

# Extreme examples: children in genetics of obesity research



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Children provide us with a philosophical and an emotional conundrum, ‘how did we come to be as we are’?...it suggests that our theories of society and culture are bound up with our theories of the child, their capacities, behaviour and responsibilities”

Henrietta Moore, 2004

# Methods

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- Ethnography of Genetics of Obesity Study (GOOS) since November 2003
  - Observation in Laboratory. Interviews with team members
  - Observation in Clinical Research Facility when “interesting families” are brought in for further investigation
- In-depth interviews with up to 3 generations from 17 families (age >6 years, n=62):
  - 6 newly referred families to GOOS (interviews are conducted over two time periods, prior to and following the receipt of genetic results)
  - 11 families who have already received a genetic diagnosis for obesity and had varying rates of contact with GOOS.



House of Commons  
Health Committee

## Obesity

Third Report of Session 2003-04

Volume I

Report, together with formal evidence

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# 1 Introduction

1. With quite astonishing rapidity, an epidemic of obesity has swept over England. To describe what has happened as an epidemic may seem far-fetched. That word is normally applied to a contagious disease that is rapidly spreading. But the proportion of the population that is obese has grown by almost 400% in the last 25 years. Around two-thirds of the population are now overweight or obese. On present trends, obesity will soon surpass smoking as the greatest cause of premature loss of life. It will bring levels of sickness that will put enormous strains on the health service, perhaps even making a publicly funded health service unsustainable.

2. Dr Sheila McKenzie, a consultant at the Royal London Hospital which recently opened an obesity service for children, offered a powerful insight into the crisis posed to the nation's health. Despite only being in existence for three years, her service had an eleven-month waiting list. Over the last two years, she had witnessed a child of three dying from heart failure where extreme obesity was a contributory factor. Four of the children in the care of her unit were being managed at home with non-invasive ventilatory assistance for sleep apnoea: as she put it, "in other words, they are choking on their own fat."<sup>1</sup>

3. A generation is growing up in an obesogenic environment in which the forces behind sedentary behaviour are growing, not declining. Most overweight or obese children become overweight or obese adults; overweight and obese adults are more likely to bring up overweight or obese children. There is little encouraging evidence to suggest that overweight people generally lose weight; there is ample clear evidence that being overweight greatly increases the risks of a huge range of diseases, and that the more overweight people are, the greater the risks. Yet paradoxically, the phenomenal increase in weight comes at a time when there is an apparent obsession with personal appearance. There are more gyms than ever, more options presented as 'healthy eating', and the Atkins diet dominates the best seller charts.



When a three-year-old girl who weighs 40 kilograms dies of heart failure brought on by obesity, you know her parents are guilty of gross child abuse

(‘Dying for another snack’ Miranda Devine 30/5/2004 *SMH*)



When a child is exposed on the front page of The Sun as the poster child for the obesity problem it seemed to us rather cruel that this was being presented as an example of how parents were stuffing their children .. It seemed a terrible indictment on the parents when we knew there was a genetic defect in this child and we knew 100 per cent that was the cause of her obesity.

Professor Stephen O'Rahilly

(Poster child for obesity died of gene abnormality. Jeremy Laurance 10/06/2004 *The Independent*)





The death has become part of the discussion about what children eat when in fact it was the result of something else entirely ... We are mixing up children's weight issues with distinct medical problems ... It is an incontrovertible fact that a genetic defect was the cause of this child's problem.

Dr Sadaf Farooqi



What's really annoyed me about this is that the two people who were quoted on the Today programme appear to have drawn conclusions about our report from the tabloid treatment of part of our report. They don't appear to have read the report .. When you've got a consultant paediatrician in a unit dealing with serious obesity saying that she's got children choking on their own fat, quite frankly it is pretty serious stuff. Had we not referred to her letter, which we do respecting in its entirety the way she put this, I think we would have been accused of suppressing some very important evidence ... My suspicion is that there is more than a whiff of medical politics between the two groups of doctors concerned.

David Hinchcliffe, Chair of the Health Committee

In this kind of climate it is not surprising that an isolated death can be turned into a modern morality tale, and that even bereaved parents, about whom we know nothing, can be accused of effectively killing their child.

([www.spiked-online.com](http://www.spiked-online.com) 08/06/2004)

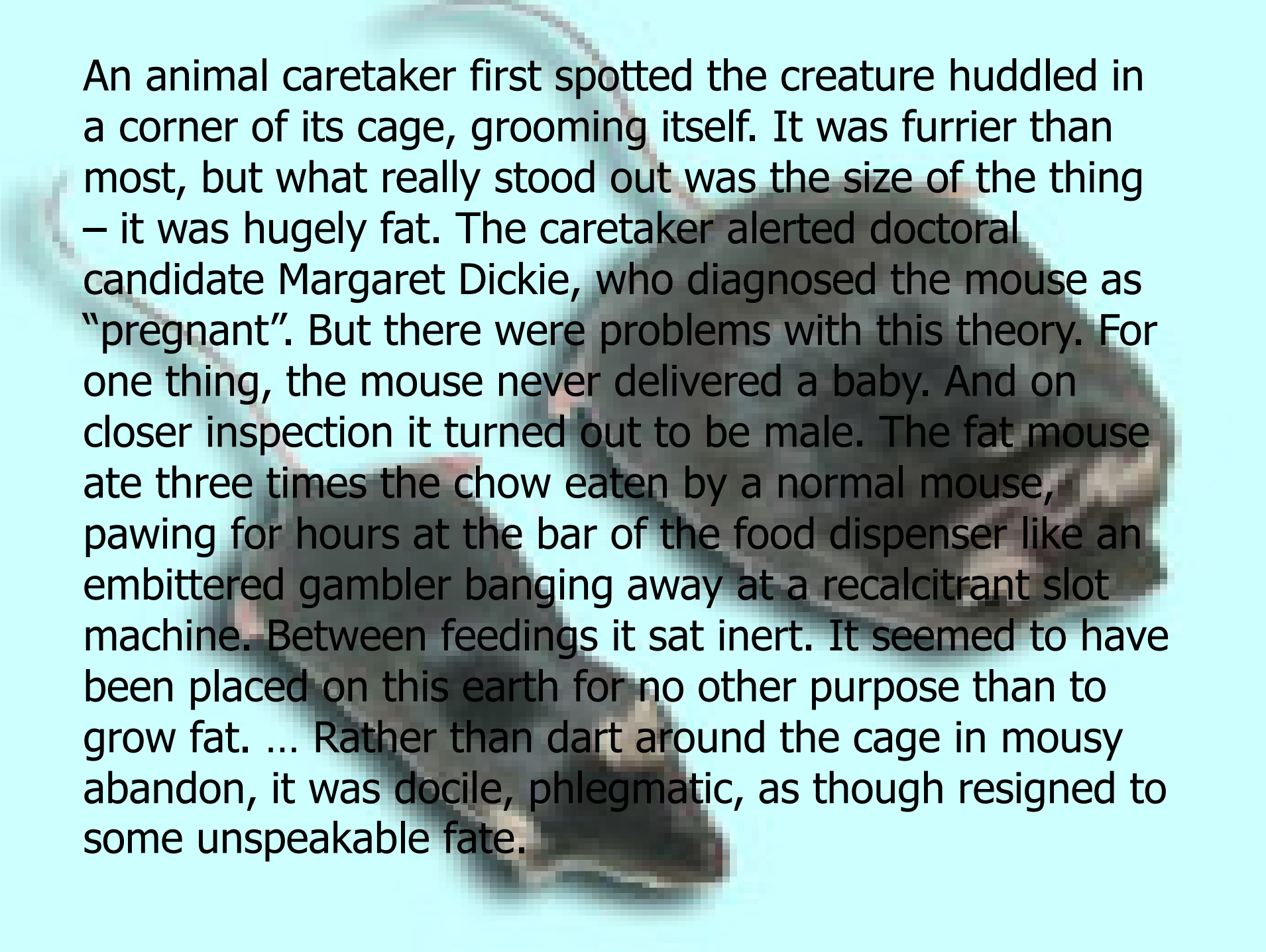
Joel: I keep trying to lose weight because something I mean there was a bloke I was reading about in the paper yesterday. There was a guy in the paper I was reading about yesterday and he's trying to lose weight, he's about 18 stone and he's about my age and he wants to lose weight because his father dropped dead of a heart attack at 45 and he weighed 28 stone. So I thought to myself, that ain't giving me long to live like that. I mean if I only live to be 45 that's not very good. Not today. But I know it will happen because your body just can't stand it.

IV: It must be quite a scary thought.

Joel: Oh yeah. I keep thinking to myself I'll be retired when I'm 60 and my Dad said yesterday "if you make it". I've got to lose some weight.

IV: Just a hard think to think about though isn't it?

Joel: Yeah I work in the cemetery and I see a lot of things you know. We had one when my Dad first started there when I was quite young and I remember him saying about it when he come home. This woman she was so heavy they had to lower her coffin into the grave with a digger. I mean, I'm 27 stone, four of my mates tried to pick me up in the wheelbarrow at college and they couldn't. So like they said if you fall over we can't help you. We can't pick you up and carry you. That's part of the problem if anything ever did happen to me, they'd need a crane to get me out the house.

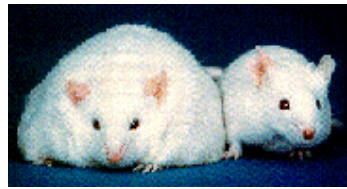


An animal caretaker first spotted the creature huddled in a corner of its cage, grooming itself. It was furrer than most, but what really stood out was the size of the thing – it was hugely fat. The caretaker alerted doctoral candidate Margaret Dickie, who diagnosed the mouse as “pregnant”. But there were problems with this theory. For one thing, the mouse never delivered a baby. And on closer inspection it turned out to be male. The fat mouse ate three times the chow eaten by a normal mouse, pawing for hours at the bar of the food dispenser like an embittered gambler banging away at a recalcitrant slot machine. Between feedings it sat inert. It seemed to have been placed on this earth for no other purpose than to grow fat. ... Rather than dart around the cage in mousy abandon, it was docile, phlegmatic, as though resigned to some unspeakable fate.



“The study of rare individuals with extreme disturbances of their physiology has long had an impact in terms of scientific understanding grossly disproportionate to the infrequency of the particular disease being investigated.”

“The parents reported that at the age of four months the cousins became possessed by a voracious hunger ... like starving explorers and concentration camp survivors, the Punjabi cousins were obsessed with thoughts of food. But ... theirs was an obsession food could not quench. They ate more than their siblings, more than their parents, more than anyone could believe. And still they wanted more. Denying food to famished children seemed in every sense cruel, so at first the parents complied with their children’s demands. Eventually, though, they took one doctor’s advice and padlocked the cupboard door. The children scavenged through the trash for soggy French fries, and gnawed frozen fish sticks from the freezer..”



(a)



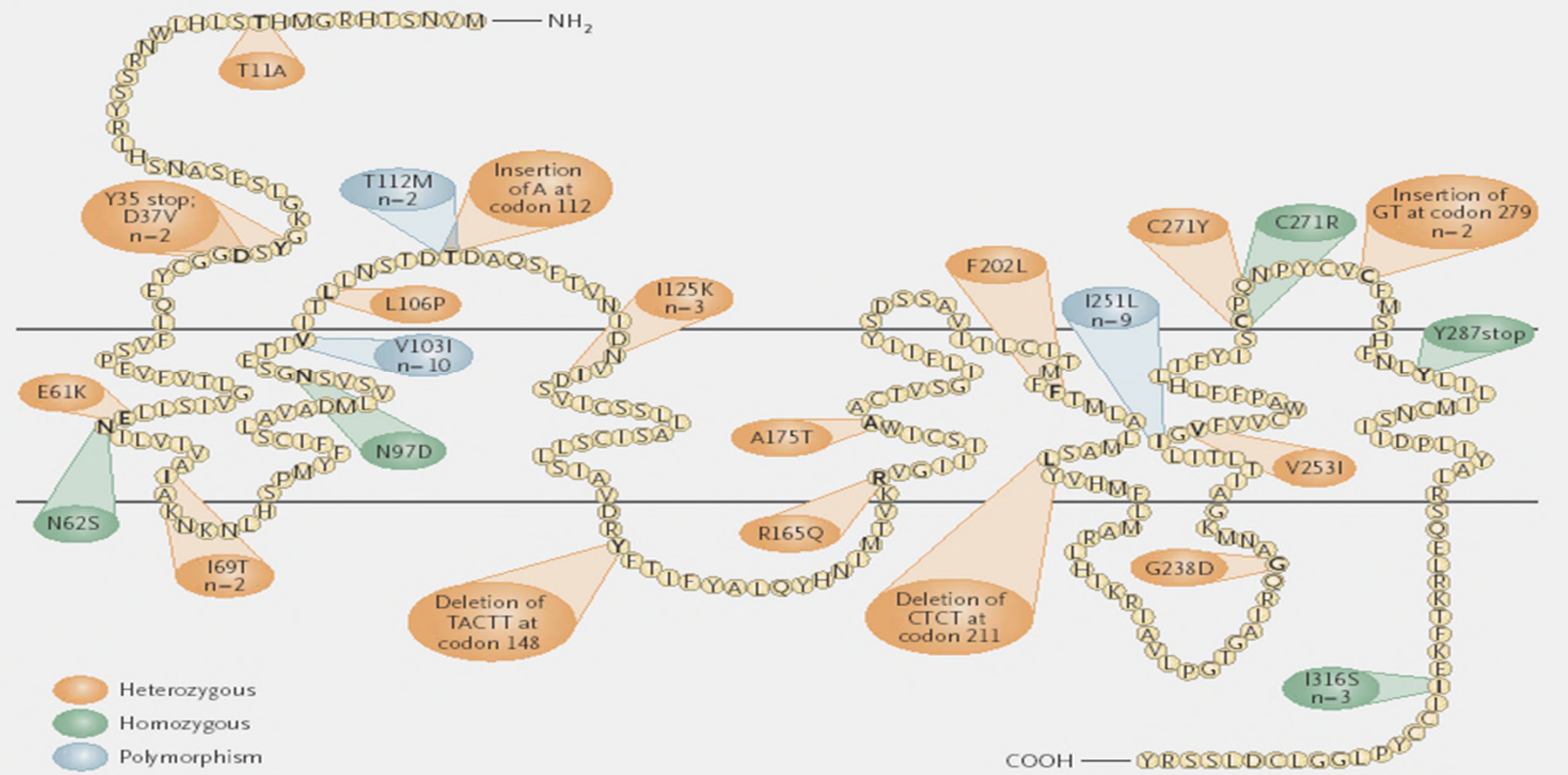
3-year-old weighing 42 kg



7-year-old weighing 32 kg

**Figure 2** Effects of leptin therapy in leptin deficiency. (a) Clinical response in a 3-year-old boy with congenital leptin deficiency; (b) energy intake at an 18-MJ ad libitum test meal before therapy versus 1 month after therapy; (c) onset of pulsatile luteinizing hormone secretion at an appropriate developmental stage in Child A compared with Child B.



**A**

- I would really like for her to not have to put on more weight. Because she's already got stretch marks. I don't want her body to get damaged prematurely any more ..... She's got them round her breasts and around here but more prominent are the scratch marks that she's got from her kitten. But she hadn't 'seen' them. Of course she didn't know what they were. I didn't know what they were at first. I know they will fade but on such a young body there shouldn't be such marks there.

(Rowena)

- When you see Rachel and when you look at her and you'll think uh-oh because her shape is not natural, you know it's not a normal shape. If she was 20 you'd assume she was pregnant. You know if you just looked at her. She's got these little short legs, so I have to try and find a school uniform that's big enough for her tummy.

(Samantha)