

Respect for Persons in Bioethics: Towards a Human Rights-Based Account

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Abstract Human rights have increasingly been put forward as an important framework for bioethics. In this paper, it is argued that human rights offer a potentially fruitful approach to understanding the notion of Respect for Persons in bioethics. The idea that we are owed a certain kind of respect as persons is relatively common, but also quite often understood in terms of respecting people's autonomous choices. Such accounts do however risk being too narrow, reducing some human beings to a second-class moral status. This paper puts forward a political approach to our standing as persons and a strongly pluralistic account of human rights that lays the ground for a more broadly applicable conception of Respect for Persons. It is further argued that this model also provides an example of a more general approach to philosophical ethics, an approach which is here called taxonomical pluralism. When it comes to Respect for Persons specifically, this principle is developed in terms of five distinct core concerns (autonomy, dignity, integrity, privacy, and vulnerability).

Keywords Bioethics · Autonomy · Respect for Persons · Human rights

While a basic right to health care has been part of the international framework of human rights since its very inception, it is not until the last couple of decades that we have started to see more detailed human rights documents on bioethics, more clearly delineating the rights of people as patients or research subjects. The two most central ones are probably the 1997 CoE Convention on Human Rights and Biomedicine, also known as the Oviedo Convention, and the 2005 UNESCO Declaration on Bioethics and Human Rights. The 2007 UN Convention on the Rights of Persons with Disabilities is however also a highly relevant document in the context of bioethics because of its implications for how we should understand autonomy.



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Medical practice and medical research hardly did without ethical frameworks before 1997 however. Not only has the medical profession been holding to a strong ethical self-understanding already since antiquity, the WMA Helsinki Declaration, first adopted in 1964 and now in its seventh revision, has been highly influential in codifying the duties of physicians and medical researchers. And since the 1970s, the field of bioethics has also seen a tremendous growth, with the four-principle model put forward by Beauchamp and Childress (2013) probably being the most well-known ethical framework for medical decision making. From a belt-and-braces point of view, having a number of different and to a large extent overlapping ethical frameworks can be seen as just providing extra ethical support for the medical profession, but with respect to consistency and coordination in law, policy, and decision making there can be a problem with having multiple frameworks. Faced with this issue some writers, like Faunce (2005), have envisaged that the human rights framework could and should subsume bioethics, whereas others have raised the possibility of convergence instead (Ashcroft 2010). Irrespective of which way you go, there is a question of just what human rights can add to bioethics.

In what follows here, the idea that will be pursued is that human rights can serve as a reasonable basic framework for considering bioethical questions, not just as setting certain basic standards for health care on a global level (e.g., Teays et al. 2014) but as a starting-point when it comes to public discussions about how to organize and regulate health care in today's societies as well as how to structure and understand concrete issues about assessing different procedures and treatment options. Human rights would then form a core of bioethics, although it would still be far from all of bioethics. Part of the reason why human rights should be able to serve this role is historical: the provision of health care has in most developed countries become more and more a central concern of our political institutions, with governments playing a significant role in regulating and facilitating the provision of health care, in many countries even largely organizing it. Medical ethics was perhaps once much more narrowly about the physician-patient relation, but in today's societies, this relation is strongly embedded in an institutional framework where the state plays a key role, even in countries where much of the actual care is still provided by private practitioners. This lays the ground for human rights, which at least qua legal regime are clearly state-centric, increasingly becoming a live candidate as a bioethical framework, where human rights can serve as an ethical starting point even for non-state actors, potentially also helping to bridge the gap between medical law and medical ethics.

Of course, to fully establish the point that human rights can (and should) be the common ground that we stand on in having discussions about health care goes beyond the scope of a single paper, so the argument here will focus at one specific positive reason for opting for a human rights approach, namely that it is unwavering in its insistence on the high and equal value of all human beings. It will however also look at two potential obstacles. The first is that this very reason for having human rights as a bioethical framework possibly only holds because human rights are lacking in a philosophically acceptable foundation. The second is that human rights are too "lawyerly" to serve as a viable framework for moral reasoning. The standard response to these issues by philosophers who are positively inclined towards human rights is to add a more typically philosophical groundwork as a basis for human rights: to make human rights look more like a traditional normative theory. The argument in this paper will run in a different direction, namely that the mismatch between human rights and



traditional normative theory can be addressed by going the other way instead, by (i) making normative theorizing look more like existing human rights frameworks and (ii) understanding the status involved in having personhood as first and foremost a political status that then informs morality, rather than the other way around. In the present paper this argument will be focused on the particular case of bioethics, more specifically on how to understand *Respect for Persons* in bioethics, but the argument also points to a more general understanding of the relation between human rights and philosophical ethics.

Ratiocentrism in Bioethics and Normative Theory

Any argument for a particular framework will at the end of the day be comparative: *this* framework is better than *that* or *those*. This also means that such arguments are inevitably tentative since there will always be many different versions of any given type of framework and it is difficult to create arguments against every single one. In painting a background picture that sets the scene for one's own argument, it is necessary to generalize. Hopefully, the background picture presented here will not be wildly off the mark, but there will certainly be nuances missing from it. Now, there are two main elements to this background that together create the problem to which an approach based in human rights is potentially a solution. The first is the strong concern in much of contemporary bioethics about not just seeing human beings as bodies to potentially be healed in different ways but also as persons which should be respected in ways that go beyond simply promoting some measure of health. The second element is about what kind of resources there are in traditional normative theory for framing or grounding this kind of understanding of human beings.

Starting with the first element, when bioethics started to pick up speed as a discipline in the 1970s, one can see a clear emphasis on understanding human beings as persons. In fact, the title of Paul Ramsey's influential 1970 book was precisely, *The Patient as* Person. Health is an important good but not the only one. Treating someone as a person is not simply about physicians doing what they expect will maximize the patient's health. In line with this *The Belmont Report*, presented in 1979, put forward a framework for dealing with research subjects that consisted of three principles: Respect for Persons, Beneficence, and Justice. The main underlying rationale for Respect for Persons was the importance of respecting autonomous agency, and obtaining informed consent was understood as the main application of that principle, but Respect for Persons was at least potentially about more than autonomy and informed consent. A year later, the first edition of The Principles of Biomedical Ethics was published and apart from splitting Beneficence into two principles, Beneficence and Nonmaleficence, it also replaced Respect for Persons with Respect for Autonomy, thus moving to close the potential gap between what it means to respect people as persons and to respect them as autonomous agents. This idea of respect for autonomy was in the end also boiled down to more or less a matter of obtaining informed consent. Tom Beauchamp notes retrospectively (2011, p. 516) that "the arrival of informed consent and the birth of bioethics occurred at exactly the same time." Now, the point here is not that this kind of ratiocentrism, putting relatively sophisticated cognitive functioning at the center of attention, characterizes all of



contemporary bioethics, but it is an important part of the bioethical mainstream, especially in an Anglo-American context. And as Therese Lysaught (2004, p. 676) has pointed out, the implication is then that "[r]espect no longer pertains to the non-autonomous. Instead, their fortunes are determined by the principles of nonmaleficence and beneficence. Insofar as Beauchamp and Childress could describe these latter two principles in little more than utilitarian terms, their protections do not carry the moral security of respect."

To set things in perspective, it should be said that this move of, more or less, equating the idea that we as human beings are owed respect for persons with the idea that we are owed respect *qua* beings capable of autonomous decision making is far from recent. It is characteristic of one of the two main traditions in philosophical ethics since the late eighteenth century, namely Kantianism. The classic Kantian position can be said to be doubly ratiocentric because it involves understanding both the grounds of full moral status and the fundamental moral principle on which we should act in terms of our capacity for autonomous decision making. That Kantian ethics operates on these two levels is nothing peculiar; on the contrary, this is only to be expected of a complete normative theory. Such theories are standardly expected to give us at least two things: (i) an account of which beings to whom we owe moral concern and why and (ii) an account of which the relevant moral concerns are that we need to act upon in dealing with those beings. Typically, we would also expect these two parts of the story to make sense in the light of each other, which in classic Kantian ethics clearly is the case.

The other major tradition in modern philosophical ethics is utilitarianism or consequentialism. Here, we typically have an understanding of the grounds for full moral status in terms of the capacity to feel pleasure or pain or to have preferences over different outcomes. On the face of it, this is not a ratiocentric account. One thing that tends to characterize the utilitarian tradition, however, is that there is often a more complicated relation between (i) and (ii). Especially in the sub-tradition following J.S. Mill, there is a strong emphasis on respect for autonomy as a way of promoting the good. This is part of the reason why bioethicists like Beauchamp and Childress do not think that they have to make a choice between Kantianism or utilitarianism, because irrespective of which fundamental normative approach one adopts, one can still understand their four-principle framework as a reasonable framework in bioethics. Utilitarian thought can of course be pursued in another direction as well, one that is critical of the very idea that respect for persons is an important concern, but since the aim in the present context is to understand respect for persons as a concern in bioethics, that kind of approach will be set aside. What matters here is that to the extent that utilitarians care about respect for persons, it tends to largely be in terms of respect for autonomy.3

³ Among leading contemporary bioethicists, John Harris could be taken as an example of someone working in this tradition; in his own words his approach is "broadly consequentialist—with strong libertarian tendencies" (2004, p. 177).



¹ One of the main sources of opposition to this kind of picture is feminist ethics in general and feminist bioethics in particular, for instance in developing relational approaches to autonomy that are often less ratiocentric in character (e.g., Mackenzie & Stoljar 2000).

² Albeit with a quite distinct and original understanding of autonomy, as emphasized by O'Neill (2002).

A ratiocentric approach to full moral status, what can be called *foundational ratiocentrism*, is deeply problematic in that it simply does not seem to fit with how many of us understand the moral status of human beings. We do not think that we only owe the highest moral concern to human beings capable of sophisticated cognitive functioning. Even to the extent that ratiocentric foundationalists can tell a story about why all human beings in the end still have moral standing, there will always be a sorting of people into those for whom there is a short and simple answer as to why they have moral standing and those where there is a more complicated and indirect explanation. There will accordingly be a difference in the extent to which the moral status of different people presents us with live questions, leaving some human beings, as Eva Feder Kittay (2005) has put it, *on the margins of moral personhood*. A Benthamite approach to moral status fixes this but, at least with respect to common sense, goes too far in the other direction: making humans and other animals into equals and potentially undermining the very idea of respect for persons as a reasonable normative ideal.

Potentially one can do normative ethics (and bioethics in particular) without going into the question of what the ground for moral status is; one can simply focus on the concrete framework instead. These are accounts that just provide us with lists of the rules or principles supposed to govern our behavior and do not go into questions about why we have moral standing. The four-principle model of Beauchamp and Childress is like that. Such accounts can however still be characterized by what might be called substantive ratiocentrism, where the ethical model is centered on protecting and promoting sophisticated cognitive functioning like autonomous decision-making. The authors of The Principles of Biomedical Ethics have insisted on their principle of Respect for Autonomy not occupying a privileged place, but not only have others explicitly seen it as "first among equals" (Gillon 2003), the recasting of Respect for Persons as simply being about Respect for Autonomy signals that the very aspect, personhood, which is often thought to separate human beings from other animals is a feature that really only attaches to cognitively high-functioning human beings. As recently pointed out by Joseph Stramondo (2016) there has historically been a conflict between the field of bioethics and the disability movement and that the prominence of the principle of Respect for Autonomy, as more or less the way in which we are respected as persons, has played an important role in this.

It might be responded that perhaps too much is being made here of specific formulations in Beauchamp and Childress, but also that even in models like theirs there is nothing that *necessitates* that less moral concern is being paid to human beings who are not cognitively high-functioning. With respect to the first point, Beauchamp and Childress are certainly just one example of contemporary bioethics, but there is no room here for an exhaustive literature review and at the very least they can hardly be

⁴ It should be said that there are possible strategies for addressing this kind of problem. One is to argue that potentiality for the relevant capacity is enough (e.g., Stone 1987); but while this might matter with respect to abortion ethics, it does little to ground the full moral status of humans with cognitive disabilities. Another is to argue that what matters is membership in a species where members typically have certain relevant capacities (e.g., Cohen 1986) or that human beings as a kind are characterized by them (e.g., Sulmasy 2007). A focus on membership will eventually characterize the approach articulated here, but to the extent that such an approach is built on ultimately anchoring full moral status in the value of sophisticated cognitive functioning, there will arguably still tend to be lingering questions about just why those who lack these capacities really matter.



said to be an unrepresentative example. The other point is more complex. It is perfectly correct in principle (indeed, very few things literally necessitate other things in human affairs), but if we understand normative frameworks as something that human beings are supposed to use as a starting-point for discussions and deliberations about ethical issues, it is still important to think about to what extent such frameworks can create expectations about what is normal and what is deviant as well as who are at the center of moral attention and who are at the margins. This is one of the main problems with substantive ratiocentrism and an important reason why the conflict that Stramondo points to cannot be resolved just by explaining how little that *logically* follows from normative frameworks that put Respect for Autonomy at the center of ethical thinking.

Can human rights, then, provide a better framework? At least on the face of it, human rights represent an approach that highlights our humanity as the ground for our moral status. It is also an approach that is much richer in terms of the rights and values that it covers, which means that it does not have a natural center in the way that many traditional normative theories have, both in ethics in general and in bioethics in particular. Unfortunately, both of these very features which make human rights into a promising framework to escape from the ratiocentrism of many other approaches can also be seen as potentially problematic, at least if human rights are supposed to function not just a backgrounding legal framework, but also a normative ethical framework in terms of which we reason together in public discussions about health care.

With respect to the foundational side, the grounding of moral status in mere humanity is rarely seen as philosophically satisfactory, e.g., John Harris describes it as a piece of "problematic self-congratulation for our particular stage of evolution" (2011, p. 18). Since an ethical framework does not essentially need a foundational story, this problem could in principle be set aside, but a reasonable foundational story does at the same time add something more to a framework than just a philosophical basis; it also adds a spirit in which the rules or principles of the framework can be interpreted and implemented. We will address this in the "Personhood and Human Rights" section. When it comes to the substantive side, one potential problem for a convergence between bioethics and human rights is precisely that while the former is oriented towards philosophy, the latter is oriented towards law. Even if we have a focus on rights, then as pointed out by James Nickel (2007, p. 20), "[h]uman rights as we know them today are the (specific and numerous) rights of the lawyers, not the (few and abstract) rights of the philosophers." The typical response by philosophers to this problem is to identify an essential core of a few rights or values, from which more specific rights can then be derived. This is, however, a strategy that seems risky given that it is the rich pluralism of right and values that potentially can enable a human rights-based approach to escape the ratiocentric character of many traditional philosophical accounts. This issue will be the focus of the "Two Kinds of Pluralism" and "Human Rights and Respect for Persons" sections, the main argument being that at least when it comes to bioethics, having this kind of richly pluralistic approach is desirable and allows us to understand the principle of Respect for Persons in bioethics in a way that is more broadly applicable than if it was simply understood in terms of Respect for Autonomy.



Personhood and Human Rights

When it comes to more developed philosophical approaches to human rights, one common strategy is to understand human rights as enabling agency and autonomy, which would seem to indicate that it is our capacity for certain forms of agency and autonomous decision-making that is the essence of our humanity; both Alan Gewirth (1996) and James Griffin (2008) are examples of this approach. Since this largely Kantian strategy would seem prone to end up in the kind of ratiocentrism that was critiqued above, it will be set aside here. Alternatively, some theorists opt for a largely Aristotelian strategy where human rights are anchored in much richer conceptions of human nature and the distinctly human good life that we are capable of leading, with human rights providing the conditions for such good lives; Martha Nussbaum (1997) and Matthew Liao (2016) are examples of this approach. But if we are worried about how philosophical accounts can, often implicitly, sort people into normal and marginal cases, it seems problematic to start out by articulating a conception of *the* good life.⁵

One problem here is that when it comes to identifying the grounds for full moral status, we tend to start out with a strongly held antecedent view on just who should be picked out by the necessary and jointly sufficient conditions that we are to articulate, namely human beings. But looked at individually, human beings vary greatly in just which characteristics they have when it comes to features that have to do with how they centrally function and which define the kinds of lives that they are capable of leading. The other potential main strategy is membership-based, but this is a strategy that readily invites the charge of *speciesism* if it is supposed to define a necessary and sufficient condition for moral standing. In the case of human rights it must, however, be remembered that they are not typically understood to amount to a complete account of all relevant moral and political norms; rather, human rights are about how our societies and our institutions should be organized in terms of the basic moral and political framework. To the extent that this kind of approach is speciesist, it is not because it implies that other animals should not have moral status, it is because it does not seek more than to articulate a coherent conception of the institutions that will form the core of good, or at least decent, human societies. The moral status of animals is then a separate question.

If we look at matters this way, one answer that readily invites itself is that the characteristic of the human species that makes human rights relevant to us is precisely that we form societies. We are not just social animals, but institutional animals. Many traditional accounts of human agency and norms, especially in the contractualist tradition, start out with a picture of the individual agent and *then* introduce institutions in order to solve problems that arise when different individuals have to interact in a limited space and faced with limited resources. Now, we certainly do share limited space and face limited resources, but on the picture suggested here, we should instead take the fact that we form societies and create institutions as a starting point and not an end point of our moral and political thinking. Political and legal institutions do not

⁵ It should be said that such accounts tend to be formulated to allow for a great plurality of ways of life, but any positive account of, say, human flourishing or central human capabilities will still be at risk of reifying ideas about what is normal, which is potentially problematic for instance in relation to persons with disabilities (cf. Cochrane 2010, p. 240).



merely play a regulative role in human life, but also a constitutive one, i.e., it is not just that we have human life and human relations and *then* we try to make things run more smoothly by introducing certain institutions. The institutions themselves always already shape the ways in which we think of ourselves in the context of society and the ways in which we form relations with other human beings. Rather than trying to identify a prepolitical moral basis for human rights, personhood as a normative status is a political standing through and through.⁶ The fact that we are institutional animals is a feature we possess as a species, or at least as belonging to communities of that species, it is not a feature that any single individual possesses. This fact that we do form societies and create institutions then raises a normative question about how we ought to do so.

Human rights provide something like a blueprint for building good, or at least decent, human societies and an important part of that blueprint is about how we conceive of each other and how we relate to other members of human society. Our full moral status is certainly something which goes beyond the political, but at its core, our standing as persons is something woven into the very fabric of societal institutions in a good society. When it comes to the question of moral or political standing, a human rights approach is, however, not merely about human beings having high and equal value as members of human societies; it also involves a particular form in terms of which our membership is understood, namely as rightholders. Why this form? In a classic paper, Joel Feinberg (1970) makes a series of thought experiments to answer the question of what is added by having rights as part of our ethical framework. After all, while the concrete goods that rights might grant us are all very nice, it is still possible that we could get all of those things without having a system of rights in our society. And what would rights add, then? For Feinberg, the answer is ultimately not about what we get, but how we get it. There is a vast difference between getting something because someone just happens to be nice to you compared to because you have a right to it. Framing our membership in society in terms of rights signals something important about how we form a society together. To conceive of people as rightholders in the broad and inclusive sense characteristic of the human rights regime, rather than to conceive of us as subjects or mere members, is to signal that society is there for our sake rather than the reverse. We are bearers of claims against society, not mere commodities or exchangeable cogs in the social and economic machinery.

The very notion of respect would in general seem to be about a form of deferential regard in relation to other people, and deferential regard is something that is clearly connected to one's standing in society. In a traditional hierarchical society this is something that the many will owe to the few, but in a society where everyone is equally considered as a rightholder, this kind of deferential regard is owed to everyone by everyone. It is about not treating other people like they are lesser beings. Respect for Persons in this sense is not just about regulating our already existing social relations; it plays a constitutive role in building a certain kind of society. Note that the idea here is not that as private individuals we should primarily relate to each other as rightholders and dutybearers in everyday life; properly human rights-based duties are held by us *qua*

⁶ The argument here ties in with a larger debate between what are often called naturalist vs. political approaches to human rights (for more on this, see Liao & Etinson 2012), a debate which cannot be delved into in the present context, although the position developed here certainly fits with the Rawlsian slogan of being *political not metaphysical* (Rawls 1985).



occupants of roles and positions in societal institutions that involve some central role of the state, at least as an overseer of the functioning of these institutions (and health care institutions are an example of this). Our standing as bearers of human rights does, however, still lay down a basic structure which creates the possibility of a misalignment when it comes to certain ways we can treat each other as private individuals. Even with what is fundamentally a political conception of personhood, there are broader implications for how we ought to treat each other and which kinds of moral outlooks that are reasonable or not.

Two Kinds of Pluralism

We now turn to the second potential obstacle: the "lawyerly" character of lists of human rights. We are here talking about pluralism in terms of how many basic rules or principles that make up a given framework. If one looks at pluralistic ethical theories in philosophy they tend to be rather modestly pluralistic. A classic theorist like W. D. Ross (1930) lists six principles. In bioethics, the most well-known theory, the principlism of Beauchamp and Childress (2013) features four principles. One of the main alternatives to principlism, the common-morality approach of Gert et al. (2006) features ten moral rules instead; but then, those rules are intended to cover all of morality. Classic Kantianism or utilitarianism are instead monistic approaches, identifying a single highest principle, but here the focus will mainly lie on how to be a pluralist, ideally in a way that does not create a normative center of gravity where some human beings end up on the margins of moral personhood.

The rich pluralism of the human rights regime means that even if we restrict ourselves to a bioethical context, it is quite clearly more complex than either of the positions formulated by Beauchamp and Childress or Gert, Culver, and Clouser. The first impulse of a philosopher when looking at declarations and conventions of human rights will then probably be to boil them down to a number of core rights or principles. Before attempting that, however, we need to distinguish between two ways of identifying core principles and two kinds of core principles. The first is what might be called the reductive approach. This is where you start with a rich plurality of ethical concerns and gradually boil these down to a few general ones. You continue until there would be a loss of content or determinateness if you were to proceed further. The simplest way to check for this is to reverse the process and see what you can derive from the basic principles or values that you have accepted (together with basic facts about human beings and societies). Say that you believe that ethical concerns like the right to privacy as well as the right to integrity can be reduced to a more general right to autonomy. For a reduction, it is then not enough that there is overlap or a general connection between autonomy and, say, privacy; rather, everything that we think is covered by the right to privacy must be derivable from how we have stated the right to autonomy (together with basic facts about human beings and societies). If we find that we cannot derive

⁷ There is another important sense of pluralism, namely the existence in our societies of many different moral outlooks. With respect to that kind of pluralism, human rights can hopefully be something around which an overlapping consensus can be formed (cf. Taylor 1999). This is an issue that will be set aside, although the more open-ended character of the taxonomical approach to principles that will be defended here should be able to facilitate inclusivity in building such an overlapping consensus.



certain ethical judgments that we would be able to derive from the more specific value or principle, then we have had a loss of content through the reduction. If we find that it is unclear whether we can derive those judgments from the more general principle, while it is clear that they can be derived from the more specific one, then we face a loss of determinateness. In either case, the reduction is inadvisable. Many reductive pluralists are presumably pluralists precisely because they find that they cannot articulate a monistic position without loss of content or determinateness.

There is also another possibility, namely what might be called a taxonomical approach, where the basic core principles instead identify the main families of concerns. This can make the whole range of specific concerns more navigable, but it can also help us in understanding those more particular concerns better: by knowing their place in the system as a whole and how they are related to other concerns their roles become more clear. These families might simply be a matter of Wittgensteinian family resemblances, but it is also possible that they identify a core feature belonging to all members, but where that core feature is too indeterminate too allow a simple derivation of more concrete values or norms from it. Take the Kantian idea that Respect for Persons might be understood in terms of how we are to treat humanity always as an end and never merely as a means. If you accept this as a basic principle as a reductive pluralist, you are committed to being able to derive all relevant concrete duties from it. But if you accept it as a non-Wittgensteinian taxonomical pluralist, you are only committed to the idea that there is a set of more concrete duties or norms or values that are all united by this idea, but in the end are nothing more than different species belonging to a common genus.

If we take, for example, the kind of basic principles that make up the Belmont framework and the principlism of Beauchamp and Childress, they can be understood in terms of ethical responses to certain basic types of threats/possibilities inherent to the human situation. The principle of Beneficence, as well as possibly a distinct principle of Nonmaleficence, covers promotion and protection of health and human welfare, both of which should probably be seen as multi-dimensional and where it is quite possible that we need to identify different sub-principles regulating different aspects of health and welfare. If we look at human rights in general, a wide range of rights (especially social and economic rights) can be seen as specifying the content of a principle like this. To a large extent, Beneficence and Nonmaleficence are grounded in needs and interests that we have as individuals and while being part of a society will certainly enable a much greater satisfaction of those needs and interests, many of them are such that we would have them even if we were to live alone on some desert island.

Both Justice and Respect for Persons do however seem to be more deeply social or political concerns. Justice has to do with handling the relative scarcity of resources or goods and would also seem to be multi-dimensional (cf. Walzer 1983), with different sub-principles regulating different areas, covering matters like equitable access to health care, fairness in prioritization, and non-discrimination. These are concerns which

⁸ A certain kind of specification is also important in the four-principle model as presented by Beauchamp and Childress (2013, pp. 17–19), but there the idea is one of making the general principle more specific in relation to some relevant area, whereas here the idea is rather to identify different species of a common genus. In the former case, we have a robust understanding of the principle that we then develop in more specific ways; in the latter, our understanding of the principle is rather like a common denominator for the species principles, which will be the ones doing the real work in our moral deliberations.



are certainly not irrelevant to the individual practitioner, but they have a strongly institutional character which suggests that they are primarily political rather than ethical in character. If we turn to Respect for Persons, we are looking at concerns that have to do with the standing we have as members of human societies and about how we relate to each other not just in terms of what we do more concretely, but also how we basically think about each other and what our underlying view of mankind is. While both Beneficence and Nonmaleficence point to concerns which a utilitarian would readily embrace (although one can certainly recognize these concerns without embracing a utilitarian calculus), Respect for Persons more distinctly raises concerns about how we cannot use individuals as means or ignore them even for the sake of the greater good. As already pointed out, it is also a principle that seems very closely connected to the kind of moral status that we share as human beings, but which is not applicable to other animals. One can potentially identify some unifying features to it, albeit relatively abstract and thin.

The taxonomical pluralist can see a point in identifying a relatively limited set of main families of values, norms, or rights. Doing so provides structure to the normative terrain that we need to navigate. Something like the threeprinciple Belmont model or the four-principle model by Beauchamp and Childress would seem to be what one should then be aiming at. Such models might perhaps be criticized for relying on principles that are too broad, but for the taxonomical pluralists they are only the first step anyway. With respect to human rights it is certainly possible to wholly eschew the level of more general, abstract principles and just focus on long lists of specific rights. But not only does it simply seem to be the case that one can identify existing such families of concerns, doing so also makes the terrain of human rights more navigable, especially for non-lawyers. And in the context of bioethics, if human rights are to be integrated into existing discussions about medical decision making, this would arguably be facilitated if they can be understood as one way of bringing specificity to approaches like the four-principle model. This kind of work also clearly seems to be an area where philosophical ethics can make a contribution.

Now, the argument up to this point has been that a human rights-based approach allows us to develop a conception of moral status involving human beings as having high and equal status, one that can be contrasted with hierarchical conceptions of what human societies should look like, but also with implicitly hierarchical normative theories. The idea is that part of the reason why the approach advocated here can serve this role is precisely its rich pluralism. The notion of there being some kind of highly substantive normative core underneath all the everyday moral complexities or the long lists of human rights can certainly seem attractive from a strictly theoretical point of view; but it is difficult, if not impossible, to articulate that kind of core without (at least implicitly) placing many human beings in the margins of what is involved in personhood. This is simply part of the logic involved in the very idea of that kind of core. In contrast, while the taxonomical approach still recognizes the need for some systematization, it keeps even the basic principles open-ended, allowing us to complete them through exploration of the actual moral and political terrain rather than by derivation from the general to the particular. We will now look at how a more



richly pluralistic account can enable us to understand a principle like Respect for Persons as more broadly applicable than if centered on Respect for Autonomy.

Human Rights and Respect for Persons

There is not enough space here for a full analysis of the content of existing human rights treaties on bioethics, but it is quite clear that they identify several concerns that seem connected to personhood and which are respect-oriented values. The CoE *Convention on Human Rights and Biomedicine* identifies dignity, identity, and integrity (Article 1), consent (Article 5), and private life and right to information (Article 10). The UNESCO *Declaration on Bioethics and Human Rights* identifies dignity (Article 3), autonomy (Article 5), consent (Article 6), human vulnerability and personal integrity (Article 8), and privacy and confidentiality (Article 9). The UN *Convention on the Rights of Persons with Disabilities* identifies dignity (Article 1 and 3), individual autonomy, including the freedom to make one's own choices, and independence of persons (Article 3), integrity of the person (Article 17), and respect for privacy (Article 22).

Even if one works from a taxonomical approach there might still be certain concerns among these that can be fully reduced to some other. For instance, the way integrity will be understood here potentially allows us to reduce concerns about identity to being about integrity. Concerns like confidentiality and the right to information are arguably reducible to being about the implications of privacy and consent about an aspect of exercising autonomy. This would still leave us with a five-member family making up the concerns involved in Respect for Persons: autonomy, dignity, integrity, privacy, and vulnerability. Of course from a moral and political perspective it is perfectly possible that there are further aspects to Respect for Persons that are not captured by current human rights treatises and one thing that characterizes a taxonomical approach is its openness for discovering new species of an already recognized genus. Still, for an approach that seeks to take existing institutions as a starting-point, which is something that characterizes a political approach to human rights, these treatises do provide the natural place to begin an investigation into what is involved in Respect for Persons in bioethics. Let us now look briefly at the five members of this family of concerns and at how not framing them in terms of simply being about autonomous decision making makes a difference to how we can come to understand their applicability, but also to how we can understand autonomy itself.

(1) Autonomy. Even if it might not always be clear from the relevant human rights documents which notion of autonomy that they rely on, the fact that the human rights approach utilizes a cluster of notions/values to conceptualize Respect for Persons actually opens up for understanding autonomy in a more substantial way or even to allow for several relevant senses of autonomy. In contrast, if autonomy is used as an overarching concept for understanding personhood we will tend to be pushed towards a relatively thin account of it in order for it to be able to serve that very general role. If we

⁹ Rendtorff (2002) presents a similar list (not surprisingly, since it is partly based in the same documents), although framed as a conceptualization of basic principles in European bioethics and biolaw. Given the addition of the 2005 UNESCO Declaration to understand such principles as specifically European does however seem too limited a view.



look at a document like the CRPD it actually involves a quite ambitious idea of autonomous decision making as something to be achieved rather than something that normally just happens unless there is undue interference (Craigie 2015) and the discourse surrounding the CRPD also tends to focus on supported decision making rather than substituted decision making for persons with cognitive disabilities (Gooding 2013). This does not necessarily invalidate the idea that respect for autonomy is often well-expressed through informed consent procedures, but it does broaden the applicability of a principle like Respect for Persons and cautions against universally having the strategy that whenever a choice is to be made, the focus should lie on finding someone, sometimes a substitute, that can sign a consent form. This would potentially also mean that autonomy (in one sense at least) is something that can come in degrees and that a reasonable goal is to enable patients to exercise control of their life situation, including their health situation.

(2) Dignity. Among the values identified here as falling under what is involved in Respect for Persons, dignity is special in that while it is sometimes used to designate a certain status or rank (Waldron 2012), one of having a worth beyond price (to borrow a phrase from Kant) and of being protected from degradation and instrumentalization, it is sometimes also used to designate a property supposed to be had by all human beings and which justifies why a principle like Respect for Persons applies to human beings. For instance, Andorno (2009, p. 230) writes that "respect for persons is just the consequence of human dignity." In the present framework, the relevant sense of personhood is about being a member of a society built on human rights and then it is dignity as part of what is involved in that package rather than as serving a more foundational role that is of primary interest. 10 Now, for a taxonomical pluralist, it is quite possible that what respect for dignity forbids is simply an interconnected family of bad things. In that sense, as Göran Hermerén (2006. p. 13) notes, we probably already have a fairly clear idea about what respect for dignity forbids: "eugenics, discrimination, stigmatization, commercialization, reproductive cloning, and degrading treatment, including trafficking and instrumentalization of human beings." It is quite possible that there is some common core to the items on this list, but the taxonomical pluralist is not committed to the existence of such a core. Dignity can still be a meaningful category. To some extent what people find degrading will vary and it might therefore be thought that such matters should simply be left to autonomous choice. There is however a phenomenon of adaptive preferences, which means that people who have gotten used to degrading circumstances will lower their expectations and adjust their preferences. 11 What one will expect in terms of how one is treated will partly be about the standing one already has as a member of society. Autonomous choices can certainly play a role in some circumstances, but there should accordingly also be a level of protection against degradation and humiliation that is non-negotiable and sets the basis for what we should come to expect. Dignity sometimes trumps autonomy, which is one reason why it cannot be reduced to matters of autonomy.

¹¹ Nussbaum (2000, Chapter 2) has a good discussion of adaptive preferences and why we cannot understand people's interests simply in terms of their preferences.



 $[\]overline{^{10}}$ This should however not be taken to mean that we cannot think of dignity as a foundational value connected to our personhood or as a way of articulating the value inherent in personhood, it is just that the present account does not need that kind of notion of dignity.

(3) Integrity. This right can potentially be understood as consisting in at least two rights, the rights to mental and bodily integrity respectively. Perhaps other forms of integrity can be identified as well (see Fjellström 2005). An idea of persons as having an untouchable core and there being important boundaries not to be crossed does however seem to be an important unifying theme (Rendtorff 2002, p. 243). It also seems that integrity is strongly connected to one's sense of self and to one's identity. A right to integrity can hardly be a right to be free from human contact, but must be about setting boundaries between acceptable and unacceptable contact. Some unwanted contacts might simply be harms that are already ruled out by other moral reasons, but some harms will also be violations of boundaries that go beyond being mere harms, and this can be explained by how they violate one's right to integrity. It should also be said that integrity and one's sense of self can be threatened by non-agential forces, such as illness. Sustained pain can, for instance, break someone down qua person; the damage one then suffers goes beyond the bare damage that is always involved in pain (Chapman & Gavrin 1999). Finally, the right to integrity is clearly applicable to human beings that are not capable of autonomous decision making. Sometimes physical restraint is used in care, e.g., in the case of people with dementia, and even though autonomy might then not be an issue, there are still strong reasons to organize care so that the use of physical restraint is minimized, in order to be respectful of the integrity of persons (Leiman et al. 2013).

- (4) Privacy. Respect for privacy is unique among the values that fall under Respect for Persons in that it to a large extent regulates behavior that happens without direct interactions with the persons in question. People will often not know about whether their privacy has been breached or not. Arguably, privacy can be breeched through the bare fact that someone has cognitive access to one's person or information about one's person, even if that someone does not make use of this access (Powers 1996). If privacy is understood in terms of restricted cognitive access, the difficult question is exactly which kinds of access that should be seen as undue cognitive access. In medicine we are dealing both with the fact that medical information is often highly sensitive as well as the fact that in order to treat patients, physicians and nurses must have relatively extensive cognitive access to facts about their patients. Complete privacy is impossible, but confidential treatment of information then becomes an important way of still honoring the patient's right to privacy. Additionally, even if complete privacy is impossible it is still important and possible to look for ways of maintaining some privacy. Woogara (2005) points to how patients often can become habituated into accepting unnecessary infringements of privacy, so while there might be a temptation to understand the right to privacy in terms of autonomy or consent, it is important that our privacy is protected beyond what we might happen to accept, especially in situations where we are weakened and prone to just go along. In fact, respect for privacy is similar to respect for dignity in that it does not just regulate the lives we lead anyway; instead, having it as a fundamental moral and political concern means having it play a constitutive role in defining our relations to each other and in building a specific kind of society.
- (5) Vulnerability. While the notion of vulnerability was actually present already in the Belmont framework (with respect to those groups where Respect for Persons could not be meaningfully formalized in terms of informed consent procedures), the UNESCO Declaration was the first major document that clearly articulated Respect



for Vulnerability as a concern in its own right. This right does not name anything that should be protected or promoted. Rather, we should be respectful or mindful of the fact that human beings are fundamentally vulnerable beings and that some humans might be in special circumstances of vulnerability. There are at least two main senses in which vulnerability is relevant in a biomedical context. First, there is a general existential sense in which we are all vulnerable and where our vulnerability is something that we are very much confronted with when we come face to face with the fact of illness (Pellegrino 1979). But there are also concerns about especially vulnerable individuals or groups and the specific measures that should be taken with respect to them (Macklin 2003). While our fundamental vulnerability is a universal feature of human existence that might be addressed by how we form societies, the exact ways in which we might be especially vulnerable will always depend on how our societies are organized, similar to how what becomes a disability depends on how society is organized. Irrespective of exactly why certain concrete vulnerabilities exist, they tend to open us up for being coerced, deceived, or manipulated. The risk of exploitation is also why sensitivity to vulnerability is so important in research ethics as well (Lange et al. 2013). This means that being sensitive to vulnerability can be an important reason for having informed consent procedures (rather than mainly seeing them as a way of letting people exercise autonomous choice), but sensitivity to vulnerability clearly goes beyond matters of consent. Precisely those groups that are not capable of consenting in meaningful ways will also tend to be especially vulnerable since they will often have difficulties making their voices heard and providing input into decision procedures that should still be respectful of them as persons.

Concluding Remarks

A complete human rights-based approach to bioethics includes more than the concerns that have been considered here and to provide an overall assessment of such an approach lies well beyond the scope of this paper. The focus has been on the principle of Respect for Persons and how it can be understood as being about a family of concerns which are interconnected, but not reducible to one another. The main advantage of such a human rights-based approach is that it makes Respect for Persons into a principle that is clearly applicable to all human beings. ¹² Exactly what this kind of respect then means more concretely will certainly vary from person to person and situation to situation and the kind of taxonomical pluralism advocated here cannot provide an algorithm for moral choice; indeed, its very rationale is that the moral landscape is too complex for such an algorithm to make sense. Taxonomical pluralism points to a conception of philosophical ethics as a form of moral cartography, not moral mathematics. To some this might be disappointing, but when it comes to working within a strongly institutionalist approach, like a human rights-based one, where the focus is on the intersection between morality, law, and politics, it is at any rate difficult

¹² It should be said that the standing of embryos is contested and they are not provided full moral standing in a document like the Oviedo Convention, where the handling of embryos is also quite clearly a product of compromise (Andorno 2005, p. 137). However, even then, the idea is that certain forms of respect will still be relevant for how we should deal with human embryos.



to see how the influence of philosophical ethics on the everyday workings of such institutions can realistically be about more than shifting the attention and ongoing conversations towards certain concerns rather than others. Even if we cannot list all the actions that, for instance, might respect or disrespect a person's dignity, recognizing dignity as a key feature of the moral landscape will still direct our attention to such actions, as well as steering our ongoing conversations about which kinds of behavior that are appropriate or not in certain directions. The kind of open-ended moral cartography that taxonomical pluralism involves might not be philosophically sleek, but it can still matter for actual practice.

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