Institutional Review Boards Need to Increase Their Understanding of Community-Based Participatory Research

Commentary on a Case Study in the Ethics of Mental Health Research

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The case study by Loue is a valuable addition to the literature but not because what she describes is exceptional. Direct personal experience and anecdotal report suggest that incidents similar to this one occur frequently. Loue's report is a contribution because issues similar to the one reported here have not been discussed or reported sufficiently to prompt corrective action. Many, perhaps most, institutional review boards (IRBs) have amassed too little experience with community-based participatory research (CBPR) projects to be able to provide effective oversight.

IRBs were developed under a research regime that was not participatory. For IRBs, the research "subject," a term communities mostly reject, is an autonomous individual who is to be protected from potential abuse by researchers. Informed consent, given by the individual, is central to this protection and is an effective method for protecting individual rights. However, when there is a community partnership, a broader, more communal, ethics may be engaged; something IRBs are not usually well prepared to address.

In this case, the Community Advisory Group (CAG) had a very different view than the IRBs of the potential risk posed to the African-American men who have sex with men who would enroll in the study. The IRB was concerned that because the Principal Investigator was well known in the community, simple association with her might cause a breach of confidentiality. The CAG saw meaningful benefits to offset the possible risk, whereas the IRB saw none. It is striking that the IRB considered that it understood the risks better than representatives of the affected community and saw their reaction as challenging its authority (Loue, 2012).

The IRB reaction is an extension of IRBs' traditional way of functioning as a command and control oversight mechanism for conventional research projects. Their response to the CAG was not substantially different from what their response would be to a wayward investigator who resisted accepting their requirements, for example, by balking at fully disclosing risks in an informed consent form. Although such an approach may be appropriate with an investigator leading a study without community engagement, it runs directly counter to all that those of us who practice CBPR have learned. Perhaps what is needed is for IRBs to travel a path similar to the one that many CBPR investigators have traveled. It is a path of learning about community engagement that ultimately leads to understanding that working with community partners requires give and take, some humility, willingness to accept that your cherished and deeply held beliefs may be wrong, and, most importantly, an ability to relinquish at least some control (Minkler and Wallerstein, 2003).

Just as some investigators have found it difficult to acknowledge that the community may be able to contribute in ways that improve the science of collaborative research, IRBs may chafe at the notion that the community has important perspectives on the ethics of human subject research. A starting point would be to convene more gatherings, conferences and workshops (Ross et al., 2010a, b, c) that bring IRB staff and community partners from CBPR projects together to better understand each other and begin to develop a regulatory approach that functions better for CBPR.

REFERENCES


