

## Postprint

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# Prenatal diagnosis and abortion for congenital abnormalities: is it ethical to provide one without the other?

Ballantyne, A. Newson, A.J., Luna, F. Ashcroft, R. (2009)

This target article considers the ethical implications of providing prenatal diagnosis (PND) and antenatal screening services to detect fetal abnormalities in jurisdictions that prohibit abortion for these conditions. This unusual health policy context is common in the Latin American region. Congenital conditions are often untreated or under-treated in developing countries due to limited health resources, leading many women/couples to prefer termination of affected pregnancies. Three potential harms derive from the provision of PND in the absence of legal and safe abortion for these conditions: psychological distress, unjust distribution of burdens between socio-economic classes, and financial burdens for families and society. We present Iran as a comparative case study where recognition of these ethical issues has led to the liberalization of abortion laws for fetuses with thalassemia. We argue that physicians, geneticists and policymakers have an ethical and professional duty of care to advocate for change in order to ameliorate these harms.

## Keywords:

abortion, fetal abnormality, Latin America, prenatal diagnosis, reproductive ethics, women

## INTRODUCTION

Since the mid 1990's, the provision of medical genetic services in Latin American countries such as Mexico, Argentina and Brazil has increased significantly. The provision of these services in public hospitals, university teaching hospitals and private clinics includes widespread access to prenatal diagnosis and antenatal screening (hereinafter PND) for the detection of fetal abnormalities. For example, molecular genetics is used regularly in large hospitals in Mexico for the diagnosis of common genetic conditions such as cystic fibrosis, hemophilia, and muscular dystrophy

(Penchaszadeh and Beiguelman 1998). Increasing access to such services in Latin America gives rise to an unusual health policy context in which fetal abnormalities are detected but parents do not have access to safe and legal abortion should they wish to terminate an affected pregnancy. This context has previously been critiqued as giving rise to a ‘therapeutic gap’ (Simpson, 2007). In this paper we argue that the juxtaposition of accessible PND and restrictive abortion law raises serious questions about the moral, social and psychological consequences for women and couples who are informed of a serious congenital abnormality, but who have no legal mechanisms to procure a termination. Genetic technologies are not neutral and the relationship between PND and abortion deserves greater attention. We argue that access to safe and legal abortion must be a component of comprehensive medical genetic services that should sit alongside PND for fetal abnormality.

There are four components to our analysis. First, we describe the growing availability of PND in Latin America and the relevant abortion laws, including a case study around abortion for anencephaly in Brazil. Second, we present three ethical problems with the status quo: psychological distress, unjust distribution of burdens between socio-economic classes, and the social and financial burdens on families and society in caring for ‘unwanted’ children who have serious chronic conditions. We recognize the complex political, religious, ethical and socio-economic factors at play in this unusual situation and acknowledge that solutions are not straightforward. In the third section we draw on Iran as a comparative case study. In Iran, public and religious debate has led to the legalization of abortion for fetuses with thalassemia. Finally, we argue for an ethical ‘duty of care’ that physicians, geneticists and public policy-makers should adopt towards women and families in this position.

In making this argument, we recognize that abortion is a contested issue and concede that our arguments are unavoidably influenced by our personal views that abortion is an ethically acceptable option for women. Indeed, it is difficult to discuss the ethics of PND in the absence of safe and legal abortion, without also engaging in discussion of the morality of abortion per se. To this end, we focus our argument on the specific issue of the therapeutic gap between the availability of prenatal screening and diagnostic services and the presence of restrictive abortion laws, as we believe this gives rise to specific ethical issues that should be visible even to those who believe abortion is immoral. We shall not engage in debate about the ethics of abortion generally, but we are of the opinion that all countries should allow abortion in the case of serious fetal abnormalities.

Likewise, we recognize that programs of PND are open to critique by scholars promoting a perspective informed by the rights and interests of those with disabilities, including those yet to be born. It is important to reflect on the goals of PND and to ensure women or couples have the opportunity to make a free and informed choice about testing or screening. This paper is, however, based on the premise that there are some congenital conditions that are so serious that women or couples are not acting unreasonably in deciding to screen for such conditions and to terminate an affected pregnancy.

## CONTEXT

This paper explores the ethical issues arising from an unusual and specific context—where PND is available but legal abortion for serious congenital abnormalities is not. In order to recognize these specific ethical issues, it is necessary to first appreciate the medical and legal particulars of this context.

## **Antenatal Screening and Prenatal Diagnosis of Congenital Abnormalities**

Most screening and diagnostic tests in pregnancy are offered during the first 20 weeks of gestation. Antenatal screening is used to identify pregnant women carrying fetuses at sufficient risk of a congenital disorder to warrant an offer of further investigation. It is generally offered to entire populations with a defined set of characteristics, such as advanced maternal age (as this increases the risk of chromosomal abnormalities). Antenatal screening techniques include administering questionnaires to see if the pregnant woman has a family history of certain conditions or screening tests such as maternal serum screening and ultrasound.

Prenatal diagnosis denotes those diagnostic tests offered by specialized clinical services to couples at-risk of giving birth to a child affected by a particular genetic condition or to women who have received high-risk results after serum screening or ultrasound. Techniques used in prenatal diagnosis include chorionic villus sampling and amniocentesis, which provide samples for subsequent karyotyping (examination of whole chromosomes) or DNA analysis. Emerging techniques involve the analysis of cell-free fetal DNA or analysis of fetal cells isolated from the maternal bloodstream. Prenatal diagnosis is a well-accepted and demanded service in Latin American middle-income countries such as Argentina, Mexico and Brazil, and is commonly recommended for women over 35 years of age (Penchaszadeh 2004; Rivera-López 2001).

One reason for screening and diagnostic testing in pregnancy is to detect the presence of a congenital disorder; that is any pathological (or potentially pathological) condition arising before birth. This encompasses a wide range of conditions, both inherited and environmentally influenced, such as the genetic conditions cystic fibrosis, sickle cell disorder and hemophilia; the chromosomal condition Down syndrome; and structural abnormalities such as spina bifida. When demographic and epidemiological transition in middle-income countries results in infant mortality falling below 50/1000 live births, congenital disorders become increasingly visible and begin to account for a higher proportion of national morbidity and mortality (Christianson et al. 2004).

### **Serious and Untreatable Congenital Conditions**

There are many congenital conditions for which there remain no effective treatments. Tay Sachs disease, for example, is an inherited lipid storage disorder that causes progressive damage to tissues and nerves in the brain. Infants affected with this condition become blind, deaf, unable to swallow, and die in the first few years of life (NINDS 2007a). Anencephaly is another untreatable congenital condition, which (contrary to Tay Sachs) does not run in families. Anencephaly is caused by a defect in the formation of the neural tube during fetal development, resulting in the absence of a major portion of the brain. Babies with this condition are typically stillborn or die within a few hours or days of birth (NINDS 2007b).

In developing countries the range of 'untreatable' congenital disorders is significantly larger than in the developed world due to limited human and financial resources. This means that conditions effectively managed in the developed world can be unmanageable in many developing countries. Phenylketonuria (PKU) is an example of this phenomenon. PKU is an inherited error of metabolism requiring a special phenylalanine-free diet in early life and during pregnancy in women with PKU (Christianson and Modell 2004). Thalassaemia is another potentially manageable congenital disorder, relatively common in communities where malaria is (or was) endemic, and in immigrant populations from these regions, including Latin America. The economic and social cost of thalassaemia is high due

to patients' lifelong need for monthly blood transfusions and treatment with the iron chelating agent desferrioxamine (Perera et al. 2000). Patients receiving treatment often live into their thirties or forties, and in high-income countries life expectancy is steadily rising to that of the general population (WHO 2006a). The costs of managing thalassemia in developing countries, however, are often prohibitively high and many patients do not have access to full treatment. In Iran for example, the estimated cost of treating 15,000 thalassemia patients is US\$200m per year (Christianson et al. 2004).

### Termination for Fetal Abnormality

Some people who undergo prenatal diagnosis choose to continue a pregnancy even if serious fetal abnormality is detected (Gadow et al. 2006; Rapp 1999). However, research and experience indicate that many women carrying a fetus affected by a serious and 'untreatable' congenital disorder prefer to terminate the pregnancy. For example, a 1991 study showed that 89 per cent of couples in Pakistan known to be carrying a fetus affected with an inherited hemoglobin disorder chose to terminate the pregnancy (Ahmed et al. 1991). A survey in Argentina and Uruguay, where abortion on the grounds of fetal abnormality is illegal, indicated that 68.2 per cent of couples undergoing prenatal diagnosis would contemplate termination of pregnancy in cases of serious congenital abnormality (Gadow et al. 2006). A recent retrospective study of 207 cases in Uruguay provides the first concrete data from a Latin American country. Of 87 couples who were informed that their fetus would develop Down Syndrome, 77 (89 per cent) opted for termination. Of 47 couples informed that their fetus carried a chromosomal abnormality with a severe prognosis, 45 (96 per cent) terminated the pregnancy (Quadrelli et al. 2007). One Argentinean scholar has indicated that in Latin America 95 per cent of women who are aware that they are carrying a fetus affected by a congenital disorder undergo abortions (Rivera-López 2002).

### Restrictive Abortion Laws and Abortion Rates

Abortion laws vary from restrictive to liberal, both between and within countries (Boland and Katzive, 2008). There are various grounds upon which abortion may be accepted, including pregnancies resulting from rape, those that pose a significant threat to the health of the mother or unwanted pregnancies. Table 1 demonstrates the proportion of developed and developing countries that permit abortion for fetal abnormality. In developed regions, 81 per cent of countries allow abortions for fetal impairment, whereas in less developed regions only 26 per cent allow abortions on these grounds.

**Table 1** Legal permissibility of abortion of fetal impairment by region\*

Level of regional development	Number of countries	Abortion for fetal impairment	
		Permitted	Not permitted
More developed regions	48	39	9
Less developed regions	145	37	108

\*Data from the Population Division of the United Nations Secretariat in *World Abortion Policies 1999*.

Abortion law throughout most of Latin America and the Caribbean is highly restrictive. In Chile, El Salvador and Nicaragua, for example, abortion is prohibited (Taucher 2004; Replogle 2007; Boland and Katzive, 2008). Exceptions to this general rule include Cuba, Colombia, Ecuador, and some in-country jurisdictions such as Mexico City (and several other Mexican states), where abortion laws

are more liberal (Penchaszadeh 2004; Boland and Katzive, 2008). Throughout Latin America, many governments and legislators have publicly linked their opposition to birth control methods with Catholic doctrine and the Catholic Church has proved inflexible in debates about contraception and abortion (Human Rights Watch 2005). Cook and Dickens argue that the rigidity of Catholic moral doctrine was entrenched by the 1870 adoption of the concept of papal infallibility in pronouncements made *ex cathedra*. As a result, no new revelations can be accepted unless they are demonstrated to be consistent with earlier rulings and there is no room for reversing or overruling existing policies on the basis that they were erroneous (Cook and Dickens 2002). However we also recognize that in some jurisdictions apparently restrictive laws may be interpreted or applied more liberally in practice, while in other countries apparently liberal laws have limited practical use due to difficulties in accessing an abortion provider (Boland and Katzive, 2008).

Under the Argentinean penal code, abortion for genetic reasons is a crime (except for the City of Buenos Aires, which passed a law in 2003 allowing abortion after six months of pregnancy for anencephaly (Luna 2007)). There are provisions for waiving the penalties associated with abortion if the life or health of the pregnant woman is in danger or if the pregnancy results from the rape of a mentally disabled woman. The interpretation of these exceptions is controversial; it could be argued that this exception be read so as to allow abortion in either the case of rape or mental incapacity of the mother. In practice, it is difficult for women who fulfill both the narrow and broad interpretations to access safe and legal abortion because there are no clear policies regulating access. Physicians and hospitals are often reluctant to perform non-prohibited abortions due to the apparent legal ambiguity and may seek explicit judicial authorization for any abortions. However, judges have previously refused to rule on these cases on the grounds that the penal code lays out the legal exceptions and therefore there is no interpretative role for the courts to play. Women requesting a lawful abortion can be caught between their physicians and the judicial process (Luna 2004).

Some courts in Latin America have allowed abortions in cases where the fetus suffers from severe abnormalities 'incompatible' with survival outside the womb, but again this is approved on an ad-hoc basis and women in general do not have an assured legal right to such services (Horovitz et al. 2004). This status quo of the availability of prenatal diagnosis without access to safe abortion also appears to go against a recommendation from the International Federation of Gynecology and Obstetrics:

*In countries where it is an accepted medical practice, whenever a severe untreatable fetal disease or malformation, incompatible with a normal life, is diagnosed by prenatal diagnosis, termination of pregnancy must be offered to the parents (Milliez, 2008, p 98).*

### **Unsafe Abortion**

It is widely acknowledged that restrictive abortion laws do little to change the overall rate of induced abortions; rather they increase the proportion of unsafe abortion (Rivera-López 2002). The World Health Organization (WHO) defines unsafe abortion as induced abortions carried out by persons lacking the necessary skills and/or carried out in an environment that does not conform to minimal medical and safety standards (WHO 2004). Fathalla, an obstetrician with extensive international experience, argues:

*In this situation [where rates of unwanted pregnancies are high], restricting access to abortions will only increase the number of illegal and unsafe abortions. The choice will not be between allowing or preventing abortion. It will be between decriminalizing abortion or allowing it only to be performed as an illegal procedure (Fathalla 1997, 238).*

Because abortion laws are typically more restrictive in the developing world, women in developing countries are more likely to have illegal abortions than women in developed countries (WHO 2004). Thirteen percent of all maternal deaths worldwide are thought to be due to unsafe abortion—equating to 68,000 maternal deaths per year (WHO 2004).<sup>1</sup> In Latin America, for example, 4.5 million abortions are carried out every year. Ninety-five per cent of these are illegal and account for 25 per cent of maternal mortality in Latin America (Penchaszadeh 2004). It is estimated that more than half a million women in Argentina undergo illegal (and typically unsafe) abortions every year, representing 40 per cent of all pregnancies (Human Rights Watch 2005). In addition to mortality there is significant morbidity. Unsafe abortion carries a risk of many other common yet avoidable health risks, including sepsis, anemia (following hemorrhage), pelvic infection, genital trauma (such as vaginal wall laceration), cervical tears and uterine perforation, injury to the bowel, and vesicovaginal fistulae (Anate et al. 1995).

### **Brazil: A Case Study**

In Brazil, the combination of accessible PND and restrictive abortion legislation leads to the predictable and difficult situation where women are informed of a fetal abnormality but do not have the option to safely and legally terminate the pregnancy (Guilam and Corrêa 2007). According to the law, abortion is prohibited except in instances of rape (Boland and Katzive 2008).<sup>2</sup> Medical genetic services are well-developed in wealthy regions of the country, and both public and private sector health professionals offer services aimed at detecting monogenic and chromosomal conditions (Marques-de-Faria et al. 2004). Yet, under Brazil's penal code, termination is only permitted where the pregnancy is the result of rape or will endanger the life of the mother (Brazilian Penal Code 1940, amended 1998). While there is no legal provision for termination for fetal abnormality, it is estimated that between 1989 and 2004, Brazilian courts authorized approximately 3,000 abortions for conditions deemed incompatible with life outside the womb (Gollop and Pimentel 2004, cited by Diniz 2007).

In 2004, Brazilian bioethicist Deborah Diniz directed an award-winning documentary telling the story of a couple whose fetus was diagnosed with anencephaly at four months, but who were not able to procure a legal abortion until the pregnancy was in its seventh month due to ongoing debate concerning the morality and legality of abortion for anencephalic fetuses in Brazil's Supreme Federal Tribunal (Diniz and Brum 2005; Diniz 2007). Judicial attitudes in Brazil are inconsistent: some judges permit abortions of anencephalic babies, yet others routinely reject them. In this case, by the time judicial permission for the abortion was granted, the fetus had to be delivered vaginally and the mother endured a 32-hour delivery. Despite court permission for the abortion, the anesthesiologists on duty at the hospital refused to provide pain relief, on the grounds of personal conscientious objection to the abortion.

This status quo is contentious both within and outside Brazil. In a statement to the Supreme Federal Tribunal during the above case, the Brazilian Human Rights, Gender and Bioethics Institute argued that the failure to consistently permit abortion in cases of anencephaly results in physical and

psychological torture and denies women their constitutional right to access health care (KaiserNetwork 2004).

## ETHICAL IMPLICATIONS

Screening for and diagnosis of congenital abnormality in pregnancy, with subsequent access to termination, is readily available in the developed world. As middle-income and developing countries are now offering screening and diagnostic services in pregnancy, we submit that these are incomplete if women are forced to choose between having a child with a serious congenital condition or risking an unsafe and illegal abortion. We recognize that not all termination requests in cases of fetal abnormality are alike, and those for some conditions (deafness, cleft palate or achondroplasia, for example) are more contentious than others. However, some serious congenital disorders lead to a very low quality of life or are incompatible with life altogether, and it is these conditions that are the primary focus of this paper. We have identified three types of harm that arise from allowing PND for these conditions in the absence of safe and legal abortion.

### **Psychological Harm**

First, being effectively forced to continue an unwanted and sometimes futile pregnancy can cause psychological trauma or harm to affected women. In most cases of congenital abnormality, the pregnancy is planned and wanted and the discovery of a fetal abnormality is traumatic. Effectively forcing women to continue with a pregnancy in these circumstances can exacerbate and extend what can already be a sad and painful process, delaying the point of closure. Given the later gestation at which many abnormalities are diagnosed, women who continue with a pregnancy often need go through full vaginal labor, a process that is physically more dangerous and emotionally more distressing than a second trimester abortion. In cases of severe congenital abnormalities, the pregnancy must be endured with the knowledge that the child will not survive or will survive for only a few years with potentially very low quality of life.

An associated harm is the disempowerment of women in the process of reproduction. Medical genetic technologies are introduced as a component of reproductive care; however, throughout most of Latin America these services provide knowledge to women but fail to provide acceptable management options that meet the needs of affected women. Women who wish to abort the fetus but who do not have access to safe services are faced with the choice of exposing their own bodies to harm through unsafe abortion or of exposing their child to suffering in the future if the pregnancy continues to term. It seems likely that this medico-legal context leaves affected women feeling powerless during their own pregnancies.

### **Social Justice**

Second, this situation raises issues of social justice and equity. Even in countries where abortion for fetal abnormality is illegal, affluent sectors of the community can often afford to pay for a safe but illegal abortion within the country or for travel to procure a safe legal abortion in another jurisdiction. Horovitz et al argue that, in Brazil:

*Those who can afford to pay for a safe abortion usually choose to terminate the affected pregnancy with no health or legal consequences. On the other hand, for most couples the option is between*

*continuation of an affected pregnancy against their will, or an illegal and unsafe abortion, with its risks of social ostracism, prison, health damage, and even death.* (Horovitz et al. 2004, 114–5)

The burden of unsafe abortion falls disproportionately on poor women, who are restricted to local clinics or precarious “at home” methods. The quality of service provided in illegal abortion clinics, by definition, is not subject to government regulation and women are often charged additional fees for antibiotics and anesthetic. Poor women who cannot afford these ‘extras’ are exposed to greater pain and risk of infection. The choice faced by poorer women, between continuing with a pregnancy against their will or an illegal and unsafe abortion, is unacceptable when the standards for ensuring safe abortions are simple and well established (WHO 2003).

Unequal access to safe abortion according to socio-economic class unfairly restricts poor women's procreative autonomy—their “right to control their own role in procreation unless the state has a compelling reason for denying them that control” (Dworkin 1993, 148). The legal foundations for women's reproductive rights are built upon a variety of human rights recognized under international law (Center for Reproductive Rights 2003). Women denied safe abortion for fetal abnormality in developing countries are deprived of an element of control in their reproductive life that is readily available elsewhere in the world, and to the wealthy sectors of their own community.

### **Socio-Economic Burdens**

Third, it is widely accepted that raising any child with a congenital disorder places an additional financial and emotional strain on couples and health systems, and ‘unwanted’ children are no exception. Providing health care and support for children affected by genetic and congenital conditions places further demands on already scarce health resources. In the absence of comprehensive public health systems, the burden of care falls on families, particularly mothers. Again, it is likely to be families that can least afford this financial burden that are most likely to be faced with it, as they are unlikely to have been able to afford a safe abortion. Women who are already struggling financially will be particularly displaced by having to raise a child they had no choice but to give birth to. By contrast, access to safe abortion in cases of severe fetal abnormality, and the chance to establish a subsequent ‘healthy’ pregnancy if desired, may protect these groups from becoming increasingly marginalized.

In addition, the birth of ‘unwanted’ children with severe congenital abnormalities places further strain on already over-burdened public health systems in developing and middle-income countries. WHO consultants have argued that optimum reproductive counseling can take place only in the context of available and affordable contraception and abortion for congenital disorders, and available and affordable resources for caring for persons with disabilities (WHO 2001). Abortion for fetal abnormality is thus an important aspect of a comprehensive service to detect and manage congenital disorders. Research indicates that a large proportion of parents faced with the news that their fetus is affected with a severe abnormality choose to terminate the pregnancy (Ahmed et al. 1991). The subsequent reduction in the birth rate of children affected with congenital disorders will free up financial and health resources for the provision of a higher level of care for those children who are born with such conditions.

In making these points, we are not arguing that the socio-economic burden associated with congenital abnormalities is such that it would warrant all affected pregnancies being terminated. Such a policy would be eugenic and an invasion of women's reproductive autonomy. Access to



voluntary, safe and legal terminations and public resources for the care of children and persons with disabilities should sit side by side. Denying women terminations for fetal abnormality places an avoidable and unnecessary strain on limited health resources. The availability of safe and legal abortion for fetal abnormality therefore supports the decision of parents who wish to terminate and those who wish to continue with the pregnancy.

## **Responses**

Some supporters of the current system might respond that antenatal screening and prenatal diagnosis can provide a beneficial service for some pregnant women, irrespective of the availability of legal and safe abortion services. The provision of screening and diagnosis, when accompanied by appropriate counseling, can help families, particularly women, prepare for the birth of an affected child (El-Shanti 2001). Further, some congenital disorders can present challenges and risks during delivery and prior knowledge will allow the birth attendants to prepare for this occurrence in advance. As such, prenatal services can be beneficial for those women and families who would choose to continue with the pregnancy even when a congenital disorder has been identified.

We do not dispute this assertion—indeed we endorse it. The availability of abortion for congenital disorders should not preclude women from continuing with affected pregnancies. Quite the opposite is true—the choice to terminate a pregnancy should always be an informed and voluntary choice of a pregnant woman. All decisions to undergo screening and any subsequent termination must be appropriately informed (with access to unbiased information) and made in the absence of undue influence from health professionals or others. The availability of legal and safe selective abortion for affected pregnancies would remove the burden placed on women who do not wish to continue with the pregnancy, while allowing women who do wish to continue to plan for the birth and subsequent care of the child. The full utility of prenatal services is restricted if legal abortion for affected pregnancies is not available, because women who would use this advanced warning to terminate a pregnancy are not permitted to do so (Aguar 2004).

We submit that in Latin America, the prohibition on abortion for fetal abnormality has remained in place (despite the increase in prenatal genetic testing and some narrow jurisdictional exceptions) in part because well-educated women with financial means and influence are comparatively unaffected by the prohibition. Wealthy women can typically afford to procure safe (if illegal) abortions in private clinics or can travel to jurisdictions where abortion is legal. Therefore women with the greatest capacity to argue against these laws are least affected by them; whereas the women most affected by the laws have the least capacity to affect legislative reform. It is manifestly unjust that women with socio-economic resources may express their reproductive autonomy while poor women bear the burden of the current policies.

## **THE WAY FORWARD: DRAWING ON THE EXPERIENCE IN IRAN**

Recent experience in Iran demonstrates that religious objections to abortion are not necessarily intractable in the face of new scientific developments such as prenatal genetic testing.

Thalassemia is a recessive genetic disease that represents a significant health burden in Iran, with around 8,000 at-risk pregnancies and 2,000 affected fetuses per year (Ghotbi 2002). A premarital screening program to identify carrier couples was initiated in Iran in 1996, and a summary of the

program from 1997–2001 showed that on average 53 per cent of carrier couples still chose to marry despite the risk (Samavat and Modell 2004). Abortion for thalassemia was not available when the screening program began (Larijani and Anaraki 2008). But at-risk couples soon demanded access to prenatal diagnosis and the option of selective abortion of affected fetuses. This increased demand for abortion in the case of fetal impairment sparked debate among the public, religious leaders, and policy makers.

Following extensive public debate in Iran, religious scholars endorsed a threshold for termination of affected fetuses under 16 weeks (Hedayat et al. 2006; Aramesh 2007; Al Aqeel 2007). The Iranian prohibition on abortion was subsequently amended in 2001 to permit early selective termination of fetuses with thalassemia (Christianson et al. 2004). In 2005 the Iranian parliament ratified the Therapeutic Abortion Act which permits abortions in the first four months if the fetus has a mental or physical impairment or the mother's life is in danger (Larijani and Zahedi 2006). The Legal Medicine Organization has defined 51 fetal and maternal health conditions for which abortion would be permitted.

Iran is a predominantly Shiite Muslim country, with a legal system founded in Shiite Islamic law or shari'a. A democratically elected unicameral legislative body, the Majlis-e Shura, drafts laws which are then checked for consistency with contemporary religious ruling by the Guardian Council (a body comprised of six religious jurists selected by the supreme religious leader and six lawyers selected by the parliament) (Hedayat et al 2006; Aramesh 2007). Hedayat et al suggest that religious support for the new abortion law was motivated in part by recognition of the fact that 80,000 illegal abortions occur annually in Iran, and the financial hardship experienced by poor families coping with long-term serious congenital abnormalities (Hedayat et al).

The Iranian case demonstrates that the introduction of reproductive genetic services can increase demand for greater access to selective abortion, leading to the liberalization of abortion law in cases of fetal abnormality. A comprehensive nationally coordinated program of medical genetic services must consider the relationship between prenatal screening and testing, the legality of abortion, and the risks to women as a result of unsafe abortion (WHO 2006b). The failure to provide for legal, safe, accessible abortions for fetal abnormalities exposes women to serious but avoidable physical, legal, social, emotional and financial harm. A key aspect of the Iranian experience was the holistic engagement of affected families, epidemiologists, geneticists, religious scholars and broader society in public dialogue (WHO 2006b; Aramesh 2007).

#### AN ETHICAL 'DUTY OF CARE' TO FACILITATE SAFE ABORTION?

As unsafe and illegal abortion will harm women carrying fetuses with a congenital disorder, an obligation exists to minimize the degree of harm. A duty of care therefore arises for geneticists, physicians and health policy advisors and to address this situation.

Physicians have a duty of care to provide appropriate post-abortion care. However, research has demonstrated that it is common for women presenting at public hospitals in Argentina, who are hemorrhaging or suffering from life-threatening infections or injuries caused by unsafe abortions, to be denied appropriate care. This can range from verbal abuse from medical professionals, to refusal

to use anesthetic during post-abortion curettage, to failure to provide care at all (Human Rights Watch 2005):

*A woman [we work with] went to the hospital in a very bad state with an abortion and she was infected and hemorrhaging. A doctor started to examine her, and when he started to see her and realized, he threw down his instruments on the floor. He said: "This is an abortion, you go ahead and die!"—Social worker, Santa Fe Province (Human Rights Watch 2005, 2)*

In 2007, it was reported that public policy in El Salvador was to require doctors by law to notify the police if they suspect that a woman has undergone an abortion, although it was unclear whether this obligation was overridden by the medical duty of confidentiality (Hitt 2007). The emotional and physical abuse of patients at the hands of physicians is unacceptable in any circumstances. While health professionals are entitled to personal views about the morality of abortion, they have a professional duty of care to provide appropriate treatment for patients, including post-abortion patients, in their care.

Drawing on the experience in Iran, although we acknowledge there are differences between Islam and Catholicism, we argue that policy-makers throughout Latin America should initiate and support dialogue between affected families, relevant medical specialists and religious leaders in order to ensure that reproductive services, including prenatal screening and selective abortion, are implemented in a manner that maximizes the health benefit to patients and families.

Geneticists who provide PND see first-hand the emotional trauma and difficult moral decisions faced by affected women and families. Medical geneticists have a professional and ethical obligation to engage in this debate—to assist in educating the public, legislators and physicians about the medical features of congenital abnormalities that are being screened for, the quality of life of affected children, and difficult decisions faced by parents in these circumstances.

We have noted that women most affected by this situation are typically socially disadvantaged and poorly positioned to initiate dialogue and affect legislative change alone. It is therefore incumbent on the professionals who are responsible for introducing and administering new genetic technologies to use their positions to draw attention to the inequity and harm associated with the current policies.

## CONCLUSION

The ethical status of abortion will remain controversial for the foreseeable future. Our primary concern in this paper has been to highlight the specific ethical issues associated with the provision of PND without legislative protection to safe abortions in cases of congenital abnormality. PND cannot be treated as morally neutral technology. These services must be considered within the broader medico-legal context in which they are offered. We have argued that the sociological and ethical consequences of introducing this technology in countries with restrictive abortion laws deserve greater attention.

Offering prenatal diagnosis in a situation where abortion is unlawful places women (and their partners) in a situation of moral hazard. To offer a service, typically on a fee-for-service basis, where abortion is a spoken or unspoken possibility in case of detection of an abnormality, and where this

would be unlawful, places many poor women in the position of making an unjust choice: a choice between continuing with a pregnancy they do not want and cannot afford on the one hand, or exposing themselves to the legal, financial, social, emotional and physical risks of an unsafe abortion on the other hand. It is unjust to allow those who already enjoy socio-economic advantages to safely terminate affected pregnancies whilst letting the burden of unsafe abortion and/or the birth of children with congenital abnormalities fall in the lap of poor patients. The status quo may be comfortable for those with the financial resources to access safe abortion but it is morally unacceptable.

Data from Latin America indicates that more than 80 percent of women and couples who know their fetus is affected with a serious congenital abnormality choose to terminate the pregnancy. It is hypocritical to turn a blind eye to the fact that wealthy women may exercise their reproductive autonomy whilst denying poor women access to safe abortion services. Safe and legal abortion for serious congenital abnormalities must be a component of comprehensive medical genetic services that should sit alongside PND for fetal abnormality, and public resources for caring for children and persons affected with a disability. It is questionable medical ethics to report women to the police even where an illegal abortion has occurred or been attempted. Those who are responsible for introducing the technology and those who witness its implementation—geneticists, physicians, policy makers—should use their voices to represent the plight of poor women faced with the unjust choice between unsafe abortion and raising a child with a serious congenital abnormality for whom they do not believe they can provide appropriate care.

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## **Notes**

1. Note that worldwide data regarding abortion rates are notoriously incomplete. Due to the fact that induced abortion is restricted or illegal in many countries and many resource-poor countries lack the infrastructure for collecting data, global statistics regarding the prevalence of abortion, including unsafe and illegal abortion, can be estimated only indirectly. World Health Organization (2004) *Unsafe abortion: global and regional estimates of incidence of unsafe abortion and associated mortality in 2000*. World health Organization: Geneva.
2. In one of this paper's author's (FL) experience, it has been suggested that abortion for fetal abnormality would be acceptable in Brazil according to jurisprudential analysis, but that there is a serious lack of providers.

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## **Response to Open Peer Commentaries on “Prenatal Diagnosis and Abortion for Congenital Abnormalities: Is It Ethical to Provide One Without the Other?”**

Ballantyne, A. Newson, A.J., Luna, F. Ashcroft, R. (2009)

We thank all the commentators to our paper, but here limit our remarks to those that directly challenge our argument. We have critiqued an unusual policy context in which prenatal diagnosis (PND) for congenital abnormalities is available, but therapeutic abortion is not. We accept there are two potential solutions to this dilemma: (i) Removing PND services; or (ii) liberalizing abortion laws to allow abortion for fetal abnormality. For additional reasons, however, improved access to abortion is a preferable response to this problem. First, as several commentators noted, the rationale for PND is not always to procure an abortion (Kon 2009; Sperling 2009; Zivotofsky & Jotkowitz 2009). Second, women of means may simply travel elsewhere to access PND, just as they can travel now to obtain safe abortion of pregnancy. This would further entrench socio-economic inequalities in access to healthcare. Third, the removal of PND in countries with restrictive abortion laws would further increase the healthcare gap between developed and developing countries. Fourth, it is unusual for health interventions to be withdrawn after the public has accepted them as standard component of their healthcare, at least where they are safe and clinically effective. Therefore the current situation should be resolved by liberalizing abortion laws rather than removing access to PND.



Buccafurni and Chang (2009) interpret our argument as being motivated by cost-management. This is not our intention. Our argument is primarily motivated by women's reproductive freedom and the minimization of harm from the introduction of PND. We point out that allowing women and couples the option of aborting fetuses affected by a severe congenital abnormality could free healthcare resources to provide a better level of care for those families that are caring for an impaired child. We share their concern that this level of care is currently inadequate. Providing a socio-economic analysis of further marginalization was beyond the scope of our paper but it seems reasonable to claim that if an already poor family effectively has no choice but to have a child with a severe disability (who will require health intervention without adequate state support) then they will be worse off.

Sperling (2009) argues that our focus on legalizing abortion is misguided; that we assume the law is an impediment to people deciding whether to abort in cases of fetal abnormality when in fact this is not a salient factor. This critique misinterprets our argument. The law can limit access to safe abortion, but is rarely a determining factor for whether women do decide to abort. In fact we said that prohibition rarely leads to a reduction in abortion rates. We also disagree with Sperling's final claim that the status quo is acceptable because the benefits of access to PND without abortion outweigh the harms we have described. The psychological, financial and safety implications of the status quo suggest to us that this is incorrect.

Two commentators question whether our analysis is underpinned by assumptions about the lesser moral worth of fetuses with congenital abnormalities (Wasserman & Asch 2009; Buccafurni & Chang 2009). Buccafurni and Chang additionally hypothesize that despite accepting abortion for fetal abnormalities, we would not accept abortion for social sex selection. This appears to imply that sex does not confer lesser moral status, while impairment does.

Our argument does not carry the intention to eliminate disability, but to offer women full reproductive choice through having access to a range of interventions post-PND should they choose it. Admittedly, this may imply that it is worse to prevent abortions in the case of fetal anomaly than other circumstances; but this is because the hardships faced by women are likely to be greater, not because the fetus has lesser moral worth.

Wasserman and Asch (2009) also note that we have not shown that it is more harmful to raise a baby with impairment than an unplanned but non-disabled baby. Although we have not provided comparative evidence for this claim, we do assert that raising a child with a severe impairment in low-resourced middle- or low- income countries is likely to place greater strain on families than will raising an unwanted but non-disabled child. While this is not a necessary truth, in most such societies not only are "disablist" attitudes prevalent, support services, welfare payments, and impairment-minimizing environments are currently lacking or underfunded. To explain a wish not to assume this higher burden as implying disablist attitudes is to discount the moral salience of the prevailing material and structural conditions.

This response does not entirely overcome Wasserman and Asch's critique of our position, however, since much the same can be said about sex selection in sexist or misogynist societies. We do agree that abortion on the grounds of fetal sex is *prima facie* wrong where it involves injustice to women. There is however a difference between these two grounds for abortion (severe impairment, sex): in the former there is an implication that severe impairment will have significant medical and social implications for the baby, the parent(s), and public health; whereas even in the most sexist societies

it is not the case that having a daughter is medically problematic. In an anti-disablist society these may be equivalent. But in current society medical and public health perspectives are that, other things being equal, disability is something that couples should be able to choose to prevent.

On the other hand, social scientists have shown that PND may not only be interpreted clinically to detect abnormality but also culturally to reinforce that a first or second trimester fetus is a 'baby,' thus constructing the pregnant woman as already a mother, and the fetus as already having a personality and rights, reinforcing the notion of maternal responsibility over reproductive autonomy. We suggest that rather than PND without access to abortion being an unqualified benefit to pregnant women, it in fact constructs them more firmly in accordance with the prevailing cultural and social norms of motherhood. This is a delicate argument; but its essence is that it matters morally who offers PND, why they offer it, and what options it leads to; and that there is a morally relevant difference between PND initiated by doctors in connection with health promotion (medically conceived) and PND initiated by women in connection with sex for social reasons. How far that escapes Wasserman and Asch's powerful challenge is something we will have to take up on another occasion.

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