

*family*

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**Abstract**

This paper is a response to the "Discussion paper on the ethics of limiting life sustaining treatment" by the National Health and Medical Research Council (NH&MRC) (File number 10338). The various organisations believe the NH&MRC assumes that disability in itself makes a life of low quality and value and therefore can often justify a decision that an infant should die. The paper quotes from various Declaration of Rights principles and rejects any notion that society should approve of the killing of infants even if future quality of life **may be** an issue. **Keywords: Ethics**



# LIVES OF GREAT VALUE

A Response to the National Health & Medical Research Council paper "The Ethics of Limiting Life Sustaining Treatment", from -

## **REDFERN LEGAL CENTRE**

73 Pitt Street, Redfern 2016  
A community legal centre which operates the Intellectual Disability Rights Service.

## **DISABILITY COUNCIL OF NSW**

8 Bent Street, Sydney 2000  
Nineteen people with disabilities and family members and advocates appointed by the NSW Government to advise it on disability matters.

## **DOWN'S SYNDROME ASSOCIATION OF NSW**

PO Box 2356, North Parramatta 2151  
Has a membership of ???, most of whom are parents of people with Downs Syndrome.

## **FAMILY EDUCATION UNIT**

C118 Cox's Road, North Ryde 2113  
Provides information and education for families with a member who has a disability.

## **CITIZEN ADVOCACY NSW**

70 Macquarie Street, Parramatta 2150  
The peak citizen advocacy organisation in NSW.

## **ACTION FOR CITIZENS WITH DISABILITIES**

256 Victoria Avenue, Chatswood 2067  
Has over 300 members, most of whom are parents of people with disabilities.

We have considered this paper from the perspective of people with a disability, their families and advocates. We have a number of very considerable concerns about the paper.

### **LIVES NOT WORTH LIVING?**

The NH&MRC paper seems to assume that a disability of itself make a life of low quality and value and therefore can often justify a decision that an infant should die.

This view is apparent, for example, in the statement on page 23 in the paper as published in *The Lamp*,

"The dilemma is whether all such infants should receive all possible life sustaining treatment for the sake of a few intact survivors." <sup>1</sup>

This statement seems to assume that treatment is only justified if the result is a child with no disabilities. See also the discussion of the case of 'Julie' on page 23.

We wonder what experience the writers of the paper have had with people with disabilities. They seem unaware of the rich quality lives that people with disabilities very often lead, rich not only for themselves but rich also in their impact on those around them and on society generally.

In any event, it is hard to see how it can ever be safely said that a life that has just begun and which may continue for many years will not be worth living.

There is much to be said for the views of Mr Justice McKenzie in the leading Canadian case in this area:

"I do not think it lies within the prerogative of any parent or of this court to look down upon a disadvantaged person and judge the quality of that person's life to be so low as to not be deserving of continuance... It is not appropriate for an external decision-maker to apply his standards of what constitutes a livable life and exercise the right to impose death if that standard is not met in his estimation... I cannot accept [the parents'] view that Stephen would be better off dead... This would mean regarding the life of a handicapped child as not only less valuable than the life of a normal child, but so much less valuable that it is not

<sup>1</sup> *The Lamp*, May 1989, pages 22-30.

worth preserving. I tremble at contemplating the consequences if the lives of disabled persons are dependent upon such judgements."

*Re S.D.* [1983] 3WWR618

Where a life appears to be miserable, a fundamental question is whether the life is inherently miserable or whether the apparent misery is the result of a lack of adequate support services for the person. If, as is more likely, the issue is one of inadequate support services, the answer is clearly to demand that those services be provided. This view is in accordance with the United Nations *Declaration on the Rights of the Child* (principles 2, 4 and 5), the *Declaration on the Rights of Disabled Persons* (principles 3, 6 and 7) and the *Declaration on the Rights of Mentally Retarded Persons* (principles 2, 3 and 4).

For example, the *Declaration on the Rights of Disabled Persons*, principle 3 states-

"Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age which implies first and foremost the right to enjoy a decent life, as normal and full as possible."

And principle 6-

"Disabled people have the right to medical, psychological treatment, .... to medical and social rehabilitation, education....and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration."

We reject as ethically repugnant the notion that society should approve of infants being killed because we are unwilling to comply with international instruments to which our nation has subscribed.

Further, the *International Covenant on Civil and Political Rights*, article 6, paragraph 1 states-

"Every human being has the inherent right to life. This right shall be protected by law. No-one shall be arbitrarily deprived of his life."

Even if one accepts that future quality of life should be a relevant factor, there is also the massive problem of reliably predicting that quality. It is

common for parents of people with disabilities to have been given very unreliable predictions about the future capacities of their infants. It is common for these predictions to have been overly pessimistic.

Such prediction is extremely difficult. "It is impossible for anyone to make a pronouncement with any degree of certainty of the future functional abilities of children born with Downs Syndrome."<sup>1</sup>

Predictions about quality of life are often based on assumptions about available support services for people with disabilities. Such predictions are fraught with uncertainty. Certainly there have been very considerable improvements in the availability and quality of services for people with disabilities in Australia in recent decades. Also, advances in technology have created many new ways in which people with disabilities can be taught skills, can communicate with others, can be more mobile and can otherwise achieve their potentialities.

Predictions are also based on current medical science and the way in which it can or cannot assist the person. Again, one only has to look at the medical advances of recent decades to see how unreliable such predictions may prove.

Predictions about quality of life can also be based on stereotyped and prejudiced views about people with disabilities and about what is a high quality life. For example, the common assumption that people with disabilities are generally incapable of performing remunerative work is being strongly challenged by many employment services set up under the Commonwealth *Disability Services Act* 1986. However, we would dispute the more underlying assumption that being productive or remunerative makes a person somehow more valuable, and the consequent devaluing of people who are unable to perform remunerative work.

Our view then is that a person's disability should be irrelevant to the decision of whether or not they receive medical treatment.

As set out above, the United Nations *Declaration on Rights of Disabled Persons* confirms that people with disabilities "have the inherent right to respect for their human dignity". We subscribe to the following statement by Nicholas Tonti-Filippini:

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<sup>1</sup> Dr Michael Ryan, Paediatrician, "Severely disabled children and the law", *CID News* 3/86, page 13. See also Bonnie Steinbock, "Infanticide", in Laura and Ashman, *Moral Issues in Mental Retardation*, CroomHelm, London, 1985, at page 123.

"Respect for the lives of the disabled is essential to an unconditional respect for them as persons. No community could be considered to love and respect a group within it if that group were subject to the community's judgments about whether or not they were so worthless as to warrant being destroyed."<sup>1</sup>

### LIMITED MEDICAL RESOURCES

The NH&MRC paper refers to the increasing divergence between what medical science can achieve and what society is willing to provide the resources to allow to happen in individual cases. To this we say two things. First we place a very high premium on the value of human life and would therefore argue that society should be willing to put very considerable resources indeed into this purpose. One only has to look at the resources put into other purposes, for example the new Parliament House in Canberra or the Darling Harbour redevelopment in Sydney to see that those resources are available. Second, to the extent that there are scarce resources, we say simply that disability and potential disability should be irrelevant factors in deciding how those resources are to be divided up.

### INTERESTS OF OTHERS- CAN THEY JUSTIFY NON-TREATMENT?

The writers of the NH&MRC paper appear to regard the the distress and other interests of other people as relevant to a decision about whether a child should be allowed to live. See, for example, paragraph (c) at the top of page 23 in *The Lamp* and the two paragraphs at the foot of the second column on page 27.

This view perhaps comes through strongest in the statement on page 28, "It is, after all, the family that must live with the consequences of the decision." This statement seems to regard the child as an irrelevancy.

Families deserve every support at what is an extremely difficult point in their lives. This support needs to be ongoing. Our society should be providing this support. There is a clear danger here of the distress of families being misused by society as a justification for killing infants and thereby avoiding society's responsibilities to provide adequate assistance to people with disabilities and their families.

<sup>1</sup> Nicholas Tonti-Filippini, *Life: A Right or a Privilege*, paper presented at 1987 Annual Conference of AAMR, the National Association on Intellectual Disability, at page 4.

In any event, we frankly find it staggering that the distress or inconvenience of families or others could be regarded as relevant factors in deciding whether or not a child should have its life taken away.

We feel that there can be no compromise on the view that the best interests of the child must be the paramount consideration in any decision-making. This view gains support in British and Canadian case law. See *Re B* [1981] WLR 1421, *Re S.D.* [1983] 3WWR 618. The United Nations *Declaration on the Rights of the Child* contains a similar requirement.<sup>1</sup> The Australian College of Paediatrics takes the same view<sup>2</sup> as did the U.S. President's Commission for the Study of Ethical Problems in Medicine.<sup>3</sup>

David Mitchell rebuts arguments for the interests of others being taken into account, as follows:

"Firstly, there is the view that the preservation of human life exceeds all other considerations and that while handicapped persons can have negative effects on other persons, under no circumstances can these jeopardise their rights to life. Secondly, from a utilitarian perspective, it is argued that not only are the presumed negative effects unpredictable (Mittler, 1984), with some families appearing to benefit from the presence of a handicapped child (Mitchell, 1986) but also that for society to condone euthanasia would be to jeopardise its overall humanitarian quality and to impede research efforts aimed at improving the quality of life (Powell & Hecimovic, 1985). Furthermore, euthanasia is not the only way in which the strains of coping with a handicapped person can be alleviated; the provision of better support services for families is surely a more morally defensible course of action to pursue (Shearer, 1985)."<sup>4</sup>

Having said all this it will be understood that it is thoroughly beyond our belief that it could be suggested that the distress and anxiety of 'friends, health professionals and others' could be regarded by the NH&MRC as

<sup>1</sup> See Human Rights Commission, *Legal and ethical aspects of the management of newborns with severe disabilities*, AGPS, 1985, para 77.

<sup>2</sup> Human Rights Commission, *op cit.* page 71

<sup>3</sup> President's Commission for the Study of Ethical Problems in Medicine, *Deciding to Forego Life-Sustaining Treatment*, Washington DC, 1983

<sup>4</sup> D.R. Mitchell, "Ethical and legal issues in providing medical treatment for seriously ill handicapped persons", *Australian & New Zealand Journal of Developmental Disabilities*, 1985, Vol 10, No 4, 245-256 at page 252.

relevant to a decision about whether an infant should be allowed to live (p.28 in *The Lamp*).

### **COMMUNITY VIEWS AND NEEDS- SHOULD THEY PREVAIL?**

The NH&MRC paper attaches considerable weight to community views and needs. The introduction to the paper states that "good ethical decisions can only be made by knowing the needs and reasonable judgements of the community at large".

At the head of page 30 in *The Lamp*, it is suggested that families should be allowed to make decisions about treatment unless they wish to do what will not be tolerated by society. The problem here is that people with a disability have historically been segregated away from society so that society in general is not well aware of disability issues.

In a survey published in the *Sydney Morning Herald* on August 9, 1986 a question was posed to 2000 Australians - "How should doctors treat severely deformed babies?" 41% of people said that doctors should "withhold treatment and allow them to die without suffering" and 27% said that doctors should "provide treatment to keep them comfortable but not use all methods to keep them alive". How could society's views on this issue possibly be said to be well based?

We should also compare the situation with that of, for example, Nazi Germany. It may very well be that society there supported the extermination of Jews and indeed the extermination of people with a disability which was also occurring.<sup>1</sup> Is the NH&MRC saying that these practices were therefore ethically justified?

Clearly, there is a need for limits on the extent to which the majority is allowed to impose its views on a vulnerable minority, perhaps most especially in relation to matters of life and death.

### **WHO SHOULD DECIDE?**

We have fundamental concerns with the common viewpoint that it should be left to families and doctors to make decisions about treatment or non-treatment. The Australian College of Paediatrics has acknowledged that major difficulties face parents as decision makers about such matters:

<sup>1</sup> An estimated 100,000 people with intellectual and psychiatric disabilities were killed in pursuance of an edict from Adolf Hitler. See Cliff Judge, *Civilisation and Mental Retardation*, Melbourne, 1987, pages 4-5.

"Firstly, making such a decision may create feelings of guilt and anxiety, and it seems inhumane to impose this additional burden on the suffering parents. Secondly, it has been argued that parents may be subject to a conflict between their own interests and those of the child. Since the latter are paramount it is important, so it is argued, that parents alone should not make the decision. Thirdly, parents would be making such an important and emotive decision at a time when their judgement may be seriously impaired; and in any case it may be difficult for them to conceive the ultimate effects of their decision on the affected child, on other members of their family or on themselves."<sup>1</sup>

Parents faced with such a decision generally know little about disability, i.e. from the perspective of what it is like to have a disability or from the perspective of what it is like being a parent of a person with a disability. Parents are therefore very dependant on the information and advice they receive. They are very vulnerable if they receive inadequate information or advice.

Meanwhile, doctors are generally not well informed about disability. Even if one accepted that an assessment of future quality of life was relevant to a decision about treatment or non-treatment (which we do not accept), it appears that doctors are ill-qualified to be making such assessments. To illustrate this, we shall concentrate on the example of infants with Downs Syndrome since this is one class of infants who have often been the subject of non-treatment decisions.

In a survey of obstetricians and paediatricians in Victoria carried out in 1981 and 1982, 89% of obstetricians and 76% of paediatricians acknowledged that there had been occasions when they had directed that less than maximum efforts should be made to preserve the life of an infant. To the question, "Under what circumstances do you consider that less than a maximum effort should be made to preserve the life of an infant?", 55.1% of obstetricians and 18.9% of paediatricians included in their answer "incompatibility with reasonable and independent life". 25.3% of obstetricians and 16.2% of paediatricians offered as an example "Downs Syndrome and other lesions". Various other disabilities were also offered as examples.<sup>2</sup> As stated above, it is impossible for anyone to make a pronouncement with any degree of certainty about the future functional abilities of a child born with Downs Syndrome. Further,

<sup>1</sup> Human Rights Commission, *op cit.*, page 69

<sup>2</sup> Singer and others, "The Treatment of Newborn Infants with Major Handicaps", *Medical Journal of Australia*, September 1983, 274-278.

"evidence that is available to us since the introduction of early intervention services suggests that it is much more likely that a Downs Syndrome infant will function in the mild range of intellectual disability rather than in the severe range."<sup>1</sup>

Knowing many, many people with Downs Syndrome, it defies our belief that anyone could suggest that a person with Downs Syndrome is unable to lead a life of high quality. This includes people with severe intellectual disabilities.

Meanwhile, in 1982 the Australian Medical Association declared that "failing to perform an operation on a Downs Syndromic child for a correctable defect is simply letting nature take its course."<sup>2</sup> Would the AMA take the same view in relation to comparable situations such as failing to resuscitate a swimmer who has got into difficulties in the surf and had a cardiac arrest, or not treating decaying teeth?

We have used Downs Syndrome here as an example. Similar issues arise in relation to people with other disabilities.

The view that doctors and new parents lack necessary knowledge about disability has considerable support, both within medical circles and disability circles, and both within Australia and internationally.<sup>3</sup>

The view that decisions about these matters should not be left to doctors alone is supported by Dix and others:

"We do not subscribe to the view that the medical profession should primarily regulate itself in this area. The risks to a society that allowed any professional group of persons, no matter how highly qualified and responsible, to decide, for example, when and with respect to whom respirators should be turned off without any external guidelines, are obvious and enormous."<sup>4</sup>

<sup>1</sup> Ryan, *op cit*

<sup>2</sup> Human Rights Commission, *op cit.* para 85.

<sup>3</sup> See President's Commission for the Study of Ethical Problems in Medicine, *op cit*; Shearer, *Everybody's Ethics- What Future for Handicapped Babies?*, The Campaign for Mentally Handicapped People, London, 1984, page 11; Prof Doherty and others, *Australian Medical Education and Workforce into the 21st Century*, AGPS, Canberra, 1988, pages 44-47.

<sup>4</sup> Dix and others, *Law for the Medical Profession*, Butterworth, Sydney, 1986, para 1233

## UNCLEAR LAW

There are also major legal questions about whether and in what circumstances parents have the legal right to make decisions about non-treatment. In *Re Jane* 12FamLR 662 at 690, Chief Justice Nicholson of the Family Court of Australia stated:

"It seems to me that the law at least establishes that parental consent is insufficient where a medical procedure involves interference with a basic human right such as a person's right to procreate unless it is clear that the interference is occasioned by some medical condition which requires such treatment. There may well be other rights which parents cannot interfere with such as, for example, the right to life."

In the one Australian case directly on point, Mr Justice Vincent said, in relation to allegations that a decision had been made to sedate a child with spina bifida, and not feed her, for the purpose of allowing her to die:

"No parent, no doctor, no court has any power to determine that the life of any child, however disabled that child may be, will be deliberately taken from it."<sup>1</sup>

The Law Reform Commission should be asked to consider clarifying the law in this area.<sup>2</sup> To the extent that there may be a need for a judicial or quasi-judicial tribunal to be involved in these decisions, consideration should be given to vesting jurisdiction in a non-adversarial, multi-disciplinary tribunal similar to the Guardianship Boards which now operate in Victoria, NSW and South Australia.

## BROADENING THE INPUT TO DECISIONS

If, despite our views, quality of life is to be regarded as a relevant issue, or indeed if a decision is in a grey area between purely medical considerations and purely quality of life considerations, we see a clear need for the decision making process to be more broadly based than just doctors and parents. This view draws support from the U.S. President's Commission for the Study of Ethical Problems in Medicine and the American Academy of Pediatrics.<sup>3</sup> Also, the United Nations *Declaration on the Rights of Mentally Retarded Persons*, principle 7, states:

<sup>1</sup> Transcript of proceedings in *Re F*, Supreme Court of Victoria, 2nd July 1986, page 9.

<sup>2</sup> For examples of legislative approaches, see Shearer, *op cit* pages 12-18; Human Rights Commission, *op cit* para 93 and Appendix B.

<sup>3</sup> Shearer, *op cit* page 9.

"...whenever... it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities."

This would appear to require at least:

- The involvement in the decision of people with expertise in disability as opposed to just expertise in medicine. This expertise should include both professional expertise such as is often held by clinical psychologists or special educators and lay expertise such as is often held by the parents of people with a disability.
- For "the right of appeal to higher authorities" to be meaningful it would at least be necessary that it is open to those involved in the decision making process to seek an independent ruling through the legal system if the rights of the infant seem to require this.

Hospital ethics committees would be an appropriate avenue through which a broader range of views could be given to parents and doctors. Where the interests of the child so required, a member of such a committee or an involved doctor could also challenge a parental decision through the legal system. Probably, these would be rare situations. Ethics committees could also formulate policies and guidelines for the hospital and provide education for hospital personnel about disability and ethical issues.

A role for ethics committees in this area is supported by a Working Party of the Australian College of Paediatrics,<sup>1</sup> the American Academy of Pediatrics and the President's Commission for the Study of Ethical Problems in Medicine.<sup>2</sup>

There may also be a role for a national statutory body to formulate national guidelines and provide advice on these issues.<sup>3</sup> An argument for

<sup>1</sup> Human rights Commission, *op cit* page 70

<sup>2</sup> Shearer, *op cit* page 9.

<sup>3</sup> See Human Rights Commission, *op cit* page 70.

this is the wide divergence in practices that currently exist around the nation.<sup>1</sup>

## CONCLUSION

We adopt the attached *Principles of Treatment of Disabled Infants* which have wideranging international support. The original version of the *Principles*, which were formulated in the United States, contains a concluding paragraph dealing with the role of United States governments in ensuring that the legal rights of infants are protected. In lieu of that paragraph, we recommend the following for Australia:

Decisions about treatment of infants are primarily the responsibility of parents whose duty it is to act in the best interests of their child. However, if non-treatment is being considered, there is a need for parents to have a wide range of information and advice, including from people with lay and professional expertise in disability. Ethics committees may provide an appropriate avenue for this to occur. If the interests of the child so require, the legal system should be invoked through child welfare laws, anti-discrimination laws or the *parens patriae* jurisdiction of the courts.

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<sup>1</sup> Forrester, "Legal and Ethical Dilemmas", *Legal Service Bulletin*, June 1989, 116-121 at page 116.

09 MAY 1986

POLICY STATEMENT OF THE AUSTRALIAN GROUP FOR THE SCIENTIFIC STUDY  
OF MENTAL DEFICIENCY

ON

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

Discrimination of any type against any individual with a disability/disabilities, regardless of the nature of severity of the disability, is indefensible.

Throughout their lives, all disabled individuals have the same rights as other citizens, including access to such major societal activities as health care, education, employment, and recreation.

These rights for all disabled persons must be recognized at birth.

NEED FOR INFORMATION

There is a need for professional education and dissemination of updated information which will improve decision-making about disabled individuals, especially newborns. To this end, it is imperative to educate all persons involved in the decision making process. Parents should be given information on available resources to assist in the care of their disabled infant. Society should be informed about the value and worth of disabled persons. Professional organizations, advocacy groups, the government and individual care givers should educate and inform the general public on the care, need, value and worth of disabled infants.

MEDICAL CARE

When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available arrangements should be made to transfer the infant to an appropriate medical facility. Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the

decision. These are very strict standards.

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It is justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

#### GOVERNMENT AND COMMUNITY SUPPORT

Once a decision to treat an infant has been made, government and private agencies must be prepared to allocate adequate resources for appropriate services as needed to child and family for as long as needed. Services should be individualized, community-based and coordinated.

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This statement was adopted from one endorsed in November 1983 by the following organisations:

- Association for Retarded Citizens
- Spina Bifida Association of America
- American Coalition of Citizens with Disabilities
- American Academy of Pediatrics
- National Association of Children's Hospitals
- American Association on Mental Deficiency

It was subsequently endorsed by several Canadian organisations.

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