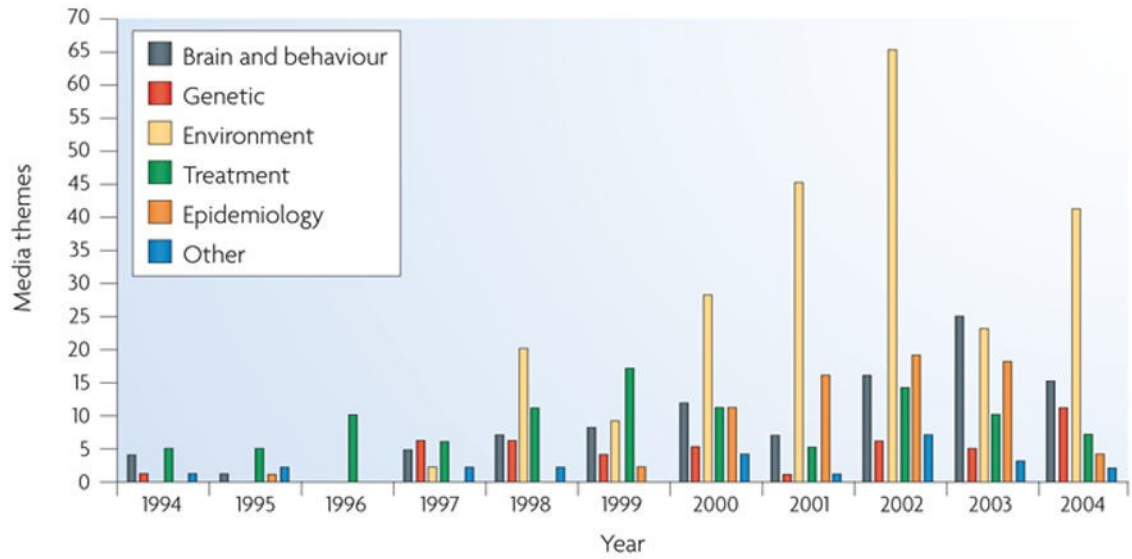


Figure 2. Themes of articles on autism in the international press (1994–2004)

Reporting focused primarily on environmental causes. A peak in 1998 corresponds to the publication of the Wakefield study that suggested a possible temporal link between the measles, mumps and rubella vaccine and autism.

Table 1

Environmental causes of autism reported in research studies

Environmental cause	Newly funded research projects	Journal articles	Print media
MMR, thimerosal or methyl mercury	23	21	225
Prenatal/fetal testosterone levels	3	3	8
Prenatal exposure to anticonvulsants	-	2	-
Obstetric complications	1	3	2
PCBs, halogenated aromatics	1	-	-
Prenatal virus (BDV, Influenza)	8	2	-
Immunological mechanism	15	4	-
Wheat and cow milk	-	-	10
High level of lead in blood	-	-	2

This table shows the sources of environmental causes of autism reported by studies occurring in the top 5% of cited peer-reviewed literature on autism, and appearing in samples of articles from the major international press. BDV, Borna disease virus; PCBs, polychlorinated biphenyls.