

Beyond Bioethics: Philosophy and Disability Studies

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If one were attempting to find a home for disability discourse within philosophy, the most obvious place to look would be bioethics. Discussions of disability are included in many of the difficult moral and biomedical issues which bioethics attempts to address, such as prenatal diagnosis, genetic testing for disabling conditions, abortion, euthanasia, sterilization of the mentally disabled, infanticide, health care resources, and questions of competence, informed consent, and quality of life. There is no doubt that the debates in these difficult areas are of great importance, not only philosophically, but for the individuals whose lives are directly affected by them. However, bioethics is not the only arena for philosophical discussions about disability.

There are many philosophical issues surrounding disability that are beyond the realm of bioethics. Philosophers have begun to explore disability in the context of phenomenology, political and social philosophy, theories of embodiment, and feminism. However, much of the current literature focuses either explicitly on physical disability, speaks more generally about "disability" without differentiating between physical and cognitive disabilities, or discusses cognitive disability in terms which do not reflect the problematic nature of the category itself. Thus, I would like to focus specifically on cognitive disability (1) because, though it has been given almost exclusive philosophical attention within a medical-moral context, I think it raises many profound questions that go beyond bioethics. I will begin with a brief sketch of the ways cognitive disabilities have been treated within bioethical discourse, give a number of reasons for going beyond this approach, and conclude with some reflections on other philosophical areas where cognitive disability is relevant and important.

Cognitive disability has been given particular attention in bioethics. Specifically biomedical questions include prenatal testing and genetic screening for cognitive disabilities, aborting fetuses with such conditions, and the sterilization of the mentally disabled. These issues are discussed from a wide variety of ethical perspectives, and additional questions are often raised regarding rights, consent, competence, and definitions of personhood (i.e., are these individuals persons, and how should we treat them?). There are also difficult legal issues which arise in the context of cognitive disabilities: wrongful birth suits (2), surrogacy battles (3), and cases of infanticide (4). Finally, the topic of cognitive disability and its association with eugenics has been raised in connection with the philosophical and political controversies around the Human Genome Project and advances in genetics (including gene therapy and genetic screening). There is a mosaic of biomedical and ethical

issues involving cognitive disability, all of which are important and relevant to health care professionals, philosophers, and most significantly, the individuals defined as cognitively disabled themselves. Yet there are additional philosophical questions concerning cognitive disability which lie beyond bioethics. Before exploring a few of these alternatives, I would first like to offer three reasons for this philosophical reorientation: the first is philosophical, and has to do with the nature and limits of bioethical discourse; the second is political; and the last, historical.

Given that bioethics generally deals with moral questions surrounding *biomedical* issues, philosophers often assume a medical model of disability. The cognitively disabled are viewed as having a medically classifiable, uniform condition (e.g. Down's Syndrome, mental retardation) with an underlying biological cause, despite the fact that in many cases the etiology is unknown (as in 75% of cases of mental retardation), and the range of severity can differ tremendously and is often difficult to predict. Some discussions are restricted to the "mild" or "severely" mentally retarded (usually focusing upon the latter) and acknowledge that the moral questions may be very different depending on the degree of severity. However, the boundaries of these categories are not always clearly defined, and the very designation of sub-groups is not unproblematic. The variety encompassed under the classification of "mental retardation", even within the sub-categories of "mild", "moderate", and "severe", makes generalizations difficult. As Robert Edgerton observes in his account of the lives of persons with mental retardation, "Mental retardation is not a unitary disorder....Both etiologically and descriptively, mental retardation is heterogenous." (5) Thus, there are many pressing philosophical questions about the nature of the classification itself. Is mental retardation a biological or social category, or both? (6) There is an undeniable social dimension to this classification, and to treat it as a unified medical disorder is to ignore its complexity and political nature. (7) As James Trent comments in his introduction to *Inventing the Feeble Mind*:

The problem of mental retardation is a social problem because it is equally a problem of mental acceleration....It is important to understand that image of mental retardation as a 'thing', the object of scientific understanding and intervention, conceals a history shaped by the implicit political choices of the mentally accelerated. (8)

Much of the biomedical and moral discourse on cognitive disability does not take into account the social nature of disability, and ignores the intricacies and ambiguities of these classifications. A striking example of this can be found in the bioethical debates about aborting fetuses with disabilities. It is not unusual for mental retardation and Down's Syndrome to be presented as the morally "unproblematic

cases", where it is clear, and sometimes expected, that a woman would choose to abort. (Things are more morally complicated in cases of physical disabilities such as blindness, or missing limbs.) This simplistic representation of cognitive disabilities obscures the important fact that it is impossible to determine their severity *in utero*, and both reflects and perpetuates the stigma associated with these conditions. I think that there is important philosophical work to be done in examining the nature and construction of these categories, as well as critically evaluating the ways in which cognitive disability is represented within bioethical discourse.

In addition to the philosophical reasons for going beyond bioethics, there is a political one as well. If one takes a survey of the topics under which cognitive disability is included in bioethics, an overwhelming number focus on whether or not it can and/or should be avoided (e.g. prenatal screening, genetic testing, the Human Genome Project, sterilization, infanticide, reproductive technology as an alternative for couples who would otherwise have a child with a cognitive disability). I would argue that there is an implicit political message being sent by restricting philosophical discourse to these biomedical issues. If philosophy is going to include disability as an area of inquiry, it is important that it include topics which do not center around one underlying theme: prevention.

The final reason for going beyond biomedical and moral considerations of cognitive disability is historical. As Trent has suggested, there is a political story intertwined with the development of classifications such as mental retardation. What I find striking about its history is that, in the mid-nineteenth century, mental retardation emerged simultaneously as an object of medical and *moral* discourse. The moral character of the individual became as important to the classification as the medical diagnosis. In fact, many researchers in the field (including Alfred Binet, the father of the intelligence tests, and Edouard Seguin, often referred to as the father of special education) included the moral aptitude of the individual in their definitions. By the 1880's the "moral imbecile" was defined as an individual whose defect was primarily moral, rather than intellectual. As we trace the history into the twentieth century, the identification of women as "feble-minded" and the incarceration of both men and women were often predicated upon their supposed immorality, not on any medical diagnosis. In light of this history, I think it is important to explore discourses which do not view the cognitively disabled as moral and/or medical problems to be solved. Many discussions in ethics focus on whether or not the cognitively disabled are persons, debate whether the severely cognitively disabled are akin to or morally equivalent to non-human animals, and question their status as members of our moral community. Unfortunately, by ignoring the history of these classifications, they often make arguments that sound remarkably similar to those presented almost a century ago. (9)

As we have seen, there are historical, political and philosophical reasons to

extend our philosophical reflections beyond a purely moral and biomedical consideration of cognitive disability. I have already hinted at some of the directions in which philosophy might go, and would like to conclude by mentioning a few more possibilities. Given the importance accorded to rationality in Western philosophical thought, we might reexamine the history of philosophy from the perspective of cognitive disability. What did various philosophers have to say about mental disability? And at what point was mental disability distinguished from mental illness? English philosopher John Locke, for example, made a distinction between "idiots" and "madmen". (10) The philosophies of Locke and Rousseau also had a great influence on the development of special education. In fact, Rousseau's definition of the infant in his famous study on education, *Emile*, is almost identical to Seguin's subsequent definition of the "idiot". What is the relationship between philosophical theories of rationality and the way in which cognitive disability was defined pedagogically, as well as scientifically? How have definitions of Reason determined the nature of Reason's opposite? (11) To what extent has the concept of Reason defined the humanness and moral character of the cognitively disabled? Just as feminist philosophers have explored male biases in the Western philosophical tradition (12), disability scholars have a rich terrain to cultivate in assessing the philosophical significance of both physical and cognitive disability.

Feminist scholarship has already contributed a great deal to the theorizing of disability. Susan Wendell, in her book *The Rejected Body: Feminist Philosophical Reflections on Disability*, offers profound insights into the nature of disability, the notion of disability as difference, embodiment, and feminist ethics. Though her book focuses on physical disability, I think that much of what she argues can and *should* be extended to cognitive disability. I am particularly compelled by her discussion of the "cognitive and social authority of medicine". She defines cognitive authority as "the authority to have one's descriptions of the world taken seriously, believed, or accepted generally as truth". (13) Her claim that persons with disabilities have had their experiences invalidated is particularly true of those who are seen as *cognitively disabled*. By definition, they lack the ability to have the kind of cognitive authority which the medical profession commands, and their attempts at self-definition have only become public in the past two to three decades. (14) There are numerous epistemological issues to be unraveled, including the production and privileging of knowledge, the possibility of individuals with cognitive disabilities acting as knowing subjects rather than scientific objects, and how the knowledge produced *about* them affects their self-perception, and ultimately shapes the categories themselves. (15)

This leads to another rich venue of philosophical reflection: theorizing oppression and power. Many philosophers have explored the nature of oppression, and while there are many theories of oppression which apply to the physically

disabled, they are not always relevant to the cognitively disabled. The problem of exclusion, in general, is particularly salient in the context of cognitive disability. Insofar as many of these individuals are deemed incapable of the kind of scholarship and theoretical work that is required to take part in philosophical discourse, their voices are almost always excluded. Given the progress made by feminists (abled-bodied and disabled) towards inclusion, this silence is especially troublesome. One solution to this problem has been offered by the French philosopher Michel Foucault. In many of his works, he examines the relationship between discourses (e.g., scientific, pedagogical, institutional), knowledge, and power. He argues that power relations imply the possibility of resistance, and that power can “come from below”. (16) He calls for “genealogical research”, a method which brings forth “subjugated knowledges....those knowledges that have been disqualified as inadequate...naive knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity.” (17) A genealogy of cognitive disability is long overdue.

These are only a few directions in which philosophers of disability might explore. (An additional task is to theorize the very distinction I have made between “physical” and “mental” or “cognitive” disability). Bioethicists and moral theorists have already established a philosophical home for disability studies. However, in an effort to generate broader and more inclusive philosophies of disability, I think that it is both philosophically fruitful and politically necessary to extend philosophical reflections on disability beyond the boundaries of bioethics.

Notes

1. I recognize the plurality of terms in current use, including “developmental disability”, “mental disability”, and “intellectual disability”. For the purposes of this paper I have chosen the term “cognitive disability”, by which I mean conditions that are believed to impair an individual’s cognitive abilities, and that do not necessarily have a biological cause or physically disabling effect (e.g. mental retardation, Down’s Syndrome). I also distinguish cognitive disabilities from mental illnesses (e.g. schizophrenia, dementia, psychotic disorders).

2. In these cases, parents of a child with a congenital abnormality or illness bring suit against a physician who has failed to provide appropriate prenatal testing or counseling, and whose failure resulted in the birth of their disabled child.

3. There was a case in Michigan where a child who was commissioned through a surrogacy contract was born microcephalic. Upon the knowledge that the biological father was, in fact, the husband of the surrogate mother, not the intended adoptive father, a battle ensued as to who was responsible for the disabled child whom neither couple wanted. See “When No One Wants the Child”, in ed. Kenneth Alpern, *The Ethics of Reproductive Technology*, (New York: Oxford University Press, 1992) 335-337.

4. The best known case is the that of Baby Doe, a child with Down's Syndrome and an esophageal defect who was left to die after his parents decided not to repair the defect because of the child's cognitive disability. See "The Johns Hopkins Case", "Selective Nontreatment of Handicapped Newborns" and "Treating Baby Doe: The Ethics of Uncertainty", in eds. Beauchamp & Walters, *Contemporary Issues in Bioethics* (Belmont: Wadsworth Publishing Company, 1994) 413-430.

5. Robert Edgerton, *The Cloak of Competence*, (Berkeley: University of California Press, 1993) 2.

6. It is worth pointing out that in the DSM-IV definition of mental retardation, there is no purely biological criterion other than age of onset (which must be before 18 years). The other criteria are IQ level, and impairment in "adaptive functioning", which are both measured by psychological tests. The latest definition provided by the American Association on Mental Retardation deliberately highlights the social nature of mental retardation, and boasts a "paradigm shift, from a view of mental retardation as an absolute trait expressed solely by an individual to an expression of the interaction between the person with limited intellectual functioning and the environment". See Luckasson, *Mental Retardation: Definition, Classification, and Systems of Supports, 9th Edition*, (American Association on Mental Retardation, 1992).

7. For an interesting account of the political factors in the genesis of Down's Syndrome as a classification, see Chris Borthwick, "Racism, IQ, and Down's Syndrome", *Disability and Society*, vol.11 No.3, 1990.

8. James W. Trent, *Inventing the Feeble Mind: A History of Mental Retardation in the United States*, (Berkeley: University of California Press, 1994) 7.

9. In an article written in *Philosophy & Public Affairs* on the cognitively disabled and justice, I was amazed to find that the author uses the terms "idiot", "idiocy", "moron" and "dullard", without qualification. These were all actual scientific sub-groups of the "feeble-minded", but were abandoned decades ago (though they remain in our everyday language as pejorative terms). See Jeff McMahan, "Cognitive Disability, Misfortune, and Justice", in *Philosophy & Public Affairs*, vol.25, 1, 1996, 3-35.

10. See John Locke, *An Essay Concerning Human Understanding*, (London: William Tegg, 1900) 105-6.

11. The French philosopher Michel Foucault examined this very question in his fascinating book, *Madness and Civilization: A History of Insanity in the Age of Reason*, (New York: Vintage Books, 1988). Though he focuses exclusively on mental illness, his work is historically and politically relevant to cognitive disability as well.

12. Genvieve Lloyd examines the "maleness of Reason" in her book *The*

Man of Reason: 'Male' and 'Female' in Western Philosophy, (New York: Routledge, 1994).

13. Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disabilities*, (New York: Routledge, 1996) 117.

14. For an excellent account of the growing self-advocacy movement, see *New Voices: Self-Advocacy by People with Disabilities*, (Cambridge, Mass.: Brookline Books, 1996).

15. Ian Hacking calls this last effect the "looping effect of human kinds". His articles "Making Up People" and "The Looping Effect of Human Kinds" both address the relationship between categories and the classified individual. See "Making Up People" in eds. Heller, Sosna, Wellbery, *Reconstructing Individualism*, (Stanford, Calif.: Stanford University Press, 1986); "The Looping Effects of Human Kinds" in eds. Sperber, Premack, Premack, *Causal Cognition: A Multi-disciplinary Approach*, (Oxford: Clarendon Press, 1995).

16. Michel Foucault, *The History of Sexuality, Volume I: An Introduction*, (New York: Vintage Books, 1990) 94.

17. Michel Foucault, "Two Lectures" in ed. Colin Gordon, *Power/Knowledge: Selected Interviews & Other Writings*, (New York: Pantheon Books, 1980) 82.