

Report for *Bulletin of Medical Ethics* (March 1998) of a Wellcome sponsored meeting

Ethical and social aspects of genetics and neuroscience

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Traditionally, the Wellcome Trust has either funded medical and scientific research that looks to the future, or else medical history research that looks to the past. The Trust plans to bridge several gaps with a new research programme: gaps between past and future, and between a range of disciplines. Now in its early planning stages, the £1 million programme on ethical and social issues, probably in genetic and neuro-scientific research, will examine current and future questions and dilemmas. It will bring together researchers from a range of disciplines in science, social science, law and philosophy. During January 1998, about 40 people met to discuss possible topics, methods, aims and disciplines to be considered for the programme. Those present - such as scientists, clinicians, leading people in law, philosophy and policy, journal editors, and the chief executives of two research councils - were taken to represent "providers" of ethical research, "users" of the research or funders.

I was invited as a "user" in being a member of CERES. CERES aims to bring together all kinds of groups and professions concerned with medical research, who seldom meet, to enable them to exchange ideas and thereby to help to raise standards and mutual understanding. The only agreed CERES policy is that consumers/health service users should be more fully involved at every stage of research from inception and selection of projects to disseminating and implementing the findings.

For two days, we debated whether there is a small or large group of social researchers (meaning the 20 or so disciplines covered by the Economic and Social Research Council, ESRC) and bioethical researchers willing and able to work on neuroscience or genetics. Some said there are too few social researchers to merit a large grants programme. Some said that applications to a planned Medical Research Council programme on social aspects of genetics a few years ago were too weak to be worth funding. Others said there are, or could be, many more competent social researchers in these areas, if only they could get funding and crawl out of the cracks or chasms between all the funding bodies which now entrap them. They include researchers working in areas closely related to genetics, such as kinship, living with disability or chronic illness, and reproductive health, and to neuro-science in many aspects of mental health. The ESRC also plans to set up a related £1 million programme, a promising start, although these are tiny amounts in comparison with the billions of dollars granted in the US to address social and ethical questions raised by genetics and neuroscience developments.

It is likely to be months before applications are invited. Meanwhile, researchers planning to apply could do some ground work to strengthen their research proposals. The Trustees are likely to favour inter-disciplinary research, so that it is worth beginning to form networks between clinicians, social scientists and law and ethics centres. Some inter-disciplinary liaison over selected topics and research theories and methods is likely to be necessary. It may take several meetings to agree on research designed to produce clear, practical findings and also theoretical analysis. Research teams may need to debate the appropriate compromise for social researchers between knowing too little about the relevant clinical specialty, and knowing so much that they lose an independent perspective. Another fine line to work on is the place of overt theorising in research: between seeming to exploit the research mainly to support theoretical work of no obvious practical relevance, or else of producing atheoretical telephone directory style reports.

The Wellcome Trust and the ESRC will favour research which involves “users” like health policy makers, related voluntary organisations, and members of related medical, nursing, counselling or advocacy groups. It is worth involving some in the research network to support and inform the project. Depressing gaps were revealed during the Wellcome meeting, when doctors would say, “We need research about ---, no one’s done any.” The few researchers would sigh and say, “A lot has been done but we cannot get our reports into your journals.” The journal editors complained that papers submitted were too crude or too soft. Gaps to be bridged became clearer through the meeting, between disciplines and specialties, and between different research theories and methods. We discussed how funders and also reviewers for grant giving bodies and for scientific and clinical journals can become more receptive to social and ethical research. Some open meetings may be held while the Wellcome programme is being designed. These could be useful if they move beyond introductory lectures to critical inter-disciplinary debates.

One question for debate is: Who are the consumers of bioethics research? Are they primarily researchers and their funders and policy makers who are influenced by bioethics insights? Are research subjects the indirect beneficiaries rather than the actual consumers? Or is it envisaged that lay people could use bioethics research reports to support and further their own concerns about genetic and neuroscience research? If a quasi-market is being promoted what might be its ethical basis?

CERES is a forum for many ‘minority’ groups who together make up a large proportion of UK society. Some genetic conditions are exclusive to, or especially common among, certain ethnic minorities and at our meetings they question the appropriateness of much mainstream research, not only to people in the UK but also to those in the poorer majority world. A few general and repeatedly made points from CERES meetings include these following concerns.

Bioethics is seen as frequently abstract and intellectually elitist. It tends to discount knowledge gained through personal experience and to favour scientific and medical accounts. Its selective views bias its relations with medial and scientific research in three main ways.

1. *In theory*, by favouring intellectual analysis over personal experience, bioethics inevitably shapes its arguments towards certain conclusions and in doing so tends to reflect and reinforce the medical pathologising of disability, of chronic illness such as diabetes, and of learning difficulties. (How many people with diabetes see themselves as ill, or people with learning difficulties feel that their life is not worth living?) One, from many examples of anti-disability language and assumptions, is the Report of the Committee of the Ethics of Gene Therapy, 1990.

2. *In policy*, bioethics tends to concentrate on personal individual perspectives, respect for the autonomy of the research subject, or for the putative autonomy of the person healed of conditions such as cystic fibrosis. Distributive justice and the politics and economics of genetic research appear scarcely to be debated by ethicists, though these are of great concern to those who attend CERES meetings. They frequently debate the preferences of affected people for simple inexpensive treatments, and the pressures on researchers to develop high-technology very costly treatments. There is concern that the government’s concern for profitable research outcomes, and the pharmaceutical industry’s all-pervading influence in health care and research drive much research into inappropriate directions.

3. *In practice*, by claiming to be the most informed and relevant non-scientific commentators on genetic research, bioethicists fill the places in publica debates and on ethics committees which could be taken by, or at least shared with, people with more direct and critical experiences and concerns. At times, bioethicists appear to collude with researchers to end critical protests and to ‘reassure’ the public, for example, through ethics committees set up by the MRC such as the recent one on intelligence trials.

These concerns raise questions about how bioethicists perceive their relationship with genetic and neuroscience researchers - as supporters, collaborators or somewhat independent critics?

How do they perceive their relationships with ‘users’ who are not only carers but also people who have the full genetic conditions? How do bioethicists consider that they serve society, and what do they mean by society and its best interests? What does and should bioethics research be like - analytical, textual, reflexive, politically engaged, empirical, theoretical? I hope these questions will be examined during the forthcoming research programmes.

