

## SONGS OF FAINT PRAISE: A REPLY FROM THE DAMNED

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**Abstract.** In this response to the commentary on our original article (Clements, Rapley, & Cummins, 1999), we examine the rhetoric of the commentary as well as some of the substantive issues raised. Although there are areas of agreement we challenge some of the views put forward in the commentary, particularly those related to the institutional power of “science”, the questions of accountability and the involvement of vulnerable people in research decision making. We argue strongly for action now to increase the checks and balances in the system and to promote more vigorously examples of good practice.

*Keywords:* Science research, ethics, accountability, vulnerability.

Whilst at one level we welcome Kiernan’s (1999) commentary as opening up the debate that we sought to stimulate and an illustration of areas of substantial agreement, we also have serious concerns about the reply. These fall into two areas – the rhetoric of the response and the substantive points made.

There is nothing in the commentary that challenges seriously the position or the facts that we put forward in our argument. Rather, the commentary seeks to undermine the thrust of our argument by the deployment of an *ad hominem* attack coupled with an extended display of “expert knowledge”. The opening gambit is crucial; after the usual niceties we are portrayed as overblown, paradigmatically ill informed, confused and ignorant about the “realities” of research and the research process. This move does important discursive work in setting up a contrast with Kiernan’s measured, sober and

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responsible position, a position which, unlike our own, will not “oversimplify the complex issues that surround research”. This ploy – the initial concession followed by sustained assault – is a favourite rhetorical move of the demagogue (Potter, 1996; Varn Dijk, 1998). It reveals this to be an ideological reply of the kind: “All is well, leave it to the reasonable blokes”. For us this reinforces the urgency of our argument. We mentioned in the original article that it was written after a dispute over the reviewing of a submission to this journal. The study in question illustrated many of the issues that we tried to articulate in our article. When these were raised in the reasonable discourse of review with reasonable academic colleagues, they were rejected as of any significance when it came to changes required and ultimately to publication. In our view, the rhetoric of the present commentary reinforces strongly the need for the professional community (which, we say again, includes ourselves) to be confronted very directly about these issues and the need for us to address them as a matter of urgency. It is no longer reasonable to avoid at all costs the giving of offence. Let us now turn to the issues of substance.

1. The commentator has problems with our notion of the scientific community as of an entity. It seems to us frankly bizarre to counter our review of the functioning of a social institution over time with an argument along the lines that “most of the people I know work hard and try to do their best for vulnerable people”. The conscious beliefs and intentions of individuals are not the issue. The scientific community is certainly conceivable as an entity, hence the use of the word “community”. (For the ways in which the power/knowledge nexus may operate in and for the benefit of science see Foucault, 1980). For the powerful nature of the discourse of a “science” of human conduct see Rose (1990) and the special issue of the *Journal of Social Issues* (1998). The members of this community are an intellectual elite with titles that command respect (doctor, professor), they usually work at universities (respected social institutions) and, because research has gained in social status from the undoubted benefits that it has brought in areas such as medicine, consumer goods and food production, the ideas of researchers have status, whether they are fully understood or not. Social science shares in this elevation of status although the benefits it has brought are less obvious. The problem is that the usual subjects of social science research are not only vulnerable as judged by their place in society as a whole, but even more so when faced with the incursions of a high status community. So the question has to be asked: irrespective of the altruism and desires of individual researchers, who has benefited most from the engagement of the powerful and the powerless in the work known as “research on vulnerable people”? From this engagement *researchers* will often get peer respect, meet objective indicators of job performance, enhance personal qualifications, increase the likelihood of future funding and career advancement, and increase the likelihood of creating more jobs for researchers. Is there equivalent pay off to the subjects of research?

2. We take exception to the equating of our broader views on the scientific community with our views on service providers. Our only concern in relation to providers was that they not be the only source of informed consent. This is both because of their role and responsibilities and our detailed knowledge of the “reality of research in learning disability” – the political pressure that may prompt providers to offer access which will enhance their status. This was a matter on which the Mansell Report (DOH, 1993)

commented specifically. This report, written by members of the scientific community for the U.K. government, cautioned service evaluators to be alert to agencies “window dressing” their provision. As a result of such agency pressure service providers may be in no position to give consent, bearing in mind the need to “be free from coercion in terms of threats or excessive rewards for participation” (p. 15). It is bad enough that the commentator used a quotation out of context but it is actually unforgivable that the authors then went on to imply that they, but not us, believe that the “majority of service providers, at whatever level, are committed to the best interests of their clients”. To buttress this argument we are given a personal anecdote about service providers agonizing over consenting to a research study. We are not told what the service providers actually decided. Our argument is quite simply that the researchers should not put staff in that position unless the other caveats, which we have identified, are attended to.

3. The commentator argues against the accountability of researchers as they do not control research agendas and cannot envisage how their findings will be used. Aside from this being a classic war crimes defense manoeuvre, a reading of the literature behind our historical background section shows clearly that this line of argument cannot be used as a general excuse. Turing’s failure to predict the laptop or DeepBlue is not the kind of prophecy that we are arguing for researchers to make. We are looking for responsible engagement with broader civil society. It does not need a referral to a bioethicist to realize that it is immoral to test virulent organisms on disabled children (the Willowbrook example that we gave). We argue for researchers to be alert to the local and proximal sorts of uses that interest groups may put their research to. It may not be easy or successful but the folklore of science now includes the well known lobbying of Oppenheimer and his colleagues that the fruits of their researches *not* be used against Japan in 1945. Voices of protest must be raised. And is it really too much to ask that research that has no likely benefits for participants, but will place considerable demands upon them, should merit recompense either by involvement in the research planning (to create benefits) and/or by a suitable level of payment?

4. We were careful not to identify our position with any particular “ism” or paradigm. We wanted to raise issues – ethical, moral, and procedural – that are relevant whatever school of thought/philosophy of science readers might subscribe to. Kiernan’s difficulty in interpreting our remarks within a positivist paradigm is self-imposed and we fail to see how our position is incompatible with the positivist research tradition. This tradition is silent on whether or not the subjects of research should be direct beneficiaries. Our mention of the emancipatory paradigm was in the context of showing a variety of ways of including the needs of subjects into research programs but we expressed doubts as to whether such a paradigm would in and of itself address all the issues that need to be addressed. Kiernan did not propose any counter arguments but rather seemed to invoke Ramcharan and Grant’s views as a means of displaying their superior ideological credentials, the rhetorical denigration of ours that we referred to in our opening paragraph.

5. This process is evident again when the commentator implies that we have argued that all research subjects should be involved “in all phases of the research process”, thereby demonstrating our stupidity in not understanding “. . . the limitations of autonomy of people with learning disabilities”. This severely misrepresents the views that we

have actually put forward. We argued for a range of ways in which people or those agreed as speaking on their behalf be involved in controlling funding, formulating questions, reviewing proposals and how remuneration would also have a role to play. A wide ranging agenda is required, with a multifaceted system of checks and balances, with much still to learn. To characterize this rather modest and messy agenda as implying all subjects must be consulted about the process of structured equation modelling is ludicrous. And to suggest that the addition of a witnessing component to research work is somehow too onerous or not likely to be accepted by colleagues seems, on the one hand, implausible and, on the other, to prove that we are right to be concerned about the moral accountability of the scientific community. Whilst Emerson and Hatton may have protested privately, they also pointed out very publicly how service evaluation work in the U.K. had almost entirely failed to compare the quality of life of people with intellectual disabilities to that of the general population (pp. 42–43).

Finally, we were dismayed by the narrow focus of the critique on learning disability. We sought to portray a broader picture. Our argument is that research work tends to be exploitative of all vulnerable people, including students, people who are ill, people with disabilities, the elderly, the poor etc. It is interesting to note in this regard that Deakin University has recently implemented a policy whereby first-year psychology students can no longer be *required* to act as subjects for post-graduate/staff research. This policy counters a strong tradition but recognizes the coercive nature of such recruitment. Students must now either volunteer their services or choose to act as subjects for payment. This is consistent with the position that we advocate. Perhaps if the idea of direct personal benefit is adopted and implemented on home ground, the extension of such practice to the broader community of vulnerable people becomes more likely. However, these matters cannot be left to chance. Immediate action is needed to multiply and to extend the few examples that there are of good practice, to set new standards and to continue on the learning process of how to do better. As we have sought to argue, these are not matters of idle conjecture but of urgent necessity.

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