Annotation

Medical genetics in the UK and the National Health Service

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Fifty years ago, as part of the recovery and regeneration after the second world war, the British National Health Service was founded, based on general taxation and providing health care to the entire population, which was free at the point of delivery. Forced through parliament in the teeth of opposition from much of the medical profession by the determined Health Minister, Aneurin Bevan, this radical development totally changed the pattern of health care in Britain, and both its successes and failures have been closely followed world wide.

When the National Health Service (NHS) was founded, medical genetics did not exist as either a medical specialty or as a field of scientific research. Human genetics had been tainted by the abuses of Nazi Germany and our knowledge of the field simply did not permit any widespread applications. Now, 50 years later, with both clinical and laboratory aspects of medical genetics well developed, it is worth asking how the NHS, as a system of health care, has handled the introduction and growth of this completely new specialty.

As far as clinical genetics is concerned, its introduction into the NHS was relatively straightforward. Without a strict "item for service" method of funding, the relatively long consultation times required were not questioned, nor was the fact that many people being seen were not actually ill. The regional basis of genetic services, based on populations of 1-5 million, was suitable for a service dealing with uncommon disorders and encouraged its location in teaching centres, rather than on a fragmented basis. Against this generally favourable scene should be set uneven geographical distribution of services, with some health regions slow to implement services, and considerable variation seen in the provision of clinical genetic services to districts remote from the regional centre.

Laboratory genetics services also proved relatively simple to integrate and develop within NHS genetics services, with cytogenetics laboratories following the "regional base" pattern of clinical genetic services, and molecular genetic diagnostic laboratories progressively established following a pilot study involving three health regions. Here, however, the problems have been

greater, with the rapid developments of molecular genetics in particular exposing the slow response in obtaining additional resources through a centrally planned system, while underfunding of capital equipment has been a particular problem in keeping pace with new technology and reflecting underfunding in the NHS generally.

The past 15 years has seen a sustained attack on the NHS as a whole, with government policy directed at reducing public expenditure and using alternate private care where possible. This has resulted in considerable damage to services and medical genetics has suffered accordingly. In addition to the overall restriction of funding, suffered under successive governments of all political complexions, the fragmentation of regional services, the introduction of market forces, and reduction of the policy and planning role of health bodies, have often caused medical genetics to be regarded as low priority by comparison with acute sector hospital services. The developing cooperation between centres in the UK to provide a network of genetic testing services was made close to impossible by the complexity and inefficiency of cross charging systems. Despite these problems, and largely as the result of determination of its staff, the NHS in general and medical genetics services in particular have survived; a reflection of public as well as professional recognition of their value.

Although the new British government in place has given a firm commitment to maintaining the NHS, it has not promised to provide more funding for it, so it is worth asking whether a different system might have helped medical genetics services to develop better, or whether a change might be beneficial in the future. Comparison with other systems suggests not.

Widespread use of private health insurance, as in the USA, may seem superficially attractive for those able to obtain such insurance, but makes an equal access, population based approach virtually impossible. The provision of health insurance for those with or at risk for chronic genetic disorders is also coming under serious threat, as in the USA this is increasingly the responsibility of employers or health management organisations, while remuneration for the time involved in genetic counselling or support is often difficult in comparison with the funding of tests. Such

a system does not promise well for the future of medical genetics or for the delivery of genetic services to the population as a whole. Many USA academic medical genetics centres, traditionally heavily reliant on service funds for their research support, are now finding difficulty in maintaining their programmes in the face of these service funding pressures.

Universal compulsory health insurance (as in parts of continental Europe) is certainly a preferable option to individual private health insurance, provided that it really is universal and does not exclude people by virtue of their genetic disorder. However, such systems can be considerably more expensive, especially if there is no system of control on demand for such items as genetic testing.

On balance, the UK National Health Service has served its population well in terms of developing medical genetics services. Its main problem since its inception has been under-funding, with a UK expenditure on health care three times less than in the USA and half that of Germany and France. It offers the prospect of a service that is planned on the basis of health

need, rather than led by consumer demand or professional gain; it can promote regionally based services working in cooperation; and it can ensure that only validated services are introduced. By maintaining those principles, along with funding levels more in line with those of other European countries, the NHS should be able to accommodate most of the necessary developments in medical genetics that are likely over the coming decade, though it will certainly not be able to satisfy all demands.

Those of us fortunate enough to have been working in the field of medical genetics in Britain during a time of remarkable developments owe a considerable debt to our NHS; now that we again have a government committed to equitable health care in the UK, let us hope that it will be bold enough to encourage and resource the further planned development of medical genetics services, so that they can continue to form an integral and essential part of medical services, both as a specialty and more generally in medical practice.