

Title: Ensuring Fair Representation of Minority Children in Research

Author: Emily E. Anderson (Based on a case in Kimberly Hoagwood, Peter S. Jensen, and Celia B. Fisher, *Ethical Issues in Mental Health Research with Children and Adolescents*, Lawrence Erlbaum, 1996)

Description: A multi-site study comparing several treatment modalities for children with ADHD using random assignment seeks to ensure fair representation and access to research benefits for minority children given issues of potential overdiagnosis and underrepresentation in care.

Headings: Study Design and Risk-Benefit Analysis; Experimental designs; Special Populations and Cultural Competence; Minors (children, adolescents); Mental health disorders, persons with

Case Type: Decision making

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Investigators on a multi-site study plan to investigate and compare the long term effects of four treatment modalities for children with ADHD: routine community care; state-of-the-art medication; state-of-the-art behavioral intervention; and combination medication/behavioral intervention. Children are randomly assigned to one of the four study arms. In order to be eligible for participation, children must be diagnosed with ADHD; children with an IQ below 80 are excluded from participation because of the need for sufficient verbal skills to participate in the cognitive and behavioral treatments.

The investigators are concerned about ensuring that minority children are adequately and fairly represented in the trial. This is not only an issue of recruitment but also of diagnosis and inclusion/exclusion criteria. The claim that some racial/ethnic minority children do not score as well as Caucasian and Asian children on standardized tests is well known. The use of a standardized IQ test to screen children may unfairly exclude minority children whose learning potential is actually better but score worse on standardized tests due to cultural/educational disadvantage.

There is also concern regarding the potential for over diagnosis of ADHD and overuse of stimulant medications for treatment in low-income African-American children. Some of the symptoms of ADHD could be mimicked by the normal reaction to a stressful or frightening environment.

What measures do you recommend the investigators take to ensure fair representation of minority children in the study?

See Hoagwood et al. (1996) for a discussion of how this case was addressed by the researchers.