

*The Ethics of Mental Health Research: Principles, Guidance, and Cases*

by James M. DuBois

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Review by Rebekah Humphreys, M.A. on June 11<sup>th</sup> 2008

In this comprehensive book James DuBois explores ethical principles and guidelines that are essential for any researcher or Institutional Review Board member to work ethically within the practice of human mental health research. While the book focuses on the ethics of research conducted with humans who have mental health disorders and provides a framework for ethical research with such humans, the ethics framework provided is applicable to research conducted with *all* human beings (not just those humans who have mental health disorders).

This is a well-constructed book with the first three chapters concentrating on laying the theoretical foundations for the ethics framework. Significance is placed on four principles: autonomy, beneficence, nonmaleficence and justice (p. 30). DuBois aims to ‘humanize’ these principles, that is, he intends to ‘explain how all ethical principles are expressions of respect for humanity’ (p. 31). As DuBois says, ‘each of the four principles is translated into a form of respect for a specific aspect of human nature’. Thus, morally relevant aspects of human beings and prescriptions about how one ought to treat human beings form the basis of the four principles.

DuBois explains how each principle has its foundation in human nature. All humans are capable of being harmed and benefited and, therefore, the principles of nonmaleficence and beneficence are applicable to humans in virtue of this capacity. Research may produce benefits in the form of certain goods, either for the human participants or for the wider community, but research may also involve harms, both physical and social ones, and these will also need to be taken into account.

In so far as humans are capable of rationality and determining their own actions, then the principle of autonomy is applicable and, in the context of research, this will involve obtaining informed consent. There are, of course, many humans who are not capable of making autonomous choices and, in these instances, special protections are required, which will prevent such people from being harmed and exploited.

The principle of justice is based on a prescription as to how we ought to treat humans, that prescription being that all humans should be treated as equals. Thus, the principle of justice is related to the idea of equality and in the research context this will involve, for example, fair distribution of goods (p.33).

The remaining chapters (chapters four – ten) deal with applied issues, such as informed consent, decision-making capacity, harms and benefits, justice, confidentiality and conflicts of interests. All these chapters contain case studies that are thoroughly examined from within the theoretical framework (presented in the beginning chapters) to illuminate the relevant ethical issues, which arise in practice. DuBois analyses the cases with clarity, allowing the reader to understand how cases should be approached and how ethical principles and guidelines should be applied.

Indeed, the subtleties of each case are taken into account; subtleties that even an experienced researcher or Institutional Review Board member may not be aware of.

Chapter ten is particularly informative, as DuBois shares his knowledge of the conflicts of interest that may cause ethical problems within mental health research. While various self-interested motivations may result in professional interests being given unjustifiably greater consideration than participant interests, DuBois pragmatically recognises that researchers need to be motivated by something in order to engage in research and their motives may be altruistic or self-interested (p. 210). Researchers should be aware of motives that may influence their behaviour (p.204). Practising research ethics is a way of managing conflicts of interests justifiably.

While regulations provide legal protections for human participants and shape the behaviour of professionals, rules and regulations, DuBois argues, should not be a substitute for ethics. Ethical decision-making in practice is not about following rules for their own sake, but about reflection and reasoning that takes account of morally relevant interests. As DuBois says, ethical reasoning 'should inspire us to go beyond the regulations in seeking to respect and benefit people in just ways' (p. 21). Indeed, those very regulations and policies, followed in research ethics, need to be defended on ethical grounds: 'We need to explain the ethical foundations of our rules in order to foster voluntary and reasonable compliance with regulations' (p. 21). Philosophical ethics is thus of utmost importance in the context of research ethics.

It must be said that DuBois' 'humanizing' of ethical principles (that is, the idea that human nature is the foundation upon which all ethical principles are derived) is suggestive of an underlying anthropocentric ethic; anthropocentrism being the view that all values are derivative from humans, and an ethic based solely on the interests of humans. Contrary to DuBois, it is not clear that characteristics inherent in human nature 'yield a theoretical foundation for principles' (p. 31).

While human beings may be the only species capable of moral agency, it does not follow that ethical principles are, therefore, derived from human nature or human characteristics. Other beings possess many of the characteristics from which ethical principles are supposedly derived. Nonhuman beings are also capable of being harmed and benefited and, indeed, some animals (it could be argued) possess a greater degree of rationality than some humans. Also, some enlightened thinkers would argue that the principle of equality should apply to nonhuman beings, and that their interests, as well as human interests, should be given equal consideration. Taking this into account, it is just not apparent that human nature is the foundation for the four ethical principles (that is, autonomy, nonmaleficence, beneficence and justice). While ethical principles should respect human interests, their application should not be restricted solely to human interests. However, 'humanizing' principles would, indeed, render such principles exclusive to human beings and exclude one large group of beings frequently used in mental health research, namely nonhuman ones. Thus, the 'humanized' principlism presented in this book may be too narrow as a universal ethic.

DuBois quite rightly states that certain people should be seen as 'vulnerable' and be given special protections in the research context. Vulnerable people may be more susceptible to harm and exploitation than other people. Such people include, for

example, mentally disabled persons, as their decision-making capacity and communicative skills can often be minimal or nonexistent. This may result in them being subordinate to others who may disvalue their interests (p. 110-113). The Willowbrook study, in which mentally disabled children were deliberately affected with live hepatitis virus (p. 14), was one study that used vulnerable participants. DuBois devotes a section in chapter six to outlining the different ways people may be vulnerable and the corresponding risks that may result from such vulnerabilities (p. 112).

In exploring whether conducting research with mentally disabled children (such as those used in the Willowbrook study) is necessary DuBois suggests that one should ask whether an alternative course of action would achieve the same aim: 'For example, in the Willowbrook study, one might argue that more research could have been conducted with animals or that adult volunteers could serve as participants' (p. 54). However, while conducting such research with fully autonomous adults would remove the problem of consent, it seems that nonhuman beings satisfy criteria considered valid for special protections as vulnerable individuals or groups.

While the use of animals in research is the norm and, admittedly, this book focuses on human research, the above considerations regarding the humanization of ethical principles and the lack of awareness that animals may not always be ethical alternatives, do seem to indicate, or provide evidence of, an anthropocentric bias and the reader should perhaps be aware of this. Indeed, DuBois himself suggests that professionals may be unaware of their biases and that such biases may, unwittingly, be related to self-interested motives (p. 204). Promoting morally good behaviour requires some form of self-awareness (p. 211, 220). Ethical analysis and reflection should seek to uncover any biases. And while DuBois explicitly states that his aim is to 'present a framework for *ethical* deliberation in human subjects research' (p. 21), an ethical framework for research conducted solely with humans need not be anthropocentric. (This is not to say that anthropocentrism can never be justified, but only that the reader should be conscious of value judgments that may influence any proposed ethic.)

Undoubtedly though DuBois is greatly aware of particular and general issues that arise in mental health research and, in spite of the above contentions, this book would be a valuable tool to all those professionals, working in the field of mental health, who have a genuine interest in ethical practice and professional ethics. As DuBois says, the book 'assumes they [the readers] want to know what is the right thing to do' (p. 220). The language used is accessible and DuBois avoids a high-level of technicality. There is an extensive index and references are to high quality journals that provide the reader with ample, well-researched further reading. Overall, *Ethics in Mental Health Research* is an informative and well-written book, providing excellent guidance for ethical decision-making in the practice of human mental health research.

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