Special Interest Group on Ethics and Intellectual Disabilities Meets in The Netherlands

The first Roundtable of the Special Interest Research Group (SIRG) on Ethics and Intellectual Disabilities was held on April 16-18 in Doorn, The Netherlands. Eighteen researchers from five countries—including Australia and Bangladesh—discussed themes like “the moral status of persons with intellectual disability,” “care as a meaningful relationship,” and “intellectual disability between ethics and political philosophy.” Also three regional reports were presented about ongoing ethical research projects in Australia, the Netherlands, and the United Kingdom.

The SIRG on Ethics and Intellectual Disabilities is sponsored by The International Association for the Scientific Study of Intellectual Disabilities (IASSID). The president of IASSID, professor Trevor R. Parmenter, who is also director of the Centre for Developmental Studies of the University of Sydney, Australia, honored this first Roundtable with his presence. Members of the SG are preparing contributions to the next World Congress of IASSID, which will be held in Seattle, USA, August 1-6, 2000. During this World Congress a second roundtable of the SIRG on Ethics and Intellectual Disabilities will be organized.

Summaries of some of the presentations held at the SIRG meeting in Doorn are included as articles in this issue of the Newsletter beginning on page 2.

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The moral status of people with intellectual disabilities is open to question from a number of perspectives. In terms of philosophical argument for example, Steven D. Edwards argues in this issue of the Newsletter, that the moral status of people with intellectual disabilities is constructed as being less than that of non-intellectually disabled individuals (Edwards, 1997). The moral status of people with intellectual disabilities is also open to question in terms of the codes of ethics / conduct that professionals working with people with intellectual disabilities, subscribe to and work within. These codes inform the delivery of services and professional relationships with people with intellectual disabilities. A third perspective from which moral status is beginning to be questioned is the citizenship status of people with intellectual disabilities, which raises questions about the relationship between the moral status of individuals and their citizenship status.

Mostly examinations based on these perspectives are undertaken in isolation from each other. Too rarely does the philosophical examination extend to a consideration of professional practice, and rarely do either consider wider implications or questions of the social status / citizenship. My suggestion here is that there is an important relationship among these perspectives that is worthy of consideration in terms of understanding the experiences, valued (?) identity, and status of people with intellectual disabilities within society.

Professional codes of ethics that relate to the “caring” professions, for example the British Association of Social Workers (BASW 1996) Code of Ethics for Social Workers, and the United Kingdom Central Council for Nursing, Midwifery and Health Visiting’s “Code of Professional Conduct” (UKCC 1992) both identify professional responsibilities and obligations to the client /service user. Both BASW and the UKCC also explicitly emphasize the “value and dignity” of every human being, irrespective of morally arbitrary aspects of identity such as age, race, sexual orientation, disability, etc. However if one examines these intentions in detail, in terms of their philosophical roots, one very soon comes across problems regarding the extent to which “clients” interests, in particular the interests of persons with intellectual disabilities, are protected or promoted.

For example the BASW code is acknowledged as being based on the Kantian moral imperative of “respect for persons,” the basis of which is the individual’s possession of rationality/rational will and the associated ability to act autonomously. The possession of these qualities constitute “personhood.” But how does this relate to individuals who do not possess rationality and the ability to act autonomously? How does it apply to those individuals who due to the extent of their intellectual disability, or through social and professional processes of categorisation and labelling, have been denied “personhood?” These questions are highly problematical when one considers the professional / service implications for people with intellectual disabilities, in that the code of professional ethics potentially fails to accommodate the vulnerable, “marginal” individuals that it is intended to protect, and whose interests it is intended to promote.

This raises important questions about how to include people with intellectual disabilities within codes of professional ethics that are derived from respect for persons. Is it simply a matter of redefining notions of personhood to include non-rational, non-autonomous individuals, or more fundamentally should we question the basis of the moral status of individuals as deriving from their individual pro-

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The Moral Status and Professional Ethics: Issues of Identity and Citizenship

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properties - their personhood? Should we, perhaps more fruitfully in terms of including previously "marginal" people, situate the moral status of individuals in terms of the social relationships between themselves and other human beings, rather than the ("valued") individual properties that an individual might possess?

In the communitarian approach to citizenship, the individual is defined in terms of her relationship to and membership in the "community," rather than her ability to act autonomously or her ascribed status as a moral being.

This immediately begs questions of the citizenship status of those individuals whose moral status has been denied and whose ability or opportunities to act autonomously may be limited or non-existent. Again, this raises questions about the moral status of people with intellectual disabilities.

If however, one takes a "communitarian" approach to citizenship, this problem is at least not so prominent, and it could be argued, is avoided to some extent at least. In the communitarian approach to citizenship, the individual is defined in terms of her relationship to and membership in the "community," rather than her ability to act autonomously or her ascribed status as a moral being. This approach, initially at least, appears to be much more sympathetic to the inclusion of people with intellectual disabilities as full citizens and in the extent to which it underpins their community presence and inclusion in society.

Hopefully this very brief analysis, and the questions it raises, suggests that not only is there a need for a careful examination of the philosophical and ethical bases of our attitudes towards people with intellectual disabilities but that this examination could usefully benefit from an approach that encompasses, moral, professional, and political analyses.

References:


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Advocates Sue for Faster Access

In March of this year advocates for the retarded in Massachusetts filed a class-action lawsuit to speed access to homes and day-care programs for persons with retardation. According to a report in the New York Times (March 21, 1999, page 27), parents of over 100,000 mentally retarded adults in the United States are awaiting assistance. Many of the parents are in their 60s and 70s and have mentally disabled family members who have been waiting for a place in a program that will assist them.

One parent, Christina Anderson, is reported to have said she has waited for a decade for a residential program for her 41-year-old daughter, Valerie. Valerie is retarded, deaf, and legally blind.

Leo Sarkissian of the Association of Retarded Citizens of Massachusetts estimated that it would take $100 million to solve the problem in a four-year time frame—just for the state of Massachusetts. The results of the lawsuit are not yet available.
Recovering The Moral Status of People With Intellectual Disabilities

Steven D. Edwards

It is plausible to claim that people with intellectual disabilities are generally accorded a moral status which is lower than that accorded to the intellectually able (see, e.g. Edwards 1997). This raises the following question (amongst others): is there any available account of moral status which recovers the moral status of people with intellectual disabilities?

During the SIRG meeting at Doorn, The Netherlands, three main strategies were discussed.

(i) Rationality: Accounts that bind moral status to capacity for rationality seem least likely to recover the moral status of intellectually disabled people since such people are characterized in terms of their reduced capacity for rationality (or at least, reduced cognitive capacity). Such accounts, if applied to issues of allocation of health care resources, for example, imply that a rational chimpanzee would have a greater entitlement to scarce resources than would a seriously intellectually disabled human being.

(ii) Sentience: The proposal to tie moral status to rationality seems overly exclusive, as just shown. So what of a more inclusive criterion such as sentience? This would mean at least that the chimpanzee and the seriously intellectually disabled person had the same moral status, and not that the former has a higher moral status. So the appeal to sentience suffers from the fatal flaw of being overly inclusive. Applied to the question of allocation of health care resources, it would imply that all sentient creatures have an equal claim on such resources. This seems highly implausible.

(iii) Being human: Given the inadequacy of both sentience and rationality as criteria for recovering the moral status of intellectually disabled people, what of tying moral status to species membership? This strategy has the merit of cohering with the intuition that in questions of moral status it is plain that humans have a higher moral standing than non-human animals. Thus there would be no question of a chimpanzee, say, being given health care resources in preference to a human who is in need of them.

However, it is common to argue that this proposal simply represents the prejudice of “speciesism”; it involves discriminating against (non-human) individuals on grounds that are morally arbitrary. Grounds such as race or gender are more usually involved in such discriminations. But here the charge is that just as racism and sexism are morally abhorrent, so too is speciesism. Intuitive claims to the effect that it is ‘obvious’ that humans have a higher moral status than members of other species seem vulnerable to the observation that is was equally “obvious” in the past that males were superior to women, Greeks to non-Greeks, and so on.

Counter-responses to save the strategy included the following: (a) It may be argued that speciesism is not in fact a prejudice of the same kind as those of racism or sexism. If this could be shown, this may be a means of deflating the force of the charge of speciesism. (b) As Professor Hans Reinders suggested, perhaps the difficulties inherent in strategies (i)-(iii) show that a wrong turning has been made in the posing of the whole question of moral status (a suggestion made also by Dr. Chris Goodey). The work of Emmanuel Levinas (1969) might fruitfully be appealed to in order to make progress on this very difficult and central problem in the philosophical problems surrounding intellectual disability.

References:


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The generic concept of intellectual disability has very imprecise boundaries, suggesting that it is socially constructed at a deep level. The boundaries have also shifted historically. Any kind of concept recognizable to us dates back only to the seventeenth century, when four main changes occurred in our thinking about human psychology. First, the mind was separated from the body and became a natural, secular realm in its own right; secondly, strict rules of classification were applied to the natural world (including the mind); thirdly, nature and nurture/society became opposites, where previously nature had been an undeterministic middle-ground between nurture/society on the one hand and necessity or fate on the other; finally, the mental life of the individual came to be seen as a seamless object from birth to death, and in pathological cases from congenital to incurable. This mind-set gave birth to modern psychology, a process in which the concept of intellectual disability was instrumental.

Politically, it facilitated the democratic notion that the mass of people were intellectually capable of giving their consent to be ruled, because it identified those who were naturally unable to consent. Sociologically, intelligence started to replace honor as the main external currency of social status. Theologically, certain thinkers extended the concept of the elect to include everyone who had "intellectual ability" or "potential," but excluded those who lacked it.

Although these changes were conceptual, they grew out of real social relationships. The new concept of a generic intellectual disability arose from the application of the new mind-set to existing population groups already deemed intellectually inferior: blacks, women, children, lower social classes. The modern concept was therefore a hypothetical abstraction, helping to redefine the subordination of these con-crete groups. When descriptions of intellectual disability appear to transcend history, it is because they are metaphysical: we are forced to keep returning to them because we cannot find a way beyond certain explanations that are deeply embedded within the Western outlook. For example, (1) our notion of the mean leads us to construct something "slow" and "deficient" (intellectual disability) by antithesis with the "speed" and "excess" of mental illness; (2) the inherent problems of our mind-body dualism compel us to return to the body in order to explain the mind; (3) our cultural fears of pollution compel us to keep seeking pathological exceptions to any attempt at inclusion.

The new concept of a generic intellectual disability arose from the application of the new mind-set to existing population groups already deemed intellectually inferior

Ethical aspects of intellectual disability also have a history. First, pre-modern "reason," as a set of common principles supplied by God, made atheists unreasonable and put them beyond any ethical consideration or justice; modern "intelligence," a set of mental operations in the individual, brought atheists back in because it assumed they were teachable and put people who were unteachable beyond justice instead. Secondly, ethics had previously been a starting-point in the investigation of nature; once the mind became a scientific realm of objective nature, ethics was separated from epistemology and became secondary to it.

Thus ethics has become a restricted sphere. Some people limit it to a discussion of the “quality” of the individual life; this has the practical advantage of being related to current social conditions, but identifies as desirable for intellectually disabled people the same things (e.g. autonomy) that define their deficit, the lack of which can also be used to justify their elimination. Radical alternatives have included communitarian ethics, a retreat into meta-ethics and hermeneutics, religious dogma, or deconstructionist scepticism: these are weakly related to social conditions and thus inherently pessimistic. Both quality of life arguments and their radical alternatives tend to mean by “ethics” an external prescription. For that reason the claim to do ethics may itself be ethically problematical. We could instead look outside existing ethical discourse, to the habitual inclusive practices of normalised environments (family, regular school, leisure activities etc.) in which the intellectually disabled individual participates.

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Rights and intellectual disability have traditionally been seen as mutually exclusive concepts within liberal theory. Recently however, relying primarily on contemporary justice theorists such as Dworkin and Rawls, this assumption has been challenged from both a theoretical and epistemological perspective (See: Stainton, 1994; Rioux, 1994). While a complete review of these arguments is beyond the scope of this short article, a basic summary of the position can be put forward.

The approach is grounded in the concept of autonomy or more loosely, self-determination, the capacity to formulate and pursue plans and purposes that are self-determined. A significant aspect of this definition is that it is concerned with capacity rather than outcomes. Certain outcomes will become important if they preclude further autonomous action, but they become important because of their impact on capacity. Simply put then, rights are conceived of as those generally necessary means which provide the basis for autonomous action.

Equality is similarly defined as equalizing to the greatest extent possible every citizen’s means to autonomous action. Again the concern is not with outcome but with the means to formulate and pursue a particular conception of the good. Hence, traditional liberal ideas of formal equality and equality of opportunity are insufficient since different people require different types of treatment to achieve the same basic capacity. (See Rioux, 1994). It is important to note that we are not talking about special rights, simply differential treatment to actualize the same rights equally.

Rights then are conceived as the individual's legitimate claims to resources and forbearances generally necessary to formulate and pursue self-determined plans and purposes. Conflict between rights is resolved by identifying which rights are more essential as generally necessary means to autonomous action. This is to be understood as referring not only to income and wealth, but to "basic capabilities" which would include physical and emotional well-being.

Rights are not of course inalienable. The demands of equality and the harm principle, conceived here as interference with another's autonomy, are the two primary means of limitation. A third factor is that of paternalism. Simply put, paternalistic intervention is only justified if there is a clear enhancement or protection of autonomy and must be aimed at enhancing or restoring the individual's capacity for autonomous decision making. The burden of proof lies with the potential intervenor and decisions on competence must be both agent and act specific. In other words, a general denial of rights to a class of persons is untenable within this model. Finally, the principle of autonomy reasserts itself once a determination of incompetence has been made. Therefore, any intervention must limit autonomy to a minimal degree and duration and, where possible, be aimed at enhancing or restoring competence.

For many people with intellectual disabilities the ability to articulate their wants and needs is limited, but this does not change their basic rights to autonomy, however limited. For this reason, a crucial aspect of a rights based system is advocacy and support from people who are personally bonded to them and as such are best able to interpret their wants and needs. As a crucial ingredient, advocacy needs to be recognized in law and funded by the state.

The role of the state is not to define what a person’s needs are or how they are to be met, but to negotiate with the individual on what needs are legitimate claims against the state and to support the person in meeting those needs in ways he or she chooses.

Some rights will be explicitly codified in charters and law, the vast majority will however be implicit in the structures, policy, and practices. What this position implies is that individuals, supported by their advocates, should not only be able to define their needs but also how those needs are to be met. The role of the state is not to define what a person’s needs are or how they are to be met, but to negotiate with the individual on what needs are legitimate claims against the state and to support the person in meeting those needs in ways he or she chooses. What defines a need (Continued on page 7)
as legitimate, is A: whether it is required to protect or promote the person’s autonomy, and B: whether the need is consistent with ensuring that the individual has an equal capacity for autonomy as any other citizen. In order to achieve this, specific structural changes are needed encompassing a move away from block services and funding to models of individualized funding and some form of independent technical advice such as a service brokerage.

With regards to ethical decision making, this position specifically excludes general considerations of quality of life and requires that any decision must be argued on the basis of what is most protective/enhancing of a person’s autonomy, not what is best for the state, family, or some generalized “person with an intellectual disability.” As above, where the individual is not able to directly consent to a given decision, those most personally bonded to the person are the best arbiters of this in most cases.

References:


**Medical Students Consider Down Syndrome a Heart Transplant Contraindication**

In a recently published survey of second-year medical students at the University of California, Los Angeles, 65 percent considered Down Syndrome a reason not to provide a heart transplant. In the same study, 35% said “low IQ” was a contraindication leaving open the question of why they were particularly opposed to transplanting persons with Down Syndrome. Since cardiac problems are known to accompany Down Syndrome and may account for part of the shorter than average life expectancy of persons with the syndrome, it is not clear why the students would be more opposed to transplanting this group than others with low IQ.

The study was conducted by Michael S. Wilkes, MD, PhD, and Stuart Slavin, MD, MEd, both at the UCLA Medical School. It appeared in *The Journal of Clinical Ethics*, volume 9, number 2 (Summer 1998). The authors compared their results to an earlier study of transplantation directors in which both low IQ and Down Syndrome was reported as being a reason not to provide cardiac transplantation. In that study as well, Down Syndrome was considered more negatively than “low IQ.” In the United States, the United Network for Organ Sharing, the national organ procurement and transplant network, has no policy restricting organ transplant to persons with intellectual disabilities.

**Bibliography**


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