

## **More Options, Less Choice? Assessing the Desirability of a National Antenatal Down Syndrome Screening Programme in New Zealand.**

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### **Abstract**

Changes to New Zealand policy in regard to antenatal screening for Down syndrome have been mooted in recent years with increasing attention paid to the potential of medical and technical interventions to “improve outcomes”. While many argue that the introduction of a national screening programme might alleviate the problems apparent with the current regime, there are considerable social and cultural ramifications to the extension of these technologies, in particular the ways in which women’s choices are structured and constrained when pregnancy is experienced in the context of routine antenatal screening. These factors suggest that the extension of screening technology to all pregnant women may not be desirable after all.

### **Introduction**

Antenatal technology has not only improved rapidly in the last twenty years, but has moved from an intervention for vulnerable and “at-risk” pregnancies to an accepted, and often desirable, component of routine pregnancies. In recent years the use of antenatal screening and diagnostic procedures has come to the fore of health policy debates, with many arguing for a universalised screening programme for Down syndrome in particular. This paper explores the arguments for and against a national screening programme, and offers some insight into the ways that technological advances in antenatal testing have impacted on women’s experience of pregnancy. While there are a number of benefits to be gained from the ability to access antenatal tests, the discursive shift of broader social issues (such as disability) towards the domain of medicine is likely to increase medical control which could impede individual women’s ability to refuse screening and reject authoritative medical

expertise. Increasing medical dominance through routine screening therefore creates more 'options' but less 'choice' (Donovan, 2006) as to how women may conduct and experience their pregnancies.

## **Background**

Antenatal screening for Down syndrome in New Zealand is currently conducted on an ad-hoc basis, occurring on an individual practitioner level, or through self-selection. In the last year, the Ministry of Health has commissioned a literature review (O'Connell, Stephenson & Weir, 2006), an assessment of current practice in New Zealand (Stone & Austin, 2006) and established an advisory group to "provide advice on the potential for a national antenatal Down syndrome screening programme in New Zealand" (National Screening Unit, 2007).<sup>1</sup> The stated goal of any future screening programme in New Zealand would not be to reduce the number of babies born with Down syndrome in a given year, but to ensure that screening and testing practices take advantage of evidence-based research and provides the highest possible level of medical safety and protection for mothers and fetuses (National Screening Unit, 2006).

When screening programmes become universalised, however, it is difficult to maintain that their purpose is to provide women with reproductive choice, as the initial decision of whether the information is wanted or not is taken from individuals and placed in the hands of health policy makers. Screening programmes, then, are often underscored by public health rationales where the goal is to "reduce the burden of disability" (Kerr, 2004; see also Lippman, 1986). This is particularly obvious when cost-benefit analyses are included in decision making processes.

Once widespread screening and diagnostic testing are in place, the decision to refuse these tests cannot remain neutral, and implies "reluctance on the part of the expectant mother to do everything in her power to assure the health and wellbeing of her developing foetus" (Browner & Press, 1995 p.320). Speaking in the Finnish context, one

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<sup>1</sup> The report of the advisory council is now available (National Screening Unit, 2007).

medical professional commented that policy makers should act with caution: where the medical profession is highly regarded and trusted, whatever tests are offered will be taken up (Ettorre, 2002).

When screening programmes are introduced to a population on the assumption that medical knowledge and technological progress are inherently desirable aspects of human existence, without regard for the social, cultural, emotional and physical consequences for individual women, the problems they have set out to resolve will simply be replaced by new ones. This paper will explore some of these arguments, and attempt to illustrate why the extension of screening technology to all pregnant women may not be desirable after all.

### **Current practice in New Zealand**

While there are many different technologies available for antenatal testing, not all of these have been available in New Zealand, available consistently across different parts of New Zealand, or available to those without the means to seek private treatment (Stone & Austin, 2006). At present, it appears that a “normal” pregnancy in New Zealand would involve a Nuchal Translucency (NT) ultrasound scan between 11 and 13 weeks, although there are great disparities among different providers and across different areas (Stone & Austin, 2006). NT scanning is undertaken to identify certain abnormalities which can be observed in the foetus by comparing foetal measurements to standardised medians. Results from this scan are calculated against factors such as medical history and maternal age, and provided in the form of a “range result” – for example, 1 in 300 is considered to be “high risk” while 1 in 1000 is considered “low risk” (Ettorre, 2002). In many countries, other “non-invasive” tests such as serum testing for particular proteins and analytes also occur in the first trimester, but these procedures are as yet unavailable in New Zealand.

Ideally, only those women who receive a “positive” screening result – usually defined as greater than 1 in 300 – would be recommended for a diagnostic test such as amniocentesis or chorionic villus sampling (CVS). These tests are invasive, and have associated miscarriage rates of between

0.5% and 1.0% (where the background miscarriage rate is 2.0%) (Stone & Austin, 2006). In many cases, women with a “low risk” range result will nevertheless seek diagnostic testing on the basis that “that 1 is me” (Ettorre, 2002 p.64).

Statistics for National Women’s Hospital show that in 2002 more than 60% of amniocenteses were indicated on maternal age alone despite the availability of NT scanning, and despite evidence that this is not best practice (National Women's Hospital, 2003).<sup>2</sup> Furthermore, public funding for the procedure remains available for any woman over the age of 35, without the need for other medical indications (Stone & Austin, 2006). While most people would agree that a reduction in the number of unwarranted diagnostic tests is inherently a positive outcome, it does not necessarily follow that the extension of screening to all pregnant women is desirable.

### **Physical risks**

Ultrasound scans are often perceived by the public to be “benign”, “passive” or “harmless” and are therefore declined less often than other more “risky” interventions (Mitchell, 2001). Despite their routine inclusion in “normal” pregnancies, there are health risks associated with the procedure that remain as yet largely unquantified. Mitchell draws attention to the fact that research “has not demonstrated that ultrasound imaging is safe, rather a lack of risk has been assumed because no adverse affects have been demonstrated clearly in humans” (2001, p.39). Research has, however, shown reduced birth weights in monkeys, and reduced cell division in mice.

Despite this, ultrasound scanning remains a popular endeavour, with pregnant mothers in New Zealand having on average 2.1 ultrasound examinations per pregnancy, with 14% having none, and 15.4% having more than 4 (New Zealand Health Information Service, 2006). Unfortunately, these statistics do not reflect whether scans above 4 or more were medically indicated, or simply a result of consumer demand.

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<sup>2</sup> Equivalent figures are not available in subsequent reports.

For many of these women, ultrasound is not offered but assumed. There is often no chance to decline, no information about what is actually being screened for and certainly no expectation of written consent (Mitchell, 2001; Stone & Austin, 2006). One consequence of this is that prospective parents are increasingly expecting their first ultrasound image to be an opportunity for entertainment - to “see their baby” - and are ill-prepared to receive bad news (Williams et al, 2005; Mitchell, 2001). Mitchell (2001) suggests that to counter this problem, a more comprehensive programme of education and information for expectant parents needs to be implemented, and a national screening programme would go some way to addressing this. However, she also stresses the negative consequences of operating on the basis that all women are “at risk”.

### **A natural process**

Browner and Press (1995) argue that the rapid increase in the use of antenatal screening technology can be attributed to two separate factors: a widespread societal belief that scientific knowledge is truth, and society’s pre-occupation with risk. Babies are now brought into the world not just by women, but by medical experts, technologies and institutions (Mitchell, 2001). Pregnancy has become a time when most women are willing to readily accept medical control, and medical practitioners are able to ensure that women engage in ‘correct’ antenatal behaviour (Browner & Press, 1995; Ettorre, 2002).

While technology has rapidly advanced the ability of medical practitioners to assert control in the related spheres of conception, pregnancy, and childbirth (as well as many other aspects of human existence) the process of medicalisation was occurring well before the arrival of modern screening technology. For example, encouraging women to exchange home births for hospital births enabled medical practitioners to assert control over birth outcomes at a time when maternal and neonatal mortality was very high (Baker, 2006; Mitchell, 2001). As technology and procedures moved from the realm of experimental medicine to that of mainstream medical practice, medical and technological knowledge have become authoritative knowledge.

Under these circumstances, institutions provide the framework for “medical socialisation” where women are taught how to interpret particular signs and signals that occur within the pregnant body, such as bleeding or lack of movement. This is especially true in the case of first time mothers, or women with a weaker association to traditional cultural beliefs (Browner & Press, 1996). Oakley (quoted in Mitchell, 2001) argues that this “enables physicians to dispense with mothers as informants” and allows technological knowledge to undermine embodied knowledge, privileging the visible over the felt. This separates the pregnant woman from what is inside her, and further encourages her to look to medical institutions and technology for answers rather than trusting herself – for example seeing an ultrasound scan as “proof” of pregnancy rather than her sore breasts or missed periods (Mitchell, 2001).

This is not to say that women do not play a role in their own medicalisation. For many women, scientific knowledge about their pregnancy is socially convenient, for example having an accurate expected delivery date, or early knowledge of twins. In many cases women are able to assess and incorporate authoritative knowledge against their own embodied knowledge, and negotiate some control over their pregnancies. Ideas and advice that can be incorporated into their existing belief structures and “personal stocks of knowledge” (Kerr, 2004 p.81) are more likely to be taken up than those which can not.

Should we assume then, that women will be able to say “no thanks” to antenatal screening? Many sociologists argue that even when individual women retain some control over their pregnancies, medicalisation leads to a “narrowing and structuring of choices” where the environment for decision-making changes such that behaviours that were once commonplace now take place in a morally charged atmosphere (Baker, 2005; Browner & Press, 1995; and Rothman, 1988 among others). Where hospital birth is routine, the decision to give birth at home becomes more difficult; where medically assisted conception is routine, the decision to remain child-free becomes controversial; and where antenatal testing becomes routine, the decision to remain unenlightened becomes virtually untenable.

## **What does antenatal testing really offer for prospective parents?**

The National Screening Unit (National Screening Unit, 2006) is adamant that the introduction of a screening programme is “not about reducing the numbers of babies born with Down syndrome, but about ensuring that screening services offered to women during pregnancy do not cause unnecessary harm to women and their pregnancies”. If antenatal screening programmes are not about improving public health outcomes, but for the wellbeing of mothers and foetuses, what do they really offer pregnant mothers and their partners?

As expected, economic analyses tend to assume that the only benefit to be gained from antenatal testing is when a foetus which is (probably) affected is able to be aborted (Mooney & Lange, 1993). While this benefit should not be underestimated, are there other less tangible aspects of antenatal testing that could have a positive effect on women and their pregnancies? Proponents of the technology usually cite reassurance, knowledge, preparedness, more choice and more control as personal and societal benefits of antenatal screening.

## **The choice is yours**

What choices do women really have, if the choice to screen or not is virtually taken out of their hands? Rothman (1988) describes this as a trap, rather than a choice. Medical ethics tend to suggest that genetic screening is only ethical if effective 'treatment' is available which further leads to the assumption that a woman ought to end an affected pregnancy (Mooney & Lange, 1993). Even where medical practitioners do ensure the availability of real choice, a woman who refuses testing and gives birth to a Down syndrome child suffers guilt and regret that would not exist if the choice had not been available to her (Mooney & Lange, 1993).

Decisions about which tests are available and to whom are made by scientists and clinicians on behalf of pregnant women, but it is pregnant women who are left with the responsibility about which particular “choice” they make (Kerr, 2004). By and large, the only choice remaining is what action will be taken if diagnostic results are positive, and it is hard to imagine a more difficult decision to make. Any woman’s decision will

be based on her societal, cultural, and family background, as well as her own reproductive history, and her aspirations for this particular pregnancy (Rapp, 1998). Rothman (1988) points out that it is not necessarily knowledge about the foetus but about the society we live in which influences our decision making. Circumstantial availability of welfare payments, respite care or insurance payments along with potential family and community support will influence the decision, and even religiosity can extend to a degree of practical and emotional support rather than just ideological influence (Rapp, 1998).

Albert (quoted in Kerr, 2004) describes this “choice” well:

While women should have free reproductive choice, that choice is anything but free in relation to disability. It is heavily circumscribed by cultural, social and economic pressures which work powerfully against a woman’s right to choose to continue with a pregnancy after an ‘abnormality’ has been detected.

Women shoulder the full responsibility for both terminated pregnancies and for “defective” pregnancies that are “allowed” to become children (Rothman, 1988). A woman’s emotional attachment to her foetus is much stronger than her partner’s - it is she who has felt movement and she who literally created the “problem” inside her (Browner & Press, 1995). While abortion for genetic reasons is often more socially acceptable than abortion per se it is equally problematic psychologically, and often more public. As amniocentesis cannot be performed safely until 16-18 weeks, results are not available until well into the second trimester. Abortions performed at this late stage more closely resemble the stillbirth of an infant, rather than an early abortion of a “foetus”, and involve pain and discomfort similar to labour pains (Williams et al, 2005). There is also a societal tendency to gloss over the fact that despite the avoided “tragedy” of a disabled child, there is still the tragic loss of a wanted pregnancy and a wanted child (Rothman, 1988).

For women who choose to continue with affected or likely-to-be-affected pregnancies, and give birth to a Down syndrome child, there are powerful social consequences. These consequences are likely to increase with the universalisation of antenatal screening, and families may find that there is less public and community support for disabilities which

might have been “avoidable” (Kerr, 2004; Mooney & Lange, 1993). Rothman (1988) expects that societal discourse will come to reflect the sentiment that “she chooses, and so we owe her nothing”.

### **Too much information?**

Western societies place a high value on individual autonomy and the availability of information which enables our autonomous decision making (Bennett, 2001; Browner & Press, 1996; Ettore, 2002). The value of information in pregnancy is often celebrated, but our “professional and cultural disposition to support medical progress” (Kerr, 2004 p.73) can lead to questions being answered that women have not asked, and are not prepared for. We seldom pause to question whether or not an information-providing technology ought to be used solely because it exists.

Many prospective parents, particularly those from a lower socio-economic or non-English-speaking background, may have no prior knowledge regarding the possibility of foetal abnormalities and in this sense screening alleviates only those anxieties it has helped to create (Browner & Press, 1995). For women who do have prior knowledge, expectations of antenatal testing and what it can offer them can be unrealistic (Williams et al, 2005). The information they are provided with may leave them with doubts about conditions that have not been tested for, or expecting that their foetus can be “cured”. Conversely, women may be given false assurances by a “negative” result, believing that their foetus has been pronounced healthy.

A “low risk” prognosis in initial screening, although ostensibly providing comfort and reassurance to expectant parents, often has the opposite result: many women will seek diagnostic testing in spite of their low risk (Williams et al, 2005). Similar findings led to the withdrawal of funding for second trimester serum screening in New Zealand when pilot studies found that a range result was not able to provide reassurance to expectant mothers even when it was considered to be “low risk” – the screening was therefore considered to be of limited value (Paterson, 2006). The questionable value of information is best demonstrated by

Mitchell's study (2001) which found that women with backgrounds in biological sciences, and therefore more scientific knowledge than the average pregnant woman, were equally unlikely to find comfort in supposedly reassuring results.

The result of these uncertainties, and the creation of anxieties that may not have existed prior to testing, is what Rothman (1988) terms the "tentative pregnancy". The first half of the pregnancy is spent waiting for test results, and avoiding commitment to either the pregnancy or the potential infant, until doctors have given the "all clear". Women become unable to find reassurance in their own bodies, and become dependant on a medical narrative of their pregnancy. They become reluctant to announce their pregnancy to family and friends, and less likely to publicly display their pregnant body by switching to maternity clothes. The fears that haunt these women's pregnancies have only existed since testing became available.

### **Focusing on the foetus**

Many argue that despite the lack of reassurance offered by antenatal screening, many women appreciate the sense of control that can be gained by discovering as much information about the foetus and pregnancy as possible. The process of medicalisation, as discussed above, encourages both pregnant women and society at large to "take full advantage of human intervention to minimise risks" (Browner & Press, 1995).

Mitchell (2001) argues that in the quest for control over their pregnancies, women have actually increased the potential for control by others. Ultrasound has been shown to increase women's levels of medical compliance, and resolve any final "ambivalence" a woman may have towards her pregnancy (a plus for anti-abortion campaigners). There is also potential for foetal health and wellbeing to be privileged above and beyond the needs of the pregnant patient – something that individual women may be willing to sacrifice for their children, but is problematic on a societal level.

Browner and Press (1995) see society's "ubiquitous scrutiny" of pregnant women as reason to believe that women have less control over their pregnancies than they would probably like to think. Rothman (1988)

questions whether women have any rights during pregnancy, or whether the foetus takes precedence? Unquestionably, pregnant women are now expected to undertake all activities in their power to ensure that their babies are born “normal” and to abstain from all “risky” behaviours (Browner & Press, 1995). Ettorre (2002) refers to this as “reproductive asceticism” where women’s bodies are seen almost as irrelevant when the health of the foetus is at stake, but at the same time are constantly under surveillance.

The very language that is used in this field denotes a certain preoccupation with the not-yet-born – i.e., “antenatal” (natal, as in, to be born) as oppose to “ante partum” (partum as in parturition, to give birth). This can also be seen in the medical literature when pregnant women are referred to as the ‘maternal environment’ or ‘foetal environment’ (Ettorre, 2002). Rothman (1988) points to the word *teratogenic* (a drug or other substance capable of interfering with the development of a foetus, causing birth defects) and its root word *terato-* (monster) to demonstrate the highly emotive context in which women conduct their pregnancies.

A focus on the foetus poses its own risks – that women become merely a “carrier”, or someone who could potentially be a barrier to providing optimum care for the foetus or future infant (Rothman, 1988). It creates dichotomies between carrier/non-carrier, low-risk/high-risk, afflicted/unafflicted and creates hierarchies between women who are “good” reproducers and “bad” reproducers (Ettorre, 2002). It also creates novel ethical dilemmas regarding medical consent – most treatments require informed consent, and in many cases written consent. Bennett (2001) notes that a higher level of coercion appears to be acceptable in pregnancy due to exceptions for “third party harm”. It is difficult to quantify exactly what “harm” to a foetus ought to entail, and it is a misnomer to say that harm is prevented when in fact what you have prevented is life.

Rothman (1988) argues that antenatal testing carried out under the auspices of “control” does not prepare expectant mothers and their partners for the reality of being a parent, whose child could suffer any number of medical or accidental misfortunes at any time after or during its birth, or be born with a condition that cannot be tested for. One clinical

geneticist interviewed by Ettore (2002) reiterated this view, stating that “if you don’t want to take a risk, you should not have a baby”.

### **Improving standards of production**

The view that screening programmes are not introduced for the benefit of pregnant women and their families but on a public health basis is supported by a New Zealand National Screening Unit (2003) document that states, “screening programmes are population health programmes and, as such, they are planned, funded, delivered and monitored from a population health perspective”. What, then, are the expected population health benefits of an antenatal screening programme? Rothman (1988) argues that the logic of industrialisation has led to the belief that “improved standards of production” can be achieved across all areas – including human reproduction - which inevitably leads to comparisons with eugenics.

Eugenics programmes were popular in the early nineteenth century as a way of “weeding out” the genes of those persons who displayed undesirable social characteristics, and often involved forced sterilisation of “bad” reproducers (Browner & Press, 1995). Policy makers and practitioners emphasise the element of individual choice within antenatal testing, however there does appear to be some danger that this kind of systematic testing could lead to not only an informal lack of choice but an institutionalised regime where women are no longer able to make choices about foetuses which have been diagnosed as “defective”, as is the case in China where the law requires that these foetuses be aborted (Su and Macer, 2005).

Regardless of who makes these choices, is it appropriate that anybody is able to “set standards for entry into the human community” (Williams et al, 2005)? There are certainly negative aspects to this commodification of children, and many see antenatal screening as a “slippery slope” leading towards selective abortion for minor impairments or for gender selection – gender is, after all, a “diagnosable chromosomal condition” (Ettore, 2002; Rothman, 1988).

### **Is a national screening programme desirable?**

It is easy to agree with Stone and Austin's (2006) analysis of the current screening situation in New Zealand as a "physical, emotional and social risk to families". Screening is offered to women as lead maternity carers (LMCs) see fit, and frequently not discussed with women at all. Screening that does occur is not always in line with international best practice, and many services are not offered at all (Chang, 2006). The failure to fund second trimester screening disadvantages those women who present later in pregnancy, which disproportionately impacts upon Maori and Pacific Island women (Low et al, 2005). As at 2006, none of New Zealand's District Health Boards had developed their own guidelines regarding screening for Down syndrome, although several had guidelines with regards to invasive diagnostic testing (Stone, 2006). It is not surprising, then, that surveys conducted among practitioners show an astounding lack of knowledge with regards to screening and diagnostic practices.

This information suggests a need for widespread education of both practitioners and expectant mothers. It suggests that eligibility and funding regimes need to be updated to reflect international best practice. But it does not necessarily reflect a need for a national antenatal screening programme. Any move towards universalising and routinising antenatal screening sends an implicit message to mothers that undergoing screening is the "right" thing to do (Bennett, 2001; Williams et al, 2005). As Kerr (2004) points out, "the very screening programmes which are promoted on the basis that they will extend choices to more women can actually reduce them".

The National Screening Unit (2005) states that screening occurs when those

...who do not necessarily perceive they are at risk of a disease or its complications are offered a test, to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications.

A universal screening programme would mean that women will have to actively resist screening if they wish to remain "blissfully ignorant"

about their pregnancies. Women who are screened “by default” who believed themselves not to be at risk, would have all the anxieties discussed above conferred upon them by information that they may have preferred not to know. All women will be subjected to difficult decision making as to what level of risk is acceptable to them, what risk of miscarriage is acceptable to them, and what decisions they would make about a potentially affected foetus. All pregnancies would become “tentative” until after the results of whichever tests were being offered and an “unobserved pregnancy” would become virtually impossible (Rothman, 1988; Donovan, 2006).

## **Conclusions**

While it is vitally important that women be educated about the possible risks posed to themselves and their foetus during pregnancy, it is also of vital importance that women are able to make informed choices about the level of information they wish to receive, and that informed consent is sought before any medical procedure is conducted. While the current state of screening and diagnostic testing in New Zealand is certainly not ideal, the introduction of a universal screening programme may not address all of the current concerns, and will certainly raise new ones.

The medicalisation of pregnancy has the potential to reduce women’s autonomy over their bodies and decrease their ability to decline tests or treatments that are considered to be in the best interests of the foetus. This increases concerns that the health issues of foetuses may be privileged over the interests of pregnant women. A universalised screening programme may also reduce women’s ability to question the value of medical information and place their trust in personal and cultural knowledge structures in relation to pregnancy.

Far from providing reassurance and control to parents, the above discussion suggests that screening can often increase the anxiety of prospective parents and further distance pregnant women from the notion that pregnancy is a routine life course experience. The widespread availability of ultrasound scans is appreciated by many parents, and is often considered an especially important way to facilitate men’s

involvement in pregnancy, but its health impacts are still largely unknown. This is particularly concerning given the number of women who undertake ultrasound scans for purely “recreational” reasons, and the fact that written consent is usually not sought.

Finally, many groups fear that the universalisation of screening for Down syndrome will gradually erode support for social services and increase the stigma attached to parenting a Down syndrome child. It is of the utmost importance that these social, psychological and cultural factors are included in any revision of current and future screening policies in addition to those factors accounted for under the medical paradigm.

### **Author's Note**

Since this paper was first written, several key documents have been released, including the Bioethics Council report *Who Gets Born?* The impact of these documents is as yet unknown, however the Bioethics Council's report in particular seems to be framed within a presumption of continuing and increasing medical intervention in conception and pregnancy.

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