

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.

The Royal College of Paediatrics and Child Health

List of questions

Responses to Questions

General Introduction:

This response is specifically concerned with the special situation of children. We are gratified that the members of the working party have highlighted as one of their terms of reference the special situation of children and those who are poor and socially excluded. For reasons given below, the perspective of children is particularly important in public health matters and it might have been helpful for the working party to have more formal representation of children's issues although we fully accept that it may be difficult, on a working party, to achieve representation of all those who have legitimate claims in this area.

The definition of public health provided by the faculty of public health of the RCPUK refers to both science and art of preventing disease, prolonging life and promoting health. This particular definition more clearly sets apart the moral obligations of public health to avoid harms and provide benefit. The tension between these two obligations, and that of respecting the right of individuals to exert as much self-determination as they are able, and to do so justly and fairly lies at the heart of many public health dilemmas.

Few could plausibly object to the provision of adequate, un-crowded accommodation, with appropriate water supply and sanitation as proper public health measures that reduce harm and promote benefits and surely few, if any, would choose to live in accommodation that did not meet these criteria. Such interventions which are of enormous public health benefit have minimal impact on individuals right of self-determination because they do not impact upon their liberty rights to an extent that we might find morally unjustifiable. It may therefore be useful in deliberations about some of the case studies and scenarios to delineate specifically between the principles of beneficence and non-maleficence.

The position of children as opposed to other weak, vulnerable and potentially incompetent individuals is different because in part of their development and other potentials. Although it is a truism to say that children are our future, most in fact do grow into competent adults who are able to make informed choices about their life and health. Children, as they grow, acquire competencies at rates that vary and which may not be adequately recognized. However, many young children have no active role in decisions that affect their own destiny. Moreover their capacity in this regard only develops to the extent that it is encouraged and supported by others. Indeed there is a moral obligation for carers and others to enhance children's' capacity and provide them with the information and support that they require in order to acquire it. There is also an obligation to provide an environment, which allows children to make free choices and to support them if and when they fail.

The physical weakness and vulnerability of young children, especially to infection, malnutrition and abuse, means that we also have moral obligation of active protection rather than merely deliberately not harming them. The duty to enhance health is therefore particularly important in childhood but may conflict with the carers' views as to what is in their own child's best interest and their claim that they should be free to act as they see fit in the upbringing of their child. A child's protection rights may therefore conflict with the parents' liberty rights.

It may be difficult to know what constitutes a child's long-term best interests until childhood is past. This is particularly important if we accept Barker's hypothesis that many adult onset diseases have their origins in foetal or infant life. Additionally infants and children may acquire behaviours from their parents or the environments in which they live that harm them. Such examples may include eating habits and the type of food eaten, smoking behaviour and later

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alcohol consumption. The extent to which exposure to such factors may compromise a child's future autonomy is not clear. If it is true that children who live in houses where there is more smoking are more likely to take up smoking themselves and to become addicted to it, is this a behavioural consequence or a reflection of an inherited pre-disposition to take up addictive behaviour. Children may need protection from the autonomous choices of others, while at the same time facilitated to make informed choices of their own.

To this extent children are the recipients – maybe unwittingly – of paternalistic intervention in the truest sense. They have no votes that might influence how others behave towards them, nor is it easy to infer what they themselves might want in any given circumstances, always provided that they were able to choose. Presumably they would want good health for themselves, but perhaps not to the extent that might cause harm to others, or would consume a disproportionate amount of resources. However this might be taking altruism by proxy a little too far. However it seems reasonable to suggest that an abused child might wish that the abuse might cease, but not want to be separated from his or her parents.

The State also have a legitimate interest in the health of children, but may only infringe the rights of parents to the extent that can be morally justified and proportionate. Nonetheless the State may wish to intervene in unfettered choices as to the sex of offspring in IVF or other reproductive techniques, and might wish to prevent the economic consequences of pre-term delivery on surviving babies and families by advocating IVF techniques that reduce the risk or prematurity and multiple birth. Equally the State may have obligations to ensure that children have equality of opportunity regardless of race, gender, disability or genetic makeup. Presumably it also has obligations to compensate them if public health policies result in harm. The State also has obligations to ensure that children have equality of opportunity regardless of race, gender, disability or genetic makeup. Ideally a child's potential should not be compromised by the poor state of health of parents as determined by socio-economic factors, or even their personal responsibility for it. To do otherwise might suggest that the child somehow shares the moral responsibility for the behaviour or circumstances of the parent, which would seem unreasonable.

1. The definition of public health

- Do you agree with the definition of public health introduced above (“[W]hat we, as a society, collectively do to assure the conditions for people to be healthy”¹)? If not, please explain why. What alternative definition would you propose?

We would personally favour a definition that highlights the distinction between avoiding harm and promoting good e.g. that of the RCP as given above. Otherwise there is a need for a statement as to what constitutes “healthy” in this context.

2. Factors that influence public health

- Do you agree that interactions between the following five factors are the main influences affecting public health: the environment, social and economic factors, lifestyle, genetic background, preventative and curative health services? If so, do you think some are more important than others? Are there other factors we should include? If so, what are they?

We are in broad agreement with the factors listed. However the importance of individual factors is likely to vary in different case scenarios. Social and economic factors may impact on the microenvironment and lifestyle of individuals. They could be associated with a change in emphasis in health from an illness service to a prevention service. The change presumably requires a change in attitude or philosophy of public health towards a more beneficent approach as opposed to one with a greater emphasis on prevention of harm. A greater emphasis on

¹ (Institute of Medicine (1988) *The Future of the Public Health* (Washington, USA: The National Academies Press).

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3. Prevention of infectious diseases through vaccination

- Some countries² have a compulsory rather than voluntary system of vaccination. On what basis can such policies be justified to achieve herd immunity? Should they be introduced in the UK?
- 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, what are they?

Whether compulsory vaccination can be morally justified depends on such factors as the prevalence of infection, its nature, mortality and morbidity and the presence or absence of effective remedies and the side effects of vaccination itself. As an example, in the UK smallpox vaccination was compulsory for many years, it then became optional as risks and severity of smallpox declined and then abandoned altogether when smallpox was officially eliminated. Similar parameters might be applied to other vaccinations. Whilst vaccination may be justified to prevent harms to others, it is difficult to see how it can be justified – or imposed – to provide herd immunity if we believe that individual liberties are morally important. Society would need to agree collectively that it was willing to sacrifice individual liberties to eliminate the effect of free riders and this seems unlikely to prevail unless we are to restrict free choices in other morally relevant areas.

Parents who have their children vaccinated do consent to the process but to the extent to which they are informed and given alternatives maybe limited. For example families may believe that combination vaccines or complex e.g. adjuvant containing vaccines have more side effects than single vaccines, yet they are not offered the latter, presumably for reasons of efficacy and utility. Here parents may believe that they are prevented from exercising free choices on behalf of their child, genuinely believing that the choice that they would make conveys more benefit than harm. They might argue that in the natural state children's immune systems are not exposed to multiple infective agents and that they are not designed to do so.

In contradistinction there have been cases in which the vaccination or immunisation of a child has been sanctioned by a court of law on the grounds that the risk to the child if vaccination is not carried out is substantial. An example would include hepatitis B. Similarly parental behaviours that reduce the risk of vertical transmission of HIV to children are encouraged but do not seem to have been the subject of legal sanction if parents disregard them. Parental behaviours that are likely to affect the future health of their child in a significantly adverse way would seem to require moral if not legal sanction. However in the current UK law, which arguably does not pay adequate recognition to foetal rights, it is unlikely that this could be enforced.

4. Control of infectious disease

- Control measures for specific diseases depend on how infectious a disease is and how it is transmitted. For infections that are directly transmitted from person to person, what justification would be required to render interventions such as forced quarantine, which helped to control the outbreak of Severe Acute Respiratory Syndrome (SARS) in Asia, acceptable in countries such as the UK where such measures may be considered to infringe civil liberties? If you think such measures cannot be justified, what are the principal reasons?

² Countries with mandatory vaccination policies include the USA and France. In these countries children must have received certain vaccines before they can start school.

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- In general, the earlier that an outbreak of disease is detected, the easier it will be to control. What would be suitable criteria to determine in what circumstances, and to what extent, the state should provide more resources to develop methods of preventing outbreaks of serious epidemics in other countries?
- Travel and trade are key factors in the spread of infectious diseases. Global travel and exchange of goods are increasing rapidly. Each day, two million people travel across borders, including around one million per week between developing and developed countries. Disease-causing organisms and vectors can therefore spread quickly around the world.³ Are new measures needed to monitor and control the spread of infectious diseases? If so, what would be promising strategies?
- Under which circumstances, if any, would mandatory testing for highly infectious and life-threatening diseases such as tuberculosis or HIV/AIDS be justified?

One factor, which seems to be important, is the ease with which people now travel large distances. Given that this is the case and that the spread of disease maybe more rapid than before, it seems plausible to argue that substantial risks of harm to others might be sufficient justification for infringement of civil liberties. There are circumstances in which restrictions on behaviour are acceptable, either to prevent harm to individuals or to others, e.g. seatbelt legislation, crash-helmet legislation etc.

The State has limited powers to intervene in the affairs of other countries. However one might argue that if there were a significant and substantial threat posed by the spread of illness from other countries then it would be reasonable to provide support to that country dealing with the spread of disease, if it lacked the resources to do so for itself.

There seems no ethical reason why global strategies for the monitoring and control of spread of infectious diseases should not be developed provided that they have consent and consensus of those involved and provided that any impact that they might have on individual liberties is ethically justifiable.

There may be circumstances where testing for highly infectious and life threatening diseases might be mandatory. Firstly, if it could reasonably assume that the person that carried the disease was intending to cause harm to others and needed to be prevented from doing so. Secondly, if the person concerned was unconscious or incompetent and not able to give informed consent and the risk to others could not be contained by normal infection control measures.

³ USA National Intelligence Council (2000) *The Global Infectious Disease Threat and Its Implications for the United States – Factors affecting growth and spread: International trade and commerce*, available at: www.cia.gov/cia/reports/nie/report/nie99-17d.html, accessed on: 19 Apr 2006.

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5. Obesity

- Food is closely linked with individual satisfaction and lifestyle. This means that any strategy that seeks to change people's behaviour is likely to be perceived as particularly intrusive. How should this sensitivity be considered in devising policies that seek to achieve a reduction in obesity?
- While there is clear evidence about the extent and scale of obesity, there is far less clarity about what measures should be adopted by the government and other stakeholders to prevent it. In view of this uncertainty, what would be suitable criteria for developing appropriate policy?
- What are the appropriate roles and obligations of parents, the food industry, schools, school-food providers and the government in tackling the problem of childhood obesity?
- Is it acceptable to make the provision of NHS services dependent on whether a person is obese or not (see example in Section 4.2 of Part B)? If so, what criteria should govern whether or not interventions are provided, and should similar criteria be developed for other lifestyle-related health problems that are significantly under the control of individuals?

A libertarian approach suggests that competent adults have a right to make informed choices about lifestyle provided that they do not pose harms to others. The issue is therefore is whether the consequences of the mortality and morbidity associated with obesity do harm others and what pressures might be exerted to overcome them. Socio-economic considerations are important because it may be that the new epidemic of obesity affects those of lower socio-economic status, whose choice of a healthier lifestyle may be limited and who may lack opportunities to change.

With regard to children there have been suggestions that the development of severe obesity maybe regarded as a child protection issue occasioned by parental neglect or failure to promote or secure a better lifestyle. Such an approach may be ineffectual as it produces a culture of guilt and imposes responsibility without necessarily changing behaviours. There are also concerns as to the extent that, as yet undefined generic predisposition may play in some cases of childhood obesity and the extent to which over consumption becomes an addiction. There is also a wider political issue that concerns the moral responsibility of food producers and marketers who sell instant type food or foods with high salt and fat content. Their position might be regarded as analogous to tobacco companies and alcohol producers who would both argue that they only satisfy a market driven need for their product and behave appropriately in informing consumers of its composition and the dangers associated with its consumption. Yet at the same time they do advertise their products widely in ways which may not convey the health orientated messages e.g. drink advertisements.

With respect to exercise and to other lifestyle choices it is unclear how much these are driven by economic considerations, and media interests rather than ethical principles. It seems clear that obesity, like tobacco and alcohol consumption produce harms. Those who are not competent to make informed choices need to be protected from them. Education or information is necessary to enable individuals to develop competence and make informed choices. Special help is required for those whose socio-economic status or genetic predisposition puts them at increased risks.

Arguably these are not solely public health issues because they involve significant political and economic considerations and consequences. Clearly it is possible to promote healthy lifestyles but at the cost of individual choice and at the expense of significant business interests and resource allocation.

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Smoking

- The effects of smoking on health have been known for a very long time. Comprehensive measures by governments to prevent harm to the population are relatively recent. In your view, what are the reasons for this delayed response? Are there any lessons that can be learned from other countries, or from strategies pursued in other areas of public health?
- What are the responsibilities of companies that make or sell products containing hazardous substances, such as nicotine, that can be addictive? Should they be prosecuted for damaging public health or required to contribute to costs for treatments?
- Should smokers be entitled to higher than average resources from the public healthcare system, or should they be asked for increased contributions? Would similar charges be justified for other groups of people who deliberately or negligently increase their chances of requiring public health resources, such as people engaging in adventure sports?
- Smokers argue that they choose to smoke. What rights does the state have to impose sanctions to prevent them from smoking? Does the state have the right to prevent the sale of tobacco, which is known to be addictive and highly dangerous? How vigorously is it reasonable for the state to act to prevent children and teenagers from smoking?

Much of the considerations that apply to obesity also apply to smoking. However children are the innocent victims of adult habits especially if they are exposed to passive smoke with its consequences. Whether exposure to smoke and the culture of smoking in turn predisposes them to take up such habits is difficult to know, but it is unlikely to be an insignificant factor. The State has already imposed sanctions on smoking in certain circumstances and over time has sought to change the culture of smoking so that it is socially unacceptable. The interest of tobacco companies and the revenue that they produce for the State are factors and though not strictly speaking matters of public health are a significant driving force that may serve to reduce the States desire to prevent smoking.

It seems reasonable to suppose that the same sanctions that might be exerted on smokers with regard to provision of health care resources should not be exerted on their children, whose illness might be related to passive smoking by their parents.

The issue of addiction cannot be ignored. We doubt that the majority of smokers argue that they choose to smoke. Since nicotine is extremely addictive, as indeed is alcohol, they may have very little control over their behaviour. The State should support those who wish to overcome their addiction, but imposing a ban may merely drive smoking underground so to speak, and maybe unlikely to eliminate it. Clearly the State should do everything in its power to prevent children and teenagers from becoming addicted to smoking. They should also provide adequate treatment to overcome their addiction and from health problems that may occur.

7. Alcohol

- The effects of excessive consumption of alcohol on the health of individuals and society have been known for a very long time. It can be argued that in view of the significant harm to individuals and society, comprehensive measures by governments to prevent harm are lagging behind those for tobacco. In your view, what are the reasons for this?

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- In view of the impact of excessive consumption of alcohol on individuals and society, what are the roles and responsibilities of agents other than the government to limit consumption? Are there different responsibilities for producers and, for example, retailers? If so, which?

The social consequences of excessive consumption of alcohol on child health are more indirect. Excessive consumption by parents maybe associated with abuse, domestic violence and failure to provide adequately for children. The association between alcohol consumption and domestic fires with fatal consequences is a more direct link. Similar constraints apply to alcohol manufacturers and advertisers, as do to providers of fast food and tobacco manufacturers. Similar political and socio-economic constraints also apply.

8. *Supplementation of food and water*

- Fortification of some foodstuffs such as flour, margarine and breakfast cereals has been accepted for some time. Why has the fluoridation of water met with more resistance? What are the reasons behind international differences in the acceptance of fluoridation of water? What criteria are there that determine acceptance?
- Which democratic instruments (for example, decision by Parliament or local authority, consultations or referenda) should be required to justify the carrying out of measures such as fluoridation?
- Achieving population benefits of fluoridation means restricting choice of individuals. Children benefit the most from fluoridation. However, as with vaccinations, adults, rather than children, are making decisions about whether or not to receive the intervention. Under what circumstances is it acceptable to restrict the choice of individuals in order to protect the health of children?

Children are more likely to benefit from supplementation of food and water than adults. However it is adults who determine policy on grounds of exercising their autonomy and by appeal to personal liberty. Those who impose restrictive or unusual diets on their children will find themselves the subject of censure or prosecution because they fail to act in their child's best interest. If it can be shown that supplementation of food and water is in the best interests of either certain classes of children or individual children then it seems reasonable that parents should not overcome this. The criteria for determining best interests may be purely those of net clinical benefit over harm, but probably do need to take account the wider range of wishes, beliefs, preferences and values of those concerned. To what extent wishes, values and preferences of parents as opposed to children should be allowed to override the best interests is conjectural but perhaps the reasonable child or reasonable person standard would be that which would be acceptable in English law. In other words the child should receive supplements of the food and water if a reasonable child in these circumstances might make the same choice.

9. *Ethical issues*

- In your view, is there one of the following principles that is generally more important than the others: autonomy, solidarity, fair reciprocity, harm principle, consent, trust (see Section 5 in Part B)? If so, which one and why? Are there any other important principles that need to be considered?
- Can these principles be ordered in a hierarchy of importance? If so, how would such an order relate to the five case studies (infectious diseases, obesity, smoking, alcohol, and the supplementation of food and water)? 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?
- In cases such as vaccinations or fluoridation parents decide on behalf of their children. Which ideas or principles should guide parents in their decisions?

The tendency in society has been to place autonomy as paramount. It is difficult to see how respecting autonomy of adults protects sufficiently the interests of children. Clearly a duty to benefit others, even with its paternalistic connotations is a significant one as far as children are concerned. In the case of children fair reciprocity seems not to be significant, unless one accepts the principle that children can be taught to be responsible members of society by example and should show their capabilities of this in order to receive benefits. In this case, the principle of solidarity would seem more important. With respect to consent it is important that the consent of parents is obtained for interventions, which have an impact on

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children. However there may be circumstances in which refusal of parents cannot be accepted, especially if this is likely to produce harm to the children.

Although it is tempting to suggest that principles maybe ordered in the hierarchy of importance it does not seem to be applicable for each and every circumstance. The order would have to be re-defined for each new case study by consensus, in the case of children, however, the principles of beneficence and non-maleficence as well as justice appear to be important.

Where parents decide on behalf on their children, clear criteria on which they should do so should be related to best interests. How wide or how narrow best interests might be interpreted and what the results of this might be are matters of debate. A very narrow view of best interests might be that any intervention should confer net benefits over harm. This begs the question as to whether the benefits should be purely clinical or should be psychosocial, socio-economical etc. The wider view of best interests involves taking into account wishes, beliefs and aspirations which may involve parental wishes beliefs and aspirations more than they do those of children who may not be regarded as competent to exercise them. Further criteria might be that of a reasonable child or a particular child. For the reasonable child standard the basis might be what a reasonable child might want in these particular circumstances. For the particular child's standard which is far more respectful of individual autonomy, the criteria might be what this particular child were to want in this particular set of circumstances.

The case studies have been chosen because we think that they highlight a number of important ethical tensions and conflicts between different agents, ranging from individuals to families, to NGOs, companies, healthcare professionals and the state. Other case studies could have been chosen to illustrate the same types of tensions and conflicts. We would be interested to hear if you think that there are other types of ethically relevant issues concerning public health that we should address.

Some of the questions asked with reference to a specific case study also apply to other case studies, for example whether people who accept some kind of damage to their health as part of their lifestyle, such as smokers, should be entitled to fewer resources from the public healthcare system, or be asked for increased contributions. Respondents are welcome to comment on these specific questions in a general manner.

We have briefly alluded to matters, which are of increasing concern for general health. These include, in paediatric terms an increasing number of children conceived by IVF, now about 1% of the population. More significant, numerically are the public health needs of asylum seeking children, or those dependents granted leave to remain. Those entering the UK in these circumstances now represent over 5% of the new UK births each year. The public health consequences of consanguinity on children so born also need to be considered.

We would be happy to provide more input into any of the points raised in this response if it would be helpful to do so.