Individual rights and social justice

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Running through the election speeches of various political leaders leading up to the Australian Federal election in October 2004 were two competing discourses. The first, and the dominant one, emphasised the individual. The second emphasised the provision of public services. These views were not always confined to a single political party.

Individuals, so it was argued, have the right to choose to send their children to a private school that reflects their personal values – and should be helped to do so by government financial support to these schools. Individuals have the right to hold private health insurance, with greater freedom in the choice of health care provider. There was the right of the individual to climb the 'ladder of opportunity'. There was the assumption that the tax burden on individuals should be reduced. Direct financial support was needed for families with young children; if individuals are the product of stable families they would hold the values that were seen to underpin a productive society.

The other discourse emphasised large social and systemic issues, especially government funding for health and social services. There was support for equal access to a sound educational system and, in health, support for a robust public hospital system, universal health insurance and bulk billing by general practitioners.

Overall, economic issues were seen to be of paramount importance, especially the interest rates that would be levied against families holding high mortgages. The question lurking behind the provision of better public services was who was going to pay for these services? Would tax rates be raised? Raising taxes was seen as the result of bad economic management. Good fiscal management was emphasised to the exclusion of responsibility for good moral conduct in government. It is worth noting that, while individual choice was favoured, this did not include women's right to choose an abortion or the right to gay marriage.

Public health by its very nature is aligned with those who favour collective responsibility for the provision of good public services. We have argued in this Journal that a robust public system for dealing with infectious disease is essential and collective action to sustain the environment has direct health consequences. But, we have also argued for health promotion programs that deal with individual behaviour, such as smoking tobacco or unsafe driving. Often the individual and the systemic are combined, for example, when a tax on tobacco products is used as part of a program of smoking cessation. Between these two extremes, we have focused on the health needs of communities and geographic regions.

Any discipline or practice that covers anything from the individual to the systemic runs the risk of delivering a thin coverage of any one issue. In this Journal, we have argued that the diversity of public health is its strength, especially as we have developed a corresponding diversity in our research methods so that the evidence on which we base our practice has a sound basis. In this issue, we argue that public health activities at these various levels are integrated and given coherence by a set of shared values. The most important of these values is a concern for social justice.

Social justice is one of those ideas that is often invoked and seldom analysed, although it is something we all treasure. While advocacy is an important part of public health practice, we see the role of the Journal as analysing the evidence for our strong beliefs, submitting them to peer review, and opening up a debate about these sometimes difficult issues. So it is in this issue of the Journal, which opens with Julian Disney's editorial on poverty public health and social justice in the light of the Federal election.

Sarah Mares and Jon Jureidini report the psychiatric assessment of children and families in immigration detention who were referred for assessment to a child and adolescent health service as showing very high levels of psychopathology, much of it attributable to traumatic experiences in detention. Zachary Steel and colleagues document the poor mental health status of a near complete sample of children and their families from one ethnic group held for an extended period of time in a remote detention centre, describing detention-related traumatic symptoms and the effect of detention on parenting. These two papers are complemented by Linda Shields' comparison of Australia's solution with the very different approaches of two Nordic countries and Deborah Zion's reflection on the dilemmas of care within unjust frameworks.

The impact of health policy and funding on inequalities is highlighted by David Brennan and John Spencer in their account of the deterioration in dental health among older people associated with the loss of public dental programs in the late '90s. There is some good dental news from Anne Sanders: most of us – unlike our parents – are very unlikely to lose all our teeth.

Lawrence Lam's Brief Report proposes a new approach to measuring the impact of premature death based on loss of productive years of life. In a Point of View, Gavin Mooney's reflects on possible public health lessons for Australia from the history of South Africa. Phyll Dance and colleagues describe a successful process to analyse the needs for aged care services for Indigenous people in the ACT, including the implementation of change.

Public health action is the core of public health, demonstrated in this issue by the description by Trang Vu and colleagues of the costs and benefits of improved infection control in the prevention of variant Creutzfeldt-Jakob disease in Australia, Paul Dietze and colleagues' description of characteristics of non-fatal opioid overdoses attended by ambulance services in Australia and a report of the incidence of hepatitis C among injecting drug users on opioid replacement therapy, by Richard Hallinan and colleagues. John Toumbourou calls for ethical guidelines on the vexed question of compensation for research participants. Finally, the friends and colleagues of the late Jill Cockburn remind us of her great contributions to public health research and practice.

This issue, as the last for 2004, contains a full author and subject index, as well as a list of our reviewers for the year.

More challenges for public health in fight against poverty

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Public health initiatives have historically played major roles in preventing or reducing poverty and social injustice, both in Australia and overseas. This applies especially to meeting basic needs such as safe water, sanitation, nutrition and primary health care. But major challenges remain and new ones are emerging.

Within Australia, there can be little doubt that the highest priority is to improve the health of Indigenous people. For example, despite living in a relatively wealthy country their life expectancy is about the same level as applies in Bangladesh. Better opportunities to study, work and enjoy good housing could substantially improve their overall health outcomes. But their ability to take advantage of any such opportunities can be drastically affected by ill-health arising from earlier lack of health care or by the prevalence of illness and early death among relatives.

Despite our allegedly successful economy, homelessness and unemployment remain major causes and consequences of poverty, hardship and injustice in Australia. On any given night about 100,000 people are homeless and 100 families with children are turned away from refuges. There are more than half a million jobless families and more than 100,000 people who have been unemployed for more than 12 months. The real level of unemployment is about double the official rate when account is taken of the exceptionally high proportion of part-time employees who want more work and the number of people who have gone on a disability or sole-parent pension because they cannot find work.

The linkages between unemployment, homelessness and ill-health are widely acknowledged. There is less recognition, however, of the health problems arising for workers and their families from big increases in job insecurity and overwork during the past 20 years or so. Australia ranks very poorly in these respects by comparison with almost all other developed countries. The resulting incidence of severe stress and relationship breakdowns is being aggravated by inadequate public investment in transport, child care and other measures to help combine work with family responsibilities.

Other special concerns arise from large increases over recent years in the number of one-adult households as a consequence of changing attitudes towards marriage, less secure employment, higher house prices and greater life expectancy. Sole-parent families tend to have especially high levels of financial hardship and stress, and to be more economically vulnerable in the event of ill-health. Older people who are living alone are also especially at risk. The apparently inexorable growth in the number of one-adult households has substantial implications for health services and outcomes in coming decades

The levels of poverty and hardship will almost certainly worsen within the next few years as the realities of Australia's economic circumstances begin to be felt. While our governments have about the lowest levels of debt among developed countries, our levels of corporate and household debt are higher than almost all of them. We have been living far beyond our means and, among other things, competitively bidding up house prices to levels that are depriving an increasing proportion of the population from the security of home ownership in times of financial adversity, ill-health or frailty.

These problems have been exacerbated by poor economic policies, including taxation reform, on the part of both Commonwealth and State Governments. Many people who are concerned about poverty and hardship regard close consideration of these issues as being beyond or beneath them. Yet some of the current policies have fundamentally adverse effects on both the incidence of hardship, including ill-health, and the availability of public and private resources to ameliorate it. This applies, for example, to the supply of secure and adequately remunerated work, access to affordable housing and health care, and the availability of informal family support.

Poverty and severe hardship is, of course, a more severe and widespread problem in many other countries. Substantial improvements have been achieved in countries such as China and India during the past decade or two but many African countries, in particular, have experienced either deterioration or no significant improvement Within our own neighbourhood, Indonesia and Papua New Guinea have especially severe levels of poverty and several other countries are experiencing rapid increases in AIDS-related problems.

Many of the improvements in developing countries during the past 50 years or so have stemmed largely from public health initiatives. They include greater proportions of people having access to safe water, sanitation, basic nutrition and essential vaccination. As a result, considerable progress has been made in relation to maternal and child mortality, life expectancy, restriction of infectious diseases and other key concerns. They have been accompanied, and often assisted, by notable improvements in the availability of basic education, including a reduction in discrimination against education of girls.

Nevertheless, more than two billion people still lack adequate sanitation. At least one billion people have incomes below $US1 a day. More than 800 million people are under-nourished and more than 100 million young children are not receiving primary education. Life expectancy is falling substantially in several

African countries principally as a result of AIDS, for which fatality rates around the world are often closely linked with poverty.

In 2000, a unique UN summit of heads of government led to the adoption of eight Millennium Development Goals (MDGs), most of which involve specific numerical targets to be achieved by 2015. They include, for example, reductions of at least two-thirds in child mortality, three-quarters in maternal mortality, and one-half in the proportions of people who lack access to safe water or suffer hunger. They also include halving the proportion of people with incomes below $US1 a day, achieving universal access to primary education, and reversing the spread of HIV/AIDS and malaria.

The Australian Council of Social Service and Australian Council for Overseas Aid played significant roles in lobbying at the UN over many years for adoption of the MDGs. They did so in the belief that among the vast array of internationally agreed targets, a small number of specific and measurable targets that are ambitious but not wildly unrealistic should be agreed upon as top priorities for action. It was recognised that most developed countries would already have achieved the goals, although not perhaps within some groups (regrettably including Indigenous Australians). But it was hoped that those countries, and international organisations such as the World Bank and IMF, would make specific commitments to help other countries achieve them.

Within the Asia-Pacific region, the UN estimates that at present only two of the targets are likely to be achieved by 2015. They relate to improvements in income and in girls' access to education. The targets that are regarded as unlikely to be achieved include those relating to child and maternal mortality rates and access to water. In Africa, it is unlikely that any of the targets will be achieved on time. Yet most rich countries of the world continue to fall far short of the agreed target for provision of overseas aid and continue to impose economic policies in areas such as trade and taxation that actively discriminate against poorer countries.

Many Australians in the public health field have made and continue to make outstanding contributions to the fight against poverty and hardship at home or abroad. Nevertheless, much remains to be done and during the next decade the international economic environment may become less conducive to progress (except for major emerging powers such as China, India, and perhaps Brazil).

The fight to achieve greater emphasis on reducing poverty and social injustice will not be easy. The voices and actions of many concerned Australians will need to spread beyond their established fields of expertise to include key underlying causes of hardship, especially in economic policy. They will need to go beyond their accustomed circles in order to join people with whom they may have little in common except an active or awakeable sense of fairness and compassion.

This need motivated the recent establishment of an annual Anti-Poverty Week in Australia to highlight problems of poverty and severe hardship and to strengthen efforts to address them. It is concerned with poverty both at home and abroad and is held in mid-October each year to coincide with the UN's International Anti-Poverty Day (17 October).

The special week was established in the belief that most Australians are more concerned about poverty and hardship than is commonly recognised by political and economic pundits. It aims to encourage people to demonstrate this concern, and the breadth of the general constituency for action, by organising their own local or regional activities on whatever particular issues they wish.

Anti-Poverty Week deliberately does not adopt any official policies of its own or require proposed activities to be submitted for approval. Its organising principle is "let a thousand flowers bloom". In its first two years, the week has grown to involve more than 80 different events around Australia, many of which are in outer suburbs, regional cities and country towns.

Special efforts are being made to encourage participation by people whose main interests are in health and education. The consequences of poverty are often especially damaging in these areas and preventive or remedial action can be particularly effective. They also involve many articulate and resourceful people whose voices could augment substantially the small number of social workers, church leaders and academics who tend to be seen as the core of anti-poverty advocacy.

When carefully and dispassionately analysed, the recent federal election results are not inconsistent with the view that most Australians care about poverty and social injustice. But they do emphasise the need for the type of broad and inclusive outreach beyond traditional enclaves and constituencies that the week seeks to develop.

Sources

For further information about Anti-Poverty Week, see www.antipoverty week.org.au

In relation to poverty and related hardship in Australia, see Senate Community Affairs Reference Committee, *A Hand Up not a Hand Out* (Senate, Canberra, 2004); Australian Institute of Health and Welfare, *Australia's Welfare 2003* (AIHW, Canberra, 2003); Australian Bureau of Statistics, *Measures of Australia's Progress* 2004 (ABS, Canberra, 2004); R. Tiffen and R. Gittins, *How Australia Compares* (Cambridge University Press, Sydney, 2004).

In relation to international poverty and related hardship, see the United Nations Development Program, *Human Development Report* (UNDP, New York, 2004); United Nations Economic and Social Commission for Asia and the Pacific, *Promoting the Millennium Development Goals in Asia and the Pacific* (UN, New York, 2003).

Caring for detained asylum seekers, human rights and bioethics

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What is our innocence? / What is our guilt?
All are naked / None is safe
(Marianne Moore)

Michael Hall, a nurse working first at Curtin detention centre and then on Christmas Island, was asked to escort two pregnant women to the mainland. They were being forcibly separated from their families, including their other children, to be taken to the mainland to have their babies. Their families were not allowed to accompany them because once on the mainland they could apply for refugee status. The women would not do so alone because they wished to maintain the family unit. They were also not informed of their legal rights. Hall refused to escort the women on the grounds that he found the practice ethically unacceptable. [1]

His stance raises many issues concerning the relationship between medical ethics and human rights, and tests the limits of professional obligation when just systems are not in place. [2] The psychiatrist Louise Newman has characterised the dilemma as "an intrinsic conflict between the desire to provide appropriate care, and the compromising of this by supporting a pathological system". [3] It is one example of the problem of 'dual loyalties', where healthcare professionals experience a "clinical role conflict between professional duties to a patient and obligations, express or implied, real or perceived, to the interests of a third party such as an employer, insurer or the state". [4]

Issues related to dual loyalty conflicts vary considerably. The most serious and obvious example relates to healthcare providers' direct involvement in torture, [5] a practice that directly opposes medicine's primary aim to "protect and promote health". [6] However, in situations where doctors and nurses are also disempowered, some argue that there may be an obligation to minimise harm. A doctor may believe that his presence may actually lessen the level of harm inflicted on the victim during violent interrogation and so may feel an obligation to be present.

The problem of professional ethical practice in corrupt political environments is also portrayed by Jane Steere and Terence Dowdall in their description of working as psychologists in South Africa during apartheid. The ethical complexities inherent in trying to treat mental illness under such a regime were exacerbated by the fact that the broader social system in which they had to work violated their profession's ethical principles, leaving them with the dilemma of providing either no treatment or treatment that they considered to be unethical. [7]

The issue of wrongdoing by involvement with an unjust institution is fundamental to an analysis of Hall's dilemma and many other cases where doctors, psychologists and nurses have tried to treat asylum seekers held in detention centres. These include the forced treatment of hunger strikers and returning children suffering from mental illness to detention or keeping them separated from their families. For those committed to healing, any course of clinical action in these circumstances does not serve the best interests of the patients in question, who remain imprisoned for long periods, often separated from family members. Their distress, anxiety and depression can be seen as normal reactions to the terrible circumstances in which they find themselves, for which the most effective treatment is the re-establishment of liberty and other basic rights. [8] The Dutch psychiatrist Annemiek Richters elucidates the problem when she states that:

> ... for asylum seekers and refugees, mental disorders characterised by standardised psychiatric diagnosis may often be better described as normal reactions to abnormal political, social and cultural situations. As physical integrity cannot withstand the dissolution of the social personality, it is at the level of the political, social, and cultural that healing should occur. [9]

The problem of 'dirty hands'

The dilemma faced by Michael Hall is an example of what Stephen de Wijze refers to as the problem of 'dirty hands'. De Wijze suggests that when a person with the intention of acting morally has to choose between the lesser of two evils because of the immoral acts or projects of others, he suffers as both a perpetrator and a victim. [10] He states:

> ... by being forced to engage in the evil projects of others, an agent suffers the violation of her moral autonomy and selfhood. By participating in 'dirty acts', the agent is changed, morally speaking, by doing evil (having intentionally caused the evil circumstances to persist) and her victims are changed by suffering evil. (p 217)

How can we think about Hall's refusal to continue to provide care to the women in detention? Does participation in an obviously unjust and harmful system validate his refusal? Is this the central ethical question that we need to consider and, if not, what other ethical course of action is open to Hall and those who find themselves in similar situations?

Medical ethics and refusing to treat

Recent accounts of healthcare workers' obligations and refusal to treat in the bioethics literature focus on the safety of the healthcare worker on the one hand, and upon conflicts of conscience on the other. [11]

When personal safety is an issue, there is some consensus that it is reasonable to expect doctors and other healthcare professionals to take on some personal risk, although there is also recognition that healthcare institutions must provide means to ensure the physical safety of such workers. Professional issues involving conflict of conscience are more problematic and take several forms. For example, a professional may be bound to perform tasks that she finds personally morally offensive, while recognising their importance if a just society is to continue. A doctor might be obliged to keep a patient on life support that he knows will be of

little use and is taking up valuable resources because he has inherited a duty to prolong life under most circumstances and believes that such a duty is just.

Hall's dilemma is different again, as he is being required to support, through his actions, a separation that he believes to be both unjust and harmful. To ask how patient autonomy can be respected in such a situation draws us away from bioethical discussions that focus on decontextualised encounters between doctors and patients, and forces us to consider the important connection between autonomy and freedom.

Protecting autonomy: two bioethical accounts

Respect for the decisions made by rational patients is a fundamental component of respect for autonomy, and is the cornerstone of Western bioethics. The view of autonomy most commonly in use by healthcare practitioners relies on principalism, as set out in Tom Beauchamp and James Childress' work, *Principles of Biomedical Ethics*.[12] According to this model, respect for patient decision-making is achieved and facilitated through maintaining confidentiality, providing information and maintaining a high standard of truthfulness about treatments and their outcome. However, Tom Faunce has suggested that the principalist approach is essentially isolationist. By this he means that the "... approach presents these principles as arriving like some *deux ex machina* rather than evolving ... from foundational social and professional virtues".[13]

There have been many critiques of the principalist view of autonomy, and its lack of analysis in which choices are made. In response to such criticisms, Susan Sherwin, Anne Donchin and Chris MacDonald have developed a different way of thinking about autonomy, sometimes referred to as 'relational autonomy'. This view relies upon an idea of autonomy as socially dependent.[14] Rather than imagining an autonomous person as free from constraints, they suggest that an autonomous person is deeply involved in relationships with others, whose acts facilitate her forming and fulfilling her own goals.[14-16] Susan Sherwin suggests that for autonomy to have value, certain social conditions must be in place that provide meaningful options. These conditions should be embedded in both personal and political supportive structures.[15] Autonomy, therefore, is not a simply a matter of preserving negative rights to non-interference.[14]

The principalist view of autonomy seems to have little application in Hall's case. Even if Hall observed all the rules that facilitate autonomy, the women concerned were so constrained that the term itself seems meaningless.

The second, or 'relational' view of autonomy, is slightly more illuminating. On this view, the ethical standing of Hall's actions in protecting the already limited autonomy of the women rests on a powerful but simple question: what do the women and their families themselves want? If they found Hall's presence to be of value, especially in the light of the rest of their treatment, and they wished for his assistance, there may be a case to be made

that he should indeed have accompanied the women. If, on the other hand, the families asked him to take a stand, his refusal can be seen as an act of advocacy. However, it is clear that the women in question did not have sufficient options to determine a meaningful life course. Thus discussions of autonomy – even relational autonomy – in reference to asylum seekers in detention has a somewhat hollow ring, and illuminates the inadequacies of bioethics when divorced from a discussion of human rights and political freedoms.[15,16]

The importance of social justice in discussions of bioethics has a relatively short but important history, and developed rapidly in relation to clinical research and HIV/AIDS in developing countries, and focused on the issue of autonomy and informed consent in this setting. Many commentators suggested that relying on a view of autonomy based only upon the subjects' ability to make rational decisions with little or no analysis of the kinds of choices, freedoms and rights available to those involved, rendered the concept of autonomy meaningless.

The political philosopher Joseph Raz suggests that autonomous action must be based upon "an adequate range of options to choose from" (p 373).[17] Raz is not referring to the numbers of options, but what these options actually consist of. He gives two examples that demonstrate just how numbers of options alone are meaningless in securing or promoting autonomy. The first story concerns a 'Man in a Pit', whose choices are limited to "whether to eat now or a little later, whether to sleep now, or a little later, whether to scratch his left ear or not" (p 374).[17] His second example concerns a 'Hounded Woman' who spends her whole life on a desert island, trying to escape a carnivorous creature which is trying to devour her. Raz suggests that while both these subjects have choices, they cannot be called autonomous, for "... one has only trivial options to choose from ... The other person's predicament is the opposite one. All her choices are potentially horrendous in their consequences" (p 374).[17]

Refocusing bioethics

In their recent analysis of human rights, social justice and bioethics, Paul Farmer and Nicole Gastineau Campos ask: "If access to health care is considered a human right, who is considered 'human enough' to have that right?" (p 249)[18] They call upon those involved in healthcare practice and in bioethics to refocus discussion on the relationship between freedom, social justice and health.[19]

How might an analysis that begins with these ideas elucidate the dilemmas faced by healthcare professionals acting within an unjust framework? Of primary importance is the idea that public health and healthcare systems are unquestionably political.[20] As Paul McNeill states:

> *[Public health] is political in the broad sense by being concerned with a group of interests within a community that may be competing with other interests. It is also political in the particular sense of being involved in power and authority, either in the exercise of authority or in reaction to those who exercise it, and thus engaged actively in issues of politics and government. (page 495)[20]*

McNeill suggests that the correct ethical response for dilemmas like Michael Hall's is advocacy and political action.[21] If we consider Hall's decision in the context of his witnessing and publishing accounts of inhumane treatment, we also see him involved in an act of advocacy that goes beyond the ethical predicament of whether or not to accompany the women in his care.

The importance of collective action

There is, in the recent history of public health, a model for the way in which collective political action can strengthen freedom and expand the numbers of choices that are made available. The advent of HIV/AIDS in Australia, for example, led to gay community-based action that changed the way in which HIV prevention and research was carried out, and the means through which drugs were made available to desperately ill patients.

Early in the epidemic, many HIV-positive, gay community-attached men, particularly in Melbourne and Sydney, organised informal means through which early HIV/AIDS therapeutic trials were subverted and challenged. The gay press, particularly the *Sydney Star Observer*, also provided challenging commentary concerning HIV/AIDS treatments.[22] Gay community-attached, HIV-positive men also started to circulate newsletters specifically dedicated to empowering other people living with HIV and AIDS, in which they advocated a philosophy of empowerment and active partnership with the medical profession.[23]

AIDS councils were established in all Australian states initially run by volunteers, with strong connection to gay activist politics.[24] These councils went on to form an important part of the public health bureaucracy and mobilised other community groups. This, in turn, profoundly influenced both research and treatment, especially the insistence that promising drugs would be made available to those who needed them through compassionate access schemes, that the development of treatments was consistent with the needs of affected communities, and that those most affected by the disease would enter into research partnerships with clinicians.

Conclusion

It is undeniable that collective action by medical colleges and associations enhances efficacy and lessens the burdens on individuals, thus increasing the possibility for effective and ethical healthcare for asylum seekers. Another important issue relates to the problem of working in unethical and unjust conditions, and the effect this has upon the integrity of the healthcare provider's "moral autonomy and selfhood".[10]

In his recent commentary on the issue of torture in Abu Ghraib prison, Robert Jay Lifton describes the acculturation process that creates "atrocity-producing situations",[25] in which ordinary people begin to engage in acts that they would, in other circumstances find morally repugnant. In the case of providing healthcare in a detention centre, engaging with other healthcare professionals could facilitate the development of collective ethical approaches, provide emotional support, and make possible strategies through which professional guidelines were backed up with a blueprint for action.[26] Finally, collective engagement might provide a just environment with which nurses and doctors would have frequent contact, in order to keep at bay the normalisation of a world in which human rights violations are commonplace.

Acknowledgements

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