

Title: Personhood and Intellectual Disabilities

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Abstract

Notions of personhood have been indispensable cornerstones in ethical theory. Ideas of self-determination and autonomy are invariably placed at the centre of moral reasoning while bio-medical ethics rely heavily on theorising that uses concepts such as the value of human life and the worth of individuals (Beauchamp and Childress, 1994). Research into the causes and conditions of intellectual disabilities and mental retardation has thrown up some awkward questions and issues for ethical theory that either philosophers or scientists working in learning disabilities are just beginning to appreciate (Reinders 2000; Nussbaum 2006). The approaches used in practical day-to-day issues range from intuitive ethical arguments to strict rule-guided behaviour, which in turn may be utilitarian or de-ontological in character.

On the other hand, strong voices of advocacy for people with learning disabilities have urged the recognition of the social dimension of intellectual disabilities. Both approaches, however, leave the core of ethical confusion untouched:

How does our increased knowledge about the genesis, pathology and conditions of intellectual disabilities resonate with our ethical theories that rely so heavily on one or another notion of human autonomy and self-determination?

Keywords: Onora O'Neill, John Rawls, liberalism, intellectual disabilities, personhood, ethics, morality

The notion of personhood lies at the centre of liberal political philosophy. It plays a crucial role in concepts of justice and hence in the structure of political institutions. Rawls is just one political theorist amongst many who spent much work on defining the conditions for justice from an initial starting point that includes assumptions about human autonomy, rationality and the ability to engage in reciprocal relationships. However, personhood has also been at the centre of much controversy. Whether or not political philosophers embarked on their theorising adventures armed with Rawls's notion of personal autonomy, the question of what constitutes a minimal or more substantial account of human nature was always at the heart of philosophical debate. Traditionally, those theorists endorsing broadly speaking liberal political institutions have included in their initial assumptions some account of instrumental rationality or the ability to reason about the life projects of individual human lives.

Over the last decade or so, doubts have been raised that the debate between utilitarianism and constructivists, or between virtue ethics and notions of procedural justice have captured the entirety of what is problematic in ideas of personhood. Philosophers have pointed to the issue that there exist a whole range of people in

every society that simply do not meet the criteria which are necessary to either participate in deliberating on the basic structure of political institutions (justice) or to form coherent ideas about life projects to be pursued (a conception of the good). People with profound intellectual disabilities may also not be able to fulfil the fundamental requirement for obligatory relationships which is that duties and rights are reciprocal. Yet, why should this be a problem? Virtue ethicists have long argued that obligations to vulnerable people feed on a reservoir of compassion and morality rather than on reciprocity that characterises usual economic and social co-operation. Do we not have at our disposal already all we need to answer those who question the equal status of people with intellectual disabilities in our society? What has changed?

A recent discussion about autism and people with autism may serve as a good example. In a publication of an open letter to 'The Independent' a group of advocates for people with autism urge government and other associations dedicated to improve the lives of people with autism to concentrate on treatment and cure for autism. A rejoinder from an influential campaign group rejected this call and argued that such a call for a cure of autism would imply that there is something wrong with autism that stands in need of correction. They insisted that autism was a condition which only leads to a disability if and when society fails to treat people with autism appropriately. A call for research into a cure would, so they argued, give the impression that people with autism suffer from a deficiency that somehow must be alleviated through treatment. Rather autism as a disability, so the group suggests, is a result of society failing to provide adequate opportunities for people with autism.

There is no need to go further into the detail of this exchange, but it is noteworthy that it played out against the contrasting background of medical and social models of disability and it is also worth mentioning that advocates for people with autism are found on both sides of the divide. The discussion about the desirability of a cure for profound intellectual disabilities has become topical because of the possibilities that are offered by genetics (Munger et al., 2007). There can be no doubt that the advance in medical science will radically alter our conception of disabilities and profoundly challenge the way in which we think about notions of perfectibility of human nature. This affects intellectual disabilities probably more than any other forms of impairment. (Although I acknowledge that recent legislative proposals such as the Embryo Bill going through parliament at the moment may be discussed predominantly with view of research into dementia, intellectual disabilities pose the greatest challenge because so far impairments cannot be remedied in a post-natal phase (Stowe et al., 2007)).

Yet, again, what does this have to do with personhood? Is this not solely a medical question, hence a problem of technology rather than ethics? In contrast to this view I believe that concepts such as personhood are central to the discussion on questions of technologies that are made possible by medical progress. There is no value neutral way of introducing and employing new technologies. Novel medical insights raise questions of desirability, applicability and permissibility. In other words, it throws up issues of justifications for decisions that appear simply matters of medical expertise but in fact touch upon our most deeply held beliefs about human nature.

So, the possibility of treatment, prevention and cure for cognitive impairment is intimately connected with society's and individual's duties to prevent harm and avoid

injury to others. Often in the nascent ethical debate on intellectual disabilities, concerns are raised from the point of view of what the possible effects may be on carers and disabled people (Stowe et al., 2007). One argument that is made again and again is whether or not the possibility that has opened up with genetic screening would ultimately amount to social pressure on prospective parents to undergo procedures to ensure no child with impairment is born. If parents may resist the pressure for genetic screening, so the scenario goes, the refusal to prevent a life with intellectual disabilities may lead to a shift in thinking about resource implications for this family. In other words, if impairments are preventable why should society pay for additional support for the new born person if parents had been educated on their choices and made an informed decision about not undergoing genetic screening.

I have some problems with this line of argument. It may capture quite accurately the state of alarm in some groups of society in the face of future genetic developments. However, I find it implausible to assume that informed choices establish obligations or rights against or for claims of support. Similar cases are already with us and do not prompt us to argue in favour of withdrawing support or resources from families or, say, individuals who suffer from debilitating diseases. I find it difficult to imagine that a diver who has failed to equip himself properly despite being warned about the possible consequences of his actions is denied help or support subsequently if an accident indeed occurs. Our duties to others, so I would argue, rests on assessments of need and vulnerability, not on the agent's ability to make informed judgements within reason (this does not preclude that we try to avoid mentally ill people making decisions with harmful consequences to themselves and others).

Yet I believe this is a skirmish that fails to address the real problem inherent in the clash between genetic and medical possibilities and intellectual disabilities. So, again where does personhood features in the complex relationship between genetic technologies and our conception of justice and ethics? In a nutshell it touches on the question of what we owe to each other. What is the range and extent to which we can be said to be obliged (within a broadly democratic and redistributive political order) to other people? I have already mentioned that one difficulty may be that people with intellectual disabilities may be in states of dependencies for their entire life (although it is worth mentioning here that even people with profound intellectual disabilities can work if societies make support available and that this greatly enhances their quality of life and independence (Beyer, 2006). Relationships with people with cognitive impairment may therefore lack the reciprocal character that interaction with others exhibits. Two issues have emerged in the more recent literature and I will sketch briefly both, only to dismiss the first while developing a more detailed argument on the second.

It has been pointed out by many researchers in the field of intellectual disabilities that our assumptions what makes a life worth living is informed by conceptions of abilities and capacities that are in fact not essential to the pursuit of a good life (Schramme, 2002). This issue has most impassionately been debated under issue of the quality of life for people with intellectual disabilities in contrast to quality of life for non-disabled people. There is also a growing literature that critically investigates the reasons for differentiating quality of life of people suffering from ill health and otherwise healthy persons (Wulff, 2002). With regard to social and political justice and inter-personal duties I find this has no direct bearing on ethical issues. Our

obligations to others do not shrink or expand in relation to good or ill health, disease or well-being. Rather they are independent of contingent aspects of particular people in specific circumstances. This does not mean that illness does not raise ethical issues at all such as the need for additional support and assistance. But these issues do not touch upon the fundamental set of obligations or rights that we or others are said to have towards each others qua being persons. Illness or lack of health calls for assistance because of a remediable situation, and hence rights to the provision of support are not universal either. That does not rule out feelings of compassion that may supplement existing institutions charged with remedial action. Yet it does not affect the nature of personhood as such except that personhood may provide us with a notion of good health that acts as a counterfoil to determine ill-health. As we will see, this however does not trigger rights or duties.

The second issue that has emerged in recent debates is the role rationality , instrumental or otherwise, plays in frameworks of justice and ethics. The nature of rationality is, of course, one still shrouded in mystery and although philosophers have traditionally treated it as self-evident, serious problems lurk in the thicket between philosophy of mind and capacities to reason, psychology and consciousness. This paper however will attempt to review one particular version of personhood and examine its potential to mitigate the idealising features of notions of personhood in concepts of justice and ethical theory. In formulating an inclusive conception of personhood that acknowledges the deficiencies of the various liberal notions, it is the explicit aim of this paper *not* to draw on virtue ethics since, as argued before, compassion and empathy are resources open to individuals at any time but do not apply to the process of defining the shape of political institutions and the scope of their obligations.

Before I turn to O'Neill's account of justice and virtue it is only fair to rehearse some of the criticism that has been levelled against abstract notions of justice if only to demonstrate that none of those strike deep enough to address the problems we encounter when we include people with intellectual disabilities into our deliberations about justice. In a way then I would like first to establish a case for the need for something akin to O'Neill's version of ethics.

Reinders has not been the only one who articulated some serious doubts about the notions of justice which rest on assumptions about human abilities and cognitive capacities that may not be met by people with intellectual disabilities (Reinders, 2000). His account is however suffused with experiential undertones and it relies heavily on dialogical constructs of justice. I have doubts as to the viability of such a version of social justice but will suspend any further investigation until later in the paper when we deal with O'Neill who may serve as an interesting contrast to his theoretical efforts.

Critics of universalist or constructivist ethics are not in short supply of course. The most outspoken is probably John Gray. His charge, though eloquently put, also lacks a certain substance. Gray, like many others, takes Rawls as the main advocate of abstract notions of justice, a version of constructing political order with minimal assumptions about human nature. He criticises that 'the rational justification of liberal political morality' has practically proceeded as part of an Enlightenment project

which ‘promotes autonomous human reason and [has] successfully eroded and destroyed local and traditional forms of moral and social knowledge’ (Gray: 216-17).

He is scathing of all those attempts to construct justice by deploying ‘an unhistorical and abstract individualism in the service of a legalist or jurisprudential paradigm of political philosophy’ (Gray: 8) which Rawls shares with Gauthier and Nozick according to Gray. Surveying the rubble left by overambitious Enlightenment philosophising, Gray is sceptical about the resources left for building coherent moral theories and defines the task of current conceptual work in ethics thus: ‘We need to consider how to think and act in a culture that has been transformed irreversibly by an Enlightenment project that has shown itself to be self-consuming.’ (219) Although very articulate in his attacks on the deficiencies of Rawls’s approach, what he calls abstract universalism, he fails to offer any coherent alternative beyond a call to accept pluralism and diversity in all its forms as a given in the modern world. With this lack of alternatives, Gray does identify the core of the problem with ‘abstract individualism’ largely along the lines of Sandel’s earlier critique of Rawls when he writes:

‘Consider ... the central category of the intellectual tradition spawned by Rawl’s work – the category of the person. In Rawls’s work... this is a cipher, without history or ethnicity, denuded of the special attachments that in the real human world give us the particular identities we have. Emptied of the contingencies that in truth are essential to our identities, this cipher has in the Rawlsian schema only one concern – a concern for its own good, which is not the good of any actual human being, but the good we are all supposed to have in common, which it pursues subject to constraints of justice that are conceived to be those of impartiality.’ (6)

Whether Gray is correct in this description of Rawl’s concept of the person is less significant than the fact that the main thrust of his argument is directed at the removal of contingent attachments we all happen to have and the result this has on the concept of justice. The upshot of Rawls’s attempt to abstract from ‘substantial bonds’ that make our identity, Gray argues, results in a conception of the good that applies equally to all. This is important in our context since it is in fact a wrong conclusion, Rawls’s notion of personhood does not deliver the same vision of justice in society for all, even though this may be based on false notions of the good life. Gray overlooks that Rawls’s schema has an additional flaw.

Rawls’s notion of the person is not only devoid of any meaningful attachments that make sense of our intuitively felt obligations to significant others in our lives, but it operates with substantial commitments to an idea of the political and social nature of human beings built on the capacity to reason. So, in a sense, Gray’s critique, though correctly lamenting the lack of contingent bonds that structure people’s lives, fails to notice the substantial assumptions at the heart of Rawls’s notion of person which in effect render his conception of justice inapplicable to a whole group of people in society who do not have the ability to reason. One objection may be that Rawls is quite modest in demanding only a capacity to reason instrumentally (Rawls). Yet, from a perspective of intellectual disabilities the requirements for instrumental rationality are high indeed.

Since Gray offers little to supplant Rawls's notion of personhood with anything more appealing we may move swiftly on to those thinkers who have equally articulated doubts about abstract notions of the person yet inquired into the conditions for a full flourishing life as it should animate any coherent notion of social and political morality. MacIntyre would be a plausible candidate in the search for a more rounded version of personhood, since he formulated his critique of modern moral philosophy in *After Virtue* (MacIntyre, 1981).

The strength of MacIntyre's argument lies without doubt in his sophisticated analysis of the sources for shared moral traditions and practices. He argues that modern societies in the West are characterised by a moral discourse that has lost the vocabulary to meaningfully relate to the practices that inform ethical principles. The modern world lacks the moral terminology to render the fragmented ideas about morality coherent in a grander vision of the conception of the good life. His resuscitation of the Aristotelian/Thomist version of human nature however lacks credence and conflicts with reality. His analysis may be helpful in establishing just how far we have moved from coherent ethical practices and a moral theory that accords with those practices, yet his diagnosis is not followed up by a prescription of what to do in the face of fractured moral precepts. Even Gray's advocacy of agnostic acceptance of post-modern life with 'groundless practices' seems more appealing than a speculative return to an Aristotelian/Thomist concept of human nature.

Amongst those who have laboured against any abstract notion of personhood Kittay is probably that one who moves most closely to an ethics that draws its force from contingent forms of inter-personal attachments and feelings of empathy (Kittay, 2005). Her account of moral obligations to people with intellectual disabilities is informed by a deeply personal dimension and gains a depth that other ethical theories do not possess. Yet, it is exactly this personal dimension which shifts her constructions of duties and rights in our context too far towards imperfect virtue ethics, something that unfortunately defeats its universal ambitions. Nussbaum's capabilities approach is more firmly anchored in the universalist project, not least because it takes Rawls's work as its starting point.

Nussbaum's framework to think about justice and people with profound intellectual disabilities is an unashamedly essentialist project (Gimmler, 2002). In resuscitating an Aristotelian notion of the good and reconciling this vision with Rawls's concept of justice, Nussbaum attempts to identify a list of capabilities that are fundamental to effective agency in social and political domains (Nussbaum, 2006). These capabilities apply to all, and are designed to avoid the exclusivity of other criteria such as capacities to reason that are conventionally part of the constructivist project. Nussbaum describes her approach as an outcome-oriented one, in contrast to Rawls's procedural perspective (174).

In effect, she advocates for the incorporation of ends of human agency when framing questions of social and political justice. The inclusion of a number of capabilities may raise the spectre of incommensurability, something that Rawls was keen to avoid by accepting only a minimal conditions of reasoning in the original position. Nussbaum however treat her own list as 'central human entitlements' (166) and the question arises how these entitlements are to be assessed in moments of conflict. She addresses (but ultimately equivocates on this) this problem by pointing out that 'there must be a

prior evaluation [of the capabilities], deciding which are good, and, among the good, which are the most central, most clearly involved in defining the minimum conditions for a life with human dignity' (166).

This passage is most puzzling. Rawls highlighted the intricate nature of the ethical dilemma arising from injecting comprehensive or substantive notions of good into the stage at which people (in the constructivist sense) design social and political institutions. It was deemed to be one of the cardinal problems that needed to be addressed in order to extricate constructivism from foundationalist interpretations of justice in society.

Nussbaum's account of Neo-Aristotelian justice surprises even more if one examines more closely the list of capabilities. In fact, none of them are explicitly designed to take account of the problems that hitherto contributed to exclude people with intellectual disabilities from constructing political and social institutions. Nussbaum is unapologetic about this, however. She argues that human capacities to care and empathy will play a complementary role to her basic principles of justice and the list of capabilities. She believes that a more comprehensive list of capabilities would 'create discrete orders of citizens' (185) and 'there are, then, good reasons why the capabilities list is single, even though the conceptions of flourishing are plural' (186).

This may however produce the 'discrete orders of citizens' that she was eager to prevent. In fact, she admits as much when she talks about Sesha (Kittay's daughter) and that we are caught in a dilemma when describing the quality of her life:

'Either we say that Sesha has a different form of life altogether, or we say that she will never be able to have a flourishing human life, despite our best efforts' (187).

But didn't Nussbaum set out to dispel exactly those kinds of conclusions? And does this not strike someone who is involved with people with profound intellectual disabilities as ultimately counter-intuitive? After all, people with intellectual disabilities may have a happy life if they get the support they need. Nussbaum's conclusion seems hasty and also worrying if we consider that it leads her to concede the possibility that the lives of people with intellectual disabilities may not be human lives in the conventional sense.

In the remainder of the paper I will examine O'Neill's attempt to reconcile virtue ethics and conceptions of justice. Her work originally focused on Kant's ideas of public and private reason and her later work retains the merits and universalist ambitions that the Kantian project exemplified (O'Neill, 1996).

Her most important contribution to the debate on theories of justice is however to have turned attention to the scope of justice and the criteria that are at work in including and excluding individuals from social and political institutions. While she professes the aspiration to salvage some universal account of justice she also aspires to reconcile more substantive precepts of morality. In the course of her defence of the categorical imperative she formulates the core of a universal conception of justice that retains references to particular attachments and can acknowledge contingent circumstances of moral action (O'Neill, 1993). In a way then her approach pursues a theory that is more radical than Rawls's in its attempt to revitalise the transcendental

foundations of Kant's formal constructions of reason while at the same time it pays tribute to the particularistic groundedness of our ethical standing in everyday life. Her claim is that out of an analysis of the Kantian categorical imperative, substantive principles of ethical action can emerge (O'Neill, 1996).

In a perceptive critique of virtue ethicists and justice theorists she highlights their respective weaknesses. While virtue ethics must necessarily overly rely on particularistic practices that prevail in specific communities, abstract theories of justice must rest on some notion of (abstract) rule that may fail to deliver the criteria for its applicability in times of diversity and plurality of practices. As particular ethical practices may well violate intuitive ideas of human ethics and hence they may fail to meet universalist aspirations of equity, universalist theories of justice in the Rawlsian mode work with hollowed out notions of personhood that renders unintelligible particular attachments.

The great advantage according to O'Neill of virtue ethics is that they afford us a clear focus for ethical concern, which in turn can differ from the bearer of moral obligations. In other words, reciprocity is not a precondition for entering ethical bonds. On the other hand, virtue ethics do not possess the distance from specific practices which allows agents to re-consider and revise attachments by reference to ethical precepts.

Her solution for this dilemma is to specify foundations for moral action (O'Neill, 1996). These foundations then act as vehicle for evaluative processes of universalisability of any action in question. What are these aspects of moral action then? O'Neill embeds her discussion of the supplementary function of virtues in an examination of the shortcomings of abstract principles of justice. The force of her argument originates in the question whether or not certain practices that superficially adhere to principles of justice can be desired to be universal by an individual agent in a specific community, not an idealised one. This illustrates that she has not renounced the constructivist project but tried to locate it in particular communities and to reconcile it with the reality of people possessing actual bonds and commitments. This particularistic approach also shines through in her crucial discussion of why certain boundaries and limits on human activity derive from conditions of vulnerability shared by all. She writes:

'Human beings begin by being persistently vulnerable in ways typical of the whole species: they have long and helpless infancy and childhood; they acquire even their most essential physical and social capacities and capabilities with other's support; they depend on long-term social and emotional interaction with others; their lives depend on making stable and productive use of the natural man-made world.' (192)

This condition of extensive and unavoidable vulnerability that all human beings share however may only establish principles of justice which cannot account for specific bonds and commitments we have to significant others in our lives. O'Neill goes on to claim equally universalisability for those ethical principles that go beyond notions of abstract justice.

'Principles of justice can be derived from the requirement of rejecting inclusive principles of injuring... An analogous pattern of derivation shows that inclusive

principles of indifference to and neglect of others also cannot be universalised. [...Since] no vulnerable agent can coherently accept that indifference and neglect should be universalised, for if they were nobody could rely on others' help; joint projects would tend to fail; vulnerable characters would be undermined; capacities and capabilities that need assistance and nurturing would not emerge; personal relationships would wither; education and cultural life would decline. It follows that those with plans and projects, even of the most minimal sort, cannot regard indifference and neglect as universalisable.' (193-194)

On the face of it, O'Neill succeeds in constructing a virtuous account of political and social morality that retains the most prized element in Kantian philosophy, the universalisability of ethical principles, its universal appeal and applicability while at the same time avoiding the pitfalls of furnishing simply formal accounts of justice. O'Neill's parameter of ethical activity is abstract and particular at the same time, it speaks to the specific commitments we have in our lives and takes account of the obligatory force that comes from universal imperatives.

Yet, a second closer look reveals a remarkable gap in her vision. For indifference and neglect to be rejected as universalisable principles agents must base their calculations on some notion of reciprocity. The problem in our context is that we were looking for a concept of justice that integrates people with intellectual disabilities into the frame of ethical theory despite their inability to reciprocate in the way O'Neill seems to take for granted: to mutually assist in the pursuit of life projects, to be able to rely on each other, or to contribute to education and cultural life in society. It remains questionable whether or not people with profound intellectual disabilities can meet these demands.

She may have succeeded in showing that frameworks of social justice are conceivable that extend beyond abstract duties and rights and that virtues that support strong particular networks of commitment and bonds can be thought of as universalisable. This lifts the burden that was conventionally placed on notions of personhood and the abilities that were essential to deliberating the principles of justice that structured political and social order. Rationality and capacity to reason may not be prominently placed anymore in O'Neill's conception of a virtuous and just society. Yet, her account retains an element of reciprocity that may still be beyond those most vulnerable in our society. The search for a notion of political and social morality that can accommodate the special circumstances of life with intellectual disabilities continues.

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