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THE MORAL SIGNIFICANCE OF INTELLECTUAL DISABILITIES

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SUMMARY

In this summary I will explain the main questions and arguments of my study. I will also discuss briefly the relevance of moral philosophical inquiry from the viewpoint of special education.

This licenciate dissertation consists of two published articles (Vehmas, 1999a, 1999b) in which I discuss the moral significance of intellectual disabilities.¹ This dissertation falls under the study of *applied ethics* in which ideas and theories from general studies of goodness and right action are applied to particular circumstances and problems of some profession or occupation, and standard philosophical techniques are used to define, clarify, and organize the ethical issues found in its domain (for ethical argumentation see Tooley, 1983, pp. 11-18). In this dissertation this means at least three things: (1) clarifying and evaluating statements and terms that are vague or ambiguous (e.g., the moral significance of intellectual disabilities and “normality”); (2) detecting and rejecting unreasonable factual claims of a non-ethical sort (e.g., as regards the experiences of families with children with intellectual disabilities); (3) showing that some ethical position is logically inconsistent in some respect by using counter-examples or working out the consequences of a given position that would not be consistent with its premises (e.g., objectivity vs. subjectivity of human well-being; see Vehmas, 1999b, p. 115).

The research questions of this study are: (1) Do infants with intellectual disabilities have poorer prospects for a happy or “full” human existence than so-called normal infants? (2) Can a child with intellectual disability reasonably be seen as an excessive burden from the perspective of the family and society? That is, do the interests of the family, society and “the next child in the queue” override the interests of an infant with intellectual disability? Having discussed these two questions, I have also attempted to answer the following questions: (3) Is it wrong to kill intentionally, actively or passively, newborn babies because of their intellectual disabilities? (4) Are infants with apparent or presumed intellectual disabilities morally less entitled to life than infants without intellectual disabilities? (I have discussed these questions in Vehmas, 1999b.)

¹ By the concept of “intellectual disabilities” I refer to conditions that The American Association on Mental Retardation (1992) defines as mental retardation.

I discuss these four questions by criticizing the position put forward by the well-known utilitarian bioethicists Helga Kuhse, Peter Singer and James Rachels whom I will take the liberty of calling as *bioutilitarians* (see Vehmas 1996, p. 19, 1999a, p. 37). Utilitarianism is a consequentialist moral theory, i.e. an action is morally right if it produces at least as much good (utility) for all people affected by the action as any alternative action the person could take instead. According to classical utilitarians the aim of moral actions is to maximize happiness and minimize suffering (see Mill, 1861/1991). Bioutilitarians define happiness as the satisfaction of preferences. The wrongness of an action is related to the extent to which the action prevents certain interests, desires or preferences from being fulfilled. (See Kuhse, 1987; Kuhse & Singer, 1985; Rachels, 1986; Singer, 1993.) In this position the good of individuals is to be determined by their own values, rather than by an impersonal evaluation of the quantity and quality of their pleasures and pains (Warren, 1997, p. 65). In addition to the four questions posed above, I have examined two characteristic points of bioutilitarianism: (1) a normative idea of a normal human being and a full human existence; (2) an intelligist intuition, i.e. the life of a more intelligent human is, because of its mental quality, more valuable than the life of a less intelligent human. (This analysis is presented in Vehmas, 1999a.)

The arguments of bioutilitarians concerning the moral status of infants are based on utilitarian moral theory and Michael Tooley's (1972, 1983) theory of personhood which explicates the issue of what kind of beings have the right to a continued existence. Kuhse, Singer and Rachels have based their own ideas on Tooley's theory or, at least, their position is equivalent with it. According to Tooley (1972) only beings who are able to value their own existence have a serious right to life. Beings that are not able to value their own existence cannot be wronged by killing them for their death deprives them of nothing they can value. In order to be able to value one's own life a being must be self-conscious, it must be aware that it has a life to value: "An organism possesses a serious right to life only if it possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity" (p. 44). This means that abortion and infanticide at least shortly after birth must both be morally acceptable (see Kuhse & Singer, 1985, pp. 195-196; Tooley, 1972, p. 64, 1983, p. 412).

When discussing infanticide Kuhse, Singer and Rachels stress mental properties as the most relevant factor morally: belonging to the species *Homo sapiens* is morally irrelevant in itself.

This emphasis in their position is based on Tooley's theory of personhood and leads to the conclusion that all beings should be treated equally (regarding the issue of taking life) on the grounds of things such as self-awareness, capability for abstract thought, the capacity to have hopes and aspirations for the future and the capacity for meaningful relations with others. Because of this, Singer (1990, p. 20) concludes that "if we had to choose to save the life of a normal human being or an intellectually disabled human being, we would probably choose to save the life of a normal human being" and that "we should give the same respect ... to the lives of those humans at a similar mental level" (p. 21).

The moral and thus practical significance of the questions that are examined here is not limited merely to infanticide as such. Rather, the main focus and interest is to examine the bioutilitarians' arguments about intellectual disabilities as morally significant factors and how adopting a certain perspective on disability can greatly affect our moral judgments regarding people with intellectual disabilities.

I have argued that the arguments of the bioutilitarians are based on misleading and biased information about the characteristics of individuals with intellectual disabilities and their quality of life. The main flaw in their position is a one-sided individualistic approach to disability and its presumed outcomes as regards, for example, human well-being and family functioning. Briefly, the bioutilitarians base their view on some vague concept of an ideal human being who is able to think, talk, and live independently. Individuals with intellectual disabilities, as well as aged and mentally ill people, are thought to be "marginal" people in the sense that they are dependent on our concern. However, in this sense individuals with intellectual disabilities are not really marginal, but distinctively human: just like every other human being, they are dependent on other people's concern and care.

I argue that inter-personal relational connections are the cornerstone of humanity; we are relational beings. One may reasonably value certain features as more valuable than others from one's own perspective but to extend this judgment for the purpose of putting people into a moral ranking order is highly arbitrary. All human beings are dependent or interdependent and the significance between different forms of dependency is determined by the cultural context as shameful or acceptable. Therefore, we really do not have a reasonable basis for judging different

human beings as less valuable than others on the basis of the nature of their dependency.

Intelligence or any other individual characteristic in itself does not guarantee an individual's happiness. Happiness and contentment are mainly the result of the relationships between an individual and a community. Individual characteristics, especially intellectual properties, are relevant from the point of view of happiness if they are accordant with or contradictory to communal values, norms, and expectations. In other words, I have a better chance of being happy if I am the kind of a person that the surrounding community expects me to be.

There are objective factors that weigh on one's prospects for a happy or good life. Intelligence may be one of them, but there a lot of other factors as well, such as relationships with other people, the environment etc., which may count a great deal more than intelligence when assessing the prospects for a satisfactory life.

Kuhse and Singer (1985, pp. 146-155) give the impression that most families with children with intellectual disabilities achieve a poor level of adaptation because the child's disability is in itself a factor that strains family members too much. Generally speaking, however, the lives of these families are not miserable, as Kuhse and Singer suggest. Coping with the stress that a child with intellectual disability may cause depends highly on the support which the family receives. Just as in the case of the quality of life of an individual, the burden experienced by the parents depends very much on the prevailing attitudes and practices in the community. If the community sees children with intellectual disabilities primarily as useless burdens and propagandizes against them, it is highly probable that the quality of life of these children will be poor, and that their parents will see them mainly as burdens because of the propaganda.

Although it would be dishonest to deny that in some cases children with intellectual disabilities are an undesirable burden to their family the reasonability of the idea that a child with Down syndrome, for example, is an excessive burden to her/his parents and siblings is, however, problematic in the first place. The burden argument is commonly connected to parents' criteria for a good life. Quality of life is constituted to some degree by how actual life corresponds with the criteria which people assume to constitute a good life. Therefore, in many cases parents think that a child with intellectual disability is an excessive burden to them simply because such a child

does not fit into their plans (see Kuhse & Singer, 1985, p. 186). Situations like this can be solved by (a) getting rid of the child, or (b) reforming the criteria for a good life. The latter, more dynamic alternative, seems much more attractive since life is full of unexpected surprises. If all unexpected things in life are sources of overwhelming stress, we really do not have a chance to achieve contentment or happiness at all. “The problem of handicapped infants”, as Kuhse and Singer (1985) put it, is thus very much a result of the fact that parents eagerly anticipate “the birth of the usual perfect baby” (p. 184). If parents hoped for a child with prospects for a happy life instead of a *usual perfect* baby the problem of newborn infants with intellectual disabilities would probably not be as significant as it is seen now by many parents and philosophers.

As regards the economic interests of society Kuhse and Singer (1985, pp. 165-166, 168) stress that there is a limit to how much we should pay to save a life. When resources are finite, we cannot make infinite provision for every life. The practical conclusion of this is as follows: more money for severely handicapped infants will mean less money for others in need. In present day Western societies this issue is, however, primarily a matter of values: if something is seen as valuable, there is certainly enough money to invest in a target we value. Thus, to view infants with intellectual disabilities as less entitled to life than “normal” infants on the basis of the economic interests of society seems overly purpose-oriented because individuals with intellectual disabilities are not in an economic sense a significant burden to society.

How should we regard the possible “interests” of the next child in the queue? Are they to override the interests of an infant with disability? Kuhse and Singer (1985, pp. 158-161) think that the life of a healthy as-yet-unconceived possible child is more important than the life of a disabled fetus or infant because the healthy possible child, unlike the “defective” fetus or infant, “has a high prospect of a normal and happy life” (Hare, 1976, pp. 369). This position is based on a view that fetuses and infants are *replaceable* beings. Fetuses, infants, and possible children are in the same moral category because none of them has an interest in a continued existence. In that sense, it is logical to think they are all morally equal considering their right to life.

The logical conclusion of Kuhse’s and Singer’s position is to see a possible normal child as more valuable than an actual newborn child with disability since a normal child will possibly have better prospects for a happy life. This conclusion certainly seems disturbing. The possible child -

argument presented by Kuhse and Singer equates the actual or potential interests of an actual human being to the possible interests of a hypothetical possible human being. In no other case would it even be considered that a hypothetical possible child is morally equal or even more valuable than a newborn infant were it not the case that the infant in question had a disability. Can intellectual or any other disabilities reasonably be seen as such great tragedies as to make a hypothetical possible normal child more valuable than an actual child with disability, or, can we predict the trajectory of *any* new life? If the argumentation presented in my article (Vehmas, 1999b) is sound, the answer is clearly negative.

As regards the issue of the justification of infanticide, the crucial thing is to evaluate whether the death of an infant can be seen as an evil that deprives her/him of being alive (see Nagel, 1979, pp. 1-10). Most of the infants with intellectual disabilities have the prospect to be able to reciprocate in authentic caring relationships. Only very few individuals with intellectual disabilities have problems living a satisfactory life or a life worth living, which means that death would, indeed, deprive them of life. Accordingly, there are very few infants who can reasonably be seen as objects of infanticide.²

Bioutilitarians criticize those that see humans as having a moral priority over animals for being speciesist. By *speciesism* they refer to “a prejudice or attitude of bias in favor of the interests of members of one’s own species and against those of members of other species” (Singer, 1990, p. 6). Bioutilitarians do avoid speciesism in the sense that they see all intellectually equal beings as morally equal, irrespective of their species. However, bioutilitarianism is an *intelligist* moral enterprise for it discriminates against people on the grounds of their intelligence. By *intelligism* I refer to placing people on the basis of their poor intellectual functioning in a morally inferior position to other people.

The obvious contradiction in bioutilitarianism is connected to their difficulty in identifying themselves either with the utilitarian position presented by Jeremy Bentham or that of J.S. Mill. Bentham (1789/1970) represents a position based strictly on the desires, preferences, or interests of a being: “The question is not, Can they *reason*? nor Can they *talk*? but, Can they *suffer*?”

² It should be noted that people with mild intellectual disabilities constitute the great majority of all people with intellectual disabilities (Macmillan, Siperstein & Gresham, 1996, pp. 357-358).

(chap. 17, 4, 2b). This is the position which Peter Singer in particular emphasizes when discussing the moral status of animals. In the case of euthanasia and infanticide, however, the bioutilitarians seem to identify themselves with the ideal utilitarian position presented by J.S. Mill (1861/1991): "It is better to be a human being dissatisfied than a pig satisfied; better to be Socrates dissatisfied than a fool satisfied" (p. 140). This passage reflects what I would call an *intelligist intuition* - a view that sees *a priori* the existence of an intelligent or an intellectually normal human as more valuable than the existence of an individual with an intellectual disability.

Bioutilitarianism is an example of a moral position which ignores the social constructionist nature of disability, namely that disabilities are created socially and derive their meaning through social interaction. An approach like bioutilitarianism locates the problem merely on the individual and inevitably has unfortunate consequences for the moral and social status of intellectually disabled people. The implications of a purely individualistic approach to intellectual disability can appear in several ways. The primary result of this individualistic position is that different kinds of procedures are aimed at the abnormal individual and the surrounding community is left intact. This approach marginalizes disabled people socially and morally and gives permission to debar disabled people from full participation in society. Various social arrangements that have influenced the lives of disabled people such as involuntary sterilization, segregated institutions, and practices that exclude disabled people from bathrooms, from transportation, from places of work or denying them life-saving medical treatment, reflect the idea that disabled and especially intellectually disabled people are, because of their abnormality, less valuable human beings than so called normal people.

A one-sided individualistic interpretation of disability inevitably leads to assumptions such as that of Kuhse and Singer (1985), namely that the lives of intellectually disabled people more or less lack 'the unique features which are commonly and reasonably regarded as giving special value to human lives' (p. 143). On the grounds of these kinds of assumptions it is difficult to see the lives of people with intellectual disabilities as good or meaningful and the mission of empowering them with the right to decide autonomously on their lives and regarding them as equal citizens becomes of secondary importance. In order to abolish the marginalization and oppression of people with intellectual disabilities they have to be regarded as equal, not merely as objects of caring (see Silvers, 1995). If this is to be achieved, one must recognise the social

constructionist dimension of disability. If society is not willing to question its expectations, values and practices which disable some people, the enterprise of empowering disabled people as equal citizens is hopeless.

Philosophical examination of questions like the ones presented here is rare in the field of special education and disability studies. Merely for this reason one may be inclined to think that philosophical examination is of secondary importance in special education. This kind of position is clearly false.

Special education (as education in general) is essentially a value-based enterprise. Educational as well as habilitational and medical practices have the aim of serving the interests and good of individuals and society. The way we value the lives of individuals with intellectual disabilities inevitably affects our attitudes towards these people and the way we strive to assist children with disabilities to live fulfilling lives and to develop their potential. Special education cannot thus be effective if its value-based aims are not defined satisfactorily. Any educational institution (just like, for example, medicine) is at heart a moral community and its members are bound together by knowledge and ethical precepts (see Pellegrino & Thomasma, 1993, ch. 3). In order to promote educational practices in such a way that, for example, special teachers would work for the good of children with intellectual disabilities and not exploit (intentionally or unintentionally) their vulnerable position, we should construe a plausible moral philosophical basis for special educational practices. Therefore, philosophical discussion, for example, of the moral value of the lives of people with intellectual disabilities can have significant theoretical and, consequently, practical implications as well.

As I have argued, disability in itself is a social concept. Disability is an effect of either the social and material arrangements of society or an organic impairment of an individual (or the effect of both of these causes). Impairment does not necessarily cause restrictions on an individual's capability of mental or physical functioning. Disability is essentially a normative concept because it expresses how a human being is assumed and expected to function. Physical or mental abilities are essential constituents of humanity not merely because these abilities differentiate us from most non-human animals as individuals but because they make possible the communal and relational aspect of human life. The concept *disability* reflects the idea that a person with a

disability lacks a certain ability which could contribute to her/his well-being as a human and as a contributing member of a community. Abilities are good and useful whereas *disabilities* may be impediments as regards human flourishing. Thus, the whole idea of disabilities is that they may threaten our project of being good and desirable human beings and therefore our project of pursuing a good life may be jeopardized. Sociological or psychological research, for example, can illuminate on what basis certain conditions are created and defined as disabilities but the essential core of the concept disability is ethical. The crucial point, then, is to examine the relevance and soundness of the norms that cause us to define certain conditions and ways of functioning as disabilities. The fundamental question is: what conditions or ways of functioning can on sound normative grounds be regarded as disabilities? When we examine these kinds of questions carefully, we inevitably start to discuss different views of a good life and have thus stepped into a fully-fledged moral philosophical discourse. Therefore, although moral philosophical inquiry is at present quantitatively marginal, it is the essential substance of special education and disability studies.

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