

A Medical Research Council Initiative in Mental Handicap

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A report has recently been published on a workshop on mental handicap research, convened at Warwick University on the 29–30 July 1993 under the auspices of the Medical Research Council's Neuroscience Approach to Human Health Initiatives (NAHH) Steering Committee. This NAHH Committee had identified a need to foster research in relatively neglected areas such as mental handicap. The aim of this workshop, bringing current researchers in mental handicap together with those who might bring expertise from related areas, was to specify problems peculiar to the field, and opportunities and priorities for research through discussions of approaches that have been successfully employed in other areas of research which might be applicable in mental handicap. The report of the workshop (Medical Research Council, 1994) has recently been widely disseminated to the research community and to those involved in caring for individuals with mental handicap, giving the latter good advice if they wish to be serious players in the research field.

At the workshop, Professor Rutter outlined factors in this relative neglect including *inter alia* the professional isolation of mental handicap; inadequate classification systems; disagreement about terminology (for example, the currently popular British term – learning disability – does not apply to the mentally handicapped in the US); and difficulties over consent to research. Such socio-political obstacles had led to a retreat from medical research in mental handicap issues, dating back to battles in the '60s between the social sciences and medical sciences in the US over research priorities in mental handicap (which medical sciences lost).

The workshop concluded that current research in mental handicap was becoming increasingly fragmented; that there was a dearth of longitudinal studies into specific disorders; that the specific hypothesis-testing 'single question' approach was more likely to be productive than tackling mental handicap on a broad front; that non-invasive imaging techniques were presenting new opportunities (e.g. magnetic resonance spectroscopy (MRS) and near infrared spectroscopy (NIRS)) in the understanding of the development and neuropathology of the brain *in utero* and perinatally; that increasing sophistication of neuropsychological tests (and validation of existing tests) was required; most of all, researchers

from other fields must be encouraged to contribute to genetic and environmental studies in mental handicap. Autism was a model where the condition had become clearly defined, where a series of hypotheses for underlying impairments had been tested and several disciplines had provided input leading to real progress. Such approaches might now be applied to mild mental handicap which may become 'the new frontier' for research.

In order to meet the need for interdisciplinary teams, the workshop recommended that funding bodies might consider creating a research unit or institute for research in mental handicap to ensure cooperation between scientific disciplines, and a brain and/or DNA bank should be set up as a national resource. Parent organisations partnership, and multicentre cooperation, is necessary. There are very few clinical departments in the UK adequately multidisciplinary and able to provide a suitable training environment. These should be encouraged to provide training fellowships, studentships and courses on the application of new technologies in mental handicap.

The American example

The MRC initiative provides an overdue sense of direction but the individual clinician with a research interest is unlikely to be able to generate a national research momentum. International comparison can be misleading but the term 'neglect' is indeed more applicable to research endeavour in mental handicap in the UK than in the US, where there has been a politically-directed national impetus and a network of experienced multidisciplinary research groups with core central funding for biomedical and applied science. In the '60s the concerns in this MRC report were being tackled in American legislation. In 1970, Public Law 88/164 instituted a National Institute of Child Health and Human Development programme of research into mental handicap. Its Mental Retardation and Developmental Disability Branch (MRDDB, 1993) provides training grants, conference grants, individual research grants and core support for Mental Retardation Centres, of which there are 14 (for example, the Kennedy Krieger Institute in Baltimore). PL88/164 also instituted the University Affiliated Programs (UAP) for applied research,

which meet with the biomedical Mental Retardation Centres at the annual Gatlinburg Conferences.

There is as yet no equivalent in the UK of the University Affiliated Programs. In the US, these 52 UAPs have developed as clusterings of professionals to provide academic foci in teaching and applied research. While recognising the importance of Health Service (applied) research, the MRC considered that the first step to further research should focus on biological questions. The Medical Research Council's initiative has been a helpful spur to this. There are distinguished Applied Mental Handicap Research Centres in the UK, but the network is tiny, and also needs encouragement to develop more

multidisciplinary UAP systems. Such initiatives might, however, start locally – by researchers from several disciplines in the UK forming more identifiable hubs of mental handicap research. The mental handicap research base is indeed too small and delicate.

References

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