

RCR Topic: Protection of Human Subjects

Catchy Title: Discussion Partners or Human Subjects?

Case: Fiona, a philosophy graduate student specializing in bioethics, is writing a dissertation that addresses how personal identity and decision-making authority are affected by dementing illnesses. She is interested in how family caregivers might support, or conversely, undermine the persistence of a sense of autonomous identity among the relatives for whom they care. She discusses her topic with her aunt, who is caring for Fiona's grandmother, and then on a couple of occasions with people in her aunt's support group for Alzheimer's caretakers. Fiona finds those discussions very enlightening, and they end up influencing the way she conceives of certain important parts of her project.

When Professor Hindel, Fiona's outside reader, sees a draft of her dissertation, he notices in her acknowledgements that the course of the dissertation has been influenced by the input of several members of the support group. Professor Hindel maintains that the discussion with the caregivers constituted research on human subjects, and that it was not reviewed by the university's IRB (Institutional Review Board). He refuses to allow Fiona to proceed to her defense until and unless she receives the IRB's opinion that her discussions with the support group were consistent with standards for protection of human subjects.

Fiona and her director are very disturbed by Professor Hindel's decision, regarding it as reflecting a misunderstanding of what the purpose of IRB review ought to be.

Discussion Questions:

1. Did Fiona's conversations with the support group constitute research on human subjects according to university guidelines? According to federal regulations? How could Fiona learn more about this topic?
2. Quite apart from your answer to question #1, *should* activities like Fiona's undergo any sort of review by IRBs? Why or why not?
3. Apply the three principles (respect for persons, beneficence, and justice) from the Belmont Report to this situation.
4. Where can Fiona and her dissertation committee learn more about this topic?