

# Anti-vaccination movements and their interpretations

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## Abstract

Over the last two or three decades, growing numbers of parents in the industrialized world are choosing not to have their children vaccinated. In trying to explain why this is occurring, public health commentators refer to the activities of an anti-vaccination ‘movement’. In the light of three decades of research on (new) social movements, what sense does it make to attribute decline in vaccination rates to the actions of an influential anti-vaccination movement? Two sorts of empirical data, drawn largely from UK and the Netherlands, are reviewed. These relate to the claims, actions and discourse of anti-vaccination groups on the one hand, and to the way parents of young children think about vaccines and vaccination on the other. How much theoretical sense it makes to view anti-vaccination groups as (new) social movement organizations (as distinct from pressure groups or self-help organizations) is as yet unclear. In any event there is no simple and unambiguous demarcation criterion. From a public health perspective, however, to focus attention on organized opponents of vaccination is appealing because it unites health professionals behind a banner of reason. At the same time it diverts attention from a potentially disruptive critique of vaccination practices; the critique in fact articulated by many parents. In the light of current theoretical discussion of ‘scientific citizenship’ this paper argues that identifying anti-vaccination groups with other social movements may ultimately have the opposite effect to that intended.

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## Conceptualizing resistance to vaccination

Whatever the fears of infection, the introduction of compulsory smallpox vaccination, in the 19th century, did not meet with universal acclaim. When the Dutch government reacted to an 1871 epidemic by requiring that all school children be vaccinated there was widespread objection (Egers & Streefland, 1997). In 1881 a *Bond ter Bestrijding van Vaccinedwang* (Association to Oppose Compulsory Vaccination) was established. With many clerics among its membership, the *Bond* opposed compulsory vaccination on the grounds it represented

an infringement of individual liberty. Objections to vaccination out of religious conviction had to be respected, according to the *Bond*: a view that was finally accepted, with exemption allowed on religious grounds, in the early years of the 20th century. In the United States resistance became particularly strong at the same time, with the Anti-Vaccination Society of America founded in 1879 and many other similar organizations emerging in the years following (Kaufman, 1967). A prime concern in the United States too was to influence or seek the repeal of public health legislation. According to Kaufman, many leaders of these organizations were ‘irregular physicians’ (including homeopaths), whose right to practice could be threatened by state intervention in health care. Manufacturers of patent medicines,

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also worried by legislation that could limit their trade, were another source of support. Although Kaufman's paper gives little sense of these Societies' popular appeal, their political impact at their height seems to have been significant. "By the 1930s," he writes, "having repealed compulsory vaccination laws in many states, instigating destructive riots in Montreal and Milwaukee, and fighting vaccination through the courts, the movement began to disintegrate..."

Something similar happened in England and Wales, where laws passed between 1853 and 1871 made vaccination of infants against smallpox compulsory. People who could afford it could have their child vaccinated by a medical practitioner, whilst those who could not were directed to state-paid vaccinators who functioned under the aegis of the Poor Law Guardians. Not only was the whole Poor Law structure and administration seen as cruelly stigmatizing, but poor law vaccination officers (civil servants appointed to seek out non-compliers) could and did prosecute parents who failed to comply with the law, especially working class parents. Nadja Durbach has studied the resistance that emerged. As she explains it, British working class protest must be seen principally as resistance to the growth of state 'disciplining' of the body (Durbach, 2000, 2002). She distinguishes the concerns of middle class Liberal reformers, largely focussed on matters of individualism and liberty, from those of the huge numbers of working people attracted to the movement and what it stood for.

Central to the discourse both of those advocating vaccination, and to the national anti-vaccination movement that had emerged by the 1860s, was a language of citizenship to which both sides appealed. "For those who promoted vaccination the procedure was part of the duty of good citizenship, for it protected the entire population from disease". The citizenship of the working class, symbolized by extension of the right to vote, entailed this shared obligation. By contrast

Good citizenship, Mary Hume-Rothery—secretary to the National Anti-Compulsory Vaccination League—advanced, did not mean enforcing public health measures. Rather, it entailed respecting the bodies of one's neighbours. It is not "*decent*, in a free country, even to talk of legalising bodily assault and possible murder on the bodies of a fellow-citizens' children". (Durbach, 2002, p. 64)

British anti-vaccinationists were largely drawn from the respectable working class, some being also "active in the co-operative movement, friendly societies, and trades unionism, and many were teetotallers, vegetarians, and religious sectarians". Although the movement was national, there were concentrations in the self-same working class areas that tended also to provide a focus

for "the other working-class reform and self-help movements with which anti-vaccinationism was aligned".

The conscientious objector to vaccination might have good reasons for his or her belief, based on experience or inquiry, and these merited respect. The conscientious objector, one writer pointed out, was a "parent residing in England, who, by reason of certain mild or bitter experiences of his own, by observing what has occurred in other families, by studying the special investigations of gifted scientific men, and by personal 'bed-rock' inquiry into the real nature of vaccine itself, has become so firmly convinced of the futility, repulsiveness, and dangers of the operation of vaccination, that he cannot, as a devoted and intelligent parent, conscientiously consent, to subject the beloved children of whom he is natural protector, to such a rite" (Furnival, 1902, quoted by Durbach, 2000).

Here too much of the resistance was against the compulsory nature of vaccination, rather than vaccination itself. Protestors claimed the right to opt out for reasons of conscience. A Royal Commission on Vaccination was appointed in 1889 in response to anti-vaccination pressure. It sat for seven years before coming up with compromise proposals, though it took until 1907 before the law was changed to allow for a right to opt out.

Gradually these movements seem to have declined. Of that in the United States, Kaufman writes that its demise "can be explained in terms of the improvement in medical practice and the growth of state and federal control over public health. The irregulars began to disappear with the rigid medical licensure laws, and the "accidents of vaccination" became fewer..." (Kaufman, p. 478).

Today the view is frequently expressed that anti-vaccination movements are re-emerging. Over the last two or three decades, concern about vaccine safety has grown. Many parents in the industrialized world are now choosing not to have their children vaccinated. The resulting decline in vaccination rates has provoked considerable concern on the part of public health authorities. Once vaccination rates fall below some 90% the fear is that 'herd immunity' benefits will be lost, pathogens will circulate freely, and risks will multiply. In some places, for example in parts of the UK, this is now happening. In trying to explain why this is occurring, public health commentators frequently refer to the activities of an anti-vaccination 'movement'.

For example, a recent paper in the *British Medical Journal*, "comparing arguments from the present-day anti-vaccination movement...with those of its 19th century counterparts" found "uncanny similarities, suggesting an unbroken transmission of core beliefs and attitudes" (Wolfe & Sharp, 2002). These authors continue

regardless of how the medical establishment feels about anti-vaccinationists, it is important to understand that they have deeply held beliefs, often of a spiritual or philosophical nature, and these beliefs have remained remarkably constant over the better part of two centuries.

In the same vein, other commentators have stressed the manipulation of public opinion through the media. Thus Poland and Jacobson of the Mayo Clinic write that “Anti-vaccine groups have taken advantage not only of the internet to increase their presence in the debate, but also to exaggerate, publicize and dramaticize[sic] cases of vaccine reactions to the media and the public” (Poland & Jacobson, 2001). Their efforts are facilitated by an “inadequate scientific knowledge base within the media, and an irresponsible tendency towards the sensational”. Ray Spier, editor of the journal *Vaccine* shares this critique of the role of the media “In a sensation starved media, the exacerbation of single incidents into major disasters is one temptation too far for most the media commentators. By contrast the *successful* prevention of diseases in tens of millions of individuals is virtually ignored” (Spier, 2002).

It is common to attribute substantial ‘achievements’ to the anti-vaccination groups. For example, focussing specifically on pertussis, Gangarosa and colleagues (drawn from the WHO, the CDC, and other prestigious institutions) conducted a country-by-country analysis in which they correlated the existence/non-existence of anti-vaccination groups with changes in the incidence of pertussis occurring in the 1970s and 1980s (Gangarosa et al., 1998). Their findings, based on this inter-country comparison, “provide strong evidence of a causal relation between movements against whole-cell pertussis vaccine and pertussis epidemics”.<sup>1</sup>

Poland and Jacobson write that “This movement has resulted in major disruptions and even cessation of vaccine programs, with resultant increased morbidity and mortality”... “in measurable ways the anti-vaccine movement has impacted state and national public health policy, and jeopardized individual and societal health”.

What sense does it make to attribute decline in vaccination rates, in industrialized Western countries, to the actions of an influential anti-vaccination movement? The rhetorical or practical utility, from a public health point of view, of referring to an anti-vaccination *movement* may derive from the associations the term is likely to evoke among predominantly medical readerships. The implication is that resistance or opposition to

vaccination shares the radical ideology and disruptive practices commonly associated with other familiar ‘movements’ (the women’s movement, the student movement, the environmental movement...). But whilst those arguing the merits of vaccination rely on the common associations of the term ‘social movement’, social scientists have spent three decades examining the concept and its many real world exemplifications. How valid is it to view current vaccination-related concerns and protests in the industrialized world from a ‘social movements’ perspective? What light does such a perspective throw on those concerns and protests and, by the same token, what does it exclude from consideration? In getting to grips with these questions I will review two sorts of empirical data drawn largely from Britain and the Netherlands: relating to the claims actions and discourse of anti-vaccination groups on the one hand, and to the way people (specifically parents of young children) think about vaccines and vaccination on the other. First however we need to think a little more carefully about the concept of a social movement and its applicability in the health area.

### Health related social movements

Current theorizing on social movements (some authors prefer to speak of new social movements whereas others reject the epithet ‘new’) provides too large and complex a literature to be adequately reviewed here. Reflecting the plethora of perspectives, organizing concepts and theoretical objectives,<sup>2</sup> much of the literature is concerned with the relative explanatory power of alternative conceptualizations, but it seems in fact to be just as much about what exactly has to be explained. What is it about (new) social movements that needs to be explained? Should we try to relate the emergence of protest behaviour to circumstances (or social problems) and the grievances to which they give rise: the original focus of theorizing in the field? The earliest approach, this could imply that we seek the explanation of organized non-compliance in objective features of vaccination practice: compulsion, payments, or whatever may be the source of grievance. This is not the view of public health experts, as we saw. In the theoretical literature, too, it has lost much of its ground. Critics of this ‘grievance approach’ argue that social problems aren’t objective facts to which social movements react: they have to be constructed (or ‘re-framed’) as such. It would then be the work of ‘re-framing’ that would need attention, and movements’ success in achieving this re-framing. We would then explore the discursive practices made use of in trying to bring about a reconceptualization of vaccines as risky or unsafe. This

<sup>1</sup>However “Anti-vaccine movements have had some beneficial effects. Their call for safer vaccines underscored the need for acellular vaccines against pertussis and their efforts have encouraged surveillance of adverse events and development of vaccine-injury compensation programmes”.

<sup>2</sup>For a useful introduction see Morris and Mueller (1992).

perspective does indeed underlie some of the analytical work of public health commentators, disclosing the deployment of pseudoscience, dramatizations of individual cases and so on. Or then again, should our focus be on the correlates of effective political mobilization and impact on decision-making? A careful and sophisticated study of resistance to nuclear power in Europe, for example, compares political mobilization by the anti-nuclear lobby in different countries, as well as the political choices ultimately made (Koopmans and Duyvendak, 1995). Koopmans and Duyvendak want to know whether discursive success—convincingly arguing that it made sense to view nuclear energy as dangerous and unnecessary rather than as the solution to national energy needs—is enough of an explanation. It is not, they conclude. Since the arguments available were more or less the same in all the countries they studied, the fact that some were far more effective than others in terms of mass mobilization and political impact has to be explained differently. The concept central to their analysis is then that of political opportunity. It is differences in the way politics works in different countries, or the contingent fact of one or other party being in power, that help explain differences in the impact of re-framing on popular opinion and political choices.

Not all of today's social movements are oriented to so sharply defined an issue as this. Writing a decade ago, Shakespeare contrasts the disability movement with other examples of what are (or were) commonly viewed as new social movements (Shakespeare, 1993).

Having explained the range of issues that concern disabled people, from benefits and anti-discrimination to the creation of a new political identity, Shakespeare sets out to assess the relevance and the utility of interpreting organizations of and for the disabled in terms of 'new social movements theory'. His starting point is a definition provided by Scott. "A social movement is a collective actor constituted by individuals who understand themselves to have common interests and, for at least some significant part of their social existence, a common identity. Social movements are distinguished from other collective actors, such as political parties and pressure groups, in that they have mass mobilization, or the threat of mobilization, as their principal source of social sanction, and hence of power". What makes 'new' social movements new? Unconventional ways of expressing popular protest is a characteristic many refer to. Some distinguish them from older organizations by virtue of their focus on sought changes in civil society rather than in politics or the political process; not on redistribution questions but on identity or other 'post-materialist' concerns. One of the best-known studies of health related movement organizations, Epstein's study of HIV/AIDS activism, takes this view. Central to the self-understanding of movements such as this, argues

Epstein, is a focus on the values of autonomy and identity (Epstein, 1995). Epstein argues that membership of a disease/condition specific group may *become* the source of a political identity, though one very different from the class-based political identities of the past. Not only do participants in "new social movements" such as this one tend to be middle class, they don't have much to say about class. Their struggle isn't principally for distributive justice, but "a struggle over cultural forms—what Habermas calls the 'grammar of forms of life'". Their emphasis tends to be on 'personal and intimate aspects of human life', their organizations tend to be 'segmented, diffuse and decentralized', and their theatrical protest tactics emphasize civil disobedience and a politics of representation.... The strategy of the movement organizations discussed by Epstein entails a critique of biomedical science

The failure of the experts to solve the problem of AIDS quickly, as they were "supposed" to do, has heightened popular resentment and diminished the credibility of the establishment; it has also opened up more space for dissident voices

...and at the same time an attempt to press science into service of the organisation's goals. Shakespeare's view, however, is somewhat different. Disability movement organisations, he points out, transcend the distinctions said to separate old from new movements. Organisations have different emphases, but taken together, the movement as a whole focuses both on identities and on redistribution, both on social relations and on representation in the political process.

It is interesting to compare Shakespeare's theorization of the disability movement with Carroll and Ratner's. These authors compare the attempts of three Vancouver (Canada)-based organizations to build "oppositional culture" in the face of "both colonising and marginalising moves by capital and the state" (Carroll and Ratner, 2001, p. 606). Their analysis of the work of The Centre ("a gay-lesbian-bisexual-transsexual community"), End Legislated Poverty (British Columbia's largest anti-poverty organization), and the BC Coalition of People with Disabilities (CPD), compares these organizations in terms of their orientation to politics of recognition or redistribution and, in another dimension, to 'affirmation' or 'transformation'. These are categories that they take from earlier work by Nancy Fraser (Fraser, 1995). Mobilization for collective action, according to this perspective, is only one of the tasks that engages these organizations, though in practice the most challenging. Also necessary in 'building oppositional culture' (the shared radical project in which each organization is taken to participate), is the constitution of alternative identities and communities, and "the invention of [...] practices that (a) address existing *needs*

in innovative and empowering ways [...] while (b) pressing affirmative politics [...] into a principled politics of social justice” (Fraser, 1995, p. 624). “All this,” they write, “entails a programme of moral and intellectual reform that constructs a passage from received needs, capacities and identities to new collective subjectivities”. How does each organization articulate and sustain a form of oppositional culture? In terms of the analytic categories used they appear to be quite different. The CPD, for example, is seen as engaging in community building and in the “construction of disability as a *political* identity” (‘transformation’) as well as in helping individual people with disabilities in gaining access to the social welfare system (‘affirmation’). This organization, like The Centre and unlike End Legislated Poverty, does not aim at changing society except in so far as deemed necessary to end discrimination and promote integration. With their focus on a shared ‘oppositional culture’, Carroll and Ratner come close to the perspective developed by political theorists like Chantal Mouffe, who views diverse social movements as collectively articulating the common identity of the “radical democratic citizen” (Mouffe, 1992, see also Lichterman, 1995).

Although I have not attempted to provide a comprehensive overview of the social movements literature, I think this discussion provides sufficient sense of the range of that literature for us to move forwards and consider what it might mean to speak of an anti-vaccination movement.

### **The growth and organization of vaccine fears: Britain and the Netherlands compared**

In the early 1970s evidence that vaccination against pertussis (whooping cough) was sometimes associated with highly unpleasant side effects was accumulating. In most cases these side effects, though alarming to parents, were local, not serious, and disappeared quite quickly. More worrying, however, were new reports linking the vaccine with possibly permanent brain damage in a small number of cases. Gordon Stewart, from Glasgow University, was one who did much to attract attention to the possible risks of this vaccine: going so far as to suggest that its risks outweighed its benefits (Stewart, 1977). In Britain public confidence in pertussis vaccine fell dramatically, and vaccination coverage dropped from 70–80% to around 40%. In the Netherlands by contrast, although Stewart’s conclusions regarding possibly serious side effects of the pertussis vaccine were known in public health circles no corresponding decline in public confidence occurred. Recently the suggestion has been made that Britain “played a central role in defining, promoting, and ultimately exporting this dispute” (Baker, 2003).

How to understand the difference between these two countries in response to the suggestion of possible risk? Was what occurred in Britain an expression of some underlying discontent with the way vaccination was administered, so that the new worries were—for some—the straw that broke the camel’s back? Whilst vaccination is (and was then) both free and voluntary in both countries there are some differences in its organization. In the Netherlands most children are vaccinated at an Infant Welfare Centre (*Consultatiebureau*) whereas in Britain the GP plays a larger role. Dutch experts do commonly attribute the country’s very high immunization rate (averaging around 95%) to the effective organization of vaccination services, and an efficient surveillance system. (Inspectie voor de Gezondheidszorg, 1998; Paulussen, Lanting, Buijs, & Hirasings, 2000). And the fact that British GPs are paid to meet immunization targets has rendered their advice suspect for some. But these payments were only introduced in 1990. The responses that Stewart’s work evoked were, significantly, very different.

In Britain, experts disagreed about the validity of Stewart’s conclusions, and the pages of the *British Medical Journal* are full of their disagreements. Still more important is the fact that controversy extended far beyond the medical profession. The *Guardian*, for example, covered the controversy at length, with numerous reports of parents claiming compensation for what they believed the damage caused by the whooping cough vaccine (Heida, 2002). An Association of Parents of Vaccine Damaged Children (APVDC) was set up. Responding to these claims, and to the Report of a Royal Commission on civil liability and compensation for personal injury, the British government introduced a Vaccine Damage Payment Act in 1979. The Royal Commission (chaired by a judge, Lord Pearson) had expressed the view that “Vaccination is recommended by the State for the benefit of the community, and where it causes injury, the State ought to provide compensation as part of the cost of providing protection for the community as a whole”. Reviewing provisions of the Act more recently, the political editor of the *Daily Express* has suggested that they were no more than “a device to puncture pressure for proper compensation”.<sup>3</sup> “Pearson accepted then, as it is accepted now, that there can be no proof that brain damage is a direct result of a vaccination. But he wanted the law changed so that parents could sue for damages, in a “balance of probabilities” that the damage was linked to vaccination.” The *Express* journalist, Anthony Bevins, argued that the paltry sums to be paid by the State where brain

<sup>3</sup>Anthony Bevins’ article ‘Betrayal of the child victims of vaccination’, published in *The Daily Express* on 16 May 2000, can be found at [www.charge.org.uk/about/bevins](http://www.charge.org.uk/about/bevins) (visited September 2004).

damage was deemed substantial fell far short of this change to the law. In the Netherlands there was no comparable pressure for compensation payments. Nor did Stewart's work generate any public disagreement among experts. Discussions in the principal Dutch medical journal (*Nederlands Tijdschrift voor Geneeskunde*) referred to British studies reporting brain damage, though to no reports of equivalent Dutch studies. Through the whole of the 1970s neither the daily press, nor popular women's magazines carried any reports whatever of possible risks of brain damage associated with the pertussis vaccine. A single report in the daily *Telegraaf*, in 1982, led to immediate follow up action by the RIV (the State Institute of Public Health, later the RIVM), which was soon able to establish that the vaccine had played no role in these children's illness. Whether because of very different response of the media in the two countries, or because of medical consensus in the Netherlands, or the prompt action of the RIV, there simply was no controversy in the Netherlands. There was no decline in public confidence in the vaccine and no decline in vaccination coverage.<sup>4</sup> The only significant change was that the RIV, producers of the vaccine, lowered the concentration of pertussis component in the compound vaccine used. In Britain, the Department of Health (DHSS) resisted pressures to remove the vaccine and tried (successfully) to reassure the public with a study, published in 1981, that rejected the suggestion of serious risk and reemphasized the benefits of mass vaccination. Gradually coverage, that had declined precipitously (to around 40%) rose again, reaching 91% by 1992.

Despite sustained, or in the British case restored, confidence in pertussis vaccine, gradual changes in perspective not reflected in vaccination statistics were taking place. A recent analysis of reporting in British newspapers found a three-fold increase in articles on vaccine-related topics published through the 1990s (from 342 in 1991 to 1450 in 2000)—but a much greater increase in the share dealing specifically with the safety of vaccines (from 17% in 1990 to 39% in the first months of 2001) (Cookson, 2002). The 1990s saw the formation of a number of new organizations

critical of vaccination: not only in Britain but in the Netherlands too.

In addition to the British APVDC, other such organizations already existed. In France, the 'Ligue Nationale pour la Liberté des Vaccinations' (French National League for Liberty in Vaccination)<sup>5</sup> had been established as early as 1954. It was and is particularly opposed to compulsory vaccination. "We regard the obligatory nature of vaccination as a violation of moral and physical personal liberty, and of freedom of conscience. We affirm that the human body is the sacred and inviolable property of the individual, and that no-one should be given preventive or curative treatment without his or her express consent". In the USA the 'National Vaccine Information Center', was established in 1982. Its founder, Barbara Loe Fisher, explains on the NVIC website that in 1980 her eldest son had been left with multiple learning disabilities as a result of his fourth DPT shot. NVIC is "dedicated to the prevention of vaccine injuries and deaths through public education. NVIC provides assistance to parents whose children have suffered vaccine reactions; promotes research to evaluate vaccine safety and effectiveness as well as to identify factors which place individuals at high risk for suffering vaccine reactions; and monitors vaccine research, development, policy making and legislation. NVIC supports the rights of citizens to exercise informed consent and make educated, independent vaccination decisions for themselves and their children".<sup>6</sup>

The 'Informed Parent', a British-based group, was established in 1992. Its objectives are said to include,<sup>7</sup> to promote awareness and understanding about vaccinations in order to preserve the freedom of an informed choice; to offer support to parents regardless of the decisions they make; to inform parents of the alternatives to vaccinations; to accumulate historical and current information about vaccination and to make it available to subscribers and interested parties. 'Justice, Awareness and Basic Support' (JABS) another British group, was established in 1994 by John and Jackie Fletcher. The Fetters met a number of parents who shared their conviction that their own child's health had been damaged by the MMR vaccine.<sup>8</sup> It presents itself specifically as a support group for vaccine damaged children and its principal objectives, according to Jackie Fletcher, are 'recognition' and 'compensation'. Nowadays JABS' homepage<sup>9</sup> focuses on the alleged link between MMR vaccine and autism ("1000 British

<sup>4</sup>In 1978, the Netherlands was struck by an epidemic of polio. This led sociologists to explore attitudes to vaccination in Dutch society, as well as explanations of refusal (Veenman & Jansma, 1980). It is well known that Orthodox Protestants in the Netherlands did not wish their children to be vaccinated, and their right of refusal was respected (Maas, 1988). They had what were, for them, good reasons "To try to protect yourself beforehand against diseases is seen as trying to escape God's righteous judgement, acting against Divine Providence...making clear that he is afraid to put his future in God's hand"(p. 26). However, whilst the mass media attributed refusal wholly to these religious views, interviews showed that other motives and considerations were also involved.

<sup>5</sup>[www.ctanet.fr](http://www.ctanet.fr) (visited November 2003).

<sup>6</sup>At [www.909shot.com](http://www.909shot.com) (visited November 2003).

<sup>7</sup>See [www.informedparent.co.uk](http://www.informedparent.co.uk) (visited November 2003).

<sup>8</sup>Interview with Jackie Fletcher by Marieke Heida, 6 March 2002.

<sup>9</sup>[www.jabs.org.uk](http://www.jabs.org.uk) (visited November 2003).

children have had their lives ruined by *something*... their parents think it was the MMR jab”) and the claims for compensation now being pursued in the British courts. Yet another group in the UK is the Vaccine Awareness Network, founded in 1997 “by two parents who were dissatisfied with the quality and availability of vaccine information”. Its objective, according to its website, is “to help parents decide whether or not vaccinate their children”<sup>10</sup> According to the VAN website, the site received over 10,000 new hits between June 2001 and June 2002.

In the Netherlands, the *Nederlandse Vereniging Kritisch Prikken* (NVKP) was also established in 1994 by “a group of people who have had experience of the negative consequences of vaccination. This experience is based on their professional activities as well as on things they have discovered as parents. It seemed as though their many questions evoked little response in orthodox medical circles. This resulted in the need to know more of the risks of vaccination, and to make this knowledge known to the general public”. One of the co-founders of the NVKP was Irma Janssen, a district nurse. Janssen explains in interview that her experience of negative reactions to vaccination, and her inability to answer many of the questions parents asked of her, had led to her involvement in the nascent NVKP (quoted by *Yaka Çi-dem*, 2003).

The NVKP<sup>11</sup> lists as its objectives: Giving information about the consequences of vaccination; to enable everyone to make a real and individual choice whether or not to vaccinate and against which illnesses; support for people who have had problems from vaccination and to advise them regarding treatment of vaccine damage; support for people who choose not to have their children vaccinated, in whole or in part; registration of negative effects of vaccinations, in particular through collecting the stories of parents; search for alternatives to vaccination; to strive for societal recognition and a good independent registration of negative effects of vaccines on health. With a membership of some 1200, the NVKP today claims not to be affiliated with any alternative view of medicine, and to be neither for or against vaccination. Its objective, it claims, is to support parents in making their own personal decisions regarding the vaccination of their children.

A new organization, the *Stichting Vaccinatieschade* (Vaccination Damage Foundation) was established early in 2003. Its objectives are said to be: support, representation and action on behalf of people (and their environments) with health problems following vaccination; to reduce the negative effects of such problems; to develop activities designed to prevent vaccine-related health problems.<sup>12</sup> In practice this Foundation has

largely focused on a discussion in the Netherlands over replacement of the ‘whole cell’ pertussis vaccine currently used by the less reactogenic ‘acellular’ vaccine now used in most of the industrialized world. The *Stichting Vaccinatieschade* has been rather successful in gaining political and media attention for its views.

Public health authorities want to know why views espoused by organizations such as these are gaining in popularity, given (as they see it) the irrationality and misunderstandings that lay at their heart. Because anti-vaccination views are most famously and most accessibly present on the internet there is a lot of concern regarding how easily parents, seeking information, stumble on them. Anti-vaccination websites have attracted particular attention despite the fact that, in the Netherlands at least, internet seems to be a significant source of vaccine-information for very few parents indeed. What do they contain, and who produces them? One study identified and studied 26 sites, of which 15 “appeared to be associated with groups or individuals advocating the use of alternative medicine.” (Nasir, 2000). “With the rise in popularity of alternative and complementary medicine among the general public, more individuals may be advised to avoid immunizations...” Wolfe Sharp and Lipsky “explored the content and design attributes of antivaccination sites that an individual might encounter in doing a typical Web search” (Wolfe, Sharp, & Lipsky, 2002). What claims predominated in the 22 English-language sites they studied? Here are the ones most frequently found

- adverse reactions are underreported;
- vaccines cause idiopathic illness (reference most frequently being made to autism, SIDS, immune dysfunction, diabetes, neurologic disorders (including ADD);
- vaccines erode immunity or provide only temporary immunity;
- vaccine policy is motivated by profit made by drug companies;
- vaccination (and surveillance) are violation of civil liberties; and
- diseases are declining anyway and holistic approaches offer a preferable alternative.

Publications cited above, authored by public health professionals, attest to a widespread professional view that resistance to vaccination can be attributed to the activities of anti-vaccination movement organizations. This strand of public health opinion seems to hold that the sources of anti-vaccination sentiment are not principally to be sought in experiences of or dissatisfaction with vaccination practices themselves (except in developing countries). Second, the principal concerns underlying organized anti-vaccination activity are of

<sup>10</sup>[www.vaccine-info.com](http://www.vaccine-info.com) (visited September 2004).

<sup>11</sup>See [www.nvkp.nl](http://www.nvkp.nl) (visited November 2003).

<sup>12</sup>[www.vaccinatieschade.nl](http://www.vaccinatieschade.nl) (visited September 2004).

two distinguishable sorts: relating to perceptions of the risks and safety of vaccines (perhaps associated with ‘holistic’ views of health care); and relating to the rights and responsibilities of citizenship (civil liberties and trust in government). Third, in a variety of ways, taking advantage of the possibilities of internet, and of the sensationalism and scientific ignorance of the mass media, these groups propagate their pseudoscientific views. Fourth, and crucially, they have already had a huge effect: disrupting vaccination programmes, jeopardizing the public health... costing hundreds of thousands of children their health. Perhaps many public health professionals, epidemiologists and vaccine scientists would agree with Spier in seeing a Luddite social movement at work here, using specious pseudoscientific arguments and dubious data to resist progress, all too effectively.

### Parental concerns in Britain and The Netherlands

In contrast with studies such as those cited above, that focus on the claims made by critical groups, a few studies by social scientists focus on the experiences, behaviour and concerns of individual parents. A recent Dutch study took a sample of 350 families with at least one child aged 0–4 and 150 families with at least one child aged between 9 and 10. A few respondents weren’t wholly sure of the vaccination status of their child/children, so that somewhere between 81% and 88% of the children were known to be wholly vaccinated. The survey showed that 75% of the respondents had had at least one discussion regarding the desirability of vaccination, typically with a physician or nurse from the home care service or the family doctor: the vast majority were satisfied with the way they’d been informed. Most (85%) had consulted published sources—mostly materials provided by the child health services. Contrasting with all the worried attention for internet sites, only 2% of these parents had looked to the internet for guidance. Only 16% felt a need of more information: these were largely the younger and better-educated mothers. The issues on which more information was felt necessary were side effects; duration of protection; the risks of not vaccinating. All in all the picture that emerges from this study is of a society that generally feels itself sufficiently well informed and that above all is willing to trust...

knowledge of and experience with children who’d had the infectious diseases and influences from the direct social environment seemed to have no, or a very minor influence, on the willingness of parents to have their children vaccinated. Further, the study shows that when the first child is born the attitude of many parents to the RVP becomes more positive, but

that this adjustment in attitude has very little basis in a systematic consideration of the pros and cons of vaccination. (Palussen et al., p. 4)

Another recent study conducted in the Netherlands finds indications that widespread trust in the vaccination programme may now be eroding. “To a growing degree one sees in society a need to make personal trade offs regarding what is good for health. This trend is particularly apparent among parents with alternative views regarding health and illness”. Various studies do indeed suggest that negative views of childhood vaccination are common among practitioners of some forms of alternative medicine (Ernst, 2002), and that unwillingness to vaccinate is particularly common among their patients (at least in Europe). The group of parents holding “alternative” views of health and medicine, for example, homeopathic or anthroposophic, is so small in number that their non-compliance has little or no effect on the overall vaccination rate (Ploch & van Staa, 2002) But because views such as these seem to be finding increasing sympathy among the population at large, better understanding of their perceptions of risk seem valuable. Ploch and van Staa interviewed parents who had refused vaccination and who belonged to an anthroposophic medical practice, as well as following an ‘on line discussion group’. These were people who, unlike the majority, did wish to make their own assessments of benefits and risks. Moreover risk assessments made by these parents could diverge from those of the public health authorities

The whooping cough vaccine that’s now in use, is no longer sufficiently effective, and that means that children can get it despite being immunised. As a parent I’d thus rather run the risk that my child gets whooping cough and acquires lifelong immunity rather than that I run the risk of having my child vaccinated and then run the double risk that he not only reacts badly to the vaccine and then also gets whooping cough.

(Ouders Online, quoted by Ploch & van Staa, 2002)

Most of the parents with whom they spoke, explain these authors, see vaccination as a dilemma for which there is no clear solution. Starting from their own individual perceptions of risk they try to make an optimal, vaccine-by-vaccine choice: decisions for which they are willing to assume responsibility.

Streefland, Chowdhury and Ramos-Jimenez draw on a comparative study of vaccination conducted in six countries, and focussing on patterns of acceptance and non-acceptance (Streefland, Chowdhury, & Ramos-Jimenez, 1999). Where research in the developing countries had found non-compliance often associated with complaints at the accessibility or organization of vaccination practice, or at the behaviour of vaccination

officials, in the Netherlands, (the only industrialized country included in this study) research had found it to be more usual grounded in religious or other beliefs. They also add the important insight that doubts cannot be understood in purely individualistic terms but are likely to become shared

Shared notions emerge when relatives or neighbours exchange accounts of their vaccination experiences (bad treatment by a health worker, a childhood vaccination with a painful side-effect), and which then colour their subsequent experiences. Together with prevailing beliefs about disease aetiology, ideas about the potency and efficacy of modern medicine, and views on the need for preventive health measures, these shared notions may be called local vaccination cultures.

In Britain Rogers and Pilgrim interviewed 19 mothers, most of whom had not had (all of) their children (fully) immunized. The majority (though not all) were middle class, in jobs requiring higher education and were over 30 (Rogers & Pilgrim, 1994). The suggestion here is that relations between an orientation to homeopathic medicine and refusal of vaccination are more complex than other writers have suggested. Some parents do make their decisions because of prior interest in homeopathy, but it can just as well go in the other direction. More crucial, perhaps, is a general commitment to holistic ideas about health (and to natural child birth and breast feeding) and a stress on the importance of life style and environment for a child's well-being.

Medical interventions, in the form of vaccination, sat uneasily with having managed to or attempted to avoid invasive techniques in preference to natural childbirth. Indeed a fundamental questioning of the desirability of immunisation seems to be an emerging feature of those advocating 'active' or 'low tech' births. (Rogers & Pilgrim, 1994, p. 20)

These views can lead to a preference for what they see as natural immunity, rather than the 'stress' to the immune system that vaccination entails. Particularly interesting in this study is the way the authors address the *process* of becoming a non-complier. For many of these mothers, non-compliance seems not so much the logical consequence of prior convictions, as a process initiated by earlier experiences (for example having had and recovered from measles themselves), or by what they are told by others (for example about children's experience of side effects) and grounded in the attempt to make an informed and active choice.

Eventual non-compliance...was associated with an informed and active choice...It was as if information and critical reflection had given them insight, which they lacked in the past and others currently lack. For

this reason, mass immunisation was construed as a political as well as an individual issue and tended to arouse strong feelings. (Rogers & Pilgrim, 1994, p. 17)

It isn't that these mothers are ignorant of the possible dangers of diseases like polio or whooping cough. They know about them, but they are sceptical of immunisation as a way of dealing with them and "the official accounts of both the risk of infection and efficacy of immunisation". (Rogers & Pilgrim, 1994, p. 26/7)

Inspired both by her personal experience (as a mother who had decided against vaccination of her child) and by Rogers and Pilgrim's study, Willianne Krijnen posed the following questions in a recent MA thesis "if the number of people who feel the necessity to weigh up different options is growing, why is this so? At what point do worries and doubts creep in?". "I have observed," she writes, "in my own environment that more often than not, contrary to popular and scientific assumptions, a (selectively) anti-immunisation stance is not based on previously held beliefs or ideologies, but is moulded by and shaped through personal experience, observations of side effects (whether first-hand or second-hand), negative advice, a personal interest in the subject, and the motivation to read the available literature" (Krijnen, 2004). Krijnen interviewed parents of children attending the same day-care centre as her daughter, in Amsterdam. These parents are not representative of the population of the Netherlands: they are above average in income and education, and many work in creative professions. For these parents, the seeds of doubt may emerge from views that had taken shape earlier, around childbirth. As one mother put it

I try to trust in a natural birth, and I try to trust in a natural pregnancy, as little intervention as possible. I try to keep it whole, to leave the miracle intact, not to be ruled by fear really, and also the feeling that this very beautiful little baby, that is so perfect, that you have to inject it so soon with all this stuff, that just feels really horrible... You have the feeling that it is a very delicate system which is ripening and has to deal with far too big an invasion, but I guess that has to do with a very primitive feeling of wanting to protect your baby

or

I think that the way we thought about it was much broader than just not vaccinating, it is not only not vaccinating, it is a whole different philosophy on life and raising your child, that has to do with how do you raise a child, how do you feed it, all that kind of stuff.

Consonant with what Streefland et al state, many of Krijnen's parents referred to the importance of conversations with friends who are also parents. More

important, perhaps, than doing what ‘the population’ did, or what the health professionals advised, was a need to ‘fit in’ with one’s own peers. Many of these parents referred to the information they’d received from friends as the information that really counted. A father interviewed by Krijnen stated

There is a huge uncertainty, and when you are uncertain about something you ask your friends. They probably have a similar uncertainty, and they have based their decision on someone else’s uncertainty, and that is how you keep the system going. And there is nothing wrong with that, everyone is looking for safety, me too. I am also happy when I meet someone who shares my views on vaccination.

Most of these parents had in fact vaccinated their children. What comes clearly out of this study is that, whatever decision they had ultimately made, parents were unhappy, in retrospect, at the difficulties in the way of deciding in a way that felt right, responsible

I have to say that that is something that is still on my mind sometimes, you know, when I heard (good friend who is anti-vaccination) I would think, shit, I should find out more. But you don’t. That is not right. It is something important really. You just do it automatically... when you are better informed it gives you a better feeling, then you can make a conscious decision. So sometimes when I hear about other people, I think, I should have done that too. I don’t mean not vaccinating necessarily, just making a more thoughtful decision. That would have been better than just going with the flow.

Could it be that the roots of anti-vaccinationism in the industrialized world lie less in prior ideological convictions or beliefs than in social interactions (with professionals, with other parents) and in their reflexive analysis?

A crucial finding of Pilgrim and Roger’s study bears on the attitude of professionals and their apparent resistance to the idea of parents wishing to make their own informed choices. Professionals seem frequently to have been seen as an obstacle to informed choice, rather than a source of advice and information. In other words, vaccination may be voluntary in theory, but that is not how most health professionals treat it in practice. The information literature they are given, in the view of these parents, reflects this same point of view: not designed to inform but to induce conformity. Full of glossy pictures, propaganda, nothing whatever on possible risks or side effects, on the duration of protection, on systemic effects on the child’s immune system. It is of no help in trying to make a personal decision since that isn’t its purpose: something particularly resented by highly educated parents accustomed to making reasoned decisions in

most aspects of their lives. The social pressure exerted on parents who ask awkward questions, trying to reason things out for themselves, is deeply resented

Well I went to the health clinic to have him weighed. The health visitor sort of came the line ‘you ought to have him weighed’. Anyway I went and they said he was due for his immunisation, ‘if you’d like to go along the corridor you can have him immunised today,’ and I said “I don’t want him immunised” and there was like this shock horror, I mean they were really shocked. But I was very annoyed. They just tell you to go along the corridor. It is not a choice is it? Even though it is not compulsory, it doesn’t feel like that. (Krijnen, 2004, p. 31)

A more recent British study, making use of a series of six focus groups, in which parents from a variety of socio-economic groups participated, half of whom had accepted and half of whom had rejected MMR, reached a similar conclusion. Results showed that parents were unconvinced by Department of Health reassurances and resented pressure from health professionals to comply (Evans et al., 2001).

### **Should we speak of an ‘antivaccination movement’?**

A starting point for this paper was the question “How valid is it to view current vaccination-related concerns and protests in the industrialized world from a social movements perspective?” In what ways is it helpful to do so?

We can now see that these questions can be interpreted in different ways. What light does such a perspective shed on the (latent) characteristics and objectives of anti-vaccination organizations? No simple ‘check-list’ of defining features can be distilled from the social movements literature. Various authors, particularly those concerned to distinguish new from old movements, stress the ‘post materialist’ concerns of ‘new social movements’. They are said to be concerned with the construction of new forms of political identity rather than with the redistribution of wealth or entitlements. Epstein, and following him other students of health-related social movements, take this view. Scott distinguished social movements from political parties and pressure groups on the ground that they have “Mass mobilization or the threat of mobilization as their principal source of social sanction”. This view is consonant with empirical work such as Koopmans and Duyvendak’s, which explores relative success in mobilization behind the reframing of nuclear power. There is a weak fit with what we have seen of the anti-vaccination groups. Many of these are indeed concerned with a reframing of vaccines as (potentially) dangerous in some

way or other: in any event as a problematic approach to safeguarding the health of children, and one largely propagated by the interests of the pharmaceutical industry. There is little evidence that they are engaged in identity politics or that they hold out the threat of mass mobilization.

The emphasis placed on ‘identity politics’ by some theorists is not seen as central by others. Both Shakespeare, focusing specifically on organizations of disabled people, and Carroll and Ratner, argue that social movement organizations differ in their orientation to questions of redistribution and of recognition (or identity). Moreover, for these authors mobilization is but one of the essential tasks of such organizations: others include the formation of an alternative ‘community’, and “addressing existing needs in innovative and empowering ways”. Here, surely, we come closer. Like organizations of disabled people, the anti-vaccination groups differ in their demands: from public acknowledgement that vaccination carries risks to demands for appropriate compensation for vaccine-induced damage (redistribution); from information and advice, to a stress on the right to autonomous choice and individual parental responsibility (recognition). Balancing this broadened classificatory scheme, into which many organizations can be fitted, is however the unifying notion of a radical collective project. From Carroll and Ratner’s perspective (as from Mouffe’s), what binds social movement organizations together is their collective attempt at building an “oppositional culture” (or empowering the “radical democratic citizen”). In how far this can be said to apply in the case of the anti-vaccination groups is a matter to which I’ll return presently. But it is the evocation of a shared project that underpins the theoretical work of ‘lumping and splitting’ that engages both Shakespeare and Carroll and Ratner.

How much *theoretical* sense it makes to view anti-vaccination groups as (new) social movement organizations (as distinct, for example, from pressure groups or self-help organizations) seems to depend on the theoretical assumptions and questions with which the study of social movements is approached. In any event there is no simple and unambiguous demarcation criterion that would enable us to say that they do or do not constitute a social movement.

The utility of social movement theorizing then remains to be established through further empirical research. One focus must be on the genesis of organizations. Pilgrim and Rogers’ study suggests that some anti-vaccination groups, at least, may be as much the result as the cause of parental concerns. The motivating perception may come from the conviction that one’s child has been injured by a vaccination. But beyond that, they found, as did Krijnen in the Netherlands, that mothers who had rejected immunization for their child, often felt a need of support for their decision and

in coping with the “deviant status” it seemed to bring with it

Q. You mentioned earlier on your support group. Why is it necessary to have a support group?

A. I think if you take the non-immunisation group, I think they are quite ostracised; as I said it is such an emotive issue. If you are with people, mothers who have had their children vaccinated, it becomes a taboo subject, so the only time you can speak about it is to other mums who have gone the same route. (Rogers and Pilgrim, p. 43)

Rogers and Pilgrim explain that this was how “The ‘Informed Parent’ had emerged: as a group for those who felt they needed the support of others in the same position. They go on “The social class and professions of many of the parents puts them in a position to affect public opinion. The emergence of new groups such as the ‘Informed Parent’ alongside the established smaller group of the organization for vaccine-damaged children is an indication that mass immunisation will come under increasing public scrutiny” (p. 44). This is not because of messages carried by internet, that this study doesn’t address, but because of growing enthusiasm for ‘natural’ ‘non-interventionist’ birth practices “likely to seep into other areas of baby and child health” and the “general growth, popularity, and spread of holism, alternative therapies and healthism. This philosophy is no longer marginal.” From a ‘grievance’ point of view, what is at issue *may* be a sense that one’s child has been damaged, but it may just as well reflect dissatisfaction with the way in which the decision to vaccinate or not had to be taken, and with the social opprobrium non-vaccination arouses.

It also remains necessary to investigate the discursive practices deployed by the organizations, inter-national variation in emphases (for example as between claims emphasizing ‘redistribution’ and ‘recognition’) and their (possible) links with oppositional groups pursuing other objectives. Whilst the *theoretical* utility of ‘lumping’ anti-vaccination groups with other social movements remains to be explored, it could make *practical* or political sense.

A few years ago Hilda Bastian, (a leading health care consumer representative) reviewed the rise of what she calls ‘consumer advocacy in health care’ (Bastian, 1998). Bastian suggests that health consumer activism arises from a number of distinctive concerns that people can share. These include what she terms “people sharing the same health condition or experience” (often evolving from self-help groups); “people with shared experience of being harmed by a product”(such as thalidomide and asbestos); “people with a shared identity” (such as racial or cultural groups, people with disabilities...) and finally groups formed “to protest particular practices or

developments on an ideological basis” (where her examples includes those protesting vaccination, as well as fluoridation of water supplies and high tech obstetric interventions). In the light of this we can understand how a consumer advocate like Bastian has no difficulty in bringing the anti-vaccination groups into her classification of health consumer/patient organizations. It is partly a matter of ideology “there is still a broad philosophy that pervades the health consumer movement... It embodies notions of individual rights (including participation in decision making), community responsibility, social justice, and accountability” (Bastian, 1998, p. 15). Bastian is trying to set out principles that can facilitate common action in the name of health care consumerism: in fact precisely the principles stressed in much anti-vaccination literature. Aside from question of principle there are matters of individual experience. The experience of not having their concerns taken seriously, a sense of having been inadequately informed, the need for mutual support: these are features that mirror those underlying the establishment of many patient/parent organizations.

Just as it makes political sense for Bastian to include anti-vaccination groups in her deliberately broad categorization of health consumer advocacy organizations, so it makes the same kind of sense for health care professionals to attribute vaccine fears to an anti-vaccination movement. The alternative, as the studies quoted earlier suggest, would be to locate the problem—in part at least—within the public health practices around vaccination. To focus attention on vociferous opponents of vaccination, and to expound ways in which they can be countered (e.g. Leask & McIntyre, 2003) is to unite public health and medical professionals behind a banner of reason and rationality. At the same time it diverts attention from other sources of dissatisfaction. The unwelcome alternative is to raise serious, complex and potentially disruptive questions regarding the ways in which medical professionals behave: a critique that, as we saw, was indeed articulated by mothers interviewed in both Britain and the Netherlands.

### **Antivaccinationism and the reconfiguration of citizenship**

For 19th century protesters matters of civil liberty, the rights of the state to intervene in the working class body, were a central issue. Thus Streefland notes that in the Netherlands, “religious and philosophical arguments could [also] serve to defend people’s rights to refuse school education and public health interventions imposed by the state by declaring the state out of bounds when interfering with such important matters as bodily integrity and becoming God-fearing adults” (Streefland, 2001, p. 164). What was at issue, in other words, was the

scope of legitimate state intervention. In today’s controversy matters of rights and liberties again loom large. But today, in the countries of the industrial North, these concerns are not propelled by the class-consciousness of a century ago. Today it’s more about the right to make an informed choice: a right (and responsibility) given growing legitimacy by a different rhetoric of health care. In the 1980s, explain Bayer and Colgrove, AIDS activists insisted that the fight against the epidemic had to be conducted in such a manner as to respect individual privacy and rights (Bayer & Colgrove, 2003). A gradual shift took place, they argue, in the ideology of public health, with individual rights and responsibilities given growing weight. As citizens, we were increasingly encouraged to think of ourselves as critical consumers, taking responsibility for our own health. Consumers, informed and empowered, have the right of choice...so why not here? Isn’t a critical stance towards vaccination, and hence the possibility of alternative viewpoints, a logical consequence of this ideological shift? The market working that is encouraged elsewhere in the health care system is surely in tension with the demands made on behalf of the public health here. Decades of emphasis on personal rights and responsibilities have encouraged growing number of educated parents, many of whom have already learned to express their preferences in opting for natural childbirth for example, to reason for themselves. For such parents the vaccination literature available and the attitudes of practitioners are deeply dissatisfying. Rogers and Pilgrim come to a similar conclusion. They point to a contradiction between the NHS policy emphasis on patients’ rights to informed consent and practices around vaccination that fail to respect those rights. What we then see is an ideological conflict at the very heart of public health, in which individual rights on the one hand, and the expert articulation of the common good on the other, are pitted one against the other.

There is a second difference. Not only have individual rights acquired a very different measure of saliency, but today’s debate includes a reflexive dimension that was not present a century ago. Health activist groups that have emerged around HIV/AIDS, genetic diseases and breast cancer most particularly, have shown the importance of contesting the deployment of science in the contemporary politics of health.

The emergence and re-emergence of infectious disease have been used to highlight the failure of science to save us, despite its triumphalist claims. The HIV/AIDS groups discussed by Epstein claimed the right, and the competence, to formulate an alternative set of demands and priorities in the language of science. Similarly some anti-vaccination organizations attempt to ground their claims in the language of science. We need simply look at their frequent references to scientific publications

claiming a link between MMR and autism, and attempts on the other side to debunk this as ‘junk science’.

In trying to counter the decline in vaccination levels that they attribute to the anti-vaccination movement and the misunderstanding that (according to them) it propagates, public health professionals have responded in a number of ways. Until recently the tendency was to assume that parental doubts have no basis in fact and therefore do not merit serious consideration. There was no interest in the possibility that resistance to vaccination might follow rationally either from reasonable beliefs or justifiable concerns. “Where consideration has been given to parents’ views they tend to be portrayed as irrational or driven by neurotic anxiety,” wrote Rogers and Pilgrim in 1994. Today, still, some are convinced that anti-vaccinationists are simply misinformed and irrational (or anti-rational). They must be made to see the truth of the matter. If their claims regarding vaccine risks can no longer be ignored, then they must be addressed and rebutted by appeal to a superior science. Not only is this sociologically inadequate, it is unlikely to have the desired effect either. ‘Sociologically inadequate’ because a sociological analysis must see both sides as mutually engaged in a process of contestation, in which the reflexive analysis of (shared) experience, differences in the assessment of risk, and the place of expertise in democratic decision making are all at stake. ‘Ineffective’ because what is being contested goes far beyond establishment of some objective measure of vaccine-risk, to the heart of modern citizenship and democratic politics.

Public health officials and experts are no longer united in their understanding of antivaccination sentiment, or in their sense of how it should best be dealt with. Indeed our own current research in the Netherlands suggests that whilst some hold to the view that people involved in the NVKP are best ignored, others feel dialogue a wiser course of action. The assumption behind the latter point of view is of course that in an appropriate deliberative forum rationality, the weight of evidence, will ultimately prevail.

A few members of the health professions seem now to glimpse that more is required than convincing evidence alone. Balinska, for example, admits the possibility of an erosion of public trust in government health authorities that have “too often insisted that “there is no risk” when later the potential dangers materialised” (Balinska, 2004). The commercial interests of the pharmaceutical industry, and government support for the industry, may cast further suspicion on their promotional messages. Restoring public faith in vaccines and vaccination, she argues, is a vital but essentially political challenge. Good information is crucial, but not sufficient. Still, this proposal for ‘vaccine advocacy’ fails to get at the heart of the matter. Inspired by the notion of ‘concordance’ (Royal Pharmaceutical Society of Great Britain, 1997),

intended to inspire a more consensual approach to drug-prescribing, a British general practitioner has recently made a more radical proposal. Concordance in immunization policy, he writes, “must mean more than evidence-based health care simplistically interpreted.” It should mean “not only applying the evidence to the individual, but also dialogue between perspectives based on different views of the world. It means an exchange of views and mutual respect between these very different views” (Vernon, 2003). He recognizes how great a step this will be for the health professions. Could dialogue based on “mutual respect” produce the desired effects?

Political theorists today draw our attention to contemporary and competing ideals of democratic politics. Deliberative democracy, acknowledging the right and the competence of the citizen, seeks to draw him/her into a process of deliberation, in which rational consideration of alternatives will lead to a satisfactory policy outcome. Such a stance would entail taking parents’ grievances and beliefs seriously and, in rational debate, looking to design vaccination programmes that better respect their agency and their competence. This is the view expressed by Dr. Vernon. An alternative theory of democracy maintains that this is naïve. Through their determination of which standpoints are admissible, the rules of debate, the scope of the agenda, inequalities of power effectively determine the outcome of such deliberation in advance (Young, 2001). An important argument in favour of vaccination, and in Britain in 1979 in favour of compensation for probable damage, has always been in terms of “the benefit of the community”. But who decides what is in the best interests of the community? In the field of vaccination this question is now looming. For the radical theorist of democracy, acknowledging the authenticity of negative experiences, whilst still accepting the coercive rights of the state, and its claim to superior knowledge, is too little. In the view of radical theorists democracy is better served by oppositional groups choosing to reject the rules of a deliberative game. Dr. Vernon’s proposal is an example of such ‘deliberative games’ These are not merely positions in theory, but alternative notions of ‘scientific citizenship’ being enacted in today’s politics, and with growing passion. “In their efforts to publicly expose existing wrongs and injustices, scientific citizens in the guise of activists will be encouraged to assume the role of producers of new scientific communications providing alternative public understandings of science and technology” (Elam & Bertilsson, 2003, p. 245). The legitimacy of the public health armamentarium, both scientific and coercive, cannot be taken for granted in the world theorists such as these and others envisage, and which many are striving to realize. Unlike the disability movement, or HIV/AIDS organizations discussed by Epstein, anti-vaccinationism has not yet found its (social) theorists. Nevertheless its appeal to individual

rights, including the right to contest official assessments of vaccine safety, could easily become a new and powerful strand in this more far-reaching political transformation. In other words, in so far as anti-vaccination organizations come to identify with the radical project that Carroll and Ratner discuss, dialogue will be ineffective. In that way, to speak of them as a 'social movement', as many in the world of public health now do, precisely by stimulating theoretical reflection on their claims, may have the opposite effect to that intended.

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