

Title: Learning

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Description: Dr. Jones collects oral histories from members of an ethnically diverse neighborhood as part of a study on aggressive behavior in children and would like to share the compiled document with community members to promote study buy-in. An IRB member claims that to do so would violate participant confidentiality.

Headings: Privacy and Confidentiality; Other privacy or confidentiality issues; Special Populations and Cultural Competence; Community or consumer representation; Racial and ethnic minorities

Case Type: Decision making

Learning

Dr. Jones, wants to study the willingness of residents in a poor, ethnically diverse community of Hispanics, African-Americans, Vietnamese, Haitians, and Filipinos to use community mental health services for any of their children who are acting out and engaging in extreme hostility and violence at school. In focus groups and discussions with community members, Dr. Jones learns that there is a high level of ethnic prejudice and that parents tend to assume that their aggressive children are responding appropriately to the insults and aggression of others. (“He is just taking up for himself.”)

Dr. Jones realizes that it would be unwise to study attitudes towards community mental health programs for aggressive children without first understanding more about how these attitudes developed. She decides to begin the project by getting an oral history of the neighborhood – how its demography developed, how it has struggled with ethnic prejudice, how its youngsters have gotten involved in this process, and what parents think should be done about the level of juvenile violence. She calls on community leaders who are eager to participate in better understanding and resolving these problems. Dr. Jones wants to operate according to best principles of community-based research which include letting the community define the problem, and seeking maximum inclusiveness within the community in the research.

Once the first round of oral histories have been conducted with all of the people who volunteer to participate, Dr. Jones plans to give the edited version back to the entire community to critique, and knows that this process will cause others who then feel excluded to ask that their story be told also. This will enhance the validity of the conclusions about the origin and nature of the problems and will maximize the buy-in to the study by community members. In turn, the results of the study would be used to shape an appropriate intervention program for the community’s aggressive youths.

An IRB member objects that letting the whole community read its history would violate individuals’ confidentiality and cannot be permitted.

As an IRB member, do you agree? Are there particular recommendations you would make to ensure that this procedure does not involve a breach of confidentiality?