

BAR-ILAN UNIVERSITY

Research Ethics among Researchers: Toward Research Practices
involving People with Intellectual Developmental Disabilities (IDD)

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Abstract

The purpose of this study is to examine the ethical dilemmas and principles involved in conducting research among subjects with Intellectual Developmental Disabilities (IDD), from the point of view of researchers and members of ethics committees in Israeli institutions of higher education. The uniqueness of this study is demonstrated by a lack of reference in Israeli University procedures and guides on ethical issues and challenges that arise in studies that involve subjects with low to medium level IDD. The study is based on the findings of two sets of 10 in-depth interviews. The first set was conducted with researchers who are actively engaged in research involving subjects with developmental and intellectual disabilities. The second set of interviews was conducted with representatives of research ethics committees at various Israeli institutions of higher education.

The study's findings highlight various ethical dilemmas, from which six main principles can be derived (in order of prevalence): the rules of work required in research among the population with intellectual developmental disabilities, previous acquaintance of researchers and members of ethics committees with population characteristics, participation of people with intellectual developmental disabilities, protection, consent is informed, and prevention and minimization of possible damages.

The findings of the study demonstrate the ambiguity and inconsistency between the various academic institutions regarding research conduct procedures among the population with intellectual developmental disabilities. Thus, the research contributes to the understanding of the ethical dilemmas and ethical principles for conducting research among people with IDD. These principles may lower research participation barriers for people with intellectual developmental disabilities, while granted study participants with a greater voice and impact on their own participation in research.