

## Paraplegia: views from the Chief Scientist Office

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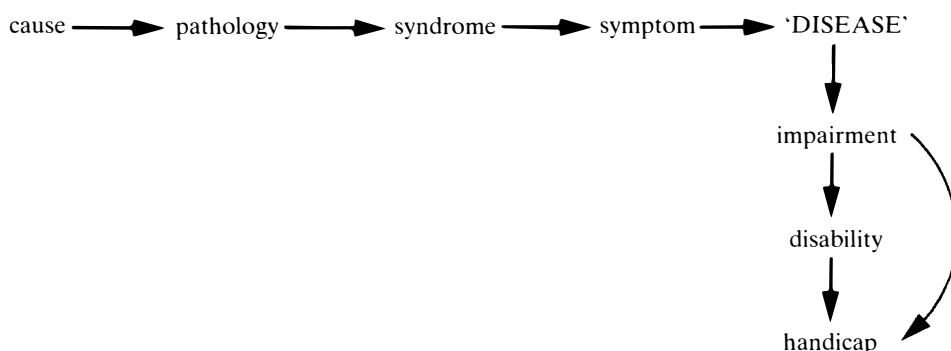
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There are many types of journals publishing articles related to medical endeavour; however, it is striking how few are devoted to diseases. What is meant by disease in this context? I would argue for a concept which requires at least 2 descriptive dimensions, one originating from a deterministic perspective typified in most textbooks,<sup>1</sup> and the second based on a teleological perspective.<sup>2</sup> They are illustrated in Figure 1.

Most journals which focus on 'disease' tend to take a causative orientation (eg *AIDS*, *Injury*, *Tubercle*) except when little is known about causation (eg *Schizophrenia Bulletin*). Concentration on an impairment is unusual. *Paraplegia* is highly unusual in focusing on the intersection between the causative axis and the disablement axis in this crude, two-dimensional model. This location offers enormous potential. One of the great strengths of this position is the ability to embrace insights from clinical science (at the intersection), from basic sciences (along the causative dimension) and from social sciences (along the disable-

ment dimension). People with disabilities have enough problems, but often they are expected to divide themselves up into neat little packages for the various professionals involved in their management. A forum which brings together professionals from different disciplines is likely to benefit service users by reducing the barriers between disciplines. To bring together not only clinicians from different disciplines, but clinicians and scientists (as *Paraplegia* does), offers enormous potential for creative cross-fertilisation.

Within the Chief Scientist Organisation, the practice of bringing together clinicians and scientists is currently carried out by our Clinical and Biomedical Research Committee, which sponsors regular joint meetings for this purpose. This has proved so successful that the practice is likely to be soon emulated by the Disability Research Committee. This method of bringing experts together is similar in principle to the formation of various advisory groups and working parties, and also characterises the problem-



**Figure 1** Two dimensions of the concept of disease.

orientated approach which has been advocated for both medical records<sup>3</sup> and medical education.<sup>3,4</sup>

Panels of clinical and scientific experts are also used by the Chief Scientist Office (CSO) to form the advisory committees which regulate much of CSO's funding of medical research. Currently, we have one main committee each for clinical and biomedical research, disability research, and health services research; a small advisory committee on health technology assessment has recently been inaugurated; and an advisory panel on evaluation of equipment and supplies is funded by CSO, although run by the supplies division of the Common Services Agency. Our approach is similar to that of the Medical Research Council; various funding mechanisms exist. Project grants usually run for one to 3 years and the maximum award is £90,000. 'Mini-project' grants run for one year and the maximum award is £4,000 to £7,000 according to the committee. Research training fellowships are available for particular health professions or for particular purposes. Some research units are supported on a programme basis with regular reviews of performance. Research can also be commissioned, and meetings supported. Roughly three-quarters of our funding supports spontaneous (ie not specifically commissioned) applications for project grants and on such applications opinions from external referees are sought.

In addition to the scientific merits of an application it is also necessary to introduce policy considerations. Policy guidance is important if research is to result in practical benefits to patients and, when the funding is from a health budget, this is a reasonable aim.

How are policies determined? There are 2 basic approaches: the scientific and the popular. The scientific approach looks at the available economic and humanitarian information on the impact of a disease (is it common? severe? long lasting or causing many years' loss of life? compared to the feasibility of doing something about it can it be diagnosed? prevented? cured? ameliorated? can carers be supported?). Unfortunately, suitable information is often not completely available for the major health

problems facing our society. Indeed, one of the major incentives for the development of the health technology assessment movement (which has been described as 'a comprehensive form of policy research')<sup>5</sup> was to provide the requisite information for logical policy development.

The alternative to the scientific approach to policy is the demotic approach, which is manifest both through individuals and through political decisions. (It is worth noting that both 'policy' and 'political' are derived from the classical Greek word 'polites', meaning citizen). The National Health Service is extremely costly, and funded by taxes paid by individuals, so it is entirely appropriate that individuals (directly and through their elected representatives) should have a say in the expenditure on the NHS – both its total amount and its distribution. Typical popular priorities (manifest, for example by charities' ability to raise funds) would favour children over the elderly, intervention over prevention, physical illness over mental illness, cure over care, the concrete over the abstract, and one-off initiatives over continuing long term effort. Some (but not all) of these priorities are consistent with the scientific approach. The value of popular opinion is greatly increased when it is well informed, and there may be room for improvement on this count. One should note that doctors have an important responsibility to inform popular opinion. One should also note that doctors are human beings (although they like to keep it well hid) and have their own preconceptions and prejudices.

Addressing public opinion is an intrinsic part of living in a democratic society and increasingly important in these cost-conscious times. Paraplegic people have played a notable role in the activity associated with the concepts of 'coming out', consumerism and normalisation (now restyled 'social role valorisation'). Paraplegics have their own Olympic Games – the Paralympics. The *Disability Arts Magazine* has recently started publication in the UK, currently dealing mainly with the physically disabled, and includes much about access (especially wheelchair access) as well as works in all modalities by and about the disabled; local

organisations claiming to support increased links between the disabled and the arts have been scrutinised to check whether they employ disabled people themselves.<sup>6</sup> We have, of course, had acts about employment of the disabled<sup>7</sup> and about access to new public buildings.<sup>8,9,10</sup> Architects have been persuaded to spend a day in a wheelchair (with wheelchair-bound guides) to help them appreciate the difficulties faced by those in wheelchairs and how they can be avoided in the design of new buildings. Like many organisations, the Scottish Office has a declared policy about the physically disabled.

The establishment of a purpose-built spinal unit in Scotland underlines the importance of paraplegia, indeed all the CSO advisory committees have priorities which

are relevant to this condition. These priorities have not been determined in isolation, but arise out of health policy and the health problems of our population. With respect to paraplegia, the areas of special interest to CSO include trauma, restricted mobility, disability and reduced self care. CSO also understands the need to fund the range of research seen in *Paraplegia*, from molecular biology, through clinical research and development of aids, to health services research and evaluation of prevention. Although we are only empowered to fund work carried out in Scotland, we appreciate the value of work carried out elsewhere and we are increasingly involved with the dissemination of research relevant to the health of the Scottish people.

## References

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- 10 Disabled Persons Act, 1981 (ch 43).