**# 1 : Case 50. Informed Consent with Vulnerable Populations**

**Situation**

Clean Analysis, Inc., a research company headed by a sociologist, Theo Gouraki, has a contract with a state agency to evaluate a large-scale program that provides in-home assistance services to persons with disabilities. The project involves merging administrative data from the service providers with information collected from the persons receiving the services. To evaluate the service providers, Clear Analysis staff visit the homes of those receiving services to interview the program participants and to evaluate the service delivery on-site. Before beginning the project, Theo sent provided a significant amount of training to his staff in how to interview persons who have disabilities that might make it difficult to interview them. He also researched thoroughly any possible problems that might lead to the participants having difficulty providing informed consent. When the researchers went to the homes, they found that very few participants refused the visits and the interviews. They also determined that most participants were very reluctant to say that there was anything wrong with their services because they were afraid the service provider would be fired or they might lose their services.

**Questions**

* Most research projects have a significant portion of possible participants who are not willing to cooperate. Should Theo have assumed there was a problem when almost everyone agreed to participate?
* Is it possible that the informed consent procedures contained some information that caused participants to fear that they would lose their services if they did not participate?
* Should Theo have reviewed his training to determine if there was something in the training that caused the interviewers to be too aggressive and perhaps intimidating when contacting the program participants?
* Should Theo have asked the participants if they agreed to have their survey data merged with their administrative records?

**Discussion**

Research on vulnerable populations requires the researcher to take special care to plan and conduct research. Theo obviously prepared himself and his staff well to meet the needs of the population. At the same time, the high level of cooperation should have indicated to Theo that there might be problems that made the participants believe they could not choose to participate in the study. For example, the informed consent statement saying the study was funded by the state agency who provided the services might have intimidated the participants if it was not accompanied by a statement that no services would be lost because of participation and that the research was aimed at evaluating the entire program, not just the services the participant was receiving.

Suppose one of the goals of the research was to determine which services are most cost-effective so the state can focus its funding where it will do the most good. In that case, some participants might lose services as a result of the research. Did Theo have an obligation to tell the respondents about that possible outcome? If he did, would it affect the responses provided by the participants.

Research on vulnerable populations who are more vulnerable because of services provided to them must be planned and conducted with significant care.

**# 2 : Case 23. Avoidance of Personal Gain**

**Situation**

The president of a small survey research firm, Mike Brown, receives a contract from a local government agency to conduct a survey of the local community to help design a policy on the most effective use of funds used to pay for heating costs of the low income and the older population. Mike has a professional interest in energy-related policies, so he includes three extra questions in the survey (at no cost to the government agency and without telling them) that he planned to analyze for a presentation at a professional meeting.

After the survey was done, Mike used the questions, along with two others collected for local government and some demographic data to prepare the paper. He did not ask the government agency for permission to use the data or allow them to review the paper because he said the data were public and the extra questions he subsidized.

**Questions**

 Did Mike inappropriately use the questions collected in the survey?

 Was it appropriate to add the additional questions without telling the government agency?

 Would it have been acceptable to analyze only the questions he subsidized?

**Discussion**

Mike’s decision to add the additional questions would be an attempt to gain at the expense of his client. The startup and design costs for a survey were paid by the client and only a little of costs of data collection were paid by Mike. In addition, he did not ask permission to use the questions that the client paid for, even if they were publicly available data.