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Access to Infertility Clinics for Single Women and Lesbians?

This article discusses the pros and cons of restricting access to infertility clinics to heterosexual couples. Single women and lesbians should be excluded not because they would not be good parents but because children need also to know and be raised by their genetic mothers and fathers.

On 28 July 2000 Justice Ross Sundberg of the Federal Court of Australia declared that the sections of Victoria's *Infertility Treatment Act 1995* which discriminated against single women and lesbians were invalid because they were inconsistent with the *Commonwealth Sex Discrimination Act 1984*. In this Act marital status is the reason for denying them access to licensed infertility treatment clinics. The effect of the ruling is that in Victoria medically infertile single women and lesbians can no longer be refused infertility treatment on the grounds of their marital status. The ruling has left in place the ban on single women and lesbians who are socially, but not medically, infertile. A spontaneous debate followed in all media outlets for a few weeks with ample comments and correspondence appearing in the nation's press. Much of the discussion has been very fruitful because it makes us all think about the roles of fathers as well as mothers in both the conception and raising of children.

A family birthday celebration.

Heterosexual Couples as Parents

Research, based on the responses of both children and parents, shows that children living with their biological parents are likely to thrive in the vast majority of intact families of heterosexual parents who care for each other and their children. Things take a turn for the worse for children when their parents' relationships sour. It is estimated that 10% of children experience divorce of their parents by the age of ten, and this rises to 18% by the age of 18 years. Sole mothers and their children often do not fare well and poverty accounts for many, but not all, of their problems.[1] London family and child psychologist Susan Golombok says it is not easy to say whether the problems of these sole mothers are caused by the lack of one parent as such or by the lack of a father

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since many fatherless children do as well as children in families with fathers and mothers.[2]

Single and Lesbian Mothers as Parents

In the case of single women who become mothers following donor insemination (DI), their children do not experience the long term effects of the trauma of parental hostility and separation since they are raised in a solo mother family from the start. Adequate social support from a network of family and friends can help single mothers to foster good family relationships. Positive family living circumstances and sufficient finances favours a successful outcome for children rather than single motherhood as such.[3] Bambi Robinson says 'the average single mother by choice is better educated and has a better (higher paying and higher prestige) job than her married counterpart.'[4] Poverty traps are, however, likely to affect the children of single mothers who lack adequate financial support. She also found that single women and lesbians have comparable parenting skills to those of married couples and that the percentage of homosexual children of lesbian couples is similar to that of heterosexual parents.[5]

adequate social support ... can help single mothers to foster good family relationships

Studies have found no differences in emotional balance, self-esteem, quality of friendships or gender identity in the sons and daughters of single heterosexual and lesbian mothers who had their children while in a heterosexual relationship. No differences were found in their parenting ability, nurturing and responsiveness to their children. Longitudinal studies found adult children from these lesbian families were well adjusted, related well with their mothers and partners and, contrary to popular expectations, most identified as heterosexual.[6]

Studies of lesbian mothers and their partners, who after 'coming out' planned their families together, found that the children conceived by DI compare favourably with children from two-parent heterosexual families in terms of socio-emotional and gender development. They generally had a close relationship with one or more of their mothers' male friends. The children of these lesbian couples enjoyed stability in family living without experiencing the disruption of divorce or separation of heterosexual parents. The co-mothers were often more involved with their children than are fathers in two-parent heterosexual families.[7]

Golombok rightly says parental responses and love count more than genetic connectedness and concludes that current findings suggest that 'aspects of family structure such as genetic relatedness, number of parents and the mother's sexual orientation, may matter less for children's psychological adjustment than warm and supportive relationships with parents, and a positive family environment.'[8]

Reasons For Access to ART

In the light of the absence of harm to children in the above studies, single women and lesbians reject the view that they cannot be good parents and that they should be excluded from access to ART. Many people in the community believe it is ethical for single women and lesbians to access infertility treatment clinics to enable them to conceive by DI or ART. In the name of autonomy, they argue that there should be no legal prohibition on the grounds of marital status against them having access to ART clinics to conceive.[9]

Reasons Opposed to Access to ART

Individual autonomy does not mean that certain aspects of children's identity and rights may be ignored in making decisions about access of single women and lesbians to ART. The commitment of mothers and fathers to each other should extend to their children who need the presence, care and love of both their mothers and fathers during their formative years. This is not merely an ideal nor an arbitrary stipulation but a requirement that responds to the natural needs of children as they develop and grow. The interests of children conceived by ART must be paramount both for parents and public policy. The law in the U.K. includes a reference to *the need of a child for a father*.[10]

The genetic bond between children and both parents entitles them to live as equal members of the family with their mothers, fathers and siblings from their birth. These irrevocable genetic relationships are the basis of their unique ties with their grandparents, aunts, uncles, cousins. Family ties facilitate building up personal confidence, mutual acceptance and lasting reassurance. One's genetic origins and relationships pertain to the identity of each person. For health reasons it is preferable to know of one's genetic origins, e.g. in cases of preventable genetic diseases.[11]
Adopted children frequently want to meet their natural parents. Research

the interests of children conceived by ART must be paramount both for parents and public policy

by social workers strongly endorses the view that the interests of children conceived by DI should take precedence over the interests of their medically or socially infertile parents or the donors of the gametes used for their conception.[12] Thousands of adoptees who have enjoyed the benefits of good social parenting 'still suffer terrible grief, confusion and genealogical bewilderment.'[13] They seek help to learn information about, and to find, their genetic parents.
The basic relationships of love, trust

and security that growing youngsters place in their parents need to be founded on truth so that they can develop their own identities. If parents cannot be trusted by children concerning their own genetic origins, whom can they trust? Little wonder that over time pressure from adults conceived from donated gametes has led to granting a legal right to children conceived from donor gametes by ART in Victoria to obtain identifying information about their genetic parents once they turn 18 years of age.[14]

The findings of the above mentioned studies of lesbian families are not definitive because the children studied were on average five-six years of age — well before teenage difficulties with parents often begin and issues of identity emerge.[15] Problems multiply if disclosure of the method of conception by donor sperm or egg is not sensitively made in good time.

It seems unethical to deliberately

the genetic father ... should also be the child's social father

plan to break the tie designed by nature: the genetic father of the child should also be the child's social father. When the genetic parents are the social parents, all other things being equal, family bonding and good relationships are more likely to be fostered. It is regrettable that some children due to some tragic circumstance, are deprived of the presence and knowledge of one or both genetic parents. If these children are adopted, they benefit when given information about their biological parents and are at risk of emotional problems if they are denied this information.[16] It seems to be clearly unethical to engineer by the use of donor gametes the conception of children destined to be raised without being able to know their biological fathers.

Rights of the Child

A child has a natural right to be reared by both mother and father. It would be akin to natural injustice for children of single and lesbian women to be deliberately deprived of the chance of being raised by their genetic fathers. It was far from the mind of the Federal Parliament in enacting the *Sex Discrimination Act 1984* to deem conception of a child to be a mere provision of a service. Effectively this law prevails over state laws to require infertility professionals at licensed clinics to treat infertile single women and lesbians. This results in children being conceived, born and raised fatherless. It is sheer reductionism to deem the procreation of children by means of ART to be just one instance among many others in the provision of 'goods and services' like employment, rent or educational opportunities for which the Sex Discrimination Act was designed. Already 'nearly 30 per cent of children in Australia do not live with their biological fathers, up from 14 per cent in 1960.'[17] Family and Community Services Minister Jocelyn Newman said 'More than one in five Australian families are lone-parent families — compared to 13 percent 20 years ago.'[18]

Public Policy

Many single women and lesbians who want to have children already conceive by informal and private arrangements. It would be impractical and almost impossible for the law to intervene in such situations if we wish to live in a democratic state. Infertility clinics, however, should be regulated by law to protect the interests of children conceived with the assistance of DI or ART.

Licensed ART clinics have their rightful place but this does not

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extend to biological enhancement to enable single women and lesbians to conceive. Parenthood, however, should not be achieved to the detriment of the authentic personal dignity and wellbeing of the child. For the reasons already given, as a matter of social policy, access to ART clinics should be restricted to heterosexual couples.

ENDNOTES

[1] Ruth Weston and Jody Hughes, 'Family forms – family wellbeing', *Family Matters* (N.53 Winter 1999) 14-20.
[2] Susan Golombok, 'New families, old values: considerations regarding the welfare of the child', *Human Reproduction* 13 (1998) 2344-45.
[3] *Ibid*. 2345-46.
[4] Bambi E S Robinson, 'Birds do it. Bees do it. So Why not Single Women and Lesbians?' *Bioethics* 11 (1997) 222.
[5] *Ibid*. 223-24.
[6] Golombok, 'New families, old values', 2345.
[7] *Ibid*. 2345-46.
[8] *Ibid*. 2346.
[9] For more on this line of thinking see Maurizio Mori, 'Is a "hands off" policy to reproduction preferable to artificial intervention?', in *Creating the Child. The Ethics, Law and Practice of Assisted Procreation*, eds. Donald Evans and Neil Pickering, The Hague: Martinus Nijhoff Publishers, 1996; 99-110; Neil Pickering, 'Naturally Conceived', *ibid*. 111-125.
[10] *Human Fertilisation and Embryology Act 1990* s. 13(5); In Victoria Australia the welfare of the child is 'paramount'. *Infertility Treatment Act*, Victoria, 1995, Clause 5.
[11] Roy Eccleston, *The Australian Magazine*, April 18-19 (1998) 12-17.
[12] See *Truth and the Child 10 years on: Information Exchange in Donor Assisted Conception*, eds. Eric Blyth, Marilyn Crawshaw and Jennifer Speirs, Birmingham: British Association of Social Workers, 1998. Reviewed favourably by Christine Harrison, *Journal of Medical Ethics* 26 (2000) 295.
[13] Cathy Smith, VANISH Inc, *The Age*, Letters, 3-8-2000.
[14] *Infertility Treatment Act 1995*, Victoria, Clause 80.
[15] Golombok, 'New families, old values' 2345-46.
[16] *Ibid*. 2343.
[17] Greg Callaghan, *The Australian Magazine*, 2-3 September 2000, 12.
[18] *The Age*, 28 August 2000.

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Norman Ford SDB

Late Term Abortion

This article will examine abortion and in particular abortion performed after 20 weeks gestation. I will focus on the different methods used and then I will discuss the ethical issues.

Abortion, commonly understood to be the termination of a pregnancy and therefore the end to the existence of an embryo or fetus, is one of the most contentious bioethical issues debated throughout the world. Most people have an opinion on abortion. Different countries hold varying positions on the 'legality' or 'lawfulness' of abortion.

Pregnancy can be divided into three trimesters. Most abortions are performed in the first trimester or early in the mid trimester. For the purpose of this paper a late term abortion will be defined as one that is performed beyond 20 weeks gestation. In the state of Victoria a medical practitioner must notify the Registrar of Births, Deaths and Marriages if a child dies after the twentieth week of pregnancy, or weighs 400 grams or more.

Methods of Abortion

The procedures used to induce an abortion depend on many factors perhaps the most important one being the gestational age of the fetus. In the first trimester vacuum evacuation and curettage is the most common procedure used. Pharmaceutical agents, abortifacients, such as Mifepristone (RU-486) can be used to induce an abortion in the first trimester. Early mid trimester abortions are usually performed via a dilatation and evacuation (D&E) procedure transcervically. This involves widely dilating the cervix so that surgical instruments can be used to remove large pieces of foetal tissue. The amniotic fluid may be drained with a suction catheter prior to evacuation of the uterus.

The methods used to procure a later mid trimester or third trimester abortion include dilatation and evacuation (D&E), dilatation and extraction (D&X, also known as intact D&E), labour induction techniques, and although rare, hysterectomy and hysterotomy. In the D&E procedure 'surgical instruments are used to extract the products of conception, followed by subsequent curettage. Because the fetus is larger (particularly the head) and because bones are more rigid at this stage of gestation, destructive procedures are more likely to be required than at earlier gestational ages. Some physicians use intrafetal or intra-amniotic administration of potassium chloride or digoxin to induce fetal demise prior to a late D&E (after 20 weeks) to facilitate evacuation.'[1] A D&X is a form of D&E and has been known as a 'partial birth abortion'. It involves 'deliberate dilatation of the cervix, usually over a sequence of days, instrumental or manual conversion of the fetus to a footling breech, breech extraction of the body except the head and partial evacuation of the intracranial contents of a living fetus to effect vaginal delivery of a dead but otherwise intact fetus.'[2] It is this partial birth abortion that has caused the most controversy and angst around the world as the method is undeniably abhorrent. This is not to say that the other abortion methods described here are not equally repugnant but in this partial birth abortion procedure the body of the fetus can be born alive and moving, then the fetus is killed in the most inhumane way. Even those who do not condemn abortion performed at an earlier stage of pregnancy have great difficulty in differentiating this procedure from infanticide. Precise data on the frequency of this procedure does not seem to be readily available but it would appear that only a small number of physicians actually perform it.

partial birth abortion has caused the most controversy and angst

Labour induction methods of abortion are likely to be used as the gestational age of the fetus increases. An abortifacient, such as hypertonic saline or urea, is injected into the amniotic sac and fetal death is caused from osmotic insult. Prostaglandins are administered to induce contractions of the uterus so that the dead fetus can be expelled. Hysterotomy involves an incision into the abdomen and uterine wall and removal of the fetus. Hysterectomy involves removal of the uterus as well as the fetus.

Abortion, while potentially having lasting adverse psychological effects on the woman can also have physical complications. These include haemorrhage, infection, retained products of conception, infection, uterine perforation and the need for further surgery. Obviously the likelihood of any of these complications is dependent on many factors including; the stage of pregnancy at which the abortion is performed, the method used, the skill and expertise of the abortionist, and the health of the woman.

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The Status Quo of Late Term Abortions in Victoria

According to the Medical Practitioners Board of Victoria *Report on late term terminations of pregnancy* in April 1998 terminations of pregnancy in the state of Victoria beyond 20 weeks gestation are carried out in two of the State's major public obstetric hospitals and only for the reasons of serious fetal abnormality and life threatening maternal illness. The fetal abnormality for which late term abortion is performed varies from one that is incompatible with life to one that would mean long term disability and dependence. Maternal morbidity may mean that the preg-

nant woman is severely ill or suffering complications of pregnancy. In Victoria during the nine years 1984 – 1992 termination was performed after 20 weeks' gestation when a diagnosis of foetal malformation had been made in 430 pregnancies.[3]

This report concludes that the reasons why terminations for fetal abnormality may not be done until late in the pregnancy may be due to some organisational difficulty or delayed diagnosis. There may be limitations in the screening process or deterioration in the fetal state or, the parents may have needed more time for counselling to consider their options. The two methods cited in this report as those used to terminate pregnancy beyond 20 weeks are (i) induction of labour with prostaglandin and (ii) dilatation and evacuation after cervical preparation with prostaglandin. There is no mention of dilatation and extraction or partial birth abortion. The method used may depend on a number of factors such as the mother's preference, the need to obtain an intact fetus for examination to enable genetic counselling, and the state of the pregnancy.

Fetal Abnormality

The enormity of the distress and sadness felt by a woman who finds out she is carrying a fetus with a serious abnormality if not experienced first hand can only be imagined. The pregnant woman has a right to full and comprehensive information about her fetus and she must be treated with compassion and given as much support as possible.
There have been arguments offered [4]

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in support of inducing a fetus with a lethal abnormality at a time of viability when it will die of its own lethal condition and not of its prematurity. However, *direct killing* of a fetus with an abnormality cannot be sanctioned in any way.

Late Term Abortion in Australia

According to the Age newspaper 24/1/1996 there is only one provider in Australia who performs late term abortions for reasons other than gross or lethal fetal abnormalities or risk to maternal life. The abortion technique reportedly used involves cranial decompression and the extraction of the brain of the fetus. The other reasons cited for late term abortion in this instance are; minor or doubtful fetal abnormalities, rape, incest, sexual abuse, extreme maternal immaturity (girls aged 11 – 14 years), those who are unaware they were pregnant, intellectually impaired women and those who have experienced a major life crisis. Judging from reports in the media there is not much community support for the practices of this provider.

Late Term Abortion Elsewhere

The incidence of 'late term abortion' varies considerably among Western countries. Exact figures are difficult to find or compare as they are not reported in a uniform manner nor is the definition of a 'late term abortion' consistent. However, two interesting figures to cite are those relevant to Israel and Denmark. In 1995 in Israel where late term abortion is unrestricted 0.4% of abortions approved were more than 24 weeks gestation. In 1996 in Denmark where late term abortion is partially restricted 0.07% of abortions approved were more than 24 weeks gestation.[5]

Abortion and the Law

Abortion in Victoria is still a crime. However it is not *unlawful* if the doctor who performed the abortion 'believes on reasonable grounds that that the act was:

(a) necessary to preserve the woman from a serious danger to her life or her physical or mental health (not merely the normal dangers of pregnancy and childbirth) which the continuance of pregnancy would entail ; and

(b) in the circumstances not out of proportion to the danger to be averted'.[6]

One would have to say that there is a certain 'vagueness' to the notion of serious danger to one's mental health.
The presence in the fetus of a serious hereditary disorder or, of a condition incompatible with life does not make

certain 'vagueness' to the notion of serious danger to one's mental health

an abortion procured for this reason lawful. The doctor would have to honestly believe that having a child who would die at or before natural birth or, who would have a shortened life span and whose life may be full of suffering, would present a serious danger to the mother's physical or mental health.

'A fetus in utero cannot be the victim of homicide, regardless of gestational age. A fetus can only be the victim of murder or manslaughter if it is born in a living state, irrespective of its capacity to survive. This may be applicable if termination late in pregnancy resulted in a live fetus.'[7] This explains why in some late term abortions the fetus is killed prior to complete removal from the woman's body.

In the United States in 1995 the 'first Partial-Birth Abortion Ban Act was introduced in Congress to make it a federal crime to perform an "abortion in which the person performing the abortion partially vaginally delivers a living fetus before killing the fetus and completing the delivery"'.[8] Since then there have been different versions of the Act, a veto of the Bill by President Clinton and much controversy and argument. Australia does not seem to have any legislation pertaining specifically to partial birth abortions.

Ethics and Abortion

Abortion arguments tend to centre on

rights — the right of a fetus to life and the right of a woman to exercise her autonomy and freedom. Those who totally oppose abortion believe that the fetus is a person from conception and therefore as a person has rights, in particular a right to life. 'Various characteristics or "indicators" of personhood have been suggested, including membership in an intelligent species (which begins with conception), having the potential to become a self-conscious rational individual, development of the basic anatomic structure of a human being, sentience and viability.'[9]

Those who condone abortion do not accept the fetus as a person at any stage and argue that the pregnant woman has the right to choose and decide its fate. There are however others who accept abortion in the earlier weeks of pregnancy but who consider that the fetus becomes a person progressively as it matures and there is a possibility of viability. These people consider late term abortion unacceptable.

It is Catholic teaching and our belief that a human embryo and fetus ought to be treated as a person from conception since they are endowed with

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inherent human dignity and deserve our respect and protection. If viability is defined as the capacity for meaningful life outside the uterus, albeit with artificial aid [10] then the killing of a viable fetus can only be the killing of an innocent human being. 'Viability is presumed to exist after 27 weeks of gestation (assuming an otherwise healthy fetus) and is presumed not to exist prior to 20 weeks. The time between 20 and 27 weeks is a "gray zone" in which some fetuses may be viable and others are not.'[11] The fetus may not have a legal right to life but it does have the moral right to the protection of his/her interests, particularly if the fetus' interests do not threaten those of the mother.

While many of the issues related to late term abortion are pertinent to abortion at any stage of pregnancy there are several of specific concern related to terminations performed at a late stage. The fetus that is aborted 'late term' may potentially be viable especially if provided with intensive care support. Therefore, to achieve the desired outcome, that is, an end to pregnancy and a dead fetus, the fetus has either got to be killed or, be left to die of its prematurity. I am not trying to overdramatise the situation but to present it as it happens. An intracardiac injection of potassium chloride or an injection of hypertonic saline or urea into the amniotic sac will cause the death of the

there is no sanitised way in which to describe the procedures

fetus and so obviously will a partial evacuation of the intracranial contents. There is no sanitised way in which to describe the procedures. Other 'babies' who are 'born' naturally at the same stage of gestation will in all probability be resuscitated (this obviously depends on where they are born and the facilities available) and given intensive care support at immense cost to the community.

The question of fetal pain during a late term abortion procedure and especially using the partial birth method should be considered. While pain management is provided when a 'baby' is delivered alive at a similar gestational age and is an important part of their care, no such relief is given to the baby aborted using the D&X procedure. According to Sprang and Neerhof 'forcibly incising the cranium with a scissors and then suctioning out the intracranial contents is certainly excruciatingly painful.'[12]

Advances in diagnostic technology and in fetal medicine have meant that the fetus in utero can be visualised, studied closely and in some instances treated and operated upon. Such intimate knowledge about and monitoring of the fetus could lead one to argue that the fetus should be regarded as a patient. Therefore, the fetus should demand the same sort of respect and care that any patient should have. Adults or children who have abnormalities or suffer from chronic illness are not directly killed. It is particularly disturbing that in fetal medicine centres in Great Britain, 'late abortion is performed for less severe anomalies, such as Down's syndrome and achondroplasia. In fact it has been suggested that a deliberate delay in genetic amniocentesis may be appropriate because of the availability of late abortion for Down's syndrome.'[13]

The ethical principle of beneficence holds that the wellbeing of the individual is worthy of respect and promotion and this should apply to the pregnant woman and her fetus. There is an obligation on the part of the physician to preserve and promote the health and wellbeing of the pregnant woman and that of the fetus and to avoid causing them harm.

The argument for the respect for the autonomy of the pregnant woman is weaker the more the pregnancy advances. As a fetus evolves into an

the fetus should demand the same sort of respect and care that any patient should have

individual capable of survival separate from its mother the argument supporting the rights of the fetus becomes stronger.

Indirect Therapeutic Abortion

In a direct abortion the intention is to kill the embryo or fetus. An *indirect therapeutic* abortion is quite a different case. In this situation the principle of double effect would support performing medically necessary procedures in order to save the life of the pregnant woman as long as there would be no direct or intentional assault on the life of the fetus. The death of the fetus may be foreseen but not intended. It would be a consequence of the medically necessary procedure and would be ethically

permissible.

Conclusion

Direct abortion is immoral regardless of the gestational age of the fetus. Late term abortion is particularly abhorrent. The methods used can only be regarded as inhumane. Sadly, some women feel they have no choice but to have an abortion. These women should not be abandoned or judged rashly and they should be given appropriate support and treated with compassion.

ENDNOTES

[1] Janet E Gans Epner, Harry S Jonas and Daniel L Seckinger, 'Late-term Abortion', *JAMA* 280/8 (August 26 1998) 726.
[2] Gans Epner et al, 'Late-term Abortion', 726.
[3] Norman A Beischer, 'Major Fetal Malformations and Perinatal Mortality Rates: The Place of Late Terminations', *The Australian & New Zealand Journal of Obstetrics & Gynaecology* 35/1 (2 February 1995) 2.
[4] See N Ford, 'Duty of Care for a Fetus with a Lethal Abnormality', *Caroline Chisholm for Health Ethics Bulletin* 2/4 (Winter 1997).
[5] Michael L Gross, 'After Feticide: Coping with Late-Term Abortion in Israel, Western Europe, and the United States', *Cambridge Quarterly of Healthcare Ethics* Fall 8/4 (1999), 450.
[6] Loane Skene, 'Prenatal Diagnosis and Late Termination: A Legal Perspective', *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 35/1 (1995) 3.
[7] Medical Practitioners Board of Victoria, *Report on late term terminations of pregnancy*, April 1998, 16.
[8] George J Annas, 'Partial-Birth Abortion, Congress and the Constitution', *NEJM* 339/4 (July 23 1998) 279.
[9] Carson Strong, 'An Ethical Framework for Managing Fetal Anomalies in the Third Trimester', *Clinical Obstetrics and Gynecology*, 35/4 (December 1992) 794.
[10] Gans Epner et al, 'Late-term Abortion', 724.
[11] Gans Epner et al, 'Late-term Abortion', 724.
[12] M LeRoy Sprang and Mark G Neerhof, 'Rationale for Banning Abortions Late in Pregnancy', *JAMA* 280/8 (August 26, 1998) 745.
[13] Frank A Chervenak, Lawrence B McCullough and Stuart Campbell, 'Third trimester abortion: is compassion enough?', *British Journal of Obstetrics and Gynaecology* 106 (April 1999) 293.

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Deirdre Fetherstonhaugh

Living with Limits: Age as a Criterion in Health Care Distribution

This article looks at age based health resource allocation as discussed by Daniel Callahan and Norman Daniels.

According to the 1996 census 2.15 million out of a population of 17.89 million were sixty five years of age and older making them 12% of the Australian population. As people age a significant growth in health care expenditure results. Per capita expenditure on persons over 65 years of age is six times more than that on people below that age level. For persons over 75 almost half of health expenditure is spent on the 13% who die within two years. Expenditure on the rest of the over 75 and older age group is only 2.7 times the average for the population as a whole.[1] These two sets of data provide the backdrop for our inquiry as to whether age should be considered an appropriate criterion when distributing scarce health care resources. Any answer to this question must confront the reality of limits in contemporary society and related questions of justice.

The Experience of Limits

The experience of limits and what implications this might have for just health care delivery came to the fore in the United States during the late 1980s. More than a decade later this controversy merits further consideration given the increasing restrictions on health care resources in contemporary Australia. The American bioethicist Daniel Callahan instigated the debate with his claim that an age criterion for access to health care might be a viable public policy initiative in a world of limited resources and ever increasing demand. Fundamentally his concern was with the social values that underpinned his society. A second philosopher, Norman Daniels, also focused on the question of an age criterion but did so by developing the notion of justice-as-fairness previously developed by John Rawls. Let us consider each in turn.

Norman Daniels' Approach

Daniels considers it important that we distinguish between *age groups* and *birth cohorts* in a society. Age groups refer to people who fall within a certain age range or who are at a certain stage of life. Birth cohorts, on the other hand, refer to a distinct group of people who have a particular history and composition. The notion of an age group abstracts from the distinctive nature of the birth cohort and views people solely in reference to their place in the lifespan.

Age groups coexist, cooperate and compete in the same political and moral setting. However, an age criterion functions in a different way than for instance claims made on the

grounds of sex or race. The age criterion operates *within* a life and not *between* lives as do criteria of sex and race.

Daniels defends the view that pure age-rationing is morally permissible under certain, very specific and restrictive conditions. His argument is couched in prudential and non-prudential terms. The prudential account uses the Rawlsian thesis of the original position. Here deliberators operate behind a veil of ignorance that limits their decision-making to issues concerning the transfer of goods within a lifespan. Saving resources so that the elderly have claim to them in their later years is possible only if access to them is reduced in the earlier stages of life. This version of the prudential argument maintains there are conditions under which a health-care system that rations life-extending resources by age is the prudent choice and, therefore, the choice that constitutes a just and fair distribution of resources between age groups.[2]

Daniel Callahan's Approach

For Daniels the challenge of limits in health care delivery is located within a justice-as-fairness framework which gives a preeminent role to the individual prudent deliberator as he or she makes decisions over a life time. Daniel Callahan, on the other hand, discusses the need for an age criterion but only when a prior social consensus on health care, the natural life span and the scope of government obligations has been arrived at. In an effort to stipulate limits to health care for the aged Callahan requires that certain important preconditions be met.[3] In doing so he rejects the standard of individual benefit (such as treatment outcome) as a norm governing the distribution of scarce health care resources.[4] What must be put in place are *categorical* limits. These are 'visible, objective, universal criteria that can be applied to all (or most) individuals and that do not require complex interpretation to be employed.'[5]

Callahan is able to take this step by limiting the parameters of human need. He rejects an open-ended understanding of need and the nexus that has increasingly been established between medical need and technological possibility. For him what ageing persons need is 'to achieve a natural life span and thereafter to have their suffering relieved.'[6] By explaining it in this way a general and socially established ideal of old age is achieved:

> We owe each other a long and decent life, a full life, but it is unreasonable for anyone to claim as long a life as might be theoretically possible regardless of the cost. Put another way, we owe each other a *natural* lifespan, not immortality.[7]

In his view, then, how does the criterion of age function in the allocation of resources debate? Callahan resists using age as a medical criterion, that is treating chronological age as if it were equivalent to other physical characteristics of the patient. Rather, he views age as a *person-centered* characteristic. This he portrays as a *biographical* standard and he insists that in light of this standard it is possible to formulate principles for terminating aggressive treatment to dying patients. He proposes three principles:

Callahan resists using age as a medical criterion

(1) After a person has lived out a natural life span, medical care should no longer be oriented to resisting death. No precise chronological age can readily be set for determining when a natural life span has been achieved since biographies vary but it would normally be expected by the late 70s or early 80s.[8] (2) Provision of medical care for those who have lived out a natural life span should be limited to the relief of suffering. (3) The existence of medical technologies capable of extending the lives of the elderly who have lived out a natural life span creates no presumption that the technologies must be used for that purpose.

With these limits to curative medicine now in place Callahan is able to propose three principles for an allocation policy in society.[9] Government has a duty (1) to help people live out a natural life span, but is not obliged to extend life by medical means beyond that point; (2) to develop, employ and pay for only that kind and degree of life-extending technology necessary for medicine to achieve and serve the end of a natural life span; (3) to provide relief of suffering for persons who have reached their natural life span.[10]

Callahan's treatment proposals and allocation criteria were intended to stir national debate.[11] The 'real, and ultimate, limits I am proposing are on unlimited medical progress' with a cut off somewhere around the age of 80, 'five years *beyond* our average life expectancy at present.'[12] Callahan has sought consistently to limit the increase in the cost of medical treatment for the elderly, not to cut the elderly off from medical treatment.

Lifespan Underpinning

A significant thread throughout the debate about distribution of benefits and burdens between generations is the lifespan paradigm. Both the communitarian Callahan and the liberal-Rawlsian Daniels use the lifespan (or life cycle or life course) as a fundamental unit of analysis. They turn, with differing emphases, to this universal category as a way of overcoming the divisiveness arising from a too narrow concentration on age-groups, cohorts, or generations.

Daniels' *prudential lifespan account* encourages individuals to think that they are saving or insuring themselves against the vicissitudes of old age and disability. The primary justification for support or care for the elderly derives not from

intergenerational obligations but from the equal opportunity to pursue one's own life plan at every stage of life. Prudence leads people to support programs not out of commitment to a common good but because of a situation in which all have a common stake. In a society characterised by mass longevity, a life course perspective can encourage a kind of solidarity between age groups.

Callahan differs in his use of the natural life span. For him the concept of the natural life span is an attempt to articulate cultural features common to a society. For that reason it is the notion of a biographical life, not a biological one that dominates. Human solidarity after all is grounded in our shared humanity as persons in society. [13]

A Satisfactory Criterion?

Daniel Callahan views the age criterion in the context of a social value system which must recognise *reasonable limits*. Norman Daniels, on the other hand, with his eye on the prudent deliberator, emphasises that it is the *reasonable thing to do* to implement limits to health care for the elderly.[14] Both approaches must now be critically assessed.

Callahan's View

Callahan's central claim is that there is a natural end to the lifespan. Medical resources should be used to get people up to the natural completion point. After that the elderly have a right only to comfort and inexpensive treatments for acute illness.[15] It follows from this that medical care needed to complete the major phases of the life cycle generates a higher moral claim than the care required to sustain life after the life cycle has been completed. According to Callahan the 'old should step aside in an active way'.[16] The age-criterion is important for rationing health care on the basis as to whether the natural life span has been completed or not.[17]

Not only does Callahan's approach rest on a controversial view about the value of life when the natural life-span is completed, it also depends on an even more dubious claim that human life has a *natural* span. The difficulty with Callahan's approach is the idea that there is some identifiable end point at which, for public policy purposes, some health care resources should no longer be funded. At one point in the discussion Callahan suggested that a lifespan of 75 years was as good as any. In *Setting Limits* he was slightly more conservative, identifying an age range of the late 70s to early 80s. The categorical nature of the cut-off point which seems demanded by his approach raises real difficulties. That a person at 74 might receive all possible medical care when another person of 76 would not creates difficulties for

the elderly have a continuing need to relief of suffering and basic nursing care

many commentators.[18]
A second difficulty with Callahan's *lifespan completion theory* is located in his demand that the elderly have a continuing need for relief of suffering and basic nursing care. What the approach fails to explain is why resources should be spent on these when others will never reach their full life-span. If their 'full' lives are over, why do they have claims for palliative and nursing care? May it not be argued that people who have not reached their full life span have claims for these same resources as well. Since basic nursing care for the elderly is a major resource investment, is it not more reasonable to dispose painlessly of those whose life-span is over so that attention can be given to those who have not yet attained the full life span.[19]

A further difficulty with Callahan's age limit has been developed in terms of the *fair innings* argument.[20] Put simply arguments that support the setting of a threshold at an age which might plausibly be considered to be a reasonable lifespan support equally the setting of a threshold at any age at all, so long as an argument from fairness can be used to support this.[21]

In light of these criticisms it is obvious that Callahan's proposal for an age criterion appears seriously flawed. It would appear to me that his primary intent was to challenge his society to confront the reality of limits. Laudable as this aim is, it is not able to be effectively articulated as a coherent and sustainable public policy criterion. Two clarifications, however, must be made at this point. First, a number of critics of the age criterion proposal have frequently overlooked a distinction that must be made between Callahan's primarily philosophical agenda, urging a moral realism in American life and health care, and his policy proposal for an age criterion for health care delivery. Second, Callahan's age criterion proposal applies to publicly funded, life-extending high-tech health care for people who have fulfilled their life span. He does not exclude the use of private funds for this purpose. This specification has frequently been overlooked by critics. These same critics have separated the public policy proposal from his more fundamental concern about the American ethos. As a stand alone policy criterion the age standard is defective and untenable for the reasons elaborated above. As a catalyst for public discussion about the central values for American society it has been quite successful. Callahan's journalistic style, philosophical preoccupation and prolific published output has not endeared him to critics who take a much narrower perspective.

Daniels' View

Daniels confronts the critic who considers that setting age limits seems as unfair as allocation of resources based on race or gender. Age, he argues, is different. What is needed is an *intra*personal rather than an *inter*-personal perspective in dealing with age as an allocation criterion.[22] The

policy task is to allocate personal shares of health care over a lifetime rather than allocating care interpersonally among cohorts of different ages. Whatever one's personal share, it seems to make no moral difference how it is allocated over one's lifetime. It is not necessary to have the same kinds of medical services available at different points in our lives. Allocation ought be based on what he calls an *age-specific normal opportunity range*. Appropriate distribution of goods provide what people need to function well at a particular age: to play sports in one's youth, to reproduce in early adulthood, to pursue a vocation in middle age, and to pursue active retirement in old age. It is a matter of prudence how an individual allocates his or her share of health care. For this reason Daniels refers to his scheme as a *prudential life-span account*. Each person is free to structure health insurance in any prudent way that is

not all allocation decisions, however, are ethical

judged appropriate to him or her.
Not all allocation decisions, however, are ethical. For them to be ethical requires that corrections be made for particular problems arising from the choices people make about their insurance. Choices must be adequately informed, empathetic, willing to take other people's life plans into account and so forth. Hence the need for a veil of ignorance — after the fashion of John Rawls' theory of justice — before those making a prudent allocation of health resources. Under these conditions deliberators would save a prudent amount for old age.

It is problematic whether Daniels' account makes clear that people choosing their health care allocation behind a veil of ignorance will choose an allocation that is prudent. Likewise it is not obvious that it is only a matter of prudence as to how resources are allocated to different stages of the life cycle. Even if it is prudent for people to save for their old age, it may not be just or fair. The Rawls-Daniels scheme is based on a model in which rational, self-interested heads of households (blinded as to their specific interests and needs) are viewed as the ones making the allocation choices. This model, however, implies that all will inevitably reach adulthood. However, the natural lottery treats some more harshly than others. They are born with congenital and genetic problems such that they will suffer from critical, fatal, or permanently handicapping conditions. If a majority of rational adults spend equally on conditions of infancy, middle age, and old age, it does not follow that it is fair to those who will never reach adulthood.

The real issue, some argue, is whether justice permits or requires limits on care for the elderly.[23] Choices ought to be constrained by what is fair rather than simply by what seems prudent.[24] The principle of fairness obliges us to deal with the just claims of those who have critical or fatal conditions in infancy. Justice also requires that we identify worst-off individuals and allocate resources so as to give such persons an opportunity to be as well off as others.

Daniels' ideal theory of justice with its view of the prudent self-directing individual making allocation decisions for himself or herself over a life-time is open to a number of basic criticisms.[25] It is not easy to see, in the world of every day allocation decisions, how Daniel's incorporates the competing choices of others in the community. Furthermore, the thin set of values relating to personal autonomy offers no guidelines for discerning whether an individual has chosen correctly or has grasped more than is right. Veatch is correct, I believe, in highlighting the justice dimensions of prudent decision-making. For Daniels, however, the fundamental atomist/liberal view underpinning his thinking makes it almost impossible for him to sustain the validity of the age criterion when communitarian concerns are raised.

Brief Conclusion

In light of the above considerations the liberal and communitarian approaches of Daniels and Callahan must be judged to have failed. They can be faulted for not having adequately considered limits in our personal and social lives. Their proposals offers partial and inadequate justifications for accepting age as a criterion when distributing scarce health care resources. While both thinkers may be thought to have failed in their undertaking the issues they raise merit serious consideration as we in Australia engage in debates about just health care and distribution of scarce resources. Whatever results must not however victimise or discriminate one particular sector of society.

ENDNOTES

[1] R Clare and A Tulpule, *Australia's Ageing Society*, Vol 37, EPAC Background Paper (Canberra: Australian Government Publishing Service, 1994), 39.
[2] N Daniels, *Am I My Parents' Keeper?*, (New York: Oxford University Press, 1988), 91.
[3] These are: (1) the establishment of national health insurance; (2) a greatly improved program of long-term and home care, with a better balance between caring and curing; (3) greater efforts to improve the daily quality of life of the elderly; (4) government limitations on health care to be restricted to federal entitlement programs such as Medicare; and (5) limits to be applied only to expensive high-technology medicine.
[4] D Callahan, *Setting Limits. Medical Goals in an Aging Society*, (New York: Simon and Schuster, 1987), 134.
[5] D Callahan, 'Rationing Health Care: Will it be necessary? Can it be done without age or disability discrimination?' *Issues in Law and Medicine*, 5/3 (1989) 354.
[6] Callahan, *Setting Limits*, 135.
[7] D Callahan, 'Intolerable Necessity: Limiting Health Care for the Elderly,' in *Facing Limits. Ethics and Health Care for the Elderly*, edited by G R Winslow and J W Walters, (Boulder, Co.: Westview Press, 1993), 8.
[8] D Callahan, 'Health Care for the Elderly: Setting Limits,' *St.Louis University Law Journal*, 33(1989) 565.
[9] Callahan, 'Rationing…,' *Issues in Law and Medicine*, 362.
[10] Callahan, *Setting Limits*, 137-138.

[11] Callahan, 'Setting Limits...,' *St.Louis University Law Journal*, 710.
[12] Callahan, 'Intolerable Necessity...,' in *Facing Limits*, 12.
[13] T R Cole, 'Generational Equity in America: A Cultural Historian's Perspective', *Social Science and Medicine* 29/3 (1989) 380.
[14] D W Brock, "Health-Care Entitlements and the Elderly: A Liberal Critique of 'Setting Limits'", in *A Good Old Age? The Paradox of 'Setting Limits'*, edited by P Homer and M Holstein, (New York: Simon & Schuster, 1990), 140-53.
[15] Callahan, *Setting Limits*, 116.
[16] Callahan, *Setting Limits*, 43.
[17] G R Winslow, 'Exceptions and the Elderly' in *Facing Limits. Ethics and Health Care for the Elderly*, edited by G R Winslow and J W Walters, (Boulder, Co.: Westview Press, 1993), 236-37.
[18] N G Levinsky, 'Age as a Criterion for Rationing Health Care', *The New England Journal of Medicine* 322/25 (1990) 1814.
[19] This argument is developed by Margaret Battin in 'Age Rationing and the Just Distribution of Health Care: Is There a Duty to Die?' in *Should Medical Care Be Rationed by Age?*, edited by T M Smeeding, M P Battin, L P Francis, and B M Landesman, (Totowa, N J: Rowman & Littlefield, 1987), 69-94. She proposes that 'direct termination of lives of the elderly more nearly achieves justice than denying them treatment...'(*ibid.*, 91).
[20] J Harris, *The Value of Life*, (London: Routledge & Kegan Paul, 1985), 91.
[21] Harris, *The Value of Life*, 92.
[22] D McKerlie, 'Equality Between Age-Groups.' *Philosophy and Public Affairs* 21/3 (1992) 275-95.
[23] R M Veatch, 'How Age Should Matter: Justice as the Basis of Limiting Care for the Elderly,' in *Facing Limits. Ethics and Health Care for the Elderly*, edited by G R Winslow and J W Walters, (Boulder, Co.: Westview Press, 1993), 222.
[24] Veatch, 'How Age Should Matter...,' in *Facing Limits*, 229, note 16.
[25] L R Churchill, 'Private Virtues, Public Detriment: Allocating Scarce Medical Resources to the Elderly', *Ethics* 100 (1989-1990) 173. ✣

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Therapeutic Use of Pluripotent Embryonic Stem Cells

This article explains how embryonic stem (ES) cells obtained from a cloned human embryo could have great therapeutic potential in medicine, but at the cost of destroying cloned human embryos to obtain these ES cells.

Background

When a somatic cell is inserted into an enucleated egg it is reprogrammed by the egg's cytoplasmic contents and as soon as the egg is activated a cloned embryo is usually formed. Cloning a human embryo by nuclear transfer could possibly occur in the same way as in sheep and other mammals.[1] After implantation in a woman's uterus, the cloned human embryo could develop into a fetus and a baby who would be practically genetically identical to the somatic nucleus donor. The cloning of a fetus or a child is commonly known as reproductive cloning. Scientists agree that 'reproductive cloning to produce human fetuses is unethical and unsafe and should be prohibited.'[2]

Therapeutic Cloning

One day it might be possible to use a patient's own body or somatic cell to clone a human embryo. After about five days at the blastocyst stage the inner cell mass could be removed. This would destroy the blastocyst. These embryonic stem (ES) cells could then be grown in culture where they can multiply and produce hundreds of ES cells. These cells are pluripotent, i.e. once taken out of culture conditions, they are capable of giving rise to all types of cells in the human body. They can also be coaxed to develop specialised types of stem cells which can give rise to cells for particular tissues in the human body. Neuronal and muscle cells have recently been formed in this way from mouse ES cells.[3] Once these techniques have been perfected, such cells could be used to treat a patient's defective bone marrow, or degenerated nerve tissue, e.g. Huntington disease. This therapy would be akin to autologous transplantation and the cells would not be rejected because they would be genetically identical to the patient's own somatic cells.[4] This sort of cloning and derivation of cells is commonly called 'therapeutic cloning'. It clearly has the potential to revolutionise the practice of medicine for the treatment of diseased organs and degenerated tissues.

Use of ES Cells

The Australian Academy of Science supports the cloning of embryos for scientific research and therapeutic purposes.[5] Julian Savulescu holds that 'it is not only reasonable to produce embryos as a source of multipotent stem cells, but that it would be morally required to produce embryos and early fetuses as a source of tissue for transplantation.'[6] The British and U.S. governments are poised to permit the therapeutic use of, and research on, pluripotent ES cells.

Right to Life of Human Embryos

Therapeutic cloning involves the destruction of human embryos to retrieve and prepare the pluripotent ES cells for laudable therapeutic purposes for patients suffering from diseases or disabilities. Human life begins at conception and from that stage is ethically inviolable: 'The human being is to be respected and treated as a person from the moment of conception; and therefore from that same moment his rights as a person must be recognised, among

which in the first place is the inviolable right of every innocent human being to life.'[7]

Reason is able to recognise human life, empirically identifiable from conception, as a basic and inviolable value not only for adults but also for children, newborns, fetuses and embryos. Without human life, other values we cherish and protect would not be attainable. There is no moral right to deliberately destroy innocent and harmless human life. Destructive use of human embryos, regardless of their derivation — naturally conceived embryos, IVF embryos or cloned embryos — is unethical, regardless of the therapeutic purposes for which this is done.

Collusion with Destroying Human Embryos

It is also unethical for doctors or researchers to benefit from, or to use, ES cells if this were in any way to involve collusion, or tacit agreement, with obtaining them by way of harming or destroying a human blastocyst. Hence, in practice, it would be unethical for scientists and their assistants to participate in research projects on ES cells obtained in this way. Their use would create a market for ES cells. The link between the destruction of human embryos and their use for therapy would be undeniable. The situation is similar to the use of fetal tissue taken from aborted fetuses for transplantation. The adoption of a policy to use this fetal tissue inevitably involves collusion with abortion.

Alternative Possibilities

To avoid the moral problems of creating and destroying cloned human embryos doors are opening to new possibilities. Adult human liver cells have been derived from stem cells in bone marrow.[8] Much could be learnt from mouse experiments where neural stem cells have produced blood cells after they were transplanted.[9] Other avenues for obtaining the desired stem cells may be found without the need of forming and destroying cloned human embryos.[10]

I conclude with the wise advice of Pope John Paul II to the 18th International Congress of the Transplant Society in Rome on 29 August 2000: 'methods that fail to respect the dignity and value of the person must always be avoided. I am thinking in particular of attempts at human cloning with a view to obtaining organs for transplants: these techniques, insofar as they involve the manipulation and destruction of human embryos, are not morally acceptable, even when their proposed goal is good in itself. Science itself points to other forms of *therapeutic intervention* which would not involve cloning or the use of embryonic cells, but rather would make use of stem cells taken from adults. This is the direction that research must follow if it wishes to respect the dignity of each and every human being, even at the embryonic stage.

In addressing these varied issues, *the contribution of philosophers and theologians* is important. Their careful and competent reflection on the ethical problems associated with transplant therapy can help to clarify the criteria for assessing what kinds of transplants are morally acceptable and under what conditions, especially with regard to the protection of each individual's personal identity.'[11]

ENDNOTES

[1] Ian Wilmut *et al*., 'Viable offspring derived from fetal and adult mammalian cells', *Nature* 385 (1997) 810-813.
[2] Australian Academy of Science, *On Human Cloning: A Position Statement*, (Canberra: 1999) 6, 13.
[3] Megan J Munsie *et al*., 'Isolation of pluripotent embryonic stem cells from reprogrammed adult mouse somatic cell nuclei', *Current Biology* 10 (2000) 989-992.
[4] Alan Trounson and Kim Giliam, 'What Does Cloning Offer Human Medicine', *Today's Life Science* March/April 1999 12-14; Alan O Trounson, 'Cloning: potential benefits for human medicine', *Medical Journal of Australia*, 167 (1997) 568-9.
[5] *On Human Cloning*, 6, 13, 17.
[6] Julian Savulescu, 'Should we clone human beings? Cloning as a source of tissue for transplantation', *Journal of Medical Ethics* 25 (1999) 94.
[7] John Paul II, *Evangelium Vitae* n. 60.
[8] Malcolm R Alison *et al*., 'Hepatocytes from non-hepatic adult stem cells', *Nature* 406 (20 July 2000) 257.
[9] Christopher R Bjornson and Rodney L Rietze *et al*., 'Turning Brain into Blood: A Hematopoietic Fate Adopted by Adult Neural Stem Cells in Vivo', *Science* 283 (22 Jan 1999) 534-37.
[10] Deborah Josefson, 'Adult stem cells may be redefinable', *British Medical Journal* 318 (1999) 282.
[11] John Paul II, *L'Osservatore Romano*, Weekly Edition in English, 30 August 2000. ✣

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