JILL JOLLIFFE ON HOW THE ADOPTION INDUSTRY EXPOSED WOMEN TO CARCINOGENS

The tumult and the shouting has died down since Julia Gillard delivered a formal apology to the victims of forced adoption, but the single mothers whose children were taken and the thousands of adoptee children affected have not forgotten their pain. It was alleviated by the apology, but big challenges still lie ahead for the adoption community. Not least among them is how a carcinogenic drug so dangerous that today it is legally restricted to use by vets for treating urinary incontinence in dogs was routinely administered to birthing single women in Australia's leading hospitals.

The synthetic oestrogen *diethylstilboestrol*, known by the acronym 'DES' or as stilboestrol, was administered to single mothers without informed consent in hospitals where unmarried women gave birth. Among them were the Crown Street Women's Hospital in Sydney and the Royal Women's Hospital (RWH) in Melbourne, with the latter – on its own admission – using the drug from 1941 to 1971. The aim was to suppress lactation so as to prevent the mother bonding with her baby, thus breaking down resistance to signing adoption consent forms in the days after the birth. According to the *2012 Senate Committee Report into Former Forced Adoption Policies and Practices*, which led to

the Gillard apology, the RWH arranged over 5000 adoptions between 1940 and 1987.

Dr Geoffrey Rickarby, an adoption expert and psychiatrist who has dedicated his life to counselling troubled victims of forced adoptions, told a NSW inquiry that doses of stilboestrol were often reinforced by barbiturates such as sodium pentobarbital, amobarbital and chloral hydrate, and that these were intended to make patients drowsy and therefore more likely to sign adoption consent forms. Ample direct testimony from the women themselves was tabled in the 2012 Senate Committee report.

According to Rickarby, the stilboestrol was given initially by injection – later doses were given by mouth – soon after single mothers delivered their babies. Rickarby told the NSW inquiry that the 'first injection was usually given in the labour ward, or shortly thereafter, and continued in vigorous doses throughout the week.'

Although the RWH apparently avoided giving mothers in the 1950s stilboestrol while they were still carrying the baby, there is no available information on the practice during the 1940s, when pregnant women worldwide were prescribed and took the drug to prevent miscarriages (for which it was wrongly indicated). The RWH is currently monitoring around 200 women in its dedicated DES Follow-up Clinic, although it is not clear from its website whether these are children of the hospital's ex-patients.

Stilboestrol belongs to a category of chemicals known as endocrine disruptors (a category that includes the defoliant Agent Orange, whose use in the Vietnam War produced a generation of severely disabled children). Stilboestrol did suppress the mother's milk, but if administered while the patient was carrying the baby, the drug, like thalidomide, could have pass through the placental barrier and harmed the child as well as the mother. Adoptee children of women exposed to DES have become known as DES daughters or sons; their children, to whom the effects can also be transmitted, are known as DES granddaughters or grandsons. These children were likely to be born – and are still being born – with genital and urinary tract deformities, with DES daughters more likely than other women to suffer infertility and ectopic pregnancies in adulthood, and DES sons at higher-than-average risk for undescended testes, testicular cancer, epididymal cysts and low sperm counts.

Women given stilboestrol were found to have suffered a probable direct effect, showing a higher incidence of breast cancer than the average population, as well as a range of gynaecological problems such as infertility, ectopic pregnancies and ovarian cysts. In a 2013 study in the British medical journal *Embryo Today*, Casey Reed and Suzanne Fenton observe that 'case-control studies ... have found that there is a slight, but consistent and significant 30–50 percent increase in risk for ... breast cancer in DES mothers'.

But it is the children taken for adoption who are the greatest concern. The most dramatic danger for DES daughters and their children is that of developing an invasive rare cancer known as clear-cell adenocarcinoma (CCA) of the vagina or cervix. Doctors fear that there may be an increase in the rate of this cancer as the baby-boomer generation advances to the fifty-plus age bracket, the age when women on average tend to develop cancers.

Furthermore, mothers subject to doses of stilboestrol while giving birth may, all these years later, still be ignorant of the identity of their stolen children who, in turn, cannot know whether or not their mothers were exposed to DES.

For Aboriginal women, the tragedy is heightened. Their treatment in unmarried mothers' homes and state hospitals adds a

new layer to the history of racial inequality in Australia. During the heyday of forced adoptions (from the 1940s to the 1970s), a new generation of Aboriginal mothers had their children stolen from them. The reason given was not racial but 'moral': their pregnancies made them 'fallen women'.

These young Aboriginal women were likely to spend their confinement in harsh institutions. In Melbourne, they could expect to be sent to the Salvation Army's Haven

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Maternity Home or work without pay in the industrial laundry at the Abbotsford Convent. In Queensland, pregnant Aboriginal girls worked at a similar laundry at the Holy Cross Retreat and Girls' Home in Wooloowin, an offshoot of Ireland's infamous Magdalene Laundries.

When it came time to give birth, they were generally admitted to city hospitals that had an established routine of removing babies for adoption, whisking them away before the mothers could see or hold them. Like other single mothers, the women were sometimes shackled to beds, their view of the newborn obstructed by suspended sheets.

Under the patchwork of state adoption laws in force at the time, mothers were generally given thirty days to sign their consent, with an embargo on the baby's removal in the five days after the birth. But the law was often flouted: many women have testified that their babies were taken straight from them in the labour ward, after which they were told to go home.

These converging black and white adoption narratives accentuate the problems facing the Australian adoption community; individuals' emotional trauma is often heightened by difficulties in tracing family members and in learning medical histories in relation to DES. This near-impossible task is compounded by the fact that hospitals consider it impractical to preserve medical records for long periods because of their bulk. The RWH's admission that it gave women stilboestrol is important to the health record of former patients, but the ward notes that record the dates, times and quantities of medications have not been kept.

In its submission to the Senate Committee inquiry, the RWH defended itself against the charge by DES Action Australia that it 'sometimes administered [stilboestrol] to overdose, without informed consent, to former forced adoption victims':

> While interviews, neonatal paediatric lecture notes, and medical records confirm the use of oestrogen as a lactation suppressant at the RWH between 1941 and 1971, neither accusations of nor evidence of overdose have emerged.

In other words, the hospital admitted to the long-term use of DES but dodged dealing with its implications by rebutting a secondary issue: its alleged use in overdose.

There were some angry responses from adoptees and affected mothers when former hospital CEO Dale Fisher attached a qualifying letter to the hospital's official submission. In it, Fisher denies allegations that the hospital treated unmarried mothers differently to other women giving birth at the hospital, arguing that there is no evidence to support this claim:

> [The hospital's internal investigation] found no evidence of illegal practices at the RWH and no evidence of hospital-wide policies that discriminated specifically against single mothers.

In response, the Senate Committee interviewed seven single mothers as well as a former nurse haunted by memories of removing newborns from their mothers; all those interviewed had been at the RWH between 1959 and 1974. Based on the testimony it heard, the Senate Committee questioned the veracity of the hospital's denial:

> In light of the evidence it has received in relation to practices at hospitals such as the Royal Women's, the committee queries whether the conclusion that it could find 'no evidence of illegal practices at the RWH and no evidence of hospital-wide policies that discriminated specifically against single mothers' may be premature.

In the aftermath of the Gillard apology there has been increased interest in forced adoption, with issues of identity still looming large. For every person who has been reunited with a lost parent or child, there are many more who have not identified or located the family members they seek. According to one health professional who does not wish to be named, there have been 65 000 adoptions in Victoria since 1928, but 'more than half [of those adopted] may not have come forward to the Department of Human Services to get their information [original birth certificates showing names of parents]'. This ball-park figure suggests that over 32 000 members of the adoption community in Victoria do not know the identity of their lost children and have no names to guide them, with adoptees equally ignorant of their parents' identity. They may not even know they were adopted as children, let alone of their exposure to DES.

Controversy surrounding stilboestrol's use in the US peaked slightly earlier than in Australia. This is partly because the Australian adoption industry remained closed to scrutiny until 1973, when the bottom fell out of it with the introduction of the Supporting Mother's Benefit, one of the many significant reforms enacted by the Whitlam government. Unmarried mothers began to refuse to give their babies up for adoption; raising children alone was now a viable economic option, and unmarried mothers no longer had to suffer the indignities of maternity homes.

By contrast, health authorities in the US, Canada, the UK and the Netherlands have been dealing with the after-effects of stilboestrol for over half a century. There have also been a number of successful class actions in these countries in favour of women injured by the drug.

Feminist health pioneer Barbara Seaman details the history of DES use in her 2003 book *The Greatest Experiment Ever Performed on Women*, describing how oestrogen-based drugs were introduced to the US market in the 1940s and became fashionable with American women, who embraced them as the fountain of youth. Labelled as safe for pregnant women, the drugs were prescribed not only to prevent miscarriages but as oral contraceptives, in hormone replacement therapy, to ameliorate morning sickness, to prevent the hot flushes of menopause and to iron out wrinkles. Seaman reports that warnings were first sounded between 1939 and 1940, when a series of articles were published in the *American Journal of Anatomy* on animals born of mothers treated with oestrogen during pregnancy. Female rat offspring had enlarged uteruses and structural changes in the ovaries, while males had 'small, improperly developed penises' and other changes to their reproductive organs.

Over a decade later, in 1953, Dr William Dieckmann of the University of Chicago published findings warning against the prescription of stilboestrol for pregnant women. Between September 1950 and November

1952, Dieckmann recruited over 2000 women (this number was subsequently reduced to 1646) to run a double-blind trial of DES's effectiveness in preventing miscarriage. He found that the 840 women who had taken stilboestrol actually had a slightly higher rate of miscarriages than those in the placebo group. Despite this, the pharmaceutical companies' relentless marketing meant the drug continued to be prescribed for another eighteen years.

The treating of pregnant women with stilboestrol also went against the warnings of Charles Dodds, the British biochemist who had published the formula in 1938. German scientists had been copying Dodds' work and later tested synthetic oestrogens on Auschwitz prisoners. He had his own misgivings about dangers the drug might present but rushed to publish the formula in the British journal *Nature* so as to put it in the public domain and prevent the Nazis patenting it for racial-cleansing programs. Dodds had never intended stilboestrol to be given to healthy women: it was, he told Seaman, designed to treat oestrogen deficiency.

Dieckmann's report was a substantial blow to the pharmaceutical industry, but the man who clinched the case was Arthur Herbst of Harvard University. In 1971, he published an article in the *New England Journal of Medicine* reporting seven cases of a rare vaginal CCA in adolescent girls and young women, described as 'an unprecedented medical occurrence'. By careful research into medical records, Herbst and his team proved that all seven had been exposed to DES in the womb.

In response to their findings, Herbst and his Harvard colleagues established the Registry for Research on Hormonal Transplacental Carcinogenesis, which was subsequently relocated to the University of Chicago. The goal of the registry was 'to collect information on all cases of cervical and vaginal clear-cell carcinoma arising in women born after 1948'.

The establishment of an advertised registry to which women with DES-related disorders could report for help allowed researchers to uncover information about where they were born and attempt to match patients with medical records from their birth as well as doctors who might have treated them.

Herbst's breakthrough was immensely significant. In April 1971, the US Food and Drug Administration finally issued an alert against the use of DES for pregnant mothers, with Australian authorities also advising against its prescription. Herbst's next move was to set up a project to identify and locate DES daughters as an urgent priority, a model that could well be applied in Australia today to rectify the tangle of lost identities and medical records that bedevil the issue.

In 1978, a national DES Task Force was established by the US Department of Health, Education and Welfare, and physicians nationwide were asked to review their files and notify women who had been prescribed the drug while pregnant. A public health campaign also resulted in an upsurge in television and press reports.

In 1992, the Chicago registry was replaced by the DES Follow-Up Study, which joined up existing study groups to form one large cohort, thus allowing for the controlled monitoring of thousands of people. It included DES-exposed men and women as well as control groups in a project following more than 21 000 cases. The study's website describes the project's rationale:

> [O]ne of the major problems in studying DES is establishing a cohort with proof of exposure. DES exposure typically occurred up to 30 or more years ago and most prenatal records have been destroyed ... Therefore, the DES

> Follow-up Study … represents the only remaining opportunity to study DES health effects on a population followed over a period of time.

Once the connection was made between the drug and cases of cervical and vaginal CCA, American health planners acted to protect those at risk. The latest update from the Atlanta-based Center for Disease Control and Prevention, in March 2013, gave the relative risk of DES daughters contracting this rare cancer as being 40.7 times greater than in the general population.

There are evident differences between the American and Australian experiences: adoption practices were not part of the main problem in the US, where stilboestrol was a component in drugs promoted to regulate hormonal problems. Women often opted enthusiastically to use them, even as profit-driven drug companies failed to test and market their products in a responsible way. In Australia, on the other hand, hospital staff used stilboestrol as an instrument of social engineering, administering the drug to unwitting volunteers.

Having admitted to administering stilboestrol – but still denying any legal liability in the matter – the RWH has taken action to remedy the practice's after-effects, establishing and operating the only dedicated medical clinic in Australia for those exposed to DES, either as mothers or babies. According to Dr Ross Pagano, the clinic's medical director, he is currently treating 200 DES daughters, with a commitment to accompany their cases life-long.

In August 2011, *DESPATCH*, the newsletter of DES Action Australia, ran a statement by Pagano calling on all young women to have annual PAP smears to ensure early detection of cervical cancer: 'Given the long-term gynaecological health of DES granddaughters is not known, the most sensible and safest option is for them to be screened annually.' He also notes that he has been seeing more young women presenting with cervical glandular cell abnormalities and that these may be on the increase, though he does stress that this observation is a 'gut feeling' based on clinical experience rather than scientific research or statistics.

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The Australian Institute of Welfare and Health lists 176 cases of CCA between 1982 and 2013, based on figures from regional cancer registries. It is probable that, given public ignorance about this disease and its causes in Australia, it is still under-reported or misdiagnosed. In the early days of the dedicated CCA registries in the US, the figures sat at double-digit numbers for long periods until the matching of children separated from mothers gained pace through research into hospital and birth records, after which they rose dramatically.

It is, sadly, too late for many who were directly exposed to DES in Australia, but urgent action can still be taken to raise awareness about the intergenerational effects of the drug and to identify those who may be at risk of developing CCA and other after-effects.

The RWH website has a series of fact sheets on the effects of DES exposure and information on how to seek a referral to its DES Follow-up Clinic in Parkville. Any DES daughters with doubts about their health status should consult them; the clinic advises that CCA of the vagina or cervix resulting from DES exposure 'can be treated successfully if diagnosed early'.