

Rights as Industry

by Sarah Bachelard

Do people who campaign for human rights belong to an industry? Sarah Bachelard investigates the sticking power of the 'industry' label; and calls for a conception of human rights based on love.

It has become fashionable in some circles to speak of those who campaign for human rights or social justice as belonging to 'industries'. Thus conservative government figures refer to the 'Aboriginal industry', commentator Padraic McGuinness speaks of civil libertarians as members of the 'bleeding hearts industry', and non-government organisations such as the Australian Council for Social Services are called 'welfare industries'.

Ostensibly, this practice simply draws attention to the fact that those who advocate for rights in these areas often earn their livings by doing so. They tend to work for organisations which have their own institutional arrangements, within which it is possible to build a career and public status, just as occurs in any other line of work. The inference, however, is that those who work for the justice or rights 'industries' are simply representing another, economically motivated interest group, like the mining or manufacturing or IT industries.

This inference has a clear denigratory purpose. If those who work for justice in various spheres can be conceptually reduced to economically motivated interest groups, then their message can be more readily written off as self-serving. For example, the human rights 'industry' is, on this view, revealed to have a vested interest in keeping alive the issue of Australia's past and present treatment of indigenous people because it provides it with an ongoing reason for being granted a voice in public affairs and because it constitutes a funding lever. The *content* of the message can then be disregarded because the critic has (he thinks) shown us the self-interest behind the rhetoric of justice.

The motives for this denigration and refusal to engage with the substance of the issues are often obvious, and may themselves reflect economic and political interests, as well as a drive to self-justification. And it is clear that the fact that one may earn a living through engaging in a particular activity is not sufficient, by itself, to reduce the content of that activity to 'mere' self-interest. As far as I know, no one has yet attempted to denigrate the message

of the church by referring to clergy as representatives of the religious 'industry'.

Nevertheless, I hesitate to write off this implied attack wholly in kind, not least because the label appears to have the kind of 'sticking' capacity which suggests that there is something there to be explored. In order to explore it, I am going to begin by giving a generous reading of what might prompt this kind of denigration of the justice 'industries'. I speak in the first person, as one who has worked in the human rights area and who has noticed these things in myself.

McGuinness speaks of civil libertarians as members of the 'bleeding hearts industry'.

On the Side of the Angels

There can be a tone of self-righteousness, a kind of shrill moral indignation, in the speech of those of us who protest and campaign, who advocate for the rights of the disadvantaged and the persecuted. We know that we are on the side of the angels, and in our own way we can fail to do justice to the complex reality of most human action and motivation. We get something out of 'being right'. This is not a remark about the impossibility of altruism: it is not just that we get satisfaction from standing up for what we believe in. It is that we get satisfaction from making those who do not agree with us wrong. We are often uncharitable to those whom we deem our ideological

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Published by the
Centre for
Applied
Philosophy and
Public Ethics

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ISSN 1324-8200



THE UNIVERSITY OF
MELBOURNE

opponents. I suspect that what those who call us an ‘industry’ pick up, and why it stings, is this smugness and satisfaction and entrenchedness of our own position in relation to these matters. By way of contrast, imagine how absurd it would have been to speak of Martin Luther King as being in the civil rights ‘industry’.

It might be suggested that the only difference between those of us involved in Australia in human rights work and Martin Luther King is that he worked in a less established institutional structure, and was personally at risk in ways that most of us are not. He was at the forefront of a radical new movement, whereas we are engaged in the hard grind of ongoing advocacy. But of course that does not constitute an argument against institutionalised structures, nor does it mean that to be ‘genuine’ a human rights worker has to be at risk. In that case, the suggestion that a comparison between us and Martin Luther King reveals something worth considering in the ‘industrial’ critique is false.

I agree that these are significant differences but I suspect that something is still shown up in the comparison. In particular, I think that the element of personal risk is central, although not in the sense that one’s life must be at risk. Later I will return to the example of Martin Luther King to connect the issues of risk and self-righteousness.

Human Rights and Revelations

For now, however, I want to put these preliminary remarks to one side and to chart another path into the question of contemporary human rights advocacy. I begin by juxtaposing two philosophical statements which will frame my discussion.

The first comes from twentieth century French philosopher, Simone Weil’s essay ‘On Human Personality’.

If someone tries to browbeat a farmer to sell his eggs at a moderate price, the farmer can say: ‘I have the right to keep my eggs if I don’t get a good enough price’. But if a young girl is being forced into a brothel she will not talk about her rights. In such a situation the word would sound ludicrously inadequate.

The second comes from Immanuel Kant’s *Groundwork of the Metaphysics of Morals*:

It is doubtless in this sense that we should understand too the passages from Scripture in which we are commanded to love our neighbour and even our enemy. For love out of inclination cannot be commanded; but kindness done from duty—although no inclination impels us, and even although natural and unconquerable disinclination stands in our way—is practical, and not pathological, love, residing in the will and not in the propensities of feeling, in principles of action and not of

melting compassion; and it is this practical love alone which can be an object of command.

Kant was suspicious of the idea that love should be the spring of our respect and care for others on two grounds. He thought that love, as a feeling, could not be commanded or universally guaranteed. And partly because of that, he thought that love ‘out of inclination’ had no moral worth. You might feel love for someone, for example, because you are naturally warm-hearted; or you might love someone because they themselves have a naturally engaging and loveable personality. But true moral respect for persons should not depend upon accidents such as these. True moral respect is the respect one has for the rational nature of every person, which exists independently of any attractive features of personality; and true moral respect arises, not because of the feelings one happens to have, but from rational self-legislation, from the determination of your will and action by duty.

What seems both attractive and true in Kant’s account is his insistence that respect for others should not depend upon our liking them, or upon their deserving or meriting respect through features of personality. People deserve respect and care whether we ‘feel’ like giving it, and regardless of what they, as individuals, are like. The link with our contemporary notion of human rights is obvious. If our duty is to respect others in this way, unconditionally, then others possess, unconditionally, the right to our respect. The language of human rights expresses and has come to institutionalise our belief that, regardless of accidents of birth and personality, every human person is deserving of the same basic regard and respect, and that each of us, regardless of our capacity for sympathy, is capable of and owes that respect to one another.

What does it mean to say that all human beings deserve respect, just because of their humanity? Or, in the words of the Universal Declaration of Human Rights, to say that ‘all human beings are born free and equal in dignity and rights’. These statements are not statements of fact, in the sense that ‘all human beings need food to survive’ is a statement of fact. Indeed, the statement ‘all human beings are born free and equal in dignity and rights’ has been and continues to be patently untrue in many places and stratas of society. Should we then understand the declaration of inherent human respect-worthiness as an assertion of how we think things *should* be, or how we would like them to be? The problem with this interpretation is that it ignores our sense that the declaration of the intrinsic worth of every human being is not an ideal, but the recognition of a truth.

To cut what could be a much longer discussion short, I suggest that we understand the assertion that human beings are born free and equal in dignity and rights as an

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expression of a *revelation* about how things really are. It expresses the recognition that every human life *matters* in the same way as every other. This assertion, against all appearance, of the equal worth of every human being is epiphanic in nature. Like all epiphanies it testifies to and attempts to make manifest the extraordinary within the ordinary, to help us to 'see' something new,

something deeper and truer in what we thought we knew.

Often such seeing is the accomplishment of art, as is shown, for example, in these stanzas of Czeslaw Milosz's poem, 'And Yet'.

*And yet we were so like one another
That lazy dragons stretching themselves in the air
Must have considered us brothers and sisters
Playing together in a sunny garden.
Only we did not know that,
Enclosed in our skins, each separately,
Not in a garden, on the bitter earth.
And yet we were so like one another
Even though every leaf of grass had its fate
Just as a sparrow on the roof, a field mouse,
And an infant that would be named John or Teresa
Was born for long happiness or shame and suffering
Once only, till the end of the world.*

To an inattentive and disengaged gaze, to 'lazy dragons stretching themselves in the air', only a partial understanding of human experience and life is available. To that view, we seem essentially all the same, 'so like one another, brothers and sisters', living contented in a 'sunny garden'. To us though, on the inside of that life, it does not feel like that, 'enclosed in our skins, each separately, ...on the bitter earth'. What that lazy gaze cannot appreciate is that as well as the sharedness or commonness of our human lives, there is a radical singularity that gives each leaf of grass its fate, each one of us a name. There is the radical and inescapable individuality that sees us each, John or Teresa, 'born for long happiness or shame and suffering/ Once only, till the end of the world'.

The poem makes vivid a truth about human life which is in one sense obvious. We each have one life to live, and only we can live it. Despite its similarity to the lives around us, my life will only ever happen once, instantiated uniquely in me. But by its showing up the naming of children against the fate of the sparrow and the leaf of grass, the poem manages to reveal what is strange and wonderful about that reality. How amazing that it should be so. And that we can see this truth about human life as amazing, that we can be struck by the wonder of the individuality and uniqueness of every human existence, born 'once only till the end of the world', is part of the back-

ground against which the declaration of the unconditional preciousness and mattering of every human being is not merely an ideal, but a deep truth. It is against this background that the assertion that all human beings are 'born free and equal in dignity and rights' can be seen as revealing something which is not simply 'there' on the surface of things but which, once pointed out, commands assent.

In my view, then, understanding the full meaning of speaking of the 'inalienable' rights of human beings depends upon us 'seeing' human beings as infinitely precious, unique and irreplaceable, each one with his own life to lead, her own mysterious fate. And, I would say, being moved or being touched by the wonder of that is part of what it is fully to understand what is at stake in our treatment of other people, part of what it is to fully respect the utter uniqueness of another individual.

The question that Simone Weil poses for us is whether the language of rights is capable of keeping alive and present to us a sense of the wonder and extraordinariness of the revelation of human preciousness. For her, it cannot. For her, the language of rights cannot reveal the radical violation done to a young girl forced into a brothel and so cannot make vivid for us what essentially is at stake in objecting to that violation. In Weil's view, rights are essentially connected to property, to contracts, to legal claims. That language then gets no grip on the desecration of the fragile and vulnerable heart and body of a young girl through rape, through the heedlessness and unrelentingness of rough men, the refusal to acknowledge the soul animating the flesh. Thus for Weil, if the notion of rights is all we have as a conceptual resource with which to articulate the wrong done to such a girl, we do not have the capacity to articulate the radical depth of the injustice thereby done.

There is no simple test for whether Weil is right about this or not. Perhaps, for example, we might argue that the concept of rights has grown since Weil criticised it, that it now resonates with much deeper connections than those she draws between 'rights' and commercial or contractual obligations. What I do think is right about Weil's critique, however, is the insight that if the language of rights is to do the work we want of it, then it must be capable of revealing the depth of what is at stake and it must be capable of moving us. This is not because, without being moved, we fail to act: it is because, without being moved, we do not fully understand. Traditionally, the name we give to what it is to be moved by the wonder of another human being, to be touched by the mere being of another person, is 'love'. And that leads me to the un-Kantian claim that the language of rights disconnected from the language and experience of love cannot reveal the full reality of another human being, and so cannot take us to the respect for other human beings which is its sincere hope.

No Justice Without Love

What, then, of the argument that 'love' is just a feeling, that it cannot be commanded, that it is too uncertain a foundation on which to build the edifice of justice? Consider this story, told by the Australian philosopher Raimond Gaita in his book, *A Common Humanity*.

Gaita tells us that when he was seventeen years old, he worked as a ward-assistant in a psychiatric hospital. Some of the patients had lived at the hospital for more than thirty years and were judged to be incurable, to 'have irretrievably lost everything which gives meaning to our lives'. Gaita writes that 'friends, wives, children and even parents, if they were alive, had long ceased to visit them' and that often they were 'treated brutishly by the psychiatrists and nurses'. There were, however, some psychiatrists who worked 'devotedly' to improve the lot of the patients and who spoke 'against all appearances, of the inalienable *dignity* of even those patients'. Gaita says that some of the nurses despised these psychiatrists with astonishing vehemence, but that he 'admired them enormously'.

One day a nun came to the ward and when she spoke to these patients,

...everything in her demeanour towards them—the way she spoke to them, her facial expressions, the inflexions of her body—contrasted with and showed up the behaviour of those noble psychiatrists. She showed that they were, despite their best efforts, condescending, as I too had been. She thereby revealed that even such patients were, as the psychiatrists and I had sincerely and generously professed, the equals of those who wanted to help them; but she also revealed that in our hearts we did not believe this.

Gaita remarks that the nun's behaviour had the power to reveal 'the full humanity of those whose affliction had made their humanity invisible. Love is the name we give to such behaviour'. In other words, the nun's response revealed to Gaita, in the same way that Milosz's poem revealed to us earlier, something that is not simply on the surface of things, but whose truth nevertheless commands assent. In the light of the nun's love for those patients, Gaita came to recognise truly and experientially, as opposed to intellectually or theoretically, their full humanity.

The nun's love in this story is not 'mere' feeling. It does not strike me as an uncertain basis for justice: in fact, it strikes me as more solid and more real than anything else. It is then a different kind of love than the love that is constitutively entwined with the liking of friendship,

or the bonds of family, or the charge of erotic love. It is a love which is, in one sense, impersonal: the nun of the story, one feels, could experience that kind of love for anyone. It is not dependent upon the qualities or personality of its recipient. But it is, in another sense, deeply personal. The nun is not detached from the felt experience of loving those whom she loves. Hers is not an intellectual assent to the proposition that all people are equally deserving of love, but is that love itself. And that love is *constituted* by the connection between the lover and the beloved. It is constituted by the openness of the lover to the individuality and wonder of the beloved.

*To love impersonally
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To love impersonally and yet personally in this way is the greatest achievement of the human spirit. It is what distinguishes the saint from the rest of us. And yet, although only saints can perform this miracle all or most of the time, almost all of us have experienced, at times when we have let go our fear, our clinging to identity and safety, at least fleeting moments of

that kind of fellowship, that exhilarating love for another, that commonness of our humanity.

I want to suggest that the possibility of that kind of love must remain alive in the background of the language of rights, if that language is to be capable of jolting us into the recognition of the individuality and preciousness of each human life. Putting the point differently, far from the language of rights and duty being able to replace the command to love our neighbour, the power of the language of rights is parasitic upon the practice of love. (Gaita makes the same point in his *Good and Evil: An Absolute Conception*.)

The Relationship between Risk and Self-Righteousness

This then brings me back to the difference between Martin Luther King and the contemporary human rights 'industry', the question of the relationship between risk and self-righteousness.

Martin Luther King devoted his life to the possibility of black Americans becoming full citizens of their own nation, being freed from 'the iron rod of oppression, ... unbearable injustice, and ... the ugly weight of discrimination'. In the end that devotion cost him his own life. And yet what is remarkable in King's writings is his refusal to demonise his 'enemies', those who persecuted and reviled him. 'Some of the most vigorous defenders of segregation', he wrote:

are sincere in their beliefs and earnest in their motives ... Some people feel that their attempt to preserve segregation is best for themselves, their

children, and their nation. Many are good church people, anchored in the religious faith of their mothers and fathers.

Time and again in his sermons he exhorted those campaigning for the civil rights of black Americans to love their enemies, to forgive those who persecuted them and who failed to recognise their humanity.

With every ounce of our energy we must continue to rid this nation of the incubus of segregation. But we shall not in the process relinquish our privilege and our obligation to love. While abhorring segregation, we shall love the segregationist. This is the only way to create the beloved community.

At risk for Martin Luther King, and for all those who took his message seriously, was not only life and physical safety, but an identity based in 'I'm right and these bigots are wrong, and I'm going to enjoy and feel satisfied about my rightness'. It was not that he vacillated about the justice of his cause, not that he hesitated in the least to name injustice and hate and persecution for what they were. But he remained open and vulnerable to the possibility of a full human relationship and engagement, even with those who hated him.

Again, I hesitate to speak other than for myself at this point, but I wonder whether it is the lack of that kind of vulnerability, the refusal of that risk of relationship with the persecutors, which taints with self-righteousness the

tone of some of us who campaign for justice. If we recognised the full humanity of those who are our ideological enemies, if we were genuinely open to the shock of their individuality rather than simply paying lipservice to their 'rights', could they so easily dismiss us as an 'industry'? If we were truly 'being the change we want to see', would our work not transcend the limits of interest group politics to point to the transformation of society as a whole? Although I think that the label 'industry' is mean-spirited and uncharitable, the fact that it has any grip at all should give those of us involved some food for thought.

Sources used in the preparation of this article include:

Gaita, Raimond, *Good and Evil: An Absolute Conception*, London: Macmillan, 1991.

Gaita, Raimond, *A Common Humanity: Thinking about Love & Truth & Justice*, Melbourne: Text Publishing, 2000.

Kant, Immanuel, *Groundwork of the Metaphysic of Morals*, Paton, H.J. (trans.), New York: Harper & Row, 1964.

King, Martin Luther, *Strength to Love*, Glasgow: William Collins & Co., 1986.

McLellan, David, *Simone Weil: Utopian Pessimist*, London: Macmillan, 1989.

Milosz, Czeslaw, *Provinces*, Milosz, Czeslaw, and Hass, Robert (trans.), New York: The Ecco Press, 1991.

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Print post approved.

Publication No. PP 337834/00003

Printed by Uniprint Pty. Ltd.

Who's Fooling Who? Self-Deception and Addiction

by Neil Levy

Addicts may be self-deceived in denying they are addicts, but even when they admit their addiction they may be deceived about its nature. This is a self-deception in which society colludes, and for which the addict cannot be held responsible.

Self-deception is a ubiquitous phenomenon in human life. Sometimes it is a relatively innocuous quirk of someone's personality—a persistent refusal to see the flaws in her partner, for instance—but sometimes it concerns matters of great importance. One area in which self-deception is commonly encountered is in relation to drug and alcohol use. The addict who deceives herself into thinking that she is in control is a stock character of popular culture, and far from unusual in real life. Is the self-deceived addict responsible for her addiction? Most people—and most philosophers—would answer in the affirmative. We are, they argue, always or nearly always responsible for our self-deception, especially so when it concerns such important matters.

I will argue that this view is false. In general, self-deceivers are much less frequently responsible for their state than is commonly believed; thinking otherwise is a hangover from a now-discredited theory of self-deception. Moreover, the self-deceived addict faces particular difficulties in recognizing the truth about herself. Our society, and especially the groups most concerned with addiction, encourages addicts to adopt views which are false. To the extent to which this is so, and addicts have difficulty resisting the pressure under which they are placed to adopt these views, their responsibility is diminished or dissipated. We, who promulgate such myths, are as much to blame as the addicts themselves.

New Conceptions of Self-Deception

How should self-deception be characterised? According to one philosophical approach (which I will refer to as 'the traditional conception'), self-deception has two features:

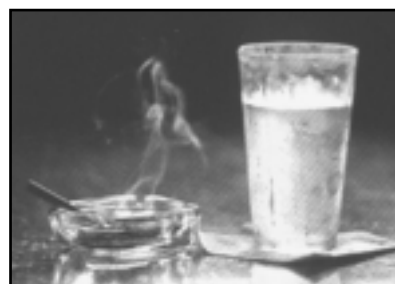
- (1) self-deceivers maintain contradictory beliefs concerning the subject of their self-deception, and
- (2) self-deception is intentionally entered into and maintained.

Because self-deceivers know the truth whereof they deceive themselves, and because they deceive themselves deliberately and intentionally, they are held to be responsible for their deception. Bishop Butler, who calls this state 'internal hypocrisy', is illustrative:

The temper itself is essentially in its own nature vicious and immoral. It is unfairness, it is dishonesty; it is falseness of heart [...] it is a corruption of the whole moral character in its principle.

But we have good reason to reject both features of the traditional conception. Both give rise to paradoxes. Contradictory beliefs are mutually exclusive, and can be simultaneously maintained only at the cost of severe irrationality. It is also difficult to see how I can intentionally deceive myself, since I will always see through my own stratagems. To be sure, both features of self-deception can be explained by postulating an unconscious, which, while knowing the truth, can deceive my conscious mind into believing a falsity, but the cost of taking this route is high. To the extent we go down this path, we risk losing the *self* from the picture; if there are two agents at work, then perhaps we should talk about two selves. More relevantly for our purposes, to the extent we suppose that the unconscious is the agent of self-deception, we lose the right to attribute responsibility to the conscious subject.

In the face of these paradoxes, some philosophers have urged that we abandon the notion of self-deception altogether. However, there is another route open to us: we can follow philosophers like Alfred Mele in developing a 'deflationary' account of self-deception. According to Mele, we need attribute to self-deceivers neither contradictory beliefs, nor an intention to deceive. Instead, self-deception occurs whenever agents treat evidence in a motivationally biased manner. Our motivation to believe a proposition frequently sets the stage for the activation of a number of well-attested mechanisms identified by psychologists, such as the confirmation bias, in which people search for evidence in support of a hypothesis rather than evidence which would disconfirm it, and the availability heuristic, in which people are more



impressed by evidence that is readily at hand. Thus we can be self-deceived without ever suspecting it.

Mele, along with other philosophers who have developed similar accounts of non-intentional self-deception, nevertheless continues to maintain that self-deceivers are typically responsible for their state. For them, it represents a culpable failure to control our beliefs, or a failure of epistemic courage in the face of anxiety. However, I suspect that the presumption that self-deceivers are responsible for their deception is the last remnant of the traditional conception. If we reject that conception, with its contradictory belief and intentionality requirements, we should also reject the presumption of responsibility. For the self-deceiver to be responsible for her belief, she must be able to *identify* it as the possible result of a biased belief formation process. But Mele doesn't give us any good reason to believe that this will always, or even usually, be the case. Once we reject the contradictory belief requirement, in particular, we have no reason to think that self-deceptive beliefs are phenomenologically unusual in any way, and, therefore, no reason to think that self-deceivers are aware *that* they are self-deceived,

or possess any means to identify *which* of their beliefs is suspect. Though self-deceivers will sometimes be responsible for their beliefs, we should abandon the presumption of culpability. Everything depends on the facts of the particular case.

There is no such thing as an irresistible or compulsive urge to consume drugs.

Self-Deception and Addiction

Is the self-deceived addict responsible for her state? Let us consider, first, the addict commonly found in writings by philosophers. The addict who populates moral psychology is a strange creature. He is typified by Frankfurt's unwilling addict, who is moved to take drugs by a 'force other than his own', or by Fischer and Ravizza's addict, who is 'passive' with regard to urges he knows it would be futile to resist. This is an addict who is *compelled* to use; whose first-order desire is literally irresistible (or whose behaviour is not altered by a normal range of incentives and disincentives). This addict is a familiar figure in our culture. She is the alcoholic who is the alcoholic for life, whether or not she ever drinks again; indeed, who was an alcoholic even before she had her *first* drink, because she has an addictive personality, because she has a genetic predisposition to alcoholism. The self-deceived addict or alcoholic, therefore, is the one who will not admit that she is like this.

Now, I see no reason at all to think that the self-deceived addict, whose self-deception consists in her denial that she is an addict, is not real. This self-deceived addict (call her the type one addict) may even be quite common.

After all, the fact that the addiction is heavily stigmatised is just the kind of incentive likely to set the biasing mechanisms typical of the self-deceiver to work. Alcoholism, for instance, will be incompatible with most people's self-image, and they might be expected to deny that they suffer from it until the evidence is overwhelming. Thus alcoholics can be expected to test the hypothesis that they are not alcoholics, to be more impressed by the occasions upon which they didn't drink than those—far more frequent—occasions when they did, to surround themselves with people who drink as much or more than they do, to convince themselves that their drinking behaviour is normal, to take the fact they hold down a job or have a roof over their heads as evidence they do not have a problem, to rationalise their drinking by claiming that it is a response to a crisis in their lives, without admitting that the crisis is the result of the drinking, and not (just) its cause. Alcoholism has been called the disease of denial, and I see no reason to doubt that this is accurate.

Is the type-one addict responsible for her self-deception? I suggested that the self-deceived are often, perhaps usually, not responsible for their state because there is no reason to suspect them of knowing that they are the victim of biased belief formation processes. However, type-one addicts often do not have this excuse. Very often, they will have good reason to suspect that they are addicted. Indeed, often their problem is pointed out to them. It is possible for the addict to self-deceive herself, in cases like this, and not be responsible for her self-deception—especially with regard to alcohol; concerning which consumption, even sometimes very heavy consumption, is widely accepted. Given that this is the case, one or two lost weekends, or a few days off work due to overindulgence, will not constitute overwhelming evidence of alcoholism, but there will come a point at which the attribution of responsibility will often be appropriate.

Whether she admits her addiction or not, however, the addict is peculiarly placed. Addiction is a characteristic concerning which self-acknowledgment is especially difficult. To see this, we need to recognize that the unwilling addict of moral psychology, the alcoholic of Alcoholics Anonymous (AA), does not exist. There is no such person, because there is no such thing as an irresistible or compulsive urge to consume drugs, and because the addict who is moved by a force which is wholly alien to her is a myth. Addicts take drugs because they get something out of doing so; not merely relief from withdrawal symptoms, but pleasure and release from life problems. While I do not deny that addicts may be sincere when they avow a desire to give up, the *wholly* unwilling addict does not exist.

But when addicts are urged to recognize their condition, and acknowledge honestly what they are, it is precisely

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this image of themselves they are asked to embrace. They are expected to renounce one false self-image in favour of another. We rightly criticise their self-deception, but ask them to abandon it in favour of *more* self-deception. Very often, we are successful. Think of AA. AA, and following it many addictions programs, demands that those who turn to it confess their alcoholism, defined as AA defines it. Thus the ritualistic formula AA demands: 'I'm Neil, and I'm an alcoholic'. The very first step of the twelve step program is a confession: 'We admit we are powerless over alcohol'.

Caroline Knapp is an AA success story, someone who has accepted that she is powerless over alcohol. She used, by her own admission, to be a self-deceiver, someone who told herself and others that she was not an alcoholic, that she could give up drinking anytime she wanted. Now she learns the truth. She goes into rehabilitation, and learns about the effects of long-term consumption of alcohol on the reward system of the brain. Now, she knows that alcoholism is physiological, not psychological. Indeed, alcoholism isn't a disease of the person at all: she describes how she learnt that 'it wasn't all me [...] it wasn't all a matter of insight and will'. Instead, it was physiological: alcoholics experience 'a set of physiological responses—a compulsiveness and loss of control—that other people don't', and over which they have no control. Accepting that she is an alcoholic, she sees that it was against her will that she drank.

Let us call the AA addict the type-two addict. Now, I claim, the self-image of the type-two addict is at least as self-deceptive as the one that it is supposed to replace. There are, no doubt, physiological components to addiction. The brain pathways, common to all chemical dependencies, have been mapped and the effects of substance dependence on the dopamine system is well understood. Withdrawal, for instance, is real enough. But the physiological components of addiction do not amount to compulsion. As Fingarette points out, alcohol consumption, even by alcoholics, is very sensitive to price, which would be surprising if alcoholism was compulsive. Beyond the fact that consumption of the drug in question is pleasant, and abstinence painful, we do not need to refer to the physiological in explaining consumption patterns. They are better explained by the mechanism of hyperbolic discounting, the mechanism by which rewards which are nearer to us in time are temporarily endowed with much greater value than more distant rewards; by 'existential dependency', in which the addict forms her life around the drug which provides its framework; and so on.

The idea of the addict propagated by AA and other such

programs—the idea of the addict as the powerless victim of physiological forces—is a myth. Moreover, though it *might* be a useful myth for some people, enabling them to stop their excessive drinking, it is a harmful myth to many others, alcoholics and drug addicts alike. It provides a convenient excuse for every relapse. It's not up to them to stop; they must wait for intervention, for a higher power (in the AA jargon) to help them; its not a free choice, there's no point resisting. It is especially powerful, even irresistible, after one drink, when, according to the AA ideology, the horse has bolted ('one drink one drunk'). But it is also powerfully militates against abstinence as well. At the very least, it prevents the addict from focusing on the role excessive consumption plays in her life, the function it serves for her, and therefore prevents her from addressing the real source of her problems.

Self-deception is motivated (false) belief. What is the motivation for the addict to accept this picture of herself? There may be more than one motive, but I suggest that an important motivation for many addicts will be that it allows them to repudiate their desire for the drug. We see how powerful a motive that might be when we understand, with Watson, how drug addiction actually functions. Appetites do not overcome our attempts at resistance by brute force; rather they seduce us. Thus,

one who is defeated by an appetite is more like a collaborationist than an unsuccessful freedom fighter. This explains why it can feel especially shameful; to one degree or another, it seems to compromise one's integrity. A parallel points holds for addictions [...] It enslaves by appeal, rather than brute force.

It may be very difficult for someone to admit that she *wants* to take the drug, that consumption now is worth more to her than abstinence (though she may *also* want not to want the drug). It may therefore be much easier to repudiate the desire, attribute it to biology, and continue drinking with a good conscience. No doubt, employment of this strategy is helped immensely by the fact that drugs like alcohol also temporarily impair our cognitive faculties, blurring our sense of responsibility and obliterating our memories.

At least one philosopher has previously noted that the belief in AA addiction is a source of self-deception. Herbert Fingarette has written well-known books about self-deception, and about alcoholism, so it was to be expected that he would notice the connection between them. Fingarette recognizes that the motive for (self-deceptively) accepting the claim that one is a type-two addict is that it allows the addict to repudiate the desire

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to consume her drug. He also seems to accept that to the extent that the addict is encouraged in this self-deceptive belief, her responsibility is diminished. Disavowal of one's desires reduces one's ability to exercise self-control with regard to them, and therefore partially excuses the self-deceiver. Her actions are no longer 'either straightforwardly voluntary or straightforwardly involuntary', and to this extent her responsibility is diminished.

However, Fingarette's account of self-deception applies much more plausibly to the type-one addict than to the type-two. Fingarette accepts something very much like the traditional conception of self-deception. According to him, self-deception is simply an avoidance of focusing on an aspect of myself or my behaviour. By such avoidance, the self-deceiver avoids 'a traumatic wound' to her self-esteem. I shall not criticise this account of self-deception here. I am more concerned, for the moment, with noticing how it prevents Fingarette recognizing the extent to which the AA model undermines attribution of responsibility for self-deception. The type-one addict might conceivably have come about her self-deception by a motivated failure to focus upon her own behaviour. The type-two addict, however, need suffer from no such failure. On the contrary, she might make a good faith and sustained effort to examine her behaviour, and yet still remain self-deceived. Powerful forces prevent her from recognizing that her belief that she is an AA addict is self-deceptive.

Let us examine how these forces work to maintain the self-deception of the type-two addict. Perhaps doubts surface in her mind as to whether this model of addiction really best fits her behaviour; whether it really is all a matter of biochemistry. Caroline Knapp certainly entertains such thoughts:

I can find countless pieces of evidence to suggest that when I put alcohol into my system I experienced a set of physiological response—a compulsiveness and loss of control—that other people don't. But I still have trouble connecting that to the concept of permanent, progressive illness. What about the times I drank and didn't lose control?

However, it would be very difficult for her to identify her belief that she is an (AA) alcoholic as self-deceptive. She has been told that *denying* she is an alcoholic is self-deceptive; even entertaining doubts is suspicious. If she feels any doubts (and of course she need not), she may well justifiably interpret them as a self-deceptive desire to deny her alcoholism. For her, self-knowledge is almost impossible, since the one view which is (truly)

not self-deceptive is widely regarded as epitomising self-deception. To the extent that she is a conscientious believer, to which she attempts to guard against self-deception, she will be steered away from the truth, and towards self-deception.

Now, if that is the case, then though the self-deceptive addict of the literature might be responsible for her deception, it is almost impossible for her to leave her self-deceptive state. If she tries, she merely substitutes one set of deceptions for another. Since the therapeutic regime, and popular culture, encourage self-deception, the self-deceptive alcoholic who 'acknowledges' her problem is not responsible for her self-deception.

This conclusion can be reinforced by considering the extent to which addiction is belief dependent. The *physiological*, as well as the psychological, effects of drug consumption are highly belief mediated. Consider these facts:

- Cravings depend, in part, on beliefs. If there is no possibility that the craving will be satisfied, it quickly subsides. Heavy smokers regularly travel on airlines *without experiencing cravings* until they disembark.
- Withdrawal symptoms can be triggered by placing an addict in a situation in which she has used drugs in the past.
- The physiological effects of placebos on addicts, taken in the belief that they are the addictive drug, can be greater than the physiological effects of the real drug, consumed in the belief that it is a placebo.

Given that this is the case, we would expect the socially (indeed, medically) endorsed belief that the craving for drugs are near overpowering to have a powerful effect on the manner in which addicts experience their addiction. At the very least, we can expect them to behave like Fischer and Ravizza's addict, to give in to their cravings earlier, in the 'knowledge' that they cannot hope to resist them. The type-two addict might relapse more frequently, and when she does, she will binge far more heavily, than the type-one addict. For her it will be true—'one drink, one drunk'; the prophecy is self-fulfilling.

Thus this myth might militate against abstinence. Perhaps more seriously, it is certainly an obstacle to addressing the real problems to which excessive consumption is a response, socially and individually. It prevents the individual from perceiving the role that excessive consumption plays in her life, by encouraging her to believe that it is not *her* at all. It encourages us, as

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a society, to spend money on medical research rather than poverty alleviation, on drug regimes rather than systematic inequality. It is a useful self-deception, perhaps, for those who are not its victims, because it is (apparently) cheap for society, and it encourages us to look away from real social problems and instead attribute the problem to individuals with unfortunate genetic inheritances. It is also, it goes without saying, a useful myth for the alcohol manufacturers, who can claim that except for a small number of people with an unfortunate genetic predisposition, their product is safe.

To the extent to which we propagate this myth, explicitly by funding substance treatment programs predicated on its assumptions, or implicitly, by funding research on the 'genes for alcoholism', through popular culture, or even through writings in moral psychology, it is we who are (self-) deceived. Those who we are pleased to call addicts suffer as a result, but so do we, through the traffic accidents and associated trauma caused, overwhelmingly, by the general run of drinkers; through the thefts and muggings perpetrated by the addict for whom no realistic treatment regimes exist; through the misallocation of research funds. The addict suffers from her self-deceptive belief, and we suffer from hers and ours. If responsibility is to be shared out, we as a society are in line for as great, or greater, a share as the addicts.

Sources used in the preparation of this article include:

- Butler, Joseph, 'upon Self-Deceit', in *Butler's Fifteen Sermons Preached at the Rolls Chapel*, London: SPCK, 1970.
- Elster, Jon, *Strong Feelings: Emotion, Addiction and Human Behavior*, Cambridge, Mass.: The MIT Press, 1999.
- Fingarette, Herbert, 'Alcoholism and Self-Deception', in Mike W. Martin (ed) *Self-Deception and Self-Understanding: New Essays in Philosophy and Psychology*, Lawrence: University Press of Kansas, 1985.
- Fingarette, Herbert, 'Self-Deception Needs No Explaining', *The Philosophical Quarterly* 48, July, 1998.
- Fingarette, Herbert, *Heavy Drinking: The Myth of Alcoholism as a Disease*, Berkeley: University of California Press, 1988.
- Fischer, John Martin, & Ravizza, Mark, 'Replies', *Philosophy and Phenomenological Research* LXI, September, 2000.
- Frankfurt, Harry G., 'Freedom of the Will and the Concept of a Person', in John Martin Fischer (ed) *Moral Responsibility*, Ithaca: Cornell University Press, 1986.
- Knapp, Caroline, *Drinking: A Love Story*, New York: The Dial Press, 1986.
- Mele, Alfred R., *Self-Deception Unmasked*, Princeton: Princeton University Press, 2001.

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Better off Deaf?

by Robert Sparrow

Robert Sparrow investigates the ethics of a Deaf couple's decision to employ a sperm donor with a family history of deafness in order to maximise their chances of having a deaf child.

Should parents try to give their children the best lives possible? Yes. Do parents have an obligation to give their children the widest possible set of opportunities in the future? No. Understanding how both of these things may be true will allow us to go a long way towards understanding why a Deaf couple might wish their child to be born Deaf and why we might have reason to respect this desire.

Criticism of Sharon Duchesneau and Candy McCullough's decision, reported in the Washington Post, to seek out and employ a sperm donor with a family history of deafness in order to maximise their chances of having a deaf child, has concentrated on two aspects of this decision. The first is that they consciously sought the birth of a child that the vast majority of people would consider to be 'disabled'. The second argument, which may or may not presume the first, questions the decision they made to bring a child into the world who is likely to have greatly reduced opportunities by virtue of being deaf.

I want to concentrate on the second of these arguments here. The idea that deafness need not be a disability and can instead be an entry point to a minority culture coalesced around a signed language, and the foundation of a cultural identity as 'Deaf', is one that I am personally sympathetic to. But this argument has been well made elsewhere, by Deaf persons themselves, and for reasons of space I shall not repeat it here. In any case, settling the question as to whether D/deafness is a disability or a cultural identity—or perhaps both—does not in itself resolve the question of the ethics of deliberately seeking to bring about the birth of a D/deaf child. One may concede that deafness is a disability but hold that this is unimportant because deaf children can have sufficient opportunities in life to justify bringing them into the world. Alternatively, one may agree that deafness is a cultural identity, but still be concerned for the opportunities available to the child as a member of that culture. The question of the obligations of parents with regard to the opportunities available to the children they choose to bring into the world remains crucial.

Width or Worth of Opportunities?

In a society which fetishises individual choice and opportunity, it may seem obvious that these are goods. For parents to have a child with less of these than some other possible child they could have had may seem like them restricting their child's future liberty by imposing their projects and values on the child. Was Duchesneau and McCullough's decision to seek out a deaf sperm donor wrong because it was likely to lead to the birth of a child with less opportunities than if they had chosen a 'normal' donor? Do parents instead have an obligation only to have children who will have the widest possible range of opportunities?

The first thing we must do is to realise how strong a claim this is. It seems exceedingly unlikely that every child could have the *widest* possible range of opportunities. Presumably there is a limited number or class of children who have such. The remainder, the vast majority, have less than this. If parents have an obligation to ensure that their children have the widest possible opportunities then most parents will fail to meet it.

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Moreover, the class of children with the widest possible opportunities is likely to be an elitist one which reflects injustice more than any 'natural' distribution of opportunities. As minority rights and disability activists have argued, many sorts of restrictions of opportunity come about as a result of the relation between the characteristics of the child (race, sex, physical capacities, etc) and the social context into which they are born. In a sexist, racist and homophobic society (such as our own) the opportunities available at birth to women, non-whites and homosexuals are substantially less than those available to white, straight men. Parents concerned to maximise their child's life prospects would therefore do well to use sex selection technologies to give birth only to male children. Mixed race couples in racist societies should embrace the use of genetic screening to ensure that they only have children whose skin colour would allow them to escape the opportunity-reducing effects of institutionalised racism. In this way, an obligation only to

have children with the widest possible range of opportunities would make parents hostage to the social structure and bigotry of the society in which they live.

Already, then, it seems likely that parents' obligation in relation to their children is only to ensure that they will have some minimum threshold of opportunity rather than to maximise their opportunities. But, even this description of their obligations, I will argue, crucially under describes them. In fact what is important, when we consider the future of children, is that they should have a reasonable range of *valuable* or *important* opportunities. In order to see this we need to push a little bit harder on the idea that we should maximise our children's opportunities.

If we grant the existence of this obligation it seems extremely unlikely that it should be discharged with the choice of the sort of child that one brings into the world. Surely, our treatment of children after they are born is equally subject to it? Indeed our ordinary intuitions suggest that parents' treatment of their children after birth, in their early childhood and formative years, is *more* constrained by an obligation of this nature. Thus while most of us would not object to parents who allow themselves to have a girl child, who will have less opportunities than her brother because of the sexism of the society into which she is born, we are likely to object strongly if they then bring her up to believe that she should not aspire to anything because she is a girl. In the current controversy, Duchesneau and McCullough's decision not to fit their son with a hearing aid—in order to make the most of the residual hearing with which he was born—has incited nearly as much hostility as their decision to try to maximise their chances of having a deaf child in the first place.

So, if we are concerned with the opportunities that children have at birth, this concern should extend to include their treatment in early childhood. In particular it should include the choices parents make about their child's education, especially early on, and the language they grow up speaking, as these are matters that may have a dramatic impact on the choices they have available to them in later life. These choices may have as much, if not more, impact as decisions about what sort of children we shall bring into the world.

Now we can begin to see just how demanding and counter-intuitive a concern to *maximise* the opportunities available to our children is.

Consider first the matter of what language(s) we should bring our children up speaking. This is a genuine and

difficult question for parents who are members of minority language cultures surrounded by a larger culture which offers more economic opportunities. Insofar as they are concerned to maximise the opportunities available to their child, parents in such a situation should ensure that their child grows up fully fluent in a language other than their own. What makes this choice a difficult one is that doing so makes it much less likely that their children will grow up speaking their language in later life and much, much less likely that their grandchildren will.

Most commentators try to soften this dilemma by pointing out that parents in this situation can teach their children *both* languages (although in fact this is unlikely to avoid the outcome that concerns the parents). This resolution is revealed as less convenient than first appears when we realise that it is true for *all* of us that our children will have more opportunities the more languages they learn. They will be able to read more literatures, travel more widely, work in more countries, etc. If members of minority-language cultures have an obligation to maximise the opportunities available to their children, by teaching them another language as well as their own, then presumably so too do members of majority language cultures. Indeed, we should all teach our

children as many languages as possible. Furthermore, given that there is a practical limit on how many languages our children can learn, it seems that we should teach them first that set of languages that will give them the *most* opportunities. At first approximation, this suggests that, in an increasingly international world, we all have an obligation to bring our children up speaking English, Spanish, Mandarin and Hindi, not necessarily in that order.

But while we might think that bringing children up speaking these languages is a good thing, we hardly feel that it is an obligation such that parents who have failed to meet it have thereby failed to be good parents. We certainly don't feel that parents are obligated to educate children in these languages at the expense of education in their own language, where this provides a reasonable modicum of opportunity. Again, it seems that parents are obligated to provide this modicum rather than to maximise the options available to their children.

However, it is when we move to consider the implications of a preoccupation with range of opportunities for education more generally that the real problems with it become clear. The desire to maximise opportunities will clash severely with other values that we feel strongly that it is the role of education to promote.

The first of these is the truth. There will be many cases

We need to push a little bit harder on the idea that we should maximise our children's opportunities.

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when, for various pragmatic reasons, a child will have many more opportunities if he or she grows up believing things which are false and which his/her parents know to be false. These may be personal and idiosyncratic beliefs which it is advantageous to hold for various psychological reasons, or they may be falsehoods widely believed across society, the espousing of which is necessary to open various doors. Imagine a society (not too far-fetched) in which the public espousal of racism, or sincere devotion to a tyrant, was necessary in order to achieve any significant position in government or business. In such a society, a child would clearly have more opportunities if she grew up believing these falsehoods. But no one would, I take it, hold that a responsible parent should consciously inculcate ideas that she knows to be false in this situation. The role of a parental educator is to teach their children the truth as they see it. As I will discuss below, this obligation is especially pressing when the truths at issue concern moral questions that the parents believe bear critically on the question of how to live a good human life.

Before we turn to the question of the values we wish to imbue through early childhood education, it is worth noting that similarly counter-intuitive results arise from the desire to maximise opportunity in relation to the character traits we wish to inculcate in children, even where these are described with as little reference to our values as possible. To see this, imagine that there is a set of specific skills that are necessary in order to pursue a successful life of crime; brazen lying, ruthlessness, skills at shop lifting, knowledge of how to steal cars, burgle houses, etc. Possessing these skills opens up a veritable vista of opportunities for a life as a pickpocket, cat burglar, confidence trickster, and so forth. But even presuming that these could be taught without jeopardising the existence of other opportunities, we do not feel that an upbringing that includes them is a better upbringing than one which neglects them. We do not believe that, because we place no value on the opportunities or life paths they open up.

The role played by our judgements about the worth of opportunities becomes explicit when we consider what sort of moral education we should provide our children. There is no reason to believe that having a strong set of moral values, for instance, will lead to one having more opportunities in life. If anything it seems likely that having no strong moral beliefs will lead to one having a wider range of opportunities. One could then become a 'moral chameleon', adopting whatever moral code will facilitate our entry to various positions of power or opportunity. One need never be prevented from becom-

ing a police officer by concern about the justice of the law, or a drug baron by scruples about the ethics of the trade. But this is hardly the result we seek from a good moral education. Instead, an important purpose of education in such values is to try to *prevent* us from pursuing certain life paths. Part of the nature of a good education is that it closes windows to people, by allowing them to realise why they are not worthwhile choices. When we consider the moral education of our children, we want them to develop values which reveal some choices as worthwhile and others as worthless. Our purpose in doing so is to encourage them to pursue certain life paths and to prevent them from pursuing others. We will count ourselves as successful in this, if they grow up making choices and adopting a lifestyle that we approve of and admire.

What we desire are not opportunities per se but valuable or important opportunities.

This is the real problem with a concern for the width of opportunities available to children when they are brought into the world; that it abstracts, and distracts us, from the question of *which* opportunities it is important that children should have. What we desire for ourselves (and others who we care about) are not opportunities *per se* but valuable or important opportunities. The mere multiplication of opportunities does not increase our chances of leading a meaningful or worthwhile life. It may even decrease our chances of doing so, if some of these options lead down paths to misery, confusion or delusion from which it is difficult to extricate ourselves. Parents should want their children to have the best life possible—this is internal to our idea of what it is to be a good parent—but the best life possible does not consist simply in the life with the widest range of opportunities. Our own judgements about what sorts of life are worth living inevitably come into the picture when we think about what sorts of opportunities children should have.

So does this mean that parents should educate and shape their children to live *the* best life possible? Should they force them into a mould determined by their most considered judgement about the nature of the good life? There are a number of pragmatic but nonetheless important reasons why this would be wrong. Firstly, to my knowledge no culture holds that there is only *one* way of living the good life. Even the strictest religious cultures typically hold that it is possible to live the good life as a farmer, or a builder, a physician, a man or a woman, or in any number of social roles. Conceptions of the good already have a range of options, through which they can be realised, built into them. Moreover, the character traits that suit a person to a particular social role or way of life, or even allow them to pursue it, are subject to a number of unavoidable contingencies. If we bring up our children with only one life path in mind, we are likely to be

disappointed if they turn out not to have the skills or inclination for it. The mere fact of our having such strong and determinate expectations may even make it less likely that they meet them, as the weight of parental expectation may be crippling for some children.

A person may believe that the best forms of life are those promoted by their own culture.

Thus while we may have strong intuitions that some life paths are, and some aren't, worth leading, we would be wise to ensure that our children have a *range* of opportunities in relation to the particular life they lead. Or, more accurately, that they have an adequate range of opportunities to live meaningful and worthwhile lives. But the extent and nature of this range will inevitably and properly be determined with reference to our own ideas about what makes a human life go well and which sorts of life are and are not worth living. This means that parents will inevitably disagree about these issues. To the extent that ideas about these questions are sustained and transmitted by cultures it also means that members of different cultures are likely to disagree about them systematically.

We may appear to have strayed a long way from the question of the ethics of a Deaf couple's desire to have a baby who is deaf. But the point of the preceding discussion was to establish that the judgement of what sort of child will have the best possible life is one that will inevitably refer to the values and beliefs of the person making it. This goes for education in general. It also goes for the decision about what sort of child to bring into the world in the first place.

Better off deaf?

The question remains, then, could parents ever have good grounds for believing that their child would be 'better off deaf'—where 'better off' is determined with reference to the worth of the range of opportunities they will have to lead a good human life? Yes. I think there are at least two different sorts of reasons that parents might have for holding this, one perhaps more plausible than the other.

The first set of reasons stem from a particular form of cultural identification that is more familiar in cases involving other minority language cultures. A person who strongly identifies as a member, and with the values, of their own culture may believe that the best forms of life are those promoted by and supported within that culture. For example, one can imagine a committed Francophile thinking that their child will have a better chance of leading a meaningful life if they have access to the wisdom contained in the French literary tradition. Or, a member of a religious culture, thinking that only life choices that acknowledge certain important religious truths have any worth. In both cases, these cultural loyalists may further feel that the majority of the ways of

life promoted in other cultures are of little value. If parents have this sort of identification with their culture, they will believe that their child will have the most opportunities to pursue valuable life courses only if they grow up as a member of their culture.

Some Deaf parents *might* feel this way about Deaf culture. That is, they might value only the opportunities made available within Deaf culture and have little respect for the ways of life pursued by individuals in the wider hearing culture. In this case they will have good reason to desire that their child should grow up as a member of Deaf culture.

In fact, not having any allegiance to Deaf culture myself, I find this difficult to imagine. Deaf culture does not seem to support the distinctive forms of life that some indigenous cultures do, for instance. The basic sets of aspirations and role models seem pretty much coextensive with those of hearing culture. To the extent that this is the case, it will not be reasonable for Deaf parents to believe that their child will have a better chance of realising their values if they grow up Deaf. They will have a better chance if they grow up in a hearing culture which, simply because of its larger size, offers more opportunities to do so.

Nonetheless, I am reluctant to rule out the possibility of this sort of argument being made. Signed languages are not easily given a written form, and this means that some Deaf cultures have developed rich story telling traditions. One can perhaps imagine a parent thinking that these contained sufficient wisdom that access to them was an important precondition for living the best life possible. Alternatively, a Deaf parent might believe that being Deaf leads to a set of capacities and experiences that are superior to those of hearing persons and that these are essential to choosing wisely between life paths. This is analogous to the argument made by those who believe that deafness is a disability that prevents deaf children from having the full range of human experiences that would allow them to choose certain life paths, such as, for instance, that of a musician. The Deaf argument here is more plausible than first appears because Deafness may involve increases in certain capacities, such as visual acuity and spatial visualisation, beyond those of hearing persons. The claim of some Deaf persons that they would not have hearing even if it could be granted to them might be interpreted along these lines.

Because our cultural values shape our assessment of options so deeply, it is very difficult to make assessments about how members of other cultures might feel about the relative value of sets of options. So while I myself

find it hard to imagine making either of these judgements I would not like to rule them out entirely.

However, the second set of reasons why a Deaf parent might think that their child will have a better life if born deaf, measured in terms of access to a wide range of valuable opportunities, are more compelling. They might prefer a deaf child, not because they believe that the ways of life promoted in Deaf culture are more valuable than those promoted outside of it, but simply because they are capable of being much better parents to a child who belongs wholeheartedly to their own (Deaf) culture.

The range and nature of the opportunities available to a person is not solely a function of which culture they are a member of but also of how confident and secure they feel in that culture. The self-respect that comes from being secure in one's cultural identity allows a person to choose confidently between the opportunities available

to them and to make the most of the opportunities they choose to pursue. Lack of confidence and insecurity about the opportunities available in a culture may be paralysing. An important role of parents is to foster and encourage their children to feel secure and confident in their cultural identity.

If a couple's children are spending a large amount of time

in a culture in which they (the parents) are unable to participate, then they may be justifiably concerned about their ability to guide, advise and support their children in relation to the choices they make in relation to that culture. They may be unable to fulfil their parental obligation to ensure that their children grow up with a secure cultural identity. This may be of especial concern if that culture is one in which the common opinion is that the parents are disabled, as this itself could constitute a serious threat to the children's confidence and self-esteem. Deaf parents may have good reason therefore to want their child to grow up in their own Deaf culture.

Conclusion

Duchesneau and McCullough's attempt to maximise their chances of having a Deaf child was made using only a knowledge of the family history of the donor concerned. But the controversy aroused by their decision resulted, at least in part, from an awareness that genetic technologies such as *in vitro* fertilisation, prenatal genetic analysis, 'gene therapy' and other techniques of genetic modification, and perhaps even cloning, are likely to play an increasing role in decisions about the sort of children we have in the future. I have suggested that Deaf parents may have two sorts of reasons for believing that

their children would be 'better off deaf'. What do my conclusions imply for the right of Deaf parents to use genetic technologies to try to ensure that they have a Deaf child?

If we are to allow the conscious shaping of a child's genotype through new genetic technologies then we must allow all parents to use them to try to ensure the best life possible for their children, *as long* as their conception of what such a life consists in is a reasonable one. These are both important qualifications.

To discuss the second qualification first. There is a wide range of reasonable conceptions of what a good human life consists in. Different people, different cultures, different religions disagree about the nature and sources of happiness and about how a good person should live. Nonetheless every individual and society must also hold that some ideas about these matters are unreasonable. This commitment is internal to having any beliefs about them at all. We currently accept that parents have the right to make many significant decisions about the interests, education and upbringing of their children. But there are limits on these parental rights, and these limits are roughly delimited by the notion of the reasonableness of the decisions they make. If parents attempt to shape their children according to an idea about the best life for a person that is obviously unreasonable, then society may choose to step in. Children are also citizens, or future citizens, and so society also has an interest in their upbringing. This interest is, for instance, reflected in the restrictions that we currently recognise on the rights of parents to educate their children. Society insists that children should be educated in order to enjoy a particular range of opportunities, regardless of whether or not these are opportunities the value of which their parents affirm.

Furthermore, the decision to allow new reproductive technologies to be employed to shape the sort of children that are born is a public as much as a private one. The technologies which today make it possible to do this exist because of research which is, directly or indirectly, publicly funded. The consequences of their widespread use may be demographic changes (for instance, in sex ratios, or the number of children born with disabilities) which are clearly of a public nature and interest. The legal and regulatory context in which they are used is determined by public policy debates. If a child is born into the world with opportunities that could not reasonably be described as conducive to the best possible life then the public shares some responsibility for this. The public therefore has a legitimate interest in decisions being made about the sorts of children that are being born as a result of the use of these new technologies. We may properly restrict their use to cases where the parents' desire for a child of a certain sort is a reasonable one.

I have argued that the desire of Deaf parents for deaf

An important role of parents is to encourage their children to feel secure in their cultural identity.

babies may be reasonable. But this judgement is problematised by the recognition that it rests on beliefs about which options and activities are valuable and central to living a worthwhile human life. Others may see the matter differently. That is, they may deny that the opportunities available to deaf children can reasonably be held to allow them the chance to have the best life possible. Given the existence of such disagreement we can only try to resolve the matter through public debate and dialogue and a process of democratic decision making.

Thus in order for Deaf parents to be granted access to genetic technologies for the purpose of having deaf babies, the majority of Australians must acknowledge that Deafness can be a source of pride rather than regret and that Deaf culture has within it the resources to offer people a wide range of opportunities, some of which might reasonably be held to be important enough to justify the belief that a Deaf child will have a better life than a hearing child. In particular, the popular misconception that deafness is a tragic disability that must inevitably blight a human life must be overcome. The strength of public hostility to the idea that Deaf parents might desire a deaf child suggests that we have a long way to go to reach this goal. However one may also hope that the publicity granted the Duchesneau and McCullough case has drawn attention to the fact that many Deaf people do not feel this way about their deafness, and to the existence of a rich and vital Deaf community and culture.

If we acknowledge the reasonableness of a cultural understanding of Deafness and an identification with Deaf culture, and if we allow the use of genetic technologies to parents wishing to have children of a certain sort, then we have no legitimate grounds to deny Deaf parents the right to use these technologies in order to have deaf babies, if they wish to do so. But the second of the qualifications raised above is much more important. It is far from clear to me that we should allow anyone at all to use the new genetic technologies to shape the genetics of their children. The impact of these choices on

the demographics of future populations is likely to be significant and far reaching. Allowing parents to use these technologies to 'improve' their children risks subjecting the nature of the human species to a eugenics directed by market forces. Their use to ensure that children are not born with various 'disabilities' risks communicating a profound disrespect for people who have the genetic conditions that the parents are seeking to eliminate. Perhaps the most valuable lesson we can learn from the controversy surrounding this Deaf couple's attempt to have a Deaf child is that the idea of 'improving' our children is more complex and contestable than is generally recognised. This in turn might lead us to think again about whether this is a project that we, as a society, wish to embrace.

Sources used in the preparation of this article include:

Barnes, Colin, Mercer, Geoff, and Shakespeare, Tom, *Exploring Disability: A Sociological Introduction*, Cambridge: Polity Press, 1999.

Davis, Dena S., 'Genetic Dilemmas and the Child's Right to an Open Future', *Hastings Center Report* 27: 7-15, 1997.

Garretson, Melvin D., ed., *Viewpoints on Deafness*, Silver Springs, Maryland: National Association of the Deaf, 1992.

Kymlicka, Will, *Liberalism, Community and Culture*, Oxford: Oxford University Press, 1989.

Lane, Harlan, Hoffmeister, Robert, and Bahan, Ben, *A Journey into the Deaf-World*, San Diego: DawnSign Press, 1998.

O'Brien, Dorothy, 'On Deaf Ears', *The Big Issue* 2: 7, 16-17, April, 2001.

Padden, Carol, and Humphries, Tom, *Deaf in America: Voices from a culture*, Cambridge, Mass.: Harvard University Press, 1988.

Culture, Medicine and Public Policy —Some Reflections

by Tony Coady

While health professionals need to be sensitive to the ‘communities of attachment’ within which individual patients may be situated, Tony Coady argues they cannot afford to be cultural relativists when it comes to the value of personal autonomy.

The word ‘culture’ has become a cult word in our contemporary vocabulary, but like many fashionable expressions, it has the power to mislead. In this brief article I won’t try to define ‘culture’ but merely signal the need for a sharper focus in discussions that invoke it. I will simply take it that culture has something to do with the meanings that a group tends to give to certain actions and behaviours and the norms, implicit or explicit, that membership in a group tends to enforce.

Some reference to what is conveyed by the word ‘culture’ is important for various reasons. One is that we cannot understand people in isolation from their backgrounds, including communal backgrounds. This point about understanding is very important in medicine and other health care dealings with people. One persistent difficulty in dealing professionally with people is the tendency to treat them as mere problems. They have problems and medical professionals are equipped to some degree to deal with the problems—but the problems will be misunderstood if isolated from the people who have them. Other facts about the people (other than their problems) are relevant to understanding the problems and to dealing sensitively with them. Such facts are not restricted to their ethnic or cultural background. Issues such as personal history, temperament, other illnesses and spiritual outlook are also significant. Thus it is important for understanding individual patients that health care professionals know as much as is feasible about the beliefs and values that patients are likely to have as a result of their involvement with their various communities of attachment. I say ‘various communities’ because it is a mistake to think that only one such attachment is possible or desirable. So culture is one of the important things to take into account in understanding patients and, more generally, populations with health problems.

One problem with culture is: who has the right to speak about what the culture demands? Who is authoritative about the nature of the cultural norms, demands and

expectations? This is closely connected with the fact that cultures are never so solidified, monolithic and unchangeable as popular discourse suggests. There are always contested interpretations of culture within it, and power plays for the determinative role in speaking for it. A classical example of this is the debate in the USA about how much latitude should be allowed to the Amish religious sect in matters such as education and the defiance of standard civic laws. (An example being the refusal of some Amish to obey a traffic law requiring the display of the reflective red and orange triangle on slow moving vehicles.)

Nearer to home, it always used to annoy me to read in the press of ‘the Catholic view’ on various contentious matters, such as abortion or infertility treatment or safe injecting houses. On most of these issues there are many considered outlooks that can reasonably lay claim to be called a ‘Catholic view’. In a tightly structured bureaucracy such as the Catholic Church has unfortunately become, it is not surprising that views of the hierarchy are given considerable weight, but it is unfortunate if they are emphasised to the exclusion of competing positions. Luckily, the media is nowadays much more attuned to the existence of conflict and dissent within religious communities, especially Christianity, but we all need to be more aware that the same thing is true of other religious communities and cultural groups. Many of us are only now becoming alert to the degree of dissent, conflict and contention that exists (and has existed for some time) in the aboriginal community. Acknowledgment of such complexity is not a negative comment on their lives, but an admission of a universal fact about groups of any sort.

But understanding people and ‘where they are coming from’ is not the end of the matter. Health professionals have to advise and help them with their illnesses and problems. Here there has been something of a tendency in much public discussion of cultural difference to deplore the prevailing individualism of our society (or of ‘the dominant culture’). Transferred to the medical scene

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this means that the hard-fought and almost won battle to give due weight to patient autonomy is coming under fire. Confidentiality is also at risk.

I was at a conference not so long ago where a number of social workers were advocating that in their dealings with an aboriginal community they should treat the community as their client and not the individuals who sought their assistance. Autonomy and confidentiality were mere Western values. This implied a carefree breaching of confidential communications in ways that could have had devastating effects upon individuals. Another interesting example bearing on this matter was the study conducted by some researchers in Gambia in West Africa. They were concerned with whether the prevailing view of informed consent fitted with Gambian culture. They asked parents of children who were offered HIB vaccination for their consent and then inquired into the basis of their decisions. 137 accepted the vaccination and 52 refused. Of those who refused, a predominant reason was that the vaccination was experimental and might have bad effects. The parents were given the opportunity to seek advice and only 1% sought the advice of traditional community or religious leaders. Clearly, these Africans were able and keen to process information about proposed health care, valued their autonomy, and made decisions on a basis intelligible to anyone.

To return to my social workers. Practices such as they proposed go well beyond the search for understanding of the patient or client. They go well beyond the attempt to determine the mature patient or client's real desires and interests. They basically constitute an assault upon those interests and desires and a denial of the individual's legitimate personal and civil rights. Whatever the importance of group and cultural membership, it cannot be right to let the group decide for the patient unless the patient wants it to. (This seems to me clear in the case of adults. The situation with children requires more subtle treatment, though some presumption of autonomy is defensible even here.)

Some common attitudes to culture seem to me not only to involve a failure to comprehend the complexity of cultural groups and the power relations within them, but also a failure to understand the potential oppressiveness of groups, whether they be religious, ethnic, cultural or political. Communitarian writers in their (extreme, in my view) reaction against real and supposed faults in the liberal political tradition are fond of reminding us of the way communities can be supportive of personal growth and integral to personal identity. There is undoubtedly something in this. Our lives are wrongly understood if we are viewed as atomistic individuals disconnected from tradition and intimate contemporary relationships to others. But there is no point in being blinded by sentimentality about such connections. Families are clearly

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basic to the development and identity of individuals, but even families can be abusive, dominating, stunting and crippling to the individuals in them. If this is true of families, it is even more likely to be true of wider group associations, though in different ways. Individuals need both the support of groups and protection from them.

While on the subject of families, I am reminded of a workshop my wife and I participated in last year in Singapore. It was called 'Self, Community and Family'. It was a good workshop and I learned a lot about the various complex strands of traditional Chinese thought and contemporary Singaporean practice. As is common in Singapore there was a good deal of talk about the importance of the Confucian family. I was beginning to think that some of it was a deal too pious, when a young Singaporean political scientist got up and said, "I want to say something about the Confucian family. I live in one and was brought up in one, and as far as I can see, the central feature of the Confucian family is that my great grandmother persecuted my grandmother, my grandmother bullies my mother and my mother gets the right to bully my wife and so on through the generations." There was a moment of shocked silence and then a more relaxed, often amusing and certainly realistic discussion began about the various merits and defects of the Confucian family.

These points about culture help to show the dangers of a simple cultural relativism about values. People are able to reflect on and criticise their own cultures and they are right to do so. Autonomy, personal dignity and the right to know what your medical treatment is all about are not 'Western' values (whatever this means) but basic human values and entitlements. There are various ways in which groups and cultures influence the values that people in fact have, and the ways in which they view the world. This is one of the reasons, as I have said, why we need to understand cultural backgrounds. Nonetheless, individuals are not cemented to these values or pictures merely because they are endorsed in some way by their culture or by elements in it. In addition to culture, they can draw upon experience, reason and imagination. They can see what other cultures have to offer and can accept or reject what is on display.

People in different cultures can learn from other cultures and can change and adapt as seems sensible. People are not chained to their cultures, otherwise white Australians

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couldn't learn from Aboriginal culture better ways of respecting the land, and Christians couldn't learn the important lessons that Buddhism or Confucianism has to teach. Such transactions are inevitably two-way, and attempts to isolate and freeze cultures are not only doomed but mistaken in principle. As a footnote to this, I might add that women have a particular stake in resisting the hegemony of static cultures, since most cultures in the past have been structurally dominated by men. There is now a lively philosophical debate in the USA about the potential for conflict between feminism and some versions of multiculturalism. (An excellent book debating this issue is *Is Multiculturalism Bad for Women?*).

An amusing example of the absurdities into which cultural relativist thinking so readily leads us was provided by a report in *The Australian* (July 30/31, 1994). This concerned a 21 year-old Sydney man who got into a drunken brawl in the English city of York and had assault charges against him dropped when the court was told of the 'cultural differences' between Australia and Britain. The man, Jason Dawe, was put on a bond of £500 for one year because the magistrate accepted his defence lawyer's claim that the violent behaviour was perfectly normal in Sydney. Dawe had a 'Sydney-style' night out in York during which he laid out three men before being severely beaten up himself and landing in hospital. His counsel, claiming that such behaviour was standard Saturday night behaviour in Sydney, pointed out that Dawe had come off very much second best and didn't want to take the matter further. The prosecutor said that he would not proceed with the charges, even though they were serious, and the bench (Mr. Harry Windle) said, "We appreciate the difference in culture between our two countries. But here we take a very dim view of fighting in the street." One is inclined to think, "Poor old Poms, diddled again!" But it seems to me that a lot of the blind deference to cultural practices that is sometimes advocated in Australia commits the same folly.

This paper is based on a talk given last year by Professor Coady to the University of Melbourne Faculty of Medicine, Dentistry and Health Sciences Conference on 'The Ethics of International Research and Clinical Practice'. A shorter version of the talk will be appearing in the Faculty's journal Chiron.

Sources used in the preparation of this article include:

Barry, Brian, *Culture & Equality: an egalitarian critique of multiculturalism*, Cambridge, UK: Polity, 2001.

Okin, Susan, *Is multiculturalism bad for women? Susan Moller Okin with respondents*, (eds) Cohen, Joshua, Howard, Matthew, and Nussbaum, Martha C., Princeton, N.J.: Princeton University Press, 1999.



Post-Mortem Examinations: Removal and Retention of Organs in the United Kingdom

by Sheila A.M. McLean

Until recently, the public, and even relatives of the deceased, had very little knowledge of the practice in some hospitals of organ retention following post-mortem examination. Sheila McLean says appropriate respect for the families of the deceased in relation to organ removal and disposal must be promoted through legal change, and changes to medical culture.

In 1998, the UK Government announced that it was to establish a public inquiry into the management of children requiring complex cardiac surgery at the Bristol Royal Infirmary. In the course of hearing evidence, the Bristol Inquiry uncovered an additional cause for concern; namely, that organs had been removed from dead babies without the consent of their parents, and had been retained by the hospital, again without consent. The preliminary report of the Inquiry focussed on this issue, with its final report being published in July 2001.

The evidence which generated concern about post-mortem practices came from a heart specialist who informed the inquiry about stores of children's hearts which were kept at the Alder Hey Hospital in Liverpool, and at other hospitals throughout England. A public inquiry into the situation at Alder Hey revealed that organs had been routinely harvested from children who had died in that hospital over a number of years. The Health Secretary was not alone in feeling the findings to be 'grotesque'. Not only were organs systematically stripped from children and babies dying in the hospital, but in at least one case a human head was stored and a large number of foetuses were collected from hospitals throughout the north west of England.

Initially, it had been thought that these practices were confined to specific hospitals, and in the case of Alder Hey, to one specific doctor. However, it soon became clear that this was not in fact the case and the public concern generated by this information led to the establishment of one final committee, to report on the situation in Scotland. Unlike the two English inquiries, this committee was tasked with considering all organs removed and retained, whether from children or adults, and to make proposals for law reform. Each inquiry made a number of recommendations, with the Scottish inquiry reporting on 31 October, 2001.

Different Problems—Same Issues?

Each inquiry had a slightly different remit, but uncovered similar problems. As has been said, the original focus of

the Bristol inquiry was on the performance of paediatric heart surgeons. In Alder Hey, the focus was on the removal and retention of organs from children without parental consent. In Scotland, the trawl for information was much wider, including adult organs as well as those removed from children. Although this difference in emphasis may appear slight, in terms of practice it became significant, particularly in the case of Alder Hey. There, one particular doctor, Professor Van Velzen, was found to have systematically stripped organs from babies and children, without consent, and also to have falsified reports. The University of Liverpool, under whose auspices he held his chair, was also roundly criticised for its failure to ensure the proper functioning of Van Velzen and his department.

Where each inquiry was entirely on all fours was in their concern about the impact on families of the discovery—often many years later—that their children had not only been subject to a post-mortem examination (to which the families had consented) but that the agreement to the post-mortem examination was taken by doctors to imply authority to remove and retain organs for any number of purposes, or in some cases for no apparent purpose at all. Inevitably, this caused enormous distress, compounding the tragedy of having lost a child with the knowledge that the child they had buried had not been intact. A number of families have now had to undergo several funerals for their child as organs were identified and returned sometimes in a relatively haphazard manner, and not all organs have yet been returned to parents, as the relatively newly established Retained Organs Commission continues its job of auditing hospitals' stores of organs in England. In Scotland, an advertising campaign has just commenced to ensure that relatives know their rights in terms of having organs returned to them.

What Went Wrong?

Inevitably, the question was asked—how could such a situation have arisen? Professor Van Velzen's practices are sufficiently unique to provide little by way of an answer, but they do arguably represent an extreme example of what other doctors believed to be permissible in the

1960s and beyond, when such practices were apparently not uncommon. Further problems were also identified relating to the confusion which seemed to exist around those post-mortem examinations required by law (coroner's post-mortems or Fiscal post-mortems in Scotland), and those which were carried out at the behest of the hospital. There would seem to be a number of reasons for this. First, when children were subject to such an examination, even when it was a legal post-mortem, it was generally carried out in a hospital by a paediatric pathologist; the same person also conducted hospital post-mortem examinations. For families this could be confusing. Second, as was apparently also the case in some Australian States, there seemed to be a breakdown of communication between those legally responsible and the families concerned. Third, it was not clear who had the responsibility for dealing with possible return, or retention, of organs once a legal post-mortem examination was concluded. Fourth, there was an apparent lack of adequate respect for the role of parents following post-mortem examination, and an assumption on the part of pathologists that a proper consent had been obtained by the doctor on the ward whose job it was to do this. Although pathologists have been subject to much criticism, it is perhaps intelligible that they were unaware of the problems surrounding the quality of consent until they were confronted with this in a very public way. Finally, the process of seeking consent to removal and retention of organs seems to have been woefully inadequate.

Three broad themes emerge from this. First, that there is a need to improve on the practices surrounding legal post-mortem examinations. Although these do not require the agreement of parents, this does not, and should not, mean that there is no communication with parents. Additionally, there is a need for improved communication between the legal authorities and the hospitals in respect of disposal of removed tissue or organs. Second, there are what I will call cultural problems, and third, what I will call mechanical problems. Since improvement in the first of these problems lies in the hands of legal authorities (albeit following recommendations from each of the Inquiries) I will focus here on the problems associated with hospital post-mortem examinations, as they highlight most starkly the concerns of families and the wider community.

Cultural Problems

The history of medical practice is littered with the kinds of assumptions in which many professional groups indulge themselves. The expertise which elevates indi-

viduals and groups to the status of professional is often accompanied by an unthinking assumption of authority. In the past, in medicine, the culture of paternalism was used to justify failures in communication which would nowadays be regarded as profoundly unacceptable. Rather than information being seen as a right to which all patients are entitled, it was carefully sifted by those with the power in the doctor/patient relationship. Arguments for not disclosing information ranged from 'the patients wouldn't understand it' to 'we don't want to upset people by telling them things that might make them anxious'.

In the case of past post-mortem practice, the latter approach seems to have prevailed. Although consent was generally sought for the post-mortem examination itself, that consent was in many cases inadequate; that is, it did not follow a full explanation of what a post-mortem examination entailed, particularly in respect of information about the diagnostic necessity of removing and retaining organs such as the brain. It is certainly the case that telling newly bereaved parents about the mechanics of a post-mortem examination is an extraordinarily difficult thing to have to do. It is also the case that this information will prove to be distressing for most, if not all, of these same parents. However, the fact that this distress can reasonably certainly be predicted mandates, not a withholding of information from those who want to receive it, but rather the creation of a structure within which it is sensitively and clearly delivered, and the development of a system which allows parents to come to terms with the information in surroundings, and with people, conducive to their understanding of the information and to minimising distress.

Of course, beyond the issue of consent to the post-mortem examination itself lies a further, and perhaps more distressing reality; namely, that consent (however flawed) to post-mortem examination was taken as authority to remove and

retain organs for purposes which went beyond the diagnostic and into the realms of research and medical education. While it is clear that, for example, diagnostic work on the brain requires the brain to be fixed in formalin for a period of weeks and therefore demands its retention for that period, this was seldom, if ever, explained to parents, some of whom discovered as many as 20 years after the death of their child that this had been done. Their sensitivities are therefore not only about the failure to inform, but also about the fact that they unknowingly buried their child without a particular organ (and in some cases more than one organ). Moreover, where the purported reason for removal or retention was to advance medical research or education, it is clear that this was not

The agreement to the post-mortem examination was taken to imply authority to remove and retain organs for any number of purposes.

always done, with organs either disposed of as clinical waste or stored in medical schools, medical museums or the basements and cupboards of hospitals.

One further consideration was urged on each of the Inquiries; namely, that what happened in the past (albeit in some cases the quite recent past) should not be judged against today's culture or expectations. In other words, not telling parents about the fact that organs and tissue would be, and in some cases had to be, removed was acceptable then, but is not now. Arguably, this is a convenient but ultimately unconvincing attempt to disguise the roots of the problem. It may well be the case that today's patients are more demanding; it may well be true that our laws have developed to require more in the way of disclosure to patients and families; but it is *not* true that the fundamentals of respect for persons have only just been recognised. The right to respect and to exercise autonomy have been recognised for centuries, even if they were ignored in these cases.

Compounding these problems is the interest of medicine in making advances. Organs and tissues which were not removed or retained solely for the purpose of diagnosis could form the basis of research and educational programmes which might benefit medicine, and patients, in the future. The clinical imperative to undertake such research, and it must be said its potential career enhancing power, may also have guided some doctors to retain organs and tissue. This is all well and good, and the majority of families who gave evidence to the inquiries was clear about the benefits of medical research. Indeed, some have said that they would have welcomed the opportunity to authorise the use of their dead child's organs or tissue for these purposes—an opportunity for altruism which might have brought some good out of their tragedy; an opportunity denied to them. However, the fact remains that they should have been asked. Moreover, it is clear that in many cases no such research was undertaken, so this justification for retaining organs seems somewhat weak.

One further, and significant, problem relates to the law which governs the conduct of post-mortem examinations and in particular the removal and retention of organs for educational or research purposes. In the UK this law is found in the terms of the *Human Tissue Act* 1961—a piece of legislation which came into force in the very early stages of organ transplantation programmes. Its deficiencies became apparent fairly quickly, and 40 years on there is no denying that the legislation contributed to the current situation.

Broadly speaking, the law provides that people can opt into the system by leaving behind a declaration of their wishes regarding the use of their organs after death. Interpretation even of this apparently simple provision has not been easy, but for our purposes that debate is

irrelevant. What is important are the provisions contained in s.1(2) of the Act, which become operational when there has been no prior expressed wish by the deceased. Clearly, in the case of the children currently being discussed, it is these provisions which are applicable. In terms of the law, it is for the person 'lawfully in possession of the body' (generally the hospital authority) to make reasonable enquiries to find out whether surviving relatives have objections to the use of organs from the deceased person. Leaving aside the issue of interpreting what is a 'reasonable inquiry', and who should count as 'relatives' for these purposes, the fundamental problem is evident. The law does not give to anyone the power to agree; rather it asks the authorities to look for a negative—namely the absence of objection. When this somewhat peculiar requirement was added to what has loosely been termed a paternalistic attitude, it presumably rendered it easier for clinicians in these cases to ignore, misinterpret or manipulate the unclear terms of the law.

Worse than that, each of the UK Inquiries found evidence that the necessary enquiries had not been made of parents in any event. Although a form of consent may have been given to the conduct of a post-mortem examination, often what that examination entailed was not made clear. In particular, it appears not to have been routinely pointed out that in some cases bodies were returned missing organs such as hearts and brains. Although many health care professionals giving evidence to the inquiries relied on the cultural exigencies of the past for an explanation as to why certain information was not disclosed, the findings of the Alder Hey Inquiry were that 'the paternalistic attitude cannot be sustained as an explanation for what has occurred.' Rather the inquiry concluded, '[t]he bald fact is that on the evidence the medical profession did not properly consider the ...[*Human Tissue Act*] in the first place.' Perhaps this, in part, is the result of the fact that the *Human Tissue Act* contains no sanctions in the event of breach.

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Mechanical Problems

Turning to what I have described as mechanical rather than theoretical problems—although they cannot be fully divorced from each other—a number of additional concerns emerge. First, there were suggestions that undergraduate teaching in pathology was, if not in crisis, at least less intensive or thorough than it might have been in the past. Thus, young doctors would be less than clear themselves as to the mechanics and imperatives of a quality post-mortem examination, and therefore potentially unable to give the kind of information that respect for the families would demand. Coupled with this is the

It is not true that the fundamentals of respect for persons have only just been recognised.

fact that doctors seldom received any training in communication skills, in fundamental ethics, or in the law. Arguably, they are therefore ill-equipped to meet the demanding standards which are so vital to parents.

Secondly, it was apparent that hospital record keeping was sometimes inadequate. Families were passed from pillar to post, unable in some cases to find out whether or not organs had been retained. It is bad enough, surely, to be concerned that your child's organs might be languishing in a hospital basement somewhere without being passed from one person to the next, never getting a clear answer and steadily losing faith in the capacity of the system to provide such an answer. The poor quality of audit trail is one reason why families on occasion required several communications from the hospitals before they could be sure (or at least as sure as they could be) that all parts of their child had been returned, or that no parts of their child had been retained.

Finally, particularly in Alder Hey and Bristol, there were serious inadequacies in management. When one doctor attempted to get something done about the situation in Bristol, it was he who emerged as the villain to his professional colleagues. At Alder Hey the collections of children's hearts, body parts and fetuses were initiated in the 1940s and were well known to the management both of the Hospital and of the University of Liverpool. Between 1948 and 1988, the Inquiry found that:

...hearts were collected usually without parental knowledge or lack of objection having been established. The evidence indicates that it was normal practice to remove organs at post mortem examination and take samples for microscopic examination, thereby enabling the organ to be returned to the body for the funeral. However, any organs such as the heart or brain which had to be fixed before they could be examined, necessarily meant that not only were they usually retained without consent, but they could not have been returned to the body because they would take between six and eight weeks to fix.

Conclusion

There is much that can be said about the state of affairs which confronted these Inquiries, and the families involved. The problems are, of course, not confined to the UK and similar inquiries took place in several Australian States. Ultimately, it seems clear that dramatic steps will be needed to rectify the situation. Although it is now clear to doctors that past practices are not accept-

able, and therefore we can hope that such situations are unlikely to recur, there is no evidence that they *could* not recur. This requires, therefore, that both medical culture and the law have to change. Relevant training of doctors before and after graduation may help to introduce them to the formalities required, and to that extent is to be commended. However, training cannot make people sensitive to these issues, and therefore it seems inevitable that significantly revised legal regulation needs to be in place, so that—even if people don't understand the sensitivities—they are absolutely clear about the law's requirements and aware of the consequence of failure to meet them.

Of course, not every family wants this information—many have made that clear. But what we must learn, if nothing else, is that the opportunity for receiving it must always be there. Unsurprisingly, many families feel themselves to have been abused by the system in which they placed so much trust. Failure to restore that trust will likely have profound consequences for the practice of medicine, for medical education and research, and potentially even for organ transplantation programmes. The extent of the damage actually or potentially caused by these scandals cannot be over-stated, and requires principled, coherent and urgent change if we are not to find ourselves confronted with another such problem in the future.

This article is based on a lecture given by Professor McLean at the University of Melbourne on 29 August, 2001, as part of CAPPE's Ethics and Public Life Public Lecture Series. The lecture was jointly hosted by CAPPE and the Dean, Faculty of Law and Management, La Trobe University.

Sources used in the preparation of this article include:

Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995, UK: Command Paper: CM 5207, 2001.

The Royal Liverpool Children's Inquiry: Report, UK: House of Commons, 2001.

Independent Review Group on Retention of Organs at Post-Mortem: Final Report, Scotland: Scottish Executive, 2001. Available at <http://www.show.scot.nhs.uk/scotorgrev>.

