Sick Children
How Medial and Personal Experiences are Woven Together
By Malin Ideland

I am sitting with Daniel’s head in my knee. Daniel is autistic. He doesn’t speak, gets easily upset, lacks the ability to fantasize and has difficulties understanding verbal instructions and social rules. But he loves music. His parents, Birgitta and John Gren, are convinced that their son’s disease has been caused by an immunization. This explanation is not scientifically proved, which has consequences for the family. At the time I am visiting the family, they are in the middle of a legal process against their insurance company. Birgitta and John are claiming financial compensation for their son’s brain damage, but the insurance company asserts that autism is a genetic disease, which is not covered by the insurance. The parents’ explanation of their son’s injury is not accepted, and Birgitta and John consider it a societal conspiracy. They think that experts do not want to admit that immunization may cause brain damage, since that would decrease the numbers of children who become immune and increase the number of law suits and claims for damages (interview 1).

After several hours I leave the Gren family with my head filled with questions. If everything these despairing parents have told me is true, our children are subjects of a terrible societal conspiracy. I feel afraid and unsure. If I had to choose at this point if I should immunize my children or not, I would probably say no to the vaccination. The sick child and the desperate parents convince me, even if it is just for a little while, that the alarms about a connection between autism and immunization against measles, mumps and rubella (MMR) are true. The meeting with living evidence, Daniel, beats assurances from nurses and infection specialists that vaccination of children is totally safe.

I am not the only parent who has hesitated to vaccinate my small children. At the end of the 1990s came alarming reports that the MMR vaccine could cause autism. A British research team had found that children who had previously developed normally—they had begun to talk and have contact with people—a week after the vaccination lost contact with the world around them and retired into themselves. The research team had found traces of measles virus in these children’s intestines and saw this as evidence for the connection between the immunization shot and the autistic behaviour (The Lancet 1998:351:637–641). The research team has later been reported for fraud in this particular case and they have withdrawn their results.1

The discovery of the connection was reported in the media all over the world, and in Europe the vaccination frequency decreased by several per cent. In some areas less than 90% of the children were vaccinated, a limit that is called “herd immunity”. The same vaccine as the research team had tested was offered to all Swedish children when they were about 18 months, and also in Sweden the herd immunity was not maintained.2 The infection specialists started to worry about an epidemic that would particularly affect sick and weak children (Bergström, Mäkinen & Romanus 2001).

In interviews with parents who have either hesitated about vaccinating or have not vaccinated, several reasons for their view have been highlighted.3 One important reason is that they want to keep nature going. The parents think it is more “natural” to get diseases than to be vaccinated against them. And if it is natural it is good. Their arguments thus rely on the idea of nature’s inherent goodness. Some even think that it may be positive for children’s development to get diseases like measles. Nature’s goodness and the need for natural life is a heavy argument. Another

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theme is the thought of “the limited good”: if we prevent some diseases, something else—probably worse—will strike us.

In this article I am going to discuss a third theme, which seems to have been important for the public debate as well as for individuals’ decisions—meetings with sick children. These children have met the parents through mass media or in real life, and they had consequences for the parent’s choices. I am going to discuss why these children have been so important and how medial and real children become integrated in people’s handling of risks—for example the choice between the risk of your child getting measles and the risk of the vaccine’s side-effects.

With these sick children as a starting point I will also discuss how medial and personal experiences are woven together and jointly shape a foundation for people’s opinions and risk calculations. In the public debate the mass media are often blamed for people’s behaviour. Also in the discussion about the decreasing numbers of vaccinated children, the media have often been presented as the root of all evil. And of course, the media are important for people’s opinions on biotechnology. The media work as a filter deciding what stories are told about biotechnology. The filter is based on our cultural norms and values. And as a filter it has an influence on people’s thoughts since it tells certain stories, but not others (Ideland 2004). The mass media create frames for our interpretation of everyday life. But the media stories are woven together with the private life situation and the personal outlook of life. Consumption of media stories about biotechnology is at the same time a kind of production of private stories about biotechnology. Experiences from media and life merge and create new stories (Linderman 1996), and in this article I will show how sick children from media and real life together shape the foundations for parents’ risk calculations.

Children’s vaccination is an interesting case that can help us to understand how people relate to mass media and use them for handling risks. It is a delimited area, in the media debate as well as in people’s everyday life. Vaccinating children is something you do in a very limited period of your life, and on these occasions the thought of vaccination risks is raised, while at other times one does not think about it. It is also a subject that concerns nature and technology, parenthood and responsibility, illness and death.

To illustrate the handling of sick children I will first give examples of how they are represented in media and then how children from real life are woven into the parents’ risk calculations. Therefore I first focus on the two television programmes that started the Swedish debate on vaccination and autism. I use the word “medial experience” since I maintain that these programmes actually were so emotional that they made lasting impressions in people’s minds. These media stories should be understood in relation to personal stories about how parents have thought about vaccinating their children. After that I will show how sick children from the informants’ private life were used as arguments for both vaccinating and not vaccinating. Finally I get back to the question about sick children’s symbolic value and the integrating of media stories and personal experiences.

Medial Children
In Sweden the research findings about a possible connection between the MMR vaccine and autism were discussed in two current-events programmes, Reportvarna and Kalla Fakt. In Reportvarna the viewers meet the identical twins Heidi and Anne, two 8-year-old Dan-
ish girls. They are singing and jumping but it is obvious to the viewer that something is wrong. Their mother says that the girls were “normal” until their vaccination at the age of 15 months. But just a week after their MMR vaccination something happened, something that their mother describes as a “sudden and strong” change in the girls’ behaviour. Anne acted “as if she was sitting in a glass case”. Six months later Anne was diagnosed with autism and Heidi with Asperger’s syndrome, also a form of autism. Their mother says that she has never doubted that the vaccine caused the change of the girls’ behaviour (Reportvärna 7 September 1999).

Slightly more than a year later, Kalla Fakta put the vaccination debate on the agenda again. First the viewers meet Sofie’s crying mother, who tells the audience that “If I had been stronger, I could have protested.” The story is illustrated by pictures of, as far as we can see, a healthy and happy baby. The feature about Sofie and her mother is very affecting. The mother, Sonja, cries during her story about her daughter. The photo of the happy baby is shown again and Sonja says “this is the last one…” She tells us how Sofie, after her first vaccination, 5 months old, got cramps and they had to go to the hospital by ambulance, but the doctors could not explain the cramps. The same thing happened after the second vaccination and before Sofie was to have her MMR shot, Sonja questioned whether it was good for her daughter. “But I was recommended to continue. I was a good mother who did what I was told. Today I can see that I did wrong” (Kalla Fakta TV4 26 October 2000).

After the vaccination Sofie took cramps again. She became unconscious and stopped breathing. Her grandmother, who is a medical practitioner, was visiting the family and she gave artificial respiration while Sonja called for an ambulance…

The television audience still does not know whether Sofie is alive or not. The feature is very dramatic, but at this point it is cut and an old black and white newsreel about the blessed polio vaccine is shown.

After the newsreel the audience can relax. We are taken back to Sonja and Sofie, now about 6 years old. She is singing a song with a little help from her mum. The reporter tells us that Sofie survived, thanks to her grandmother’s medical knowledge, but that she got a difficult form of epilepsy.

After that he viewers, via the reporter, visit Kevin – an autistic boy whose parents, like Birgitta and John Gren, are fighting against their insurance company to have their son’s vaccine injury recognized. Once again we hear the same story: A child who was developing normally until the vaccination suddenly changed to autistic behaviour (in Sofie’s case – got epilepsy). All the parents are convinced that the vaccine is the root of the evil and all of them are fighting against authorities, drug companies and insurance companies to have the damage acknowledged. The features are emotional and convincing and the message is clear: the MMR vaccine may cause brain damage and our children are victims of a societal conspiracy.

The mass media work as meeting places. The desperate parents on the television screen can be described as vicarious friends. They are persons whose lives we can identify with, and we can feel sorry for them (Lilliequist 2000). The sociologist Ulrich Beck points out that there is a tendency today to describe general problems in terms of individual problems (Beck 1992:110). In particular mass media use a narrative technique to let an individual personify a larger theme (Lakoff & Johnson
1980; Levi 2000). If you tell the story about a new finding result, a disease or perhaps a medical treatment through a portrait of an individual, medical journalism has more impact on the public than if you tell the story in statistical or medical terms. Through the individual the media consumer can identify with the medical news.

It is important for the journalist to choose the right person. The person must represent qualities which harmonize with the message, and, most important, the person must arouse empathy. The autistic children fitted well in this context. The fear of one’s own child being autistic is strong. This is a disease that is culturally unmanageable, the stereotypic autistic children represent everything a “normal” child is not supposed to be – introverted, lacking fantasy and socially disabled. Children must be “normal”. Most parents’ wish for their children is that they should be “like everyone else”. Also, society controls “normal” development through check-up at the child welfare centre. The requirements that parents should ensure their children’s health and development are explicit. There are rules, but at the same time you always have a choice. Vaccinate or not?

But the freedom of choice is also connected with responsibility. The parents have to make the “right” choice. It is up to them to consider – real or imaginary – risks and make the right decision on their own. The decision can lead to serious consequences, and in the television features it is obvious that, for example, Sofie’s mother Sonja expresses her own failure. She feels responsible for her daughter’s epilepsy, since she did not protest. The ethnologist Kirsti Mathiesen Hjemdahl points out that parenthood has been an exception from cultural release. When women get pregnant they go from being free in their practices to being carriers of rules and expectations. Society has opinions on what is best for the child from the day the woman gets pregnant. But the responsibility for the child lies with the parents, mostly the mother. Parenthood has become an area where morality and responsibilities limit the individual’s freedom (Hjemdahl 2003:30 ff.; see also Bäck-Wiklund & Bergsten 1997; Beck & Beck-Gernsheim 1995). This also contributes to an increased feeling of guilt in the parents if something goes wrong – if the child is harmed, either by measles or by the vaccine. Hjemdahl writes that “Accidents are disappearing; it is always someone’s responsibility, someone who should have known better, taken better care” (Hjemdahl 2003:33, my translation). The medial children and their parents also send the message that parents have to look after their own children, since society is not prepared to do so.

The medial children gave faces to the suspicion that the MMR vaccine could be dangerous. The mass media in this case were worrying people, and right after these television features this medial experience was enough to make parents unwilling to vaccinate in some cases. But for the parents I have interviewed 5–6 years later, other experiences seem to be more important for their decisions.

Real Children

Today, about seven years after the media debate, the stories about vaccines and autism are still told on the Internet, in open day-care, the waiting room at the child welfare centre and other places where parents of newborn children meet. This happens despite the fact that the scientists have withdrawn their results, apologized and been reported for fraud. They are also told even if the infection doctors over and over again announce that there are no con-
nections between the vaccine and autism, that it is much more dangerous not to vaccinate. Why is this story still alive?

I can think of a number of reasons for why this story is still alive. One is that the diseases, measles, mumps and rubella nowadays are out of sight—and therefore also out of mind. They are not seen as a threat any more. Another reason might be that many parents have misunderstood how the immune system works. The anthropologist Emily Martin shows in her study *Flexible Bodies* (1994) how the cultural understanding of the immune system is based on the need to be flexible. A flexible immune system might perhaps need training, from diseases—not vaccines. But when I look at the interviews with the non-vaccinating parents, one weighty reason is that these parents have personal experiences that are in opposition to public medical recommendations. These experiences—from the “real world”, not from mass media—create suspicions that the staff at the children’s welfare centre do not know what they are talking about, or maybe are not telling the truth (for example, interviews 2, 3, 4). Their own stories disagree with the medical discourse. I would like to show how the individual interpretation of the medical discourse depends on the personal life situation and earlier experiences.

After my meeting with Daniel Gren I was definitely doubtful of health care in general and vaccinations in particular. John and Birgitta Gren are not the only parents who are convinced that their child’s handicap is caused by the vaccine. Several of the interviewed parents tell me that they have friends with autistic children, whose parents also are convinced of the connection (interviews 2, 3, 4). Lisa, who after many doubts finally vaccinated her two daughters, tells, for example, about her colleague who is working as a kindergarten teacher.

L: I had a colleague whose child developed autism after this (MMR-vaccination). [...] She maintains that her son was completely normal before, but that something happened after the vaccination. [...] One friend told me that she thought that it (the idea of a connection between MMR and autism) developed because many parents haven’t had too much contact with other children before their children reach the age of 18 months. So they hadn’t seen that their children were different. [...] But I felt that that was not the case with my colleague. She was educated and had seen a lot of children in her job. Then we got cold feet again and we discussed a lot about what to do with Alva (Interview 3).

It was the real children the parents talked about, not the medial children. The real children appeared as living evidence of the connection between autism and vaccination. The feeling of “being there”, having seen the uncut picture of reality, gives a feeling of authenticity. The mass media, however, had been an important part in the construction of the frame for interpreting the real children’s handicaps. The media have aroused a thought, presented an explanatory model for autism. After that personal experiences can be reflected in the medial explanatory model and they become interwoven. Mass media messages influence people when they fit together with the personal outlook on life and give meaning to the private life situation.

Other kinds of personal experiences were additional foundations for the parents’ decisions. Among other things, their own experience of having measles, rubella and mumps was important for their standpoints. This experience is something most parents of small children share nowadays. Some of us may only remember the fever and the itching. Others have memories of being sent to sick friends to get it over and done with. Very few of us remember difficult complications and dying from the diseases. Experiences of having these
diseases are probably not argument enough for vaccination. Instead the memories bring out the harmlessness of the diseases. Measles, mumps and rubella were “natural” parts of everyday life until the 1980s.

“Natural” can in this context be understood as harmless from two different aspects. The first aspect is “natural” as synonymous with “normal”. A disease “everyone” gets can not be particularly dangerous in the welfare state of Sweden. Or can it? Earlier it was “normal” to suffer from measles, mumps and rubella. But “natural” can also be understood in a more literal way. The interviewed parents emphasize their wish to “keep nature going”. Some of them maintain that they don’t want to use “too much medicine”. They accentuate that they try to avoid giving their children penicillin and antipyretics “without cause” (interviews 2, 4). And if the virus spreads in “the natural way”, it feels less dangerous than getting the same virus, in a smaller dose, through a shot. It might even be seen as positive to become sick – since you are then training your immune system.

“Natural” is used as an argument for a specific purpose. Celebrate the “natural” is something we only do on special occasions (Ideland 2002a). Biotechnologies and medicines which have been integrated in the cultural mind do not meet resistance because they are “unnatural” (Marvin 1988). Keeping nature going is seldom an argument when it comes to surgery, transplants or even antibiotics. But in a time when society is getting more and more technified and people are feeling alienated from their origin, nature is seen as the good power and technology – in some cases – is seen as the evil power. This might be an explanation for the interest in Stone Age food and alternative medication, and also for the reluctance to vaccinate. The belief in a good and kind nature might create mistrust against technology (Ideland 2002a).

But even if the parents have a trust in nature and mistrust in technology, personal experiences may lead them to vaccinate their children anyway – against some diseases, not others. Marie’s grandfather suffered from polio injuries, and therefore it was important for her to give her son the polio shot (interview 2). Pia has never had rubella; she was vaccinated against it after her first pregnancy. If her daughter does not “succeed” in getting rubella by natural causes, Pia wants her daughter to have the vaccination before she reaches her teens (interview 3).

The lack of experiences, medial as well as personal, lay the foundation of the parents’ decisions. Pia, for example, has not vaccinated her daughter against the very severe diseases diphtheria, polio, tuberculosis, tetanus and whooping-cough. She might consider giving her daughter this vaccination in the future, if there is an epidemic. But for now she cannot think of any reason to vaccinate her child. She does not know any people in the risk zone for these diseases, and is therefore not afraid that her daughter will get them. Some parents reason in the same way when it comes to why they do not want to vaccinate against measles, mumps and rubella. The risk of epidemics is so small that I don’t have to vaccinate my child. The thought of herd immunity is far away. When asked if they could consider vaccinating for other children’s sake, they answer that they have not thought about it. They are, like most parents, closest to their own child, they want to secure their own child. If there is a measles epidemic, and children suffering from measles are shown on the television, might the herd immunity grow again? Parents who then are choosing whether to vaccinate or not will have a new medial discourse to relate to,
to reflect their own experiences against at. Interpretation of personal, as well as medial, experiences is done in relation to the existing discourse (Fairclough 1995; Lindeman 1996). The changing of medial discourse also opens for the possibility of reconstructing personal stories. And then the value and meaning of biotechnologies like vaccination acquire new cultural meaning (Brodwin 2000).

Perhaps this is the media’s primary function in the construction of people’s identities, attitudes and personal outlooks of life. The media supply different stories, which we can use as a mirror. Not least of all, the media play a major part in the construction of risks in modern society (Beck 1992:23). The media define what risks people are conscious of. What is the threat of the day? Is it tsunamis, terrorists or bird flu? We can blame, or thank, the media for parents’ private risk calculations about vaccinations. But the parents’ decisions seem to be based on personal experiences and ideologies, not on what the media tell them.

**Helping Children**

The sick children run all through the stories about the parents’ arguments for and against vaccination. It may be other people’s sick children, the fear for their own children being sick, or themselves or their relatives as sick children. What these experiences have in common is that they bring risks, or the lack of risks, closer to the individuals. This closeness is crucial for how people relate to scientific risks and possibilities (Ideland 2004). The meeting with a sick child – on the television screen or in real life – is perhaps one of the most convincing arguments there is, especially for a parent at a critical point in life. Kevin, Sofie, Anne, Heidi – and for me also Daniel – are children who seem to live in another world. The ones who meet them will of course get an explanation for why they live in this different universe. How did they end up there? In all times people have searched for answers to why some children become different (Lundin 1997:123). Today we can choose among, for example, genetic, hormonal, social and psychological explanations. But sometimes there is no explanation, and autism is not yet scientifically explained, even if a genetic explanation is the one that is considered the most likely. This lack of knowledge gives rise to popular models of explanation. The MMR vaccination is one popular explanation. Before vaccination Daniel, Sofie and the others were “normal” children. And children should be “normal”, “like everyone else”, as we saw above. Therefore these children awaken special feelings, and they work with an almost unbeatable rhetorical power of persuasion.

The Swedish geneticist Bengt Olle Bengtsson (1999) claims that the argument that biotechnology will help sick children eliminates criticism against this specific technology. That is why the sick children are such a powerful metaphor. They make people feel empathy and then you, as a scientist or biotechnology entrepreneur can gain a hearing for your arguments. Gene therapy is intensively discussed, but seems defensible when it comes to helping sick children. Embryonic stem cell research encountered sympathy with some help from Daniel, 8 years old and suffering from diabetes – a disease that stem cell research might be able to cure (Ideland 2002b). Perhaps we can even understand a family who wants to give birth to a genetically adapted child who can save his or her older brother or sister, who is suffering from leukaemia.

The power of the sick-child metaphor is also obvious when it comes to media descriptions of the MMR vaccine. On the one hand, we
have infection doctors who talk about how many percent of the population have to be vaccinated, or about epidemics in Ireland and the Netherlands. On the other hand we have the faces of autistic children – medias or real. And when you, as a parent, feel insecure about whether you should vaccinate your little child or not, the second argument becomes very powerful. It is possible to identify yourself with the crying parents, who are convinced that the shot is to be blamed for their children’s handicap. The fear of your own child being hurt in the same way is indescribable. In other words, the numbers who must be vaccinated or the reports which show that there are no connections between the MMR vaccine and autism have very little effect. The sick child is a more powerful argument and is therefore integrated in parents’ risk calculations.

But, we should finally ask ourselves, why do over 95% of parents vaccinate their children? The autistic children are there as living evidence, on the television screen and in reality. The staff at the child welfare centre and infection specialists are often bad at presenting emotional arguments. But even when the debate was intensive, around 90% still chose to vaccinate. In the end parents try to see to what is best for their own child. The risk of side-effects of the vaccine was estimated as less than the risk of getting the diseases. And there is faith in Swedish health care. The personal experiences are often good, and as a parent of pre-school children you are often willing to follow advice from the child health care centre. Annika, whom I interviewed after she had vaccinated her son, told me that she hadn’t hesitated for a second. She just shrugged her shoulders when I asked if she had been worried about the alarm reports, even though she was aware of the reports (interview 5).

Maybe Anika also had read some of all denials that have been published in the newspapers. There are alternative medical discourses, just as there are alternative medical discourses (for example anthroposophical medicine). As individuals, with unique personal experiences, we reflect ourselves in the discourse that best fits with our personal life situation. In some cases it is about neglecting discourses, in other cases it is about integrating them in one’s own thinking. The mass media influence people, especially when they say what we want them to say, or maybe when they say what we expect them to say. The mass media message has to fit into the personal explanatory model for existence.

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Notes
1 In 1998 the paediatrician Andrew Wakefield et al. published an article in the Lancet about a possible connection between the MMR vaccine and autism. In February 2004 the Lancet withdrew the article, since some irregularities in the study had become known. Wakefield’s research team, for example, had been paid by an organization representing parents who were in the middle of a legal process about vaccine damage. Wakefield’s results were also criticized for how they had chosen the twelve children in the study (The Lancet 1998:351:637–641, http://image.thelancet.com/extras/statement20Feb2004web.pdf).
2 The decrease was only related to MMR. Other vaccines, for example against diphtheria, maintained herd immunity at about 99% (Bergström, Måkkinen & Romanus 2001).
3 In this project I have conducted seven interviews (including nine persons), three of them with parents who have not vaccinated their children, one with autistic Daniel’s parents, three with parents who have vaccinated their children. These people I have contacted through different channels. Some of them I have met at the children’s health centre, where I was making observations, some of them
I have contacted through personal connections and Daniel's parents. I met at a court trial. One informant I reached after a call for parent's opinions on vaccination at the website All för föräldrar (www.allforforaldrar.se). This call also resulted in 10 questionnaires by mail. It has been difficult to get in contact with parents who have not vaccinated, since they did not show up at the children's health care, and the confidentiality prevented me from getting in contact with them through nurses. In the project I have also analysed mass media stories about the MMR vaccine and discussion forums on the Internet. This article, however, is mainly based on the interviews and the television features in Kalla Pakt (TV4 26 October 2000) and Reportarna (7 September 1999). The project "Mas Media, Medicine and Power" has been financed by the Knut and Alice Wallenberg Foundation.

The stereotype of an autistic person is Dustin Hoffman's character Rain Man in the movie with the same name. In the real world autism can include everything from high-functioning persons with Asperger's syndrome, who might have small social "dysfunctions" to severely retarded. What I describe here is the stereotypical picture which is important for the fear of autism.

References
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