

relatives of affected children include: "Toodle-oo, you're not at any special risk," and "You don't want to get involved in that—it's like opening a can of worms." Such a dismissive approach is inappropriate, unprofessional, and ill informed, but the fact that many families are still unaware that tests for relatives exist suggests that it is commonplace.

In many parts of the United Kingdom it is routine to determine the genotype of individuals with cystic fibrosis. Relatives can be tested for the actual mutation known to be in the family, and the partner of someone with a family history of the disease can undergo testing for the commonest mutations, which comprise 85-90% of the mutations occurring in Britain.<sup>1</sup> Thus, couples in which both partners carry the mutation and who are at a one in four risk of having an affected child have a good chance of being identified, and it is possible to provide strong reassurance to the majority for whom testing identifies a greatly reduced risk.<sup>2</sup>

Rapid tests based on polymerase chain reaction can provide results in two or three days,<sup>1</sup> so they can be offered to couples with a family history of cystic fibrosis even when a woman is already pregnant. For those couples who are identified as carriers, urgent genetic counselling should be organised so that options such as chorionic villus biopsy at 10 or 11 weeks or amniocentesis at 15 or 16 weeks can be discussed as can the 1-2% risk of miscarriage associated with these procedures.<sup>3</sup> Cystic fibrosis is a serious, lifelong condition, and many couples who are at risk opt for prenatal testing and termination of affected pregnancies.<sup>3</sup>

Mennie et al surveyed general practitioners and found that the majority felt that screening for carriers of cystic fibrosis should be reserved for those with a family history,<sup>4</sup> yet we have seen many instances of access to testing being blocked, largely through ignorance.

In the United Kingdom the North West health region has used a booklet on cystic fibrosis, written

especially for relatives,<sup>2</sup> for seven years ([www.cfftrust.org.uk](http://www.cfftrust.org.uk)). It is being modified for national use by the Cystic Fibrosis Trust. The national booklet will provide the addresses of all regional genetics centres in the United Kingdom together with contact names and information on whether the centre accepts mouthwash samples for analysis (cells in mouthwash can provide sufficient DNA for polymerase chain reaction tests). The booklet should be read and acted on by those able to offer early help or intervention.

General practitioners may not encounter many patients with single gene disorders like cystic fibrosis. Nevertheless, couples with a family history have the right to obtain clear information to help them to make informed choices about new genetic tests. Obstetrics departments bear a similar responsibility when patients mention a family history of the disease. It is up to the doctor to offer tests or referral; patients should not have to ask. Regional genetics services are now available throughout the United Kingdom. They can be telephoned for advice on the genetic aspects of any disorder.

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## Social policy and devolution

### *Scotland's decision on long term care challenges a centralised NHS and treasury*

The Scottish Executive's dramatic decision last month not to charge elderly people for personal and social care,<sup>1</sup> in contrast to the decision of the United Kingdom's Westminster government, has created policy inconsistencies within the UK. Having gained cross party support for its motion to recognise the "benefits in providing free personal care for the elderly" and "to report by August 2001 its proposals for doing so,"<sup>2</sup> the Scottish parliament has now convened the Scottish care development group "to consider the inter-relationship with UK matters, notably the tax and social security benefits system and cross border movement."<sup>3</sup> This decision, together with the plan to abolish student fees at Scottish universities, will test the meaning of devolution, but also raises wider questions about government spending in the UK.

Sutherland has estimated the extra cost in Scotland of implementing free personal care at around £25m (£37.5m).<sup>4</sup> But the UK government's rejection of the

recommendations of the Royal Commission on Long Term Care<sup>5</sup> that personal care should be paid for from general taxation means that the Treasury made no provision for extra resources for countries or local authorities wanting to deviate from this policy. Scotland must therefore find the money from within its current block allocation or use its tax raising powers.

Historically Scotland and Northern Ireland have received a higher annual share of UK general taxation per head than England<sup>6</sup>: in 1995 Scotland's share was 19% higher and Northern Ireland's 24% higher. The Treasury select committee has, however, pointed to the lack of transparency in the block allocations to governments within the United Kingdom. Moreover, population based adjustments to the formula mean that both Scotland and Northern Ireland are rapidly losing their extra share of expenditure. This reduction has had the effect of levelling down public expenditure and public service provision in Scotland and reversing the redistributive elements of the block allocation.<sup>7</sup>

Scotland has the lowest life expectancy and highest all cause standardised mortality ratios in the UK, and, like Wales and Northern Ireland, has higher rates of long term sickness and unemployment and lower levels of income per head than England.<sup>8</sup> Critics of resource equalisation have highlighted the absence of needs based measures in the current formula.<sup>9</sup> Their inclusion in a revised formula would require greater transparency in the policy decisions that govern public expenditure allocations and draw attention to the striking inequalities in health and income distribution that exist between the various parts of the UK.

Though the so called tartan tax allows the Scottish parliament to raise extra tax revenue of around £400m, finding the extra money to fund personal care when the share of block funding is falling will be difficult. Moreover, the Treasury has the power to reduce the block allocation if Scottish local authorities increase their taxation above the limits set them by the UK government.<sup>10</sup> The Scottish care development group may find its options limited to moving expenditure around within the block—that is, personal care would be funded at the expense of other services. Therefore, whether Scotland ends up paying for personal care by reducing services or introducing charges for other services, this shifts the burden of responsibility for funding from society to the individual—the very action that the Scottish parliament wanted to counter in the sphere of personal care (and university tuition fees).

The Treasury is proving to be a general obstacle to the policy of making personal care free at the point of delivery. The UK government's NHS plan states that charges are inequitable and risk worsening access to healthcare by the poor.<sup>11</sup> Nevertheless, under the influence of the Treasury, the plan concludes, "The Government does not believe that making personal care universally free is the best use of these resources." Thus the Department of Health in England is proposing that English local authorities (and primary care trusts under delegated authority) can charge up to 55% of an individual's income for personal care.<sup>12</sup> Disabled people, as well as older citizens, in other parts of the UK may well consider migrating to Scotland for the

social and economic benefits of free personal care. These are the sorts of thorny issues Bevan had to resolve before the inception of the NHS.

The Scottish parliament's decision to make personal care a right and not a personal responsibility is the first serious challenge to Westminster from a devolved government. One likely consequence is a call for greater scrutiny of the impact of the Treasury's fiscal policies on devolved governments. The need for greater transparency in the formula that underpins resource allocation between governments is long overdue, but this will then bring into question the evidence base for Treasury imposed fiscal rules that promote the use of private finance for public sector investment across the devolved governments of the UK.<sup>13</sup> As the Labour dominated Treasury select committee said last week of the Treasury, "It has recently begun to exert too much influence over policy areas which are properly the business of other departments." It could well have added "and of other governments."<sup>14</sup> Charging for personal care could become the Treasury's nemesis.

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## Another healthcare funding review

*More of the same*

Survey 100 doctors, nurses, or members of the public at random and ask them about the NHS and most would probably put "chronic underinvestment" at the top of the list of ills. The evidence is plain—shabby hospitals, waiting lists, lack of equipment, and difficulty retaining staff. It has been ever thus. Because the NHS is largely funded through central taxation and because there is no objective way of deciding the right level of funding for the NHS "needs" the decision is a political judgment and therefore ripe for constant attack. It is also ripe for a constant search for better methods of financing health care. This week a group of medical, nursing, patient,

and private sector organisations published the latest in a long line of inquiries into healthcare funding.<sup>2</sup>

For the past 20 years real growth in NHS spending has averaged about 3% a year, though the growth curve has been more like a roller coaster ride than a steady ascent.<sup>3</sup> Last year the government pledged £19.4bn (\$29.1bn) over four years—roughly double the average in real terms, sustained for four years. While welcome, this still leaves us short compared with our European neighbours: by 2004 we will spend about 7.6% of gross domestic product on health care compared with the estimated European average of 9%.<sup>4</sup> To plug the gap through the NHS we would need to pay more

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