BODY POLITIC **Nigel Hawkes**

Fat chance of hitting obesity targets

A half hearted approach to public health may explain why health inequalities are widening

How fat are Britain's children? For heaven's sake don't ask the Department of Health.

In an exercise laughable even by the quite demanding standards the department normally sets, the first attempt to measure overweight and obesity in first year primary schoolchildren and in 10-11 year olds has proved a total fiasco.

It took 18 months, and an expert committee 30 strong, to work out how to make the measurements in the first place. Their conclusion, unsurprisingly, was that the best way to work out if children are overweight is to weigh and measure them. Then a simple calculation, or a modest piece of software, can convert height and weight into body mass index.

Given the national panic over obesity, punctuated by regular warnings that today's children will be the first to live shorter lives than their parents, you might at this point have expected some serious action. The government has, after all, set a target of halting the rise in childhood obesity by 2010. What followed, however, was a textbook example of how not to launch a public health initiative.

Primary care trusts, in the middle of a major reorganisation, were given the job of measurement. Some tried quite hard while others weren't bothered, a quarter producing no data at all. Worse still, parents were given the opportunity to opt their children out and did so, in numbers: the fatter the kiddies, the more inclined their parents were to conclude that they would rather they weren't put on the scales. It might be embarrassing, I suppose, even though the measurements were to be made privately and the results anonymised.

The outcome, as a report from the South East Public Health Observatory makes clear, is a mass of worthless data. A total of 538 400 children were weighed and measured, but that was less than half the total in these age groups. Response rates varied from area to area and the higher the response, the higher the rate of obesity. "This suggests that as response rate increases the estimates from the data more closely approach the true prevalence for the area," says the report.

It added: "Analysis of the data strongly suggests that results from the 2005-06 academic year significantly underestimate the prevalence of childhood obesity. It is therefore likely that the more accurate data anticipated in 2006-07 will appear to show an increase in obesity prevalence."

From the Department of Health's point of view, this could hardly be worse. Not only has its attempt to measure the problem failed, but a better attempt next year—should that prove possible—will inevitably make obesity look worse, even if it isn't. If it didn't make you laugh, you'd feel like crying.

Taxed with the question of what had gone wrong, a department spokeswoman said: "No one can force anyone to be weighed and measured. Children and parents obviously have the right to withhold consent."

Nonsense. If the exercise was a serious effort to begin dealing with an emerging health problem, nobody should be given the right of veto. To know how heavy our children are, we need to weigh and measure all of them, or a representative sample. To set out to measure them all and to finish with an unrepresentative sample is the worst of all worlds.

What this answer tells us is that the Department of Health, and the government, misunderstand what public health is. It is not a set of guidelines from which people can pick and choose. That is health education.

Public health is, or ought to be, much less voluntary and more prescriptive. Giving citizens the right of veto is simply asking for health inequalities to widen. The middle classes will adhere, more or less, to well meant advice while the working class and the socially excluded will not hear it or, if they do, will ignore it.

"If the exercise was a serious effort to begin dealing with an emerging health problem, nobody should be given the right of veto"

That may be why health inequalities are indeed widening, in spite of a blizzard of initiatives designed to narrow them. The gap in life expectancy between rich and poor is wider now than it was in 1999; so is the gap in infant mortality.

It is true, of course, that today there are fewer population-wide initiatives available than there once were. We have clean water, and adequate drains: the 1957 Clean Air Act cleared the skies of smoke. There is not so much left to get to grips with. Yet the government did not lead on the moves to ban smoking in enclosed public places, perhaps the only classic public health initiative taken in its term (though to his credit Sir Liam Donaldson, England's chief medical officer, did). It had to be dragged kicking and screaming through the division lobbies.

There are other examples where a lack of leadership has left the United Kingdom behind. Eight years after the United States, we still do not reinforce flour with folic acid, which would save 150 babies a year from being born with neural tube defects. Fluoridation of water is amply proved, but sparingly used. It has not spread because nobody has had the courage to risk unpopularity by championing it. Support of sport in schools and the preservation of playing fields often appears half hearted.

What we have instead are health education initiatives labelled as public health. They have their place, but their effects are limited. The childhood obesity target, modest as it is, will be missed—but unless the department changes the way it is measured, we may never know.

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THE WEEK IN MEDICINE

Ashley X: a difficult moral choice

Did the doctors and parents responsible for a severely disabled girl have the right to keep her small?

What's the story?

Until New Year's Day, Ashley X was simply the anonymous child at the heart of a family case history published in an American medical journal.

The 9 year old girl has static encephalopathy and is an infant state, cannot sit up, roll over, hold an object, walk, or talk. In a radical move, she has been receiving growth attenuation treatment for the past three years designed to keep her the size of a 6 year old, through high dose oestrogen.

The goal was to improve Ashley's quality of life and make it easier for her parents to care for her at home. More controversially, the girl also had a hysterectomy to eliminate the menstrual cycle and associated cramps, and breast bud removal to avoid the development of large breasts.

How did the story break?

Ashley's case history was published in October's *Archives of Pediatrics and Adolescent Medicine* (*Arch Pediatr Adolesc Med* 2006;160:1013-7). It did more than just stir up ethical debate in the medical community—it sparked global publicity. "Eugenics," "mutilation," "Frankenstein-esque" were some of the criticisms it set off.

It motivated Ashley's parents, a professional couple from Seattle, to go public, naming their daughter and posting family photographs on a blog on 1 January.

The blog (http://ashleytreatment.spaces.live.com/blog) took a million hits in the first 48 hours, topped the health section of Google News for several days, and has generated more than 400 press articles worldwide.

The parents have declined all media requests for an interview, choosing instead to explain their choices through their blog. Her father did speak to the *Los Angeles Times* last week: "I cannot explain something this complicated in an interview. People think it must have been a horribly difficult decision to have the treatment performed. It really wasn't."

Ashley is expected to stay at about 4 feet 5 inches all her life and to continue to weigh 75 pounds. Her parents' actions were only motivated by a desire to improve her quality of life, they say. "Ashley's smaller and lighter size make it more possible to include her in family life. We will continue to delight in holding her in our arms. [She] will be taken on trips more frequently and social gatherings instead of lying down in her bedroom and staring at the TV (or ceiling) all day long," the blog reads.

How the press covered Ashley's story?

At US magazine *Time*, journalist Nancy Gibbs spoke to Dr Daniel Gunther and Dr Douglas Diekema, the doctors involved in Ashley's treatment. "Talk to them, and you confront every modern challenge in weighing what medicine can do, versus what it can't," she wrote.

"Keeping Ashley small is a pharmacological solution for social failure—the fact that American society does not do what it should to help severely disabled children and their families"

Arthur Caplan,
MetroWest Daily News, Boston

Dr Diekema, who chairs the bioethics committee of the American Academy of Pediatrics, was brought in to consult on the case. He told *Time*: "This was something people hadn't thought about being a possibility, much less being done." Speaking of the ethics committee of the Seattle Children's Hospital, he said: "It took time to get past the initial response—'Wow, this is bizarre'—and think seriously about the reasons for the parents' request."

Gunther and Diekema's first concern was to make sure there would be no medical harm, they told Gibbs. Removing breast buds is less invasive than a mastectomy. Hormone treatment had been routinely used on too tall teenage girls in the 1950s and 1960s. The main concern was assessing the risk of thrombosis or blood clot for Ashley because no one that young had been treated with oestrogen before. However, there are few reports of thrombosis in teenage patients. "After the treatment is finished, I don't see any long term risk, and we've eliminated the risk of uterine and breast cancer," said Dr Gunther. The benefits are not just social, but also medical, he said, as more movement gives better circulation, digestion, and muscle condition, and fewer bed sores.

But in the *Washington Post*, Dr Joel Frader, medical ethicist at Chicago's Children's Memorial Hospital, wrote: "This particular treatment, even if it's OK in this situation, and I think it probably is, is not a widespread solution and ignores the large social issues about caring for people with disabilities. As a society we do a pretty rotten job of helping caregivers provide what's necessary for these patients."

Arthur Caplan, University of Pennsylvania ethicist and columnist for the *MetroWest Daily News*, Boston, agreed in an article titled "Is Peter Pan treatment a moral choice?"

"Keeping Ashley small is a pharmacological solution for social failure—the fact that American society does not do what it should to help severely disabled children and their families. Permanently freezing a person into childhood is not the answer."

Tom Shakespeare, of the Policy, Ethics, and Life Sciences Research Institute in Newcastle, who has achondroplasia, wrote on

Ouch!, the BBCi site for disabled people, that he was not impressed. In a tone heavy with sarcasm, he said: "Simple solution, say the doctors. Just keep her child sized. Pump her full of hormones, whip out her uterus, and there you have it. No more growth. One convenient, lightweight and portable family member, ideal for every home."

Some families facing similar problems were in favour of "The Ashley Treatment," pointing out the high number of severely disabled children in residential or foster care. "Having an 18 year old disabled daughter who weights 220lbs is no picnic and involves some skilful wrestling moves," wrote one parent. "Please don't judge until you've tried wrestling a 220lbs child out of the bathtub," said another.

In the *Telegraph*, Professor Raanan Gillon, emeritus professor of medical ethics at Imperial College, London, was prepared to be convinced. "I was quite shocked when I first heard about it. It seemed a straightforward case of child abuse. But when I looked into it, I changed my mind and think there is indeed a case to be made for what has happened to this girl."

What next?

At least four sets of parents would reportedly like the "Ashley Treatment" for their disabled child in Seattle. US media organisations have also taken appeals from parents.

Dr Jeffrey Brosco, from the Department of Pediatrics, University of Miami—in an editorial in the same issue of the journal in which Ashley's case history was published—was sceptical about the treatment, and whether it would even work. "While there are data that high dose estrogen treatment will make tall for age girls shorter as adults, this effect may be different in children with severe disabilities. More needs to be known," he said.

Yet he adds, "American society is fairly accepting—even encouraging—of other forms of medical therapy that seek to enhance one's existence. If in the pursuit of a more perfect appearance, adults and even teenagers can readily enlist plastic surgeons to fix or augment breasts, then perhaps we should be more circumspect about decrying the treatment proposed by Gunther and Diekema."

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WHAT'S ON BMJ.COM **FROM RICHARD LEHMAN'S BLOG: NIGHTMARE ON NEJM STREET**

Your Christmas Day came to a blurry end with quantities of port wine and Stilton cheese. You don't really remember going to bed, but soon afterwards you are aware that you have become a junior doctor working in an intensive care unit, trying to put in a central line. A sharp American voice from behind you snaps, "Doctor, your patient appears to be septicaemic. Are you aware that 20 000 US citizens die every year from catheter-related bloodstream infections?" In your panic, your hand jerks and the line flies out. Blood spurts over you, your patient, and the attending physician.

You wake up, dry mouthed and sweating. After groping for a couple of indigestion tablets you turn over and hope for better dreams. But now you are in front of a large audience in the Massachusetts General Hospital. The same sharp American voice asks you, "So, doctor, what is your diagnosis?" You see before you the attending physician, with a few remaining traces of blood in his distinguished white hair. A vast audience looks down at you. Every face wears the same expression of earnest disdain. You feel in your pocket for the clinical notes which you must have brought with you, but they are missing: your pocket is full of congealing blood. "Lymphoplasmacytic lymphoma with Waldenström's macroglobulinaemia and biclonal gammopathy," barks the attending, "and you missed it! So, doctor, can you tell us how you would go about investigating monoclonal gammopathy of uncertain significance?" You decide to confess humbly that you have never come across a case. The audience sniggers. "Maybe that's because it's present in only 3% of people over the age of 50," says the attending with an ominous smile. "You may leave the hall, doctor."

You wake again, with the hooting of the audience in your ears. This time you resolve to wake yourself properly and get up for a glass of water. Settling back groggily, you find that you are in an examination room. A number of solemn inquisitors sit before you, dressed in gowns the colour of blood. The central figure, a white haired attending physician whom you quickly recognise, begins the interrogation. "If a patient with HER-2 positive breast cancer has disease progression despite a taxane, an anthracycline, and trastuzumab, which chemotherapeutic agents should you use?"

"Err . . ."

"No doctor, not err, you will get a better response if you use lapatinib plus capecitabine. Next question: explain why simple mendelian inheritance patterns are not seen in the long-QY syndrome."

"Could it be because . . . actually, I'm sorry I haven't a clue."

"Because survival bias leads to female predominance. OK, a simple one then. Lack of which apolipoprotein predisposes to infection with *Trypanosoma evansi*?"

"Oh 'ell . . ."

"I will allow that. L-1 is the full answer. Now, what can you tell us about the biochemical defect which underlies recessive lethal osteogenesis imperfecta?"

"In all its gristly detail?"

"Hah, you are on the right lines again. Deficiency in cartilage-associated protein. And now, doctor, for which condition might you consider the use of eculizumab?"

At this you break down and shout, "You must be taking the bloody p . . .!"

"Excellent, doctor," smiles the attending. "Paroxysmal nocturnal haemoglobinuria!"

You wake up a last time and go to the loo, putting the light on to check the colour . . .

Then, a couple of days later, the *New England Journal* arrives and you check the contents:

2725: IV catheter-related bloodstream infections in the ICU
2733: Lapatinib plus capecitabine for HER-2 positive advanced breast cancer
2744: Female predominance and transmission distortion in the long Q-T syndrome
2752: Trypanosoma evansi infection linked to a lack of apolipoprotein L-1
2757: Deficiency of cartilage-associated protein and recessive lethal osteogenesis imperfecta
2765: Monoclonal gammopathy of undetermined significance
2772: Case Records of the Massachusetts General Hospital: lymphoplasmacytic lymphoma with Waldenström's macroglobulinemia and biclonal gammopathy
2786: Correspondence: eculizumab in paroxysmal nocturnal hemoglobinuria.

You had had no ordinary nightmare—you had entered a parallel universe.

You wake up a last time and go to the loo, putting the light on to check the colour . . .

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