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Bioethics And Democracy: Competing Roles Of National Bioethics Organisations

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BIOETHICS AND DEMOCRACY: COMPETING ROLES OF NATIONAL BIOETHICS ORGANISATIONS

1. INTRODUCTION

The establishment of international, transnational and national bioethics bodies has marked the development of bioethics in the last three decades. At international meetings of such bodies, in conjunction with the World Congresses of Bioethics in since 1996, up to 36 nations have been represented¹. The establishment of these national bioethics organisations (NBOs) reflects the public importance attached to the bioethical issues that have emerged from rapid advances in health care provision, health technology and medical research and their implications for human lives, social relations and state responsibilities.

The charters, objectives and processes of these NBOs are likely to influence the impact that ethics may have in the development of national policy and the effect such policy developments may have on the character and development of bioethics. Some important differences in the roles of these bodies raise questions about how the structures and procedures of NBOs affect their influence, on health and medical research policy development and in articulating bioethical debate. This paper examines tensions between the structure, focus and processes of NBOs and realisation of the democratic goals that are explicitly or implicitly reflected in the speeches or policy documents establishing NBOs. We argue for a consultative and contestable approach through which NBOs can

fulfil their roles in bioethical debate and in policy formation while preserving these democratic goals.

2. BIOETHICS AND THE DEMAND FOR PUBLIC POLICY

In establishing NBOs, states seek to establish processes that allow a diversity of views to be heard in a manner that is well informed, articulate, and responsive to both expert and “lay” public views. NBOs are typically given a range of responsibilities, including

- contributing to and stimulating public debate,
- providing expert opinion in identifying relevant issues that need to be addressed in policy deliberations, and/or
- developing public policy.

Areas of life, such as reproduction or access to health care, previously thought by liberal theorists to be wholly a matter of individual choice, and not a matter of public policy, regulation or legislative control, are now recognised by many researchers, practitioners, legislators and citizens to be matters about which the state has an interest. The source of this interest may be the state’s role as a provider of welfare services, or as a protector of individual rights, or as a defender of a “common way” or shared set of values. Each of these justifications for regulation could be viewed, in a particular case, as excessive state interference on liberal grounds, nonetheless, these positions have been put forward in recent years in a range of public, legislative and academic fora. Decisions about whether or not to regulate areas such as research involving expensive or risky medical technologies, use of stem cells in research or in

therapy, or cloning, are usually the outcome of a deliberation informed by public debate or in response to public outcry. NBOs can contribute to these decisions in varying ways. They can open up the public debate by promoting expression of the diversity of community views, clarifying that expression so that it is well-informed, articulate and responsive to both expert and 'lay' public views and can directly contribute to policy formation.

In this paper we are interested in policy development that can be described as "bioethical policy". That is, where (1) the policy is recognised as involving contentious ethical debate in the areas of health and medical research, and (2) the policy process has been designed to reflect diversity of opinion and of ethical frameworks and seeks legitimacy through processes of public consultation. We are particularly interested in examining the capacity of NBOs to meet the democratic ideal of effective participation by the public, or citizenry—especially those people directly affected by the policies—in the development of effective public policy. We provide a basic framework for policy development involving NBOs that could meet this ideal.

3. NATIONAL BIOETHICS ORGANISATIONS

Our concern with the capacity of NBOs to inform and reflect the diversity of values within a state on a bioethical policy issue in shaping policy, leads us to focus on a typical kind of NBO. The organisations to which our attention is directed are entities established by national governments, usually with a statutory base and a permanent existence, subject to periodic renewals of membership. While their terms of reference, roles, functions and tasks vary, what they have in

common is that their activities are directed to bioethical matters. Their concerns address areas of policy and legislation that are explicitly recognised to be ethically contentious: ethical issues in the provision of health care, the development and deployment of health care technology and the conduct of research in health related areas.

Because our present interest is in the relationships between and among these bodies, bioethics, liberal democracy and the development of government policy, we have not included international and transnational bioethics bodies, such as the Steering Committee on Bioethics of the Council of Europe and the more specialist ethics committee of the Human Genome Organisation (HUGO). Although we do not examine them, we recognise that the deliberations of these bodies may influence the development of national bioethics policy.

We exclude two types of national body. The first are bodies formed for narrow and specific inquiries, often into past conduct that has been ethically suspect. Examples of these include the Australian Inquiry into the Use of Pituitary Derived Hormones and Creutzfeldt-Jakob Disease², the United States inquiries into the Tuskegee³ and the radiation experiments⁴ conducted by government agencies. These inquiries may have important policy contributions to make and often represent new steps in government transparency, expose shortcomings of past regulatory systems and clarify how those can be remedied for the future. It is the narrow focus of their work and output and their short life that limits their on-going influence on policy development.

The second are national non-government NBOs: bodies with national standing but only indirect government links whose members are appointed by non-government processes and government is included among those to whom the body reports. An example of this kind of committee is the National Council on Ethics in Human Research of Canada. It has a wide range of tasks mostly related to the operation of research ethics boards (REBs) that consider and approve proposals for health related research involving humans. The Council reports to Health Canada, the Medical Research Council of Canada, the Natural Sciences and Engineering Research Council of Canada, the Royal College of Physicians and Surgeons Council and the Social Sciences and Humanities Research Council of Canada and other participating organisations. Although its status is likely to give weight to any recommendations that require state involvement, the indirect links with government are important points of distinction from those NBOs to which our primary attention is directed. To re-state: we are concerned to examine those NBOs that are established by governments as enduring bodies that can have a constant role in shaping bioethics policy.

4. ADVISORY AND POLICY -MAKING NBOs

4.1 Specific and general NBOs

Some NBOs are established with specific terms of reference or tasks but need to address bioethical issues in their performance and can take on a regulatory function. Among clear examples are the Human Fertilisation and Embryology Authority of the United Kingdom and the National Ethics Committee on Assisted Reproduction of New Zealand.

The Human Fertilisation and Embryology Authority of the United Kingdom was established by regulation following recommendations in the 1984 report of the Committee of Inquiry into Human Fertilisation and Embryology.⁵ The Authority's principal role is to license and monitor clinics that carry out in vitro fertilisation, donor insemination and research with human embryos as well as the storage of human gametes. It is also required to produce a Code of Practice for the conduct of licensed activities; keep a register of information about donors, treatments and children born from those treatments; publicise its role, provide advice to patients, doctors and clinics, keep under review information about human embryos, developments in regulated treatments and activities and advise the Secretary of State, if asked, about these matters. The Authority would clearly need to address ethical issues, but only those relevant to embryology.

The New Zealand National Ethics Committee on Assisted Reproduction was established by statute to review new and untried or innovative assisted human reproductive proposals of national importance. It is also required to develop protocols and guidelines to assist ethics committees to review such proposals and provide advice to the Ministers and National Advisory Committee on Health and Disability.

Although such NBOs work only on specified subjects, they can make important contributions to public bioethics policy development on those subjects.

Typical NBOs have been established by government with broad general terms of reference that are centred on ethical issues in health. For our purposes, these

NBOs can be divided into two categories: advisory NBOs and policy making NBOs. Advisory NBOs articulate debate about the ethical issues involved in any area of potential policy formation and may also respond to proposed policy in advising the public. Accordingly, their influence on policy is indirect. Policy making NBOs have, as a specific role, the development of bioethical policy; so that their influence on policy is direct.

4.2 Advisory NBOs

Some bodies have a general power to respond to issues directed to them from the public and to provide advice directly to the inquirer, the response becoming available as a public document. For example, the Danish Council on Ethics position paper on micro-insemination and pre-implantation genetic diagnosis sets out the ethical misgivings of eight members and the arguments that another nine members regarded as outweighing those misgivings.⁶ What is relevant about this process is that government has no priority in receiving the Council's responses to public requests for advice or opinion. Further, the advice of the Council reflects the multiple positions supported or supportable, it is not required or intended to represent public or expert consensus on the issue. Membership of these bodies usually covers a wide range of expertise and includes only those of recognised merit in fields relevant to the scope of the body's terms of reference: these need not be consultative bodies. Commonly, select sub-groups or individuals are designated responsibility for developing opinions in response to requests. We describe these as 'NBOs that are advisory and able to make open contributions to public bioethics debate'.

Among bodies with such powers are the Belgian Advisory Committee on Bioethics, the Finnish National Advisory Board on Health Care Ethics, the French National Consultative Ethics Committee for Health and Life Sciences and the Portuguese National Council of Ethics for the Life Sciences.

4.3 Policy-making NBOs

NBOs that do not have such direct public advisory powers are those national government established bodies whose characteristic mode of reporting is first to a government agency. We call these 'NBOs with defined policy-making roles'. While it is a matter of debate whether (and when) ethical matters, including bioethical matters, ought to be regulated through public policy, governments increasingly rely on NBOs to provide policy advice that may contribute to legal prohibitions on some activities (e.g. human cloning), conditions on access to public funding (e.g. access to public health research funds) or guidelines for clinical practice (e.g. guidelines on use of reproductive technologies). Clear examples of NBOs with these policy roles are the now-defunct United States National Bioethics Advisory Commission (NBAC) and the current Australian Health Ethics Committee (AHEC).

NBAC was established by Presidential Executive Order in October 1995 and lapsed in October 2001. The current President's Council on Bioethics was established in November 2001. NBAC was required to report to the National Science and Technology Council (NSTC) or other Federal agencies prior to making public its recommendations and advice: it was not required to consult public opinion, nor to seek consensus. It was required to respond to requests for

advice from the NSTC, could accept suggestions from Congress or the public concerning issues to be examined and could, subject to approval from the NSTC, identify other issues for examination. The following were the criteria for determining priority for activities:

- public health or policy urgency,
- relations of bioethics issues to goals of Federal investment in science and technology,
- absence of another suitable body, and
- the extent of interest in the issue across the government.

The integration of NBAC into government processes was also evidenced by the power of the Commission to direct recommendations to departments or agencies and request responses within designated periods.

The Australian Health Ethics Committee was established by the Minister for Health in exercise of the power and requirement in section 35 of the *National Health and Medical Research Council Act 1992* (Clth). The statutory functions of AHEC are to advise the National Health and Medical Research Council (NHMRC) on ethical issues relating to health, to develop and give the Council guidelines for the conduct of medical research involving humans and such other functions as the Minister determines. It is required to report to the Council, which in turn issues approved documents. Other than the specific reference to medical research involving humans, there is no provision relating to the sources from which AHEC can derive issues for its work. AHEC can be said, then, to have a specific responsibility to develop national policy governing research involving

human participants. Its membership comprises experts and representatives of specific interest groups thought to be commensurate to that task. Unlike NBAC, AHEC is required, under the Act, to pursue a public consultation process in relation to the health matters it considers. The scope of its public contribution to bioethical debate is framed by that policy role.

5 . NBOs IN PLURALIST LIBERAL DEMOCRACIES

In this section we explore alternative theoretical approaches to recognition of diversity in democracies, in the next section we show how these relate to the structure, role and processes of those NBOs with advisory roles and those with defined policy-making roles.

Our specific concern is to consider the relative merits of the two kinds of roles for NBOs: those whose roles are primarily advisory and those with a mandated policy-development role. We use contemporary work on democracy and public rationality to demonstrate our argument. All NBOs appointed by governments are influenced by governmental concerns (e.g. in membership and terms of reference). It is our view, however, that those NBOs with a genuinely advisory role may be better able to reflect the diversity of public and specialist opinion about important ethical matters affecting communities and thereby meet certain democratic goals of participation and public reasoning, than those NBOs that have a specific bioethics policy-making function.

By comparison, although those NBOs with specific policy-making responsibilities will have greater impact on practice, they are likely to be constricted in reflecting

a range of ethical opinion by the demands of legislative and policy-making structures (e.g. the need to produce policy which is univocal, thus papering-over diversity—abstracting different orders of disagreement under a single banner view, that policy needs to respect differences in value). Those NBOs that, in their advisory role, are expected to *initiate* public debate and to articulate the range of significant ethical standpoints on the issue under consideration may be seen to provide a better starting point for genuine democratic consideration of bioethical issues to be addressed by policy.

In summary, an NBO with an expert membership but primarily an advisory mandate can initiate debate or respond informatively to a debate initiated elsewhere about bioethical policy matters, because its membership includes articulate experts who can engage in reasoned discussion and deliberation grounded in distinct views. While advisory NBOs may not, in practice, reflect the diversity of public views on a bioethical topics, their structure better allows for realisation of deliberative ideals of public reasoning (discussed further in the next section). An advisory NBO has greater chance of reflecting a diversity of views and presenting that diversity clearly so as to widen public debate through informed and articulate intervention. Having so contributed to debate, the NBO would be able to explain the significance of the range of possible responses and to ‘road test’ public and ‘expert’ reactions to those alternatives. This approach would allow for a clearer engagement between the ethical issues (and their sources) in the debate and more clearly defended public responses into the policy process.

An NBO with expert representative membership and a defined policy making role, by contrast, is likely to have a membership less representative of the diversity of people holding strongly held views about the issue than advisory committees, due to the selection of members based on their expertise and capacity to resolve on policy. That is, insofar as the range of representatives or experts consulted is restricted by the demands of the policy-making process, subordinated view points are less likely to be reflected in their membership. Diversity is more likely to be restricted to a set range of positions demanded by the policy framework (e.g. there will be representatives of one or two major religions, not representing the range of religious perspectives that may have specific concerns with a proposed area of policy development). Such NBOs are also likely to anticipate only a limited range of ethical viewpoints and expert positions, and therefore not fully represent in their considerations the diversity of issues raised in the wider public debate. Further, they are likely to be driven by political necessity, which will reduce the scope for disagreement in the face of the need for finalising a clear policy. This will result in some views being privileged and others being discounted. However, these NBOs are more capable of directly shaping policy.

6. BIOETHICS, DIVERSITY AND DEMOCRATIC POLICY MAKING

In discussing the relationship between democratic decision-making and public policy formation we focus on the *process* of debate through which a democratic polity articulates the values held by the members of the polity, which then inform policy makers. Liberal democracies are founded on the view that different individuals or groups can and do hold different values as fundamental, and these

differences ought to be respected in policy-making.⁷ Precisely how these differences are to be respected is a matter of debate and we examine some of the alternatives below.

The legitimacy of policy in democracies depends, in large part, on the public deliberative processes that informed the policy: not on the substance of the policy, but on the process or public reasoning used to determine it⁸. In saying this we are not committed to a pluralist ethic, nor to the view that policies should be based on either consensus or compromise. Policy makers will have to make decisions, rank priorities among conflicting concerns and defend their policies on a specific set of institutional values that may not reflect the full array of values of those affected by the policy. Nonetheless, people who will be affected by policies should have the opportunity to express their views about the matter in the process of policy debate, and their contribution to the debate should not be artificially constrained by that process (for example, an imposed limit on the range of ethical issues that can be considered as part of the policy debate, or constraints on the form of submissions to the policy-makers). The ideal is to ensure that individuals have an authentic and effective voice in participating in public deliberation about topics that affect them. Policy makers draw on that public debate and engagement in setting the policy: the policy is thus informed by the public deliberations of the people affected by the policy.

Thus, when we advocate the inclusion of public views in important policy debates about bioethical issues, we do not have in mind the idea that public policy should reflect some impossible-to-realise consensus view shared by all members of a

society, nor do we assume that after a process of public deliberation the outcome resolution will not later become contestable under new circumstances. The resolution of the deliberation about how to negotiate plural values on ethically contentious issues should not be assumed to be final determinations that could not be re-opened in light of cultural or technological change. We are concerned, nonetheless, to ensure that debate about these matters does not get captured entirely by the interests of those deemed to be experts (or "guardian enclaves"⁹), nor by policy makers attempting to avoid contentious debate that could lead to unpopular decisions. Instead we argue that those who are to be directly affected by policy should have their say in the development of policy, and that all participants in these policy debates have the opportunity to reflect on and respond to expressions of the specific knowledge and experiences of the various participants. The conception of democratic deliberation that we are drawing on here, according to Cohen, "is rooted in the intuitive ideal of a democratic association in which the justification of the terms and conditions of association proceeds through public argument and reasoning among equal citizens"¹⁰. We suggest how this might be addressed in the next section. It is worth noting here Habermas' summary of the procedures involved in this approach to public reasoning:

- (a) Processes of deliberation take place in argumentative form, that is, through the regulated exchange of information and reasons among parties who introduce and critically test proposals.
- (b) Deliberations are inclusive and public. ... [A]ll of those who are possibly affected by the decisions have equal chances to enter and take part.
- (c) Deliberations are free of any external coercion. ...
- (d) Deliberations are free of any internal

coercion that could detract from the equality of the participants. Each has an equal opportunity to be heard, to introduce topics, to make contributions, to suggest and criticize proposals.¹¹

7. PUBLIC DEBATE ABOUT BIOETHICAL ISSUES: DELIBERATION AND DEMOCRACY

The question of how NBOs ought to be understood and how they ought to go about their business, when addressing issues over which there is no clear public agreement about the ethical values at stake, is one specific manifestation of a characteristic tension for any liberal democracy. This is the tension between mere toleration of ethical differences and genuine respect for those differences in policy-making, given the impossibility of ethically neutral policy-making in matters that are the subject of hot ethical debate.

The legitimacy of public policies in liberal democratic states depends, in principle, on the ability of the policy-maker to justify those policies to any reasonable member of the society.¹² Public decision-making processes that involve public consultation can be described as searching for public consensus or as seeking distributive modes of justification, a “fair” compromise between individual preferences.¹³ Over the past three decades, liberal political philosophy has worked to respond to challenges posed by feminists and communitarians in the context of demands for recognition of group difference in policy-making within pluralist societies¹⁴. These differences can strain the possibilities for meaningful consensus or question the fairness of compromise, and it is unclear that there is a neutral standing point that policy-makers can assume in their deliberations.¹⁵

Although ‘overlapping consensus’¹⁶ may be found on many topics of public policy, in the areas of bioethical policy in which NBOs are often called upon to deliberate, there is frequently little ground for such consensus to be found. Matters such as voluntary euthanasia, access to new reproductive technologies or use of genetic information raise immediate questions about the values endorsed by the society in which we may live: those of human life, inter-generational justice and individual privacy, to name just a few. Policy debate about these matters can be extremely divisive, and they raise strongly held ethical, religious and political views. Public understanding of science and public articulation of social and ethical concerns become an integral part of the decision-making underlying such policy development¹⁷. Unless the process of public policy-making in these areas attends to the tensions and multiple value-systems within society, the legitimacy of these policies will be called into question. In what follows, we contrast approaches that seek consensus through compromise between competing values with an approach that engages all affected participants in a mode of deliberation towards the defensible resolution of problems through public reasoning.¹⁸

8. THREE APPROACHES TO ETHICAL DIFFERENCE IN POLICY DEBATE.

Existing NBOs take a number of different approaches to debate, public consultation, decision-making and contribution to policy formation in relation to a specific set of ethical issues. For the purposes of this paper we will distinguish among: ‘interest group pluralism’; ‘interest group pluralism coupled with public

consultation’; and an approach that we will call ‘contested deliberation’. While most actual NBOs use somewhat mixed approaches, we have sought to highlight the tensions among these in a manner that exaggerates the effects of the differences to demonstrate our concerns.

8.1 Interest group pluralism

According to Iris Young,

In the welfare capitalist society, processes of interest-group pluralism are the vehicle for resolution of policy conflict about distributions. Client-consumer citizens and corporate actors organize to promote specific interests in receiving government goods—the oil lobby, the consumer advocates and so on. New government programs often create interest groups where they did not exist before. ...Government policy and the allocation of resources, according to pluralist theory, are the outcome of this process of competition and bargaining among interest groups.¹⁹

This approach seeks consensus, understood as “fair compromise” through drawing together a range of recognised representatives on aspects of the issue who are taken to represent different “interest groups” or “stakeholders” and who have as their task the development of a consensus that takes into account the tensions between and among these interests. Representatives are identified through their professional qualifications or expertise and/or the view that they represent a specific set of public interests. For example, NBOs discussing genetic manipulation will include geneticists, lawyers, philosophers, theologians, disability activists, epidemiologists, health economists, clinicians and counsellors

among their membership. The geneticists on the NBO can be seen as having specific professional expertise and to represent the interests of genetic scientists and clinicians, while the disability activists can be viewed as representing the interests of people with disabilities and theologians represent the interests of those who share religious concerns, and so on. If the individuals are understood to be representatives of different interest groups and are asked to come to a consensus based on the distinct interests of those interest groups, then the outcome of the process may be a compromise that each of the participants can agree to, given the competing interests of their constituencies.

One clearly contestable aspect of this approach is how interests meriting representation and appropriate representatives for those interests are identified. Some groups or interests will be represented simply because of uncritical historical-cultural assumptions about what kinds of expertise are required for these deliberations (such as the immediate inclusion of lawyers and religious representatives on NBOs). Their inclusion may be appropriate, but ought to be justified, given that representatives of other groups may have to demonstrate their particular entitlements to be recognised as representatives of a relevant interest. For example, representatives of people with disabilities, may have to argue long and hard for a place in the deliberations because they lack professional credentials for their status. Groups that are recognised by their professional standing are likely to be advantaged in such a process, as they are more likely to have access to resources to promote their cause. For example, professional lawyers or academics can participate more readily in NBOs than can other members of the community. They can take the time to attend the meetings

without loss of income, have access to the resources that may be required to prepare their case, and are often more familiar with the debating style and methods of negotiation that are commonplace in such deliberations. These representatives, with professional qualifications may also be assumed to be less openly subjective in their deliberations than those who are members of socially disadvantaged groups, because of their professional status: creating unequal conditions for participation in deliberations.

Interest group pluralism also excludes the wider public from the debate; at least it limits access to negotiations framing the debate. The deliberations between the different interest groups are not made public, the compromises are not revealed and there is no expression of a justification for why the outcome is framed in one way rather than another. Compromises of this sort are neither accountable, nor public.

Irwin says such expert-representatives achieve their exclusion by pre-framing the debate of the issues and

..that this framing misses out on more pervasive problems and anxieties.

Equally, the construction of the exercise around issues likely to be unfamiliar to participants and then providing factual information to overcome their assumed ignorance, suggests a return to the deficit theory of public groups as operating in a knowledge vacuum.²⁰

The question of pre-framing is

a central issue for consultations of this kind, especially in emerging areas of scientific concern where researchers will inevitably find themselves both

generating and collecting public views about topics that have not previously been considered - and doing so in an unavoidably artificial and decontextualised fashion.²¹

The subject matter of typical bioethical policy issues does require input from experts, for instance, those in relevant medical or scientific disciplines. However, it is less clear that the identification of ethical issues requires expertise, even if articulating those issues into bioethical discourse does. Citizens arguably can decide what for themselves is good or bad, desirable or undesirable, right or wrong. However, expressing those intuitions or opinions in a discourse that can be shared does require expertise in bioethics.

Critics of interest group pluralism note that it is an adversarial approach, and one that can stifle genuine debate, by requiring each representative participant to negotiate the “best outcome” given the interests of their group. Iris Young has argued that interest group pluralism de-politicises public life, as no critical distinction is made between the assertions of selfish interest and claims of justice or right.

Public policy dispute is only a competition among claims, and ‘winning’ depends on getting others on your side, making trades and alliances with others and making effective strategic calculations about how and to whom to make your claims. One does not win by persuading a public that one’s claim is just.²²

8.2 Interest group pluralism with public consultation

One approach that has been taken by many NBOs in attempting to avoid the problems with interest group pluralism that we have identified is to combine the interest group approach with some degree of public consultation. This approach does not seek public participation in the debate, but asks for a public response to a proposed policy determined by the interest groups' negotiations. This is a formal consultation that often does not allow for genuine public participation in the debate. The reasons for this include the following. First, the scope of public or stakeholder response is often very limited (e.g. in time frame, format of response, the questions the public are asked to address). In this way, the "pre-framing" of debate that Irwin criticised is perpetuated. Second, consultation is not genuinely public, as only some groups will be approached directly and asked to respond. Where public consultation is required, the public notices for submissions are often buried in newspapers. Even if those notices are found, only those with time and resources can respond effectively. Any particular submission will only have a marginal effect, as, often, the policy makers will be obliged merely to "have regard to" the comments made in the consultative process, but no obligation to justify selective use of the material. Third, there is usually no public access to the original submissions, which would allow for public scrutiny of the ways in which submissions were used to shape policy.

Such confined or scripted consultation falls short of Amy Gutmann's ideal of deliberative democracy. She says

At the core of deliberative democracy is the idea that citizens and officials must justify any demands for collective action by giving reasons that can be accepted by those who are bound by the action. When citizens morally disagree about public policy, they therefore should deliberate with one another, seeking moral agreement when they can and maintaining mutual respect when they cannot.²³

Equally, it would fall short of the social equality that, for Iris Young, is a goal of social justice. This refers primarily to

...the full participation and inclusion of everyone in society's major institutions, and the socially supported substantive opportunity for all to develop and exercise their capacities and realize their choices.²⁴

The shortcomings of such formal and passive consultation have been recognised and improved processes that achieve on-going interaction devised, often engaging the power of information technology with positive effect.²⁵

8.3 Contested deliberation

What appears to us to be needed is a hybrid derived from Gutmann's deliberative democracy and Young's approach to social justice. There needs to be an approach to deliberation that addresses the problem of correctly identifying relevant expertise while ensuring the capacity of those experts to participate effectively in deliberations of the NBOs. The identification of experts must be seen as contestable and the process of participation as an NBO member needs

to be sufficiently flexible (not cemented into bureaucratic practice) to allow for effective and authentic participation by all members.

Secondly, the NBO's deliberations and contribution to debate should, initially at least, be viewed as preparatory to open and unscripted public participation. The process of public discussion or consultation should be such as to allow genuine deliberation and response by the citizenry. NBOs can open-up public debate by providing or inviting well-informed, articulate expressions of the range of ethical responses held by the community to the issue at hand. Thus, NBO members need not directly mirror the diversity in the community, but need to reflect, be sufficiently aware of, and present the different views held by parts of the community in such a way that members of the wider community can see that their various views are being brought into the discussions. In this sense the NBOs have an obligation to explain the relevant issues in a manner that can be understood and considered by the interested public. In this way, we seek a merger or hybrid of the two models of NBOs discussed in section 4. We advocate an approach that takes the deliberative advantages found in advisory NBOs—suitably modified to approximate the reasoning, equality, inclusivity, publicity and freedom conditions of Cohen's ideal procedure—and the capacity to deliver policy recommendations of NBOs with policy-making mandates—again modified to promote deliberative procedures.

Clearly, not all views held by the community are such as can be coherently expressed nor should views that are openly hostile to liberal democratic values of equality and respect be presented as worthy alternative approaches in public

policy formulation (e.g. views based on outright racism or denial of basic civil rights). This distinction draws on Iris Young's concerns about inclusion and full participation of everyone in the society's major institutions (for example recognition of the civil rights of people with disabilities for equal opportunity to participate in public life). NBOs do not have an obligation to defend positions that are founded on the denial of recognition of diverse ethical stances, or the equal rights of all to participation in public life.²⁶ Rather NBOs should identify the conflicts among the different views that are held in the community and be prepared to defend or reconsider the NBO's grounds for its contribution to the debate. NBOs should be particularly concerned to reflect the diversity of views held by those directly affected by the policies under consideration and to work towards provisional and revisable agreement about policies that emerge from debate informed by this diversity.

The approach we recommend here shares some features with the approach to public reason defended by Duncan Ivison in his recent book *Post-Colonial Liberalism*. Ivison develops a pragmatic approach to legitimate public reasoning in those pluralist societies that include groups disadvantaged by historic injustice. The approach to agreement about public policy he advocates is characterised by agreements that are "*discursive modus vivendi*":

Discursive because they emerge from the constellation of discourses and registers present in the public sphere at any given time, and subject to at least some kind of 'reflexive control' by competent actors; and *modus vivendi* because they are always provisional, open to contestation and by definition 'incompletely theorized'.²⁷

Our approach to the role of NBOs in bioethics policy formation is, therefore, procedural, contestable and accountable. We believe this can be realised through a three-stage process for policy deliberation in pluralist democratic states. Stage one involves an open process of community hearings to determine whether policy is required in this area, to seek reactions to positions previously articulated by experts in the debate, and to allow presentation of community view-points. Stage two involves an identification of appropriate representatives and articulation of the relevant issues that emerged from the community hearings and presentation of a range of possible positions in response to the demand for policy and articulated concerns. The third stage involves the presentation of the expert and community deliberations to an accountable, policy-making body that is charged with developing policy that takes into account the range of views that have been articulated in both of the previous stages.

9. BIOETHICS AND LIBERALISM IN DEMOCRATIC POLICY MAKING

Recognition of many of the dilemmas that we have tried to articulate can be found in the June 1993 report of the United States Office for Technology Assessment (OTA) on *Biomedical Ethics in US Public Policy* and some reactions to it. The report reviewed the work and contributions of four NBOs; the 1974-1987 National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, the 1979-1983 President's Commission for the Study of Ethical problems in Medicine and Biomedical and Behavioural Research, the 1988-1989 Biomedical Ethics Advisory Committee and the more limited and non-

Congressional 1977-1980 Ethics Advisory Board. Of these, the report accorded success only to the 1979-1983 President's Commission.

In a comment on this report published in the *Hastings Center Report*, Joseph Palca considered that the success of the 1979-1983 President's Commission was due to the fact that it steered clear of political influence on generating its reports, had adequate staffing and funding and had a broad mandate.²⁸ In his view, the predecessors and its immediate successor had not been sufficiently free of either Congressional or executive influence. In the terms we have used, this was a use of interest group pluralism by an advisory NBO that was successful for articulating the bioethical issues because it was not established as part of a policy making process. In our view, however, this approach is limited as a means of influencing policy, precisely because of its separation from the policy-making processes.

In another response to the OTA report, George Annas suggests that any national bioethics commission whose main job is, in effect, legislation (by regulation) will focus its work at the lowest common denominator of ethics, namely, the law, and not explore wider and deeper questions.²⁹ In our terms, he identifies one of the shortcomings of the second approach we outlined above, interest group pluralism with public consultation. He rejects the OTA's recommendation that Congress "should provide a voice for biomedical ethics in public policy", saying, "To the extent that bioethics is a field based on principle rather than compromise, politics can only corrupt it."³⁰ He concludes that the challenge for bioethics in America is to learn more of politics so that it can influence politics without corrupting itself.

This corruption will occur if, he says, bioethics makes it seem that “ethical principles and practice are the result of compromise and majority votes rather than reason and virtue.”³¹

There appears here to be an assumption about the nature of bioethics, as somehow “outside” the social and political contexts that it critically examines, a view that is likely to be challenged. Nonetheless, whatever conception of bioethics is adopted, the important point is that processes involving NBOs need to be informed by ethical intuitions and opinions articulated into bioethical discourse by representatives and by public responses to a debate that is not reduced to interest group pluralism with passive and procedural (rather than substantive) public consultation. We advocate that at the third stage of policy-making on any NBO issue, there is a democratic obligation to demonstrate that all defensible positions that have been articulated through the NBO process by interested members of the wider community or by those with specific expertise have been taken into account. This obligation can only be satisfied by drawing recognisably bioethical views into debates framed to seek provisional agreement about policy. For this to be seen (or heard) to happen, there needs to be general agreement (but this agreement must also be contestable, hence open to argument) about the range of views that can be appropriately labelled as bioethical.

The contestability of the scope of bioethics and of democratic decision-making is not a reason to abandon the project of finding out how bioethics can best influence policy-making in a democracy marked by liberalism. Rather, it is

recognition of the need for careful reflection on and identification of the assumptions on which the design of NBOs and related policy making processes rest. This paper has been our attempt to open that deliberative debate.³²

ENDNOTES

- ¹ Information about these meetings can be found at <http://www.who.int/ethics/globalsummit/summits/en/index.html> (accessed 17.12.03)
- ² M. Allars. 1994. Report of the Inquiry into the Use of Pituitary Derived Hormones in Australia and Creutzfeldt-Jakob Disease. Report to the Minister for Human Services and Health, The Hon Dr C M Lawrence, Canberra, ACT. Australian Government Publishing Service.
- ³ U.S. Department of Health, Education and Welfare. 1973. Final Report of the Tuskegee Syphilis Study Ad Hoc Advisory Panel. Washington, DC.
- ⁴ U.S. House of Representatives. 1986. American Nuclear Guinea Pigs: Three Decades of Radiation Experiments on U. S. Citizens, A Sub-Committee Staff Report for the Subcommittee on Energy and Power of the Committee on Energy and Commerce. Washington, DC.
- ⁵ M. Warnock. 1985. *A question of life: the Warnock report on human fertilisation and embryology*. Oxford, UK and New York, NY. Basil Blackwell.
- ⁶ The paper is available at <http://www.etiskraad.dk/sw2447.asp> (accessed 17.12.03)
- ⁷ Some liberals argue that the state ought to be agnostic about 'the good', that liberalism doesn't espouse a particular substantive conception of the good, but rather that liberalism allows each individual to pursue his or her own substantive conception of the good; Kymlicka argues that liberalism concerns providing the conditions within which each individual can critically reflect on their conception of the good: liberalism allows for revisability of one's conception of the good. W.

Kymlicka. 1989. *Liberalism, Community and Culture*. Oxford, UK and New York, NY. Clarendon: pp. 10-11.

⁸ J. Rawls. 1993. *Political Liberalism*. New York, NY. Basic Books, p. 212ff; J. Habermas. 1988. *Legitimation Crisis*. T. McCarthy, trans. Oxford, Polity Press, p. 95ff.

⁹ A term used by Colin Finney. C. Finney. 1999. Extending public consultation via the Internet: the experience of the UK Advisory Committee on Genetic testing electronic consultation, *Science and Public Policy*, 26(5): 361-373, pp. 362-3.

¹⁰ J. Cohen. 1989, Deliberation and Democratic Legitimacy. In *The Good Polity: normative analysis of the state*. A. Hamlin and P. Pettit, eds. Oxford, Basil Blackwell: 17-34, p. 21.

¹¹ J. Habermas. 1996. *Between Facts and Norms: contributions to a discourse theory of law and democracy*. W. Rehg, trans. Cambridge, Mass. MIT Press, p. 305.

¹² J. Waldron. 1993, Theoretical foundations of liberalism. In *Liberal Rights: Collected Papers 1981-1991*. J. Waldron, ed. New York, NY. Cambridge University Press: 35-62, p. 44.

¹³ F. D'Agostino. 1991. Some modes of public justification. *Australasian Journal of Philosophy* 69(4): 390-414.

¹⁴ See for example I. Young. 1990. *Justice and the Politics of Difference*. Princeton, NJ. Princeton University Press; M. Sandel. 1982. *Liberalism and the Limits of Justice*. Cambridge, UK. Cambridge University Press; J. Rawls, *op. cit.* note 8; W. Kymlicka. 1995. *Multicultural Citizenship: A Liberal Theory of Minority Rights*. Oxford, Clarendon; D. Ivison. 2002. *Postcolonial Liberalism*. Cambridge, UK. Cambridge University Press.

¹⁵ See for example Sandel, *op. cit.* note 14; C. Mouffe. 1992. Democratic citizenship and the political community. In *Dimensions of Radical Democracy*. C. Mouffe, ed. London, UK. Verso; 225-239; W. E. Connolly. 1999. *Why I Am Not a Secularist*. Minneapolis, MN. University of Minnesota Press.

¹⁶ Rawls, *op.cit.* note 8, p. 144 ff.

¹⁷ A. Irwin. 1995. *Citizen Science: a study of people, expertise and sustainable development*. New York, NY. Routledge.

¹⁸ Cohen, *op. cit.* note 10, p. 21.

¹⁹ Young, *op. cit.* note 14, p. 72.

²⁰ A. Irwin, 2001. Constructing the scientific citizen: science and democracy in the biosciences, *Public Understanding of Science*, 10: 1-18, pp. 9-10.

²¹ *Ibid.*, p. 10.

²² Young, *op. cit.* note 14, p. 72.

²³ A. Gutmann and D. Thompson. Deliberating about Bioethics. *Hastings Centre Report* 1997; 27 (3): 38-41, p. 38.

²⁴ Young, *op. cit.* note 14, p. 173.

²⁵ For example, the United Kingdom website, <http://www.open.gov.uk/CitizenSpace> and the Western Australian website <http://www.ccu.dpc.wa.gov.au>, illustrate these developments.

²⁶ R. Macklin. 1999. *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine*. New York, Oxford University Press.

²⁷ Ivison, *op.cit.* note 14, 73-74.

²⁸ J. Palca. 1993. The Fifth Commission. *Hastings Center Report* 23 (4): 5.

²⁹ G. Annas. 1994. Will The Real Bioethics (Commission) Please Stand Up? *Hastings Center Report* 24, (1): 19-21.

³⁰ Ibid., p. 20.

³¹ Ibid., p. 21.

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