UK calls for regulation of genetic testing

Britain's beleaguered National Health Service (NHS) is coming under increasing pressure to develop a national strategy on the application and regulation of medical genetics. Initial attention, say proponents of such a strategy, should focus on the overall provision and monitoring of genetic screening services by both private companies and public institutions.

The latest proposal comes from a parliamentary committee report, *Human Genetics: The Science and Its Consequences*. After a broad-ranging inquiry that involved 12 public hearings and evidence from almost 200 witnesses, the all-party House of Commons select committee on science and technology has proposed the creation of a Human Genetics Commission, which would have broad powers.

Two main functions of this commission would be to approve all genetic screening programmes before they are introduced, and to define the circumstances in which particular types of screening or diagnosis — such as prenatal diagnosis — should be either provided or proscribed.

In its report published in mid-July, the committee also expressed particular concern about the danger that "unscrupulous companies may prey on the public's fear of disease and genetic disorders and offer inappropriate tests, without adequate counselling". To prevent this from happening, it recommends "as a matter of urgency" that its proposed commission should be able to regulate all such companies "through a process of protocol review and licensing".

The government is known to be sensitive to the issues raised in the report, some of which were covered in an earlier report on genetic screening from the Nuffield Council on Bioethics. In particular, officials acknowledge that the wide scale application of human genetics — for example, with its implied shift from curative to preventative medicine — could require a radical restructuring in the way that the NHS allocates its resources.

Michael Peckham, chief scientist in the UK Department of Health, has already commissioned two separate reports, one on the content of medical genetics, the other on its implications for the NHS. And Virginia Bottomley, the former secretary of health, announced earlier this year — partly, some claim, in a bid to pre-empt the parliamentary proposals — that her department was "looking at the possibil-

A child with cystic fibrosis receives physiotherapy.

ity" of setting up a non-statutory body of some sort to address the issues raised by genetic testing.

So far, however, the government appears to be balking at the two most significant aspects, both of which conflict with central planks in the ideology of Britain's ruling conservative party. One is the major public expenditure that

would be involved if the NHS were routinely to offer screening programmes. The other is the need to regulate private companies offering such services.

The Down Syndrome Association, for example, drew the committee's attention to the fact that, even though prenatal screening was widely available for the condition, its provision is at present 'patchy'. Similarly, Bernadette Modell, of the University of London's department of obstetrics and gynaecology, complained that screening for potential carriers of cystic fibrosis was being introduced "more slowly than expected."

The committee expresses concern at the possible link between the outcome of prenatal genetic screening and the decision by parents to abort a fetus found to have a serious genetic defect. It acknowledges, for example, that objections to abortion by parents may be sufficiently strong to outweigh their desire to spare their child eventual suffering.

Furthermore, in a warning that had important implications for Britain's system of public health care, it states that "considerations of the costs a handicapped child

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Genetic testing — services by mail order

One of the key concerns raised by the UK House of Commons select committee in its recent report on genetic testing (see above) was whether there was a need for regulation in the marketplace to ensure that appropriate standards of testing are being met and that adequate counselling is being provided. Like it or not, privately run genetic testing services are here to stay. Recently, too, mail-order testing has become available.

Believed to be the first of its kind in the United Kingdom, University Diagnostics began an advertising campaign in the August issue of the magazine *Cosmopolitan* offering mail-order testing for cystic fibrosis (CF) carriers, of which there are an estimated two million in the UK.

The company, in which University College London has a major share, charges £65 (US\$103) for an individual test, £98 (\$159) for couples. This includes an optional counselling service, by telephone or in person. Tests for CF are not routinely available through the UK National Health Service, unless a person has a known risk for the disease.

Paul Debenham, managing director of University Diagnostics, agrees that there should be regulation of the market. With the ad and the information leaflet (sent out free of charge to those who re-

spond), Debenham first cleared the wording with the Cystic Fibrosis Trust. "I did not want to be accused of scare-mongering," he says.

Martin Scott of the Trust says that mail-order testing may not be ideal, but points out that five children are born with CF every week — most to totally unsuspecting couples. The Trust hopes that the advent of mail-order testing will put pressure on the UK Department of Health to offer the test through the health service.

NUALA MORAN
London

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Courtesy of University Diagnostics