

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Public Health: ethical issues* between May and September 2006. The views expressed are solely those of the respondent(s) and not those of the Council.

SENSE

## **1. Introduction**

### ***What is Sense?***

Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide specialist information, advice and services to deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have sensory impairments with additional disabilities.

Sense has worked with deafblind people and their families for 50 years. Our services include support for families, help for deafblind people living in their own homes, day services where deafblind people can build confidence and learn new skills, and Sense-run houses in the community – where people are supported to live as independently as possible.

Sense was founded by two Mum's whose children were born with Congenital Rubella Syndrome as a result of rubella infection during their pregnancy.

### ***What is deafblindness?***

Deafblindness is a combination of both sight and hearing difficulties. Most of what we learn about the world comes through our ears and eyes, so deafblind people face major problems with communication, accessing information and mobility.

There are many causes of deafblindness. These include premature birth, birth trauma and rubella during pregnancy, which can cause babies to be born deafblind. Some genetic conditions also result in deafblindness. And any of us can become deafblind at any time through illness, accident or as we grow older.

People who are born deafblind often have additional disabilities, including learning and physical disabilities.

### ***Sense's response***

Sense has limited our response to those questions that relate to immunisation.

## ***2. Some countries have a compulsory rather than voluntary system of vaccination. On what basis can such policies be justified to achieve herd immunity? Should they be considered in the UK?***

Compulsory vaccination, in an ideal world, would lead to higher uptake, and using rubella as an example, could lead to elimination of a disease that causes lifelong, multiple disability. The US, where an element of compulsory vaccination exists in the immunisation programme, has recently announced the elimination of rubella and congenital rubella syndrome<sup>1</sup>. So it undoubtedly benefits.

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<sup>1</sup> MMWR - March 25<sup>th</sup>, 2005 / 54 (11); 279-282; Centres for Disease Control and Prevention

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Any compulsory scheme would have to take account of the public's increasing desire for choice and so allow an opt-out if it is possible to demonstrate a good reason for not vaccinating. There needs to be a debate about acceptable reasons for an opt-out. Sense would suggest that a parent disagreeing with vaccination in general would have to convince the authorities that not vaccinating their child is in that child's best interests and does not place them at unnecessary risk. A compulsory scheme would also need to be squared with the current understanding of the law on medical treatment, namely that you can't give treatment without an individual's consent.

Sense suggests three essential elements for compulsory vaccination to be considered:

- *Practicality – is it likely to succeed?*

A long-term assessment by those responsible for public health would need to show that a compulsory scheme was likely to deliver consistent, high uptake of vaccinations. Such an assessment would need to take into account the power of those promoting anti-vaccination views, and those who oppose compulsion in general.

- *Overwhelming public support*

It is inconceivable that compulsory vaccination could successfully be introduced without this, although that is not to say that all aspects of the decision have to be universally popular (I doubt the introduction of laws on seatbelts was universally popular, but we wouldn't consider repealing them now). The principle of trust becomes important in this context. Partly due to the debate played out in the media about MMR, whether to vaccinate or not has become a complex decision for many. Parents need to be able to trust health professionals and the information they are given that informs their choice. Trust can be re-established with the third element...

- *Open debate and a willingness to engage in the arguments and evidence that is presented against vaccination.*

The public debate about MMR has been dominated by anti MMR views. A few honourable exceptions aside, medical and scientific opinion has been slow to present counter-arguments and to shape the debate. There have been real reasons for caution – lower uptake of MMR has tended to follow the publicity, much of it negative; when the debate in the media has subsided uptake tends to recover. However, we live in an information rich age and the public are easily exposed to arguments on all sides so there is a greater need to engage openly and honestly with the public about the science and benefits that justify vaccination.

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<sup>2</sup> As an aside we feel strongly that the term 'herd immunity' is unfortunate and contributes to some parents' antagonism to vaccination. An alternative might be 'community protection'.

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The reality is that a compulsory vaccination programme, in today's climate is not deliverable and would be counter productive. Over the last few decades, society's emphasis on the idea of choice, and the principles of consent and autonomy have come to the fore and would be barriers to any sort of compulsory vaccination programme. What has been less evident in the public debate about MMR is individuals' and society's readiness to accept the consequences of making some decisions rather than others. For example, while there has been much focus on the call to introduce the choice of single vaccines on the NHS, there has been very little debate about whether increases in congenital rubella syndrome births would be an acceptable consequence of such a choice.

In conclusion Sense believes that in the current environment compulsory vaccination would lead to more people challenging immunisation and so less children being vaccinated. It is not deliverable and would be counter productive. Rather than debate the merits of compulsory vaccination it is more important to put effort into changing the attitudes of those who are not convinced about the benefits of vaccination.

***3. For childhood vaccinations, parents make decisions on behalf of their children. Are there cases where the vaccination of children against the wishes of their parents could be justified? If so, which ones?***

It is possible to envisage circumstances where the vaccination of children against the wishes of their parents could be justified.

- *When parents disagree*

In exceptional circumstances it is necessary for a court of law to intervene between parents who cannot agree what is in the best interests of their child and make the decision for them. In any such case the focus of the decision maker should be on what is in the best interests of the child, based on an assessment of the evidence available and on the potential risks to the child. Where possible the views of the child should be sought as well. In recent years there has been a case where two mothers opposed MMR for their daughters against the views of the fathers. The judge ruled that it was in the best interests of the children to be vaccinated because the advantages outweighed the risks.<sup>3</sup>

- *When a child is deemed to have capacity and disagrees with parents*

Much of today's vaccination programme in the UK is aimed at babies and toddlers who do not have the capacity to make decisions about risk and their best interest in the long term, so parents make the decision on behalf of the child. However it is possible to envisage a young person who was not vaccinated as a child who is deemed to have capacity who could choose to be vaccinated against the wishes of their parents. For example a young girl of 13 might know a friend whose elder brother has congenital rubella syndrome. They might ask questions about how he developed the syndrome and become informed and concerned about rubella to the extent that they choose to receive a rubella containing vaccine, even though their parents didn't

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<sup>3</sup> Wright O. Judge orders MMR jabs despite mothers' protests The Times 2003 June 14; 3.

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vaccinate her as a child because the didn't (and still don't) believe in vaccination.

Whoever is involved in the decision making process should focus on the best interests of the child, the risks they face and the views of the child. Even where a child is not deemed to have capacity, their views are valid. For example a child in reception class at a school in an area where there have been significant outbreaks of measles might hear friends, teachers or parents talking about the disease. They might be scared about catching measles. Their views should be seen as an important element in the decision making process.

The difficulty for anyone involved in the decision making process is how to assess levels of risk. There are two issues here. Firstly, if immunisation uptake rates are high, then the reality is that 'free-riders' face relatively little risk as the diseases are unable to circulate. The risks become greater as uptake drops – in the case of rubella, some immunisation but at lower than ideal rates actually shifts the burden of the disease onto those most at risk. Secondly, in the case of rubella, the risk is not to the individual child catching the disease but to others the child might pass the disease onto, particularly pregnant women.

Trust will be required in health professionals who are able to assess the level of risk individuals and communities face.

***In your view, is there one of the principles above (autonomy, solidarity, fair reciprocity, harm principle, consent, trust) that is more important than all the others? If so which one and why? Are there any other important principles that need to be covered?***

Perhaps unsurprisingly for a charity founded by two Mum's whose children were born with congenital rubella syndrome, the principles listed that guide our work, particularly work around rubella immunisation, are:

- Loyalty and mutual support to those we recognise as being in need and deserving of help – solidarity
- The obligation not to harm

However, like many working in the social care field, we also place importance on the rights of deafblind people to make independent decisions about their own lifestyles and ensuring they have the means and resources to make such decisions. This is reflected in values that guide our organisation such as self determination; a strategic objective that focuses on the individual and in the belief that a person centred approach should guide our work.

This belief in autonomy is reflected in our wider society. Political debate focuses on choice of the individual, the role and boundaries of the state, whether such a thing as society exists or not, and how much we should all contribute to services that benefit those in need and deserving of help. It can be argued that solidarity and autonomy conflict; perhaps it is useful to use the analogy of a see-saw and the need to find a balance we can all accept between our rights to lead the life we choose, and our obligations to others, particularly those in need.

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***Can these principles be ordered in a hierarchy of importance? If so, how would such an order relate to the five case studies? Would the order have to be redefined for each new case study? Are there particular principles that are of special importance to some case studies?***

### **The way we behave to others**

Individuals and the state, in choosing whether or not to immunise against rubella place themselves at the heart of a debate about how we behave towards others because immunising against rubella is not about protecting the individual being vaccinated; it is about preventing the disease circulating and protecting un-born children from contracting the virus via their pregnant mothers.

The most important principles in this debate are *solidarity* and our obligation not to *harm* others. In deciding to immunise your child against rubella you are not expecting an immediate return of reducing risks to your child's health, but you are recognising that others (particularly pregnant women) are in need of protection against rubella and they deserve your help in this. Pregnant women are in need of protection because their child may be harmed by rubella otherwise. In the first weeks of pregnancy if the mother catches rubella there is a 90% chance that the child will be born with congenital rubella syndrome (CRS) – their sight and hearing may be impaired. The heart may be damaged and there could be neurological development problems. In such circumstances the mother may consider termination. It is not often highlighted in public quite how dramatically rubella associated terminations have been reduced because of successful rubella immunisation.

What is also forgotten in the public debate about immunisation is the interdependence involved in rubella, and its immunisation. The person who contracts rubella passes it on to members of their own family, their friends, their neighbours, kids at their local school and the Mums who pick them up. So the decision to immunise or not does not impact on some distant members of society, it impacts on the local and immediate community. Sense is in touch with many parents of children with CRS who know how they contracted the virus.

The importance of solidarity suggests we have to accept we have less *autonomy* in the decision to immunise against rubella or not, specifically because the decisions affect other people not ourselves.

The debate in the UK about MMR and its possible link to autism and bowel disease has included a call for single vaccines to be introduced on the NHS because the public want an autonomous choice. However those advocating the choice have refused to address the consequences of such a choice. It would be irresponsible of the NHS to give people the autonomy they demand, believing, as they do, that it will cause harm to others.

It is not only that the consequences of individuals' decisions falls on others which reduces the importance of the autonomy principle, but that the potential damage caused by decisions not to immunise is disproportionate to the decision and autonomy people want.

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While it is important to recognise the unfairness of 'free-riders' in a rubella immunisation programme, the principle of *fair reciprocity* doesn't seem to help. What will the immunisation free-rider not be entitled to because of their lack of a contribution? How will additional contributions elsewhere in a public healthcare system make up for any harm caused by their decision to other individuals? There are less consequences or risks of a free-rider in times of high uptake than there is when uptake drops; this of course only highlights the unfairness of being a free-rider.

Perhaps one way of shaping the argument in terms of fair reciprocity is to encourage individuals and society to reflect on the wider social and economic consequences of not immunising against rubella. Our solidarity with those in need means that the costs and burden of supporting a person with congenital rubella syndrome throughout their life has to be shared with the state, and our contributions to the state should reflect this. Indeed the long term economic benefit of immunising against rubella was one of the factors that influenced Latin American states to introduce mass immunisation<sup>4</sup>.

In summary, childhood immunisation, and rubella immunisation in particular suggest the need to highlight the importance of our solidarity with others and our obligation not to cause them harm. It might be we need to frame arguments against autonomy and the unfairness of being a free-rider in part by reminding the public of the consequences of their decisions.

### **Making ethical decisions**

*Trust* and *consent* are bound together in negotiating immunisation programmes and the decisions that surround them.

Taking no action or seeking a compromise are natural behaviours when faced with a perceived difficult decision, and in the minds of those who, for whatever reason, believe that the MMR vaccine might harm their child, they become proportionate actions. A minority of parents have chosen not to trust the vast majority of scientific evidence and opinion. Instead they genuinely believe there is potential harm to their child if they vaccinate using MMR. They seek guidance from other Mum's, from friends and family; they reject guidance from those who they perceive to not recognise their fears and concerns and they often use notions of trust (or lack of it) to justify this. This is reflected in wider society where lack of trust in our leaders and established institutions is a popular argument.

Yet trust is at the heart of negotiating public health measures such as immunisation, and trust has to be two way. There is a responsibility on both decision makers, and those supporting the decisions in establishing and developing trust.

For those supporting the decisions there is a need to be open and honest about the arguments, the process for developing and testing those arguments, the conflicts of interest that exist, to engage publicly with concerns and criticisms, to share the strengths and weaknesses of the evidence supporting the arguments, and to help others understand the risks and benefits of different courses of actions.

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<sup>4</sup> The Many Faces of Rubella, March 14-16<sup>th</sup> 2005, New York, International Symposium

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Decision makers are not fulfilling their side of the trust bargain if they won't trust scientists on what they say about immunisation, because of the views others held about BSE in the past; it's ok to be more cautious given past experience but not to refuse trust for ever more. Similarly the public debate about MMR has been characterised by dismissing wholesale the views of one side or the other, by seeing the debate as black and white, by characterising those who agree with your views as good, and those who disagree as bad. No wonder trust is a casualty (and again both decision makers and those supporting decisions - on all sides of the argument – have been guilty of this)

In addition, while trust still exists in the NHS and in doctors as a whole, it will be interesting to see how the increase of private investment and decisions that are motivated by finance affects this trust.

In any mass immunisation programme those being immunised (and those who make decisions on their behalf) have to agree to take part. This might be the overwhelming public support for a compulsory programme that we argued about earlier, or it might be the option not to take part in a mass programme at an individual level. Consent is particularly important when considering treatments that carry both risks and benefits.

Our understanding of and ability to assess the risks involved is an important additional element in making decisions about public health issues. It is an area where those making decisions need support, but it is important to realise that not taking action can be as risky as taking action.

***In cases such as vaccinations or fluoridation parents decide on behalf of their children. Which ideas or principles should guide parents in their decisions?***

Parents of babies and toddlers almost exclusively make decisions that affect the lifestyle and health of the child. Two ideas should dominate:

- What is in my child's best interest?
- Where it is possible to ascertain, what is my child's view about this?

Hard as it may be it is important for parents to reflect on where their own lifestyle choices and views may be at odds with their child's best interest. The ability to be open to a range of views and to take on board advice and information from those who have a more detailed knowledge of the issues involved (e.g. over immunisation) is important. The principle here is one of being open to trust others to help you make the choice, and to reassess this trust for each decision.

It is important (and again hard) to balance what is in a child's best interest as an individual and as a member of a local community and a wider society. In the case

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Even where a child lacks the full capacity to make a decision about immunisation it is important a parent takes their views into account. The child, who is worried about measles because one of their friends has contracted it, needs those concerns addressed one way or another. Again it is important, but difficult, for parents to accept that their child's views may challenge their own.