

article

*Disability: A Voice in Australian Bioethics?*Dr Christopher Newell,¹ AM

Senior Lecturer in Medical Ethics

School of Medicine, University of Tasmania

Abstract

The rise of research and advocacy over the years to establish a disability voice in Australia with regard to bioethical issues is explored. This includes an analysis of some of the political processes and engagement in mainstream bioethical debate. An understanding of the politics of rejected knowledge is vital in understanding the muted disability voices in Australian bioethics and public policy. It is also suggested that the voices of those who are marginalised or oppressed in society, such as people with disability- have particular contribution to make in fostering critical bioethics.

In her recent Samuel Gee lecture Dame Mary Warnock critiques 'the absurd political correctness' of voices of people with disability in debates regarding 'medical ethics', questioning 'ableism' (Warnock, 1999, p.478). Whilst her critique has sweeping generalisations, it does reflect a mainstream concern with a disability critique of bioethical endeavours. Warnock's paper in *The Journal of the Royal College of Physicians of London* provides a useful opportunity for critically examining the rise of the work of people with disability in bioethics.

Rather than being 'absurd political correctness', in this article it is suggested that a disability voice, for all that it is muted and subject to ableism, offers a valuable dimension to bioethics. This is particularly the case as it utilises markedly different premises and therefore a different perspective. A particular critique is offered regarding the status quo, the history from which it emerges, and the ableism which Warnock dismisses. While the focus is on the Australian situation, one in which I have sought to bring about change, reference will also be made to selected aspects of the international situation. First, however, let me be clear that there is no one disability voice in bioethics; rather, different voices. Disability is a marginal part of the international and national bioethics communities, including in professional practice. In part, this

no doubt reflects the fact that disability, as an area of critical study and political activism, is arguably less developed than any other social grouping.

Whilst disability voices may differ on the status of the foetus, embryo and, indeed, most other topics within bioethics, much of the emerging critical work of dominant perspectives of the construction of disability and bioethics has revolved around the social nature of disability. It may also be seen in terms of oppression (Abberley, 1987) or what Warnock calls 'ableism'. As Warnock rather succinctly puts it:

The disabled are constantly put down, their point of view disallowed, because they are comparatively weak. The disabled therefore object that they, as a group with a particular point of view and particular common interests, are not only being disregarded ('marginalised') but they are actually the victims of a policy which would eliminate them all together. (Warnock, 1999, p.477)

Other writers such as Oliver (1996) also refer to this in terms of 'disablism'. Warnock also goes on to note commonality between feminist and disability groupings, in observing: 'What is common to the disabled and the feminist groups, is that both are inclined to place inverted commas around words such

as 'disabled' or 'handicapped', thus implying that such categorisations are artificial social constructions denoting nothing essential in the person' (Warnock, 1999, p.478).

There is no doubt, however, that whilst she tends to generalise somewhat, Warnock does have a point. Much of the critical disability studies literature in the 1980s and 1990s revolved around the so-called social model of disability, with the social construction of disability being clearly identified (see, for example, Oliver, 1990; Fulcher, 1989). Yet, many of us in our daily lives find that diseases or disabilities are hardly just a social construct. As I remember joking with a colleague recently, as I lay in a hospital bed, in severe pain and gasping for breath, 'of course, this is just a social construct'. Yet, there is no doubt that the meanings associated with particular disability and disease states are socially constructed and have social meanings.

It would, however, be a mistake to suggest that all of the work of those who identify as having disability or who are concerned with the social dimension of disability see disability as in some way mythical. Of course it has a tangible dimension, it is just that the meanings and representations of such artifactual dimensions are socially constituted. Likewise, Warnock fails to identify the essentially political dimension of identifying as having disability or caring for someone with disability. Rather than '... denoting nothing essential in the person', as Warnock suggests, 'disability' is inherently part of the political dimension essential for social change. This has been proposed by such Australian writers as Ian Parsons (2000) in his stimulating book *Cripples, Coons, Fags and Fems* comparing four human rights movements, and asking what makes for success in overcoming oppression. He suggests, persuasively, that it is identifying as having disability and celebrating that fact in the face of negative norms and structures which is vital, pointing especially to the gains of other social movements such as the gay and lesbian movements.

Warnock is particularly helpful in pointing to some of the reasons for the rise of bioethics. In her paper, she decries the 'politicisation of medical ethics' as if it were never inherently political, but her reference to feminist and disability arguments helps to point to the dissatisfaction with the biomedical knowledge utilised within traditional medical ethics. Such a situation helped lead to critical reflection within the trans-disciplinary endeavour which is bioethics, drawing upon a variety of intellectual tools including the insights of the social

sciences such as sociology with regard to the nature and construction of knowledge.

An historical perspective regarding the rise of disability critiques in the Australian context shows some of the problems with dominant accounts of bioethics. Much of this has been an unwritten history of which I am an integral part.

The Ethics of Limiting Life-sustaining Treatment (1988)

It was dissatisfaction with the biomedical model and its utilisation in setting ethical guidelines which led to the rise of the first national response by people with disabilities to a National Health and Medical Research Council (NHMRC, 1988) paper, *The Ethics of Limiting Life-Sustaining Treatment*. That response, by Disabled Peoples' International (Australia) Ltd. (1990), the then umbrella organisation for people with disabilities, sought to use academic arguments in pointing to the limitations of a biomedical account. It also adopted political tactics in utilising the voices of those with conditions such as spina bifida to refute the so-called medical facts utilised by the NHMRC in its discussion paper. For example, in response to statements about the status of the life of those people with disabilities, the work of Alison Davis, someone with spina bifida, was used to refute these arguments. This included her compelling review of Kuhse and Singer's book, *Should the Baby Live?*:

I was born with severe spina bifida, and am confined to a wheelchair as a result. Despite my disability and the gloomy predictions made by doctors at my birth, I am now leading a very full, happy and satisfying life by any standards. I am most definitely glad to be alive. Yet, because handicapped people are now presumed by some doctors, philosophers and Society in general to have the capacity only for being miserable and an economic burden on the community, most of those who would otherwise grow up to be like me are now aborted or 'allowed to die' (such a comfortable euphemism) at birth. (Davis, 1985, p.54)

Another political tactic involved the distribution of this critique to state/territory and federal politicians around Australia with interest in health, ethics and/or disability. There was also a media strategy which even gave rise to a debate between the Chair of the NHMRC (Dianna Horvarth) and the author (Radio program on 5AA, dated 2/12/90).

That policy moment is inextricably linked with the rise of disability as a topic of bioethical investigation from social and human rights perspectives in Australia. At the first conference of the Australian Bioethics Association in 1991, I drew upon this work to give the only paper specifically developing a critique of biomedical knowledge utilised in ethical decisions regarding people with disabilities. It is worth contrasting with the 1998 conference of the Australian Bioethics Association, where a whole section of non-solicited papers (5 in total) were presented on topics related to disability, utilising social, narrative and rights perspectives (Newell, 1999).

NHMRC Act 1992

The next policy moment of particular import is to be found in the debates to do with the *National Health and Medical Research Council Act 1992*. An analysis of the Hansard in the Senate (especially that of Monday 14 December, 1992) shows the clear intent of the Senate to address criticisms that the NHMRC needed to be open and responsive to the input of the Australian community, and not just select professional groupings.

Debate with regard to the composition of the Australian Health Ethics Committee (AHEC) saw it established under the banner of the NHMRC, but with clear statutory powers to publish ethical guidelines, with two stages of ethical public consultation, independent of the NHMRC. To date, those powers of independent publication have not been utilised. It is also significant that it was in Committee that the Senate created, in the membership of AHEC, a position for 'a person with understanding of the concerns of people with a disability'. Significantly, this differs from the description used with regard to professional categories of membership of AHEC, whereby other non-consumer representatives were described as having 'knowledge', 'experience' or particularly 'expertise', far more powerful terms. There is also a recognition of the difference between healthcare consumers and people with disabilities, in the discourses associated with health and disability in the final composition of AHEC.

It is also significant that ethical guidelines and the structures of the NHMRC are subject to parliamentary scrutiny. There is no doubt that in part this is a response to concerns by academics and minority groups, such as people with disabilities, about the way in which the NHMRC had

previously operated (see several essays in Caton, 1990).

From 1994 to 2000 I was privileged to be the 'person with understanding of the concerns of people with a disability' on the Australian Health Ethics Committee. It taught me a lot about the intersections between bioethics, social policy and law. People sitting on the AHEC have the following responsibilities under Sections 35 and 36 of the NHMRC Act, which defines the functions and composition of the Australian Health Ethics Committee. Under the Act, Council, through AHEC, must issue guidelines for the conduct of medical research involving humans. Its terms of reference are:

1. To advise the Council on ethical issues relating to health.
2. To develop and give the Council guidelines for the conduct of medical research involving humans.
3. Such other functions as the Minister from time to time determines:
 - 3.1 To develop and give the Council guidelines for ethical conduct in the health field, additional to those required for function 2 above, and for the purposes of the *Privacy Act 1988*;
 - 3.2 To promote community debate, and consult with individuals, community organisations, health professions and governments, on health and ethical issues;
 - 3.3 To monitor, and advise on, the workings of institutional ethics committees;
 - 3.4 To monitor international developments in relation to health ethical issues and liaise with relevant international organisations and individuals. (ss 35-36 *National Health and Medical Research Council Act 1992*)

Hence, what is required is more than just introducing particular disability arguments or critiques, especially given the diversity of these perspectives. It also involves assisting organisations nominating such a person to think through and name issues that people with disabilities have not necessarily explored before. For example, it is rather difficult to think through issues

to do with the status of the embryo or embryonic stem cells when many people with disability face unmet accommodation, and educational support needs. In my experience, writing guidelines often means finding the middle way, as opposed to coming up with ideologically 'pure' critiques of biomedicine.

Yet does having such a mechanism really mean that ableism is adequately dealt with? An important issue in such processes is the fact that while disability organizations named in the regulations associated with the Act may uniformly nominate a person for such committees, the choice is ultimately up to the relevant minister. It is now emerging that nominations of disability and health consumer representatives to NHMRC and other committees, are subject to significant ministerial mediation, where a background as someone critical of the status quo is not necessarily conducive to appointment to committees, hardly surprising given Caton's earlier work regarding the NHMRC (Caton, 1990).

DPI Bioethics Conference 2000

At a global level it is apparent that people with disabilities have had similar concerns to that documented with regard to the NHMRC and the dominance of medical and related professional discourse in 1990. This is documented at a unique two-day conference organised by Disabled Peoples' International (DPI) Europe. One hundred and thirty people with disabilities, and their parents, delegates from twenty-seven countries in Europe, Africa, Australia and North America, met in Solihull in the UK to discuss bioethics and human rights.

The Solihull meeting was the first time that such an international conference for and of people with disability had been held to explore and define bioethical issues from a disability perspective. Given the themes of the papers given at the conference it is indeed appropriate that the conference declaration was entitled 'The Right to Live and Be Different' (for a discussion of this see Newell, 2000). At that conference it emerged that the NHMRC Act requiring the inclusion of person from a disability perspective was a world first in terms of national bioethics councils.

Disability and Bioethics Conferences

So does this mean that Australia is well ahead of the rest of the world, given the developments identified above? Indeed, does this mean that disability within bioethics has come of

age in the bioethical community despite what Warnock suggests? In the last few years, several Australian bioethics conferences have documented how peripheral and insignificant disability is in the Australian bioethics community.

In one conference in 2000, which I attended, much of the planned venue was found to be inaccessible a few weeks before the conference, which fact was discovered only when a delegate who uses a wheelchair inquired. It was suggested that those of us who used chairs might need to be carried up stairs for some sessions – showing how far disability has not come in Australian bioethics. While well-intentioned, this shows a disturbing understanding of the realities of disability. Carrying people in wheelchairs upstairs is not only risky for someone with disability but could increase the incidence of hidden disability in the Australian community, as back injuries are likely to be sustained in trying to lift people in wheelchairs, especially electric chairs.

The real issue for several of us with disability was not so much the clear breach of legal requirements or the ethics (sustainable of course from a utilitarian perspective) but the knowledge of being outside the moral community which is the bioethics community. In my case, this is despite teaching and consulting in the area for some years. A sad commentary is found in the president of the association under whose auspices the conference was held describing at its conclusion what for some of us with disability has been a devastating conference as 'excellent' and 'the best conference yet'. Such a stark reality check is also confirmed by Clapton's insightful article 'Irrelevance Personified' with regard to an Australian bioethics conference (Clapton, 2000).

Politics and Rejected Knowledge

Indeed, a recent Australian 'Ethics in Human Research' conference, held under the auspices of the Australian Health Ethics Committee of the NHMRC (2003), included a wide variety of invited papers, including consumer and community perspectives. Yet the abstracts suggest no paper that actually names or deals with the contrast of values between people with disabilities and non-disabled accounts of health care. Indeed it is worth reflecting that the very manual commissioned by AHEC to assist Human Research Ethics Committees to undertake their work had scholars from a variety of disciplines participate. Yet, there is no recognition of the contested accounts of ethics between those with

disability and those without. This is remarkable given that AHEC has a place on it for a person with a knowledge of disability issues precisely because when the National Health and Medical Research Council Bill was debated in 1992 the Australian senate was concerned that such knowledge be incorporated into ethical deliberations.

Perhaps one of the starkest examples of the contrast between disabled and non-disabled values can be found in the following exchange between well known UK disability studies scholar and disability activist, Dr Tom Shakespeare, and Australian geneticist Professor Grant Sutherland on Australian TV:

PROFESSOR GRANT SUTHERLAND: ... I'm sure for example that Dr Shakespeare would prefer not to be handicapped.

DR TOM SHAKESPEARE: I'm happy the way I am. I would never have wanted to be different.²

Such encounters help us to re-examine the diverse project which is bioethics. They help us to understand the 'ableism' disparaged by Warnock as a dimension of everyday encounters and norms as opposed to a grand plan of exclusion. It is about our notions of nice, normal and natural and how these are enacted in the everyday. Indeed as leading disability studies scholar Mike Oliver suggests:

If the category disability is to be produced in ways different from the individualised pathological way it is currently produced, then what should be researched is not the disabled people of the positivist and interpretive research paradigms but the disablism ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society. (Oliver 1996: 143)

We may also reflect that not only at the clinical level, but even in terms of teaching and basic texts on bioethics, disability commonly features as an integral part of the big issues in bioethics. Yet, a social account of disability is rarely mentioned, and few accounts written by those of us with disability are included as valued knowledge. Rather than being marginal deviance, disability can offer some of the richest insights to bioethics *because* of its difference.

There is no doubt that there is a concern by the diverse

disability movement regarding exclusion of the voices of people with disability at a global level. This is a problem not just with bioethics but also occurs with most disciplines. Indeed, an understanding of the politics of rejected knowledge is vital in understanding the quiet disability voices in public policy (see for example Wallis, 1979; Richards, 1991). While there has been some incorporation of disability perspectives in particular levels of public policy making, it has yet to be established that this has particular impact upon practice at the grass roots level or even teaching.

The voices of those with disability, and those utilising social and human rights approaches to disability, have particular value in assisting us to critique the project which is bioethics. Medical ethics has tended to uncritically utilise biomedical knowledge without recognising the social dimensions to that knowledge. Bioethics as a broader intellectual project has tended to recognise other forms of knowledge and to move beyond Warnock's decrying 'the politicisation of medical ethics.'

Yet, there is no doubt that there is more than one disability voice regarding bioethics. This has been firmly demonstrated in the recent Australian and international debate concerning embryonic stem cells. Some have been supportive of the promise of such technology, and others have critiqued the way disability has been used in the debate (Goggin and Newell, In Press.)

Despite, and perhaps even, because of this, the lived experience of disability as a social phenomenon helps us to rethink bioethics as a project. Disability can be seen to provide a stark challenge to rethink our dominant notions of humanness, health and ethics. In particular, it is of assistance to us in re-exploring the power dynamics and discourses of the voices in bioethics. Whilst they are very quiet, there is no doubt that there are disability voices in bioethics. It is the very difference of some of those voices from dominant approaches to bioethics which provides key and exciting opportunities for revitalising and rethinking bioethics.

The Challenge for Bioethics

In this article, I have sought to show that we may find a lived ableism in bioethics, but that it is more in everyday oversights and norms than any grand agreed-upon plot to get rid of those with disability, or to silence our voices. This paper has shown, via some key policy moments, the political dimension to the

rise of a disability voice in academic and social policy aspects of Australian bioethics. Perhaps most importantly, it challenges bioethics to move from *talking about* disability to *listening to* those of us with disability. My experience as a bioethicist with disability makes me long for the day when bioethics conferences and texts routinely utilise the unmediated voices of those on the margins telling their stories as keynote realities and mainstream concerns. A disability critique of bioethics can help us to move to a situation where those with disability, and other marginal voices, are experts, rather than disembodied text contributing to the careers of others. Until this occurs bioethics will always be inherently disablist.

Contact re this article

Dr. Christopher Newell, AM
Senior Lecturer,
School of Medicine
University of Tasmania,
Private Bag 33,
Hobart, Tasmania, 7001, Australia.
Phone +61 3 62267741, Fax +61 3 62236174
Email: Christopher.Newell@utas.edu.au

Notes

- 1 Dr Christopher Newel is a person with disability and has long been involved in the Australian and international disability rights movement.
- 2 Extract from '7.30 Report', ABC TV Transcript 20/02/01. For an exploration and critique of this see Newell (2003).

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