The Injustice of Inclusion and Fair Opportunity: Exploiting Children In Medical Research for the Benefit of an Unworthy Society

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Abstract

The history of pediatric medical research has been characterized as a history of child abuse. Usually, the debate regarding the use of children in medical research has centered on questions of Autonomy (informed consent) and Beneficence (the best interest of the child based on a benefit risk analysis). The debate has rarely focused on the question of which children should participate in medical research by discussing the legal principle of Justice (prohibits use of vulnerable populations for medical research who are already overly burdened for medical research unrelated to health issues affecting them and requires that populations who participate in medical research receive a benefit). My article begins to fill this void by critically analyzing the Justice Principle’s prohibition against targeting and exploitation, which is the use of overburdened populations (minorities, children, and impoverished) because of their easy availability, their compromised position, or manipulability (targeting) for research that will not benefit them or their population (exploitation). Specifically, I discuss how researchers continued targeting and exploitation of children, in particular economically disadvantaged minority children who have been and continue to be used more in non-therapeutic and dangerous therapeutic medical research studies than other children, in the United States and abroad results in part from a misapprehension of the Justice Principle. To prevent the continued targeting and exploitation of these children, I suggest that the government adopt the Human Development Approach, which requires researchers to take into consideration the social conditions, such as lack of access to health care, that make children susceptible to targeting and exploitation in medical research. If researchers decide to use children as subjects they have a duty to provide a benefit directly to the children and to their population that alleviates some of their underlying problems, such as lack of access to medical care.

Keywords: medical research, race, Medicaid, human development, civil rights, bioethics, Justice, Belmont Report, clinical trials, poverty, vulnerable groups, children
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