

Title: Obtaining Informed Consent to Participate in Research from Mentally Retarded Adults

Author: Celia B. Fisher, *Decoding the Ethics Code: A Practical Guide for Psychologists*, Sage Publications, 2003

Description: A researcher obtains informed consent from mentally retarded adults who maintain the legal right to consent to such decisions and permission from legal guardians when necessary (with assent from the participants). Fisher presents this as an example of best practice.

Headings: Decision-Making Capacity, Assent, and Surrogate Permission; Assent; Surrogate decision makers; Obstacles to informed consent; Mental health disorders, participants with (including addictive disorders and developmental disabilities)

Case Type: Illustrative

Obtaining Informed Consent to Participate in Research from Mentally Retarded Adults

A psychologist was conducting a study on language skills involving adults with mild levels of mental retardation and developmental disabilities (MR/DD) living in community group residences. Some of the prospective participants had a parent or sibling who was their legal guardian. Other prospective participants had maintained the legal right to consent to decisions affecting their lives, but such decisions were often made in collaboration with residence staff and family. The psychologist obtained signed permission from all legal guardians followed by the signed assent of individuals who wished to participate. The psychologist obtained signed consent from all adults with MR/DD who had the legal right to consent. However, information forms were also sent in advance to the family members with whom these individuals relied on for decision making. In all situations, the psychologist did not attempt to obtain consent from a prospective participant until after a resident staff member had confirmed that the individual wanted to be approached.