

# Making sense of proposed changes to the HART Act through the lens of reproductive justice

George Parker, Strategic Advisor

The Advisory Committee on Assisted Reproductive Technology (ACART) has recently undertaken a series of consultations that asked how New Zealand should manage the import and export of gametes and embryos. The Committee was particularly interested in whether regulations should allow the import of gametes and embryos sourced in circumstances that do not comply with the principles and requirements specified in the Human Assisted Reproductive Technology (HART) Act1, which governs the use of Assisted Reproductive Technologies in New Zealand, in order to help address gamete shortages in New Zealand. New Zealand's regulatory framework for ARTs is relatively conservative by global standards, requiring altruistic donation of gametes and surrogacy and prohibiting anonymous donation. These requirements are argued by fertility providers to contribute to the shortage of gametes (in particular eggs) as well as willing surrogates in New Zealand and thus the appeal of importing gametes sourced from countries with more permissive, or no such regulations. Alternatively, ACART asked whether New Zealand should increase the levels of donor expenses available to increase supply of locally sourced gametes, raising the bigger question of whether the reliance of New Zealand fertility services on altruistic donation rather than commercial incentives will be able to be sustained given current and future

Women's Health Action has had a long history of interest and involvement in ARTs and their regulation. The starting place for our position on ARTs is the recognition of female infertility as an important and growing women's health issue and the important role ARTs play in the treatment of infertility. We also recognise that motivation to use ARTs extends beyond the treatment of infertility, offering procreative potential to queer and gender diverse people; single women; women undergoing chemotherapy; women who want to delay childbearing, and for those couples who want

to use pre-implantation genetic diagnosis to screen against disability2. Acknowledging that an estimated 1-4% of all conceptions are due to ARTs we have come to hold a pragmatic acceptance that ARTs are now an integral part of the women's health landscape. However, we believe that the debate about ARTs has a tendency to be overly focused on questions of morality, the personhood of embryos, and commerce rather than concern for women's health - both those undergoing IVF and the women whose reproductive material and embodied labour are used in ART procedures. We believe it essential that women are able to make fully informed choices, including understanding the medical risks involved, when they engage with ARTs either as donor or recipient whilst recognising that "choices" can be constrained through, for example, desperation to have a baby, familial or friendship bonds, and providers' conflicts of interest. It is also clear that access to these technologies - both publically funded and private- is currently strongly delineated by socio-economic status, ethnicity and along other axes of difference amongst New Zealand women, privileging heterosexual, partnered, Pākehā women with higher incomes3. Thus, while ARTs have created hopeful new possibilities for reproduction, they also require that we pay attention to issues of health, ethics, law and policy including: health equity in access to services, the potential health and psychological effects on women and children, the potential for the devaluation of the lives of people with disabilities, the potential for exploitation in commercialised reproduction, and discrimination against LGBTQI individuals

In pursuit of a framework for making sense of the complexities of ARTs, and in order to develop a position that progresses social and gender justice, we employ the intersectional feminist lens of reproductive justice<sup>5</sup>. Reproductive justice was first articulated by women of colour and indigenous women

Vol. 19 · Issue 3 · Spring 2015

### **INSIDE:**

- Strategy for the Health of Older Persons
- Breastfeeding and Working
- Big Latch On 2015
- Cartwright Symposium

in the United States, out of frustration that the prevailing (white) feminist paradigm of reproductive autonomy, choice and rights failed to account of the full spectrum of factors impacting women's lives and ability to control their reproductive destiny. Reproductive justice offers a model that emphasizes the structural inequalities that affect women's reproductive health and their ability to control their reproductive lives, which are "linked directly to the conditions in her community – and these conditions are not just a matter of individual choice and access"6. A reproductive justice model offers a way to balance individual autonomy and collective good in making sense of the complexities of ARTs7. The goals of a reproductive justice model of ARTs as described by The Gender, Justice, and Human Genetics Program<sup>8</sup> are

Continued on page 2

**Women's Health Update** is a quarterly publication available electronically. It features women's health issues, policy, and up to date information to enable health care professionals, community-based workers, and the public to be at the forefront of women's health.

**Women's Health Update** is published by Women's Health Action Trust with funding provided by the Ministry of Health.

Continued from page 1

to: decriminalise the reproductive decisions of women; prevent eugenic outcomes for society and policies that devalue the lives of people with disabilities; insist on high industry standards for health and safety of ARTs and access to the information necessary to make truly informed choices; affirm family formation and support equal access to ARTs, particularly for people with disabilities, women of colour, LGBTQI individuals and couples, and lowincome women; direct resources toward environmental causes of infertility and address the disproportionate rate of infertility among women of colour; integrate an intersectional analysis and a human rights framework into work on ART issues; and conduct advocacy in partnerships and coalitions with those who use and are affected by ART.

Applying a reproductive justice lens to the proposal to liberalise the import and export of gametes and embryos we asked whether allowing the import of gametes and embryos from countries with little or no regulation surrounding ARTs could increase exploitation of women - particularly young women, economically vulnerable women, and women of colour? We also asked whether a more liberalised approach to the import and export of gametes and embryos would be likely to contribute to the commodification of women's reproductive capacity and reproductive tissue? And would regulations on the import and export of gametes and embryos significantly decrease women's reproductive choices and individual control over decision-making and perpetuate unequal access to ARTs in New Zealand? Weighing the answers to these questions, we returned to

our long held position that gametes, whether sourced locally or imported, should, at least for now, be from non-commercial sources only on the basis that the risks of exploitation in the commercial 'egg trade' as it currently operates internationally are too high, and there may be other ways to address the shortage of gametes in New Zealand. As Bercovici9 argues, 'the "egg trade" takes place in a culture of inequality, raising valid concerns relating to the commodification and exploitation of reproductive materials within a context where women are subject to pervasive and persistent discrimination'. Indeed, as Bercovici goes on to observe, notably missing from the debates about the trade in eggs are discussions over the harvesting and procurement of eggs, including 'questions of donors' health and safety, disparities in payment for egg donation, and whether a woman is able to make truly informed and non-coerced choice to donate her eggs'. In other words, we are unsatisfied that a more liberalised approach to the movement of reproductive materials across boarders will promote reproductive justice at this time and are cautious of a discourse that tends towards highlighting the benefits of liberalisation while downplaying the risks

In regards to the question of increased expenses payable to donors, we agree that this holds the potential to increase the appeal of gamete donation in New Zealand but recommend that remuneration of donor expenses is actually consistent with expenses incurred by donors to ensure that it does not end up operating as a proxy for commercial payment. We also suggested that there may be other ways to increase the supply of locally sourced gametes, through for example, education and social marketing about egg donation. However, while we continue to advocate for altruistic gamete and embryo donation, and surrogacy, in New Zealand as a way to address the exploitative potential of commercialisation, we do acknowledge its limitations. These include the gendered connotations of privileging 'altruism' which assumes that the immense caring and bodily labour involved in egg donation and surrogacy can be unpaid because it is "women's work"10 and the inherent inequality in the "gift relationship" in altruistic donation where the giving can never really be mutual<sup>11</sup>. We anticipate, and support further examination on the issue of paying New Zealand egg donors and surrogates in the future.

Finally, a guiding principle of our submissions was that allowing a different set of standards and rules to apply to the import and export of gametes and embryos than those that govern the use of gametes and embryos sourced in New Zealand risks undermining New Zealand's governance of ARTs through the HART Act. We believe that any significant changes to New Zealand's regulatory framework for ARTs must be done via amendments to the HART Act rather than circumventing it, and must be informed by a national conversation to ensure New Zealand's regulation of assisted reproductive technologies is consistent with the different ethical, spiritual, and cultural perspectives held within the New Zealand population including specifically the needs, values, and beliefs of Māori (HART Act).

Footnotes for all aticles are available online at www.womens-health.org.nz/resources/womens-health-update

## Comments on the Strategy for the Health of Older Persons

Dr Sandy Hall, Policy Analyst

"Aging women represent an important and growing political constituency in both developed and developing countries. Recognising and supporting their full participation – regardless of socioeconomic status and ethnicity – will benefit the health and well-being of individuals, families, communities and nations"

Women's Health Action believes that more than a disease based view is needed to ensure all women in Aotearoa New Zealand enjoy good health when they are older. There are considerable disparities between women over 65 reflecting the effects of a range of intersecting factors including racism, homophobia and transgenerational effects of colonization, alongside structural barriers and socio-economic differences. There are also considerable gender differences between the health of older people, and women can expect to live 14 percent of their lives in poor health or disability compared to around 11 percent of men<sup>1</sup>.

In addition, the healthcare demands and "acceptable" health outcomes of older people are often discussed with an increasing problematising of aging and focus on perceived burdens. For the first time in history, long life has become a problem. Locating the idea of

good health within a particular age group or gender does not necessarily reflect reality, and age should not be equated with an inability to contribute to society. The increasing focus on the health care 'burden' of the aging populations and the view that older people, particularly women, are a drain on society is both ageist and sexist2.

Much of the knowledge from medical research is characterised by gender blindness. We need to incorporate age and gender based perspectives into policy and research and allow sex, gender and age differences to be considered in the provision of health care. Gender sensitive research is also required into cost-effective ways to help older people remain in their homes and in the community, and address the issues faced by women in particular, including safety. Illnesses that contribute to chronic disability and ill health in

older women such as migraine, osteoarthritis or domestic violence require gender based research and specific interventions.

The ageing of our population also has human rights implications. Older women, particularly those who are disabled or belong to minorities often experience multi-sectored discrimination<sup>3</sup>.Poverty is also an increasingly significant influence on women's health. Prohibitive costs, lack of transport or the absence of geriatric medicine, primary health or mental health services may prevent older women from accessing health care.4 Abuse and neglect of the elderly, particularly women, is a frequent occurrence both at home and in aged care services. It is important that access to safe effective health care is included as a basic human right and reflected across age groups and genders<sup>5</sup>.

Continued on page 3

Continued from page 2

Our research shows that recognition of the diversity of the population, attention to intersecting causes of health disparities, addressing ageism and a gender specific

approach are needed in order to achieve improved health for older women. Therefore the Older Persons Health Strategy must address gender and age discrimination, human rights and the underlying determinants of health as well as promoting environmental changes that enhance health.

# Breastfeeding and Working

Isis McKay, Maternal and Child Health Promoter

The 2015 World Breastfeeding Week (WBW) theme, which is set annually by the World Alliance for Breastfeeding Action (WABA) was 'Breastfeeding and Working - Let's make it work'. This theme revisits the 1993 WBW campaign on the Mother-Friendly Workplace Initiative. Much has been achieved in 22 years of global action supporting women in combining breastfeeding and work, particularly the adoption of the revised ILO Convention 183 on Maternity Protection with much stronger maternity entitlements, and more country actions on improving national laws and practices. The goal behind this theme is to support women to integrate productive and reproductive work, a complex and multi-level task requiring diverse strategies and engaging different partners on shared agendas.

Growing Up in New Zealand found that over 30 percent of women return to work when their children are an average age of 5 months old<sup>1</sup>. Returning to paid employment has been identified as a significant barrier to continued breastfeeding for many women<sup>2</sup>. Australian based research found that returning to work was one of the main reasons women ceased

breastfeeding, with 60 percent of women intending to breastfeed when they returned to work, but only 40 percent doing so3.

As part of Women's Health Action's ongoing work in the area of breastfeeding and working, and to align with the 2015 WBW theme, Women's Health Action partnered with Point Research to conduct surveys to better understand how employees and employers currently manage breastfeeding in the work place.

Two surveys were designed, one for employers and one for employees. The findings show significant and clear correlations between women continuing (and ceasing) breastfeeding and the support offered by employers. The results have found that women are four times more likely to stop breastfeeding by 3 months or less if they receive no employer support. This survey has also revealed that more than one third of New Zealand employers are unaware of workplace breastfeeding legislation, a figure reflected in the lack of support for breastfeeding employees.

This study shows there is an urgent need to educate and support New Zealand businesses around the benefits of

breastfeeding in the workplace and employers' legal responsibilities. Three quarters of employer respondents said they want more information and training to better support breastfeeding mothers in the workplace. The survey found that women are three times more likely to continue to breastfeed have access to a clean, accessible and private space to breastfeed or express, and are twice as likely to continue to breastfeed past 12 months if they have flexible hours and break times.

While 54 percent of the employees who responded to the survey said their employers provided them with flexible hours and/or private facilities to breastfeed, 20 percent said that no workplace support was available. Employer respondents overwhelmingly said they found providing adequate breastfeeding facilities to have a positive influence. 67 percent of employers said they saw a reduction in staff turnover. The same percentage of respondents said they found it had a positive impact on their company's public image and 69 percent reported it helped improve staff morale.

Women's Health Action intends to use the results of the surveys to shape our breastfeeding and working services going forward.

Please contact <a href="mailto:isis@womens-health.org.nz">isis@womens-health.org.nz</a> for the full survey results.

## Big Latch On 2015 - Another Big Success

Holly Coulter

This August we celebrated the 11th annual Big Latch On at 111 venues throughout Aotearoa. Part of World Breastfeeding Week, Women's Health Action has been co-ordinating the Big Latch On since the event was launched in 2005. The Big Latch On has grown each year, and this year a total of 1646 women came together across the country to breastfeed together and provide important peer support.

The Big Latch On is designed to promote breastfeeding, build community support and connect families with local services. Each year, feedback from the event shows that taking part in the Big Latch On helps women build their confidence to breastfeed, as well as raising awareness of the support available to them. Partners, family and whānau attend the Big Latch On, at locations from the Far North to Invercargill, to show their support.

As well as attending a Big Latch On venue in person, in 2015 for the second year women were able to take part online by sharing a 'Brelfie' - a breastfeeding selfie - to social media. This initiative makes the Big Latch On more inclusive for women who are unable to make it to a venue either due to illness, transport issues, or other commitments such as work. Research has indicated that the

use of technology may be a powerful tool in increasing breastfeeding rates<sup>1</sup>, and taking part online enables women to connect with other breastfeeding mothers and supporters in their own network.

The 'Brelfie' campaign has been an overwhelming success, with over 182 women taking part this year. Ninety-six percent of participants reported that taking part had a very positive or positive impact on how connected they felt to other breastfeeding mums and breastfeeding supporters.

The positive impact of the 'Brelfie' campaign was obvious in the feedback from participants, with one commenting "I attended the Big Latch on this year as well as submitting a brelfie. Last year I did not feel confident enough to attend the Big Latch on but submitted a photo." For mothers who do not feel confident breastfeeding in public, connecting with support online has the potential to help normalise breastfeeding and build their confidence.

Other feedback from the 'Brelfie' campaign included "It's awesome to see breastfeeding normalized online especially from a NZ organisation. My news feed [has] been flooded with other mums' brelfies and they're so beautiful!"



▲ The 2015 Big Latch On Promotional Poster

The importance of the campaign for building breastfeeding support for mothers of older children also emerged. One

Continued from page 3 participant commented "It was lovely to see older nurslings. I do have some friends nursing 'older' children, but it's not commonly discussed or shared".

Research has indicated that a lack of support is one of the major barriers to continuing breastfeeding<sup>2</sup>, and events such as the Big Latch On are crucial for supporting and protecting breastfeeding in Aotearoa.

A full evaluation of the 2015 Big Latch On will be completed by the University of Auckland's School of Population Health and will be available later this year.

# Cartwright Symposium: The Future of Cancer Screening in New Zealand

Julie Radford-Poupard

This August Women's Health Action, the Cartwright Collective and the Auckland Women's Health Council hosted a symposium on the 'The Future of Cancer Screening in New Zealand, Balancing the Benefits and Risks'. Topics included cervical, breast and colorectal cancer screening as well as primary prevention of these cancers. Key outcomes of the 2015 symposium included reviewing the benefits and risks of cancer screening and helping health consumers, health professionals and the Government make well-informed decisions for the future. Another important theme for the symposium was informed consent for screening programmes.

Cervical cancer has fallen rapidly in Aotearoa New Zealand since the 1990's with the National Screening Programme, although disturbingly incidences for Māori remain twice as high as for non-Māori1. The cervical screening symposium speakers and panellists highlighted the likely move from Pap cytology to HPV screening. Whilst potential 5 year screening intervals, self-screening and improved testing sensitivity compared with Pap cytology were noted, the panellists cautioned against

rushing a decision and many of the panel members made the case for co-testing in the initial phases.

The breast screening segment saw robust debate about the magnitude of over diagnosis ranging from <5% - >50%.2 Professor Ann Richardson asked the pertinent question What is the best way to provide accurate information about the benefits and risks of cancer screening, so people can make an informed choice about whether to participate'? One of the harms/limitations of mammograms identified for women in Aotearoa is finding a breast cancer that would never have caused problems during a woman's lifetime<sup>3</sup>. Unfortunately it is not possible to tell the difference between cancers that do cause problems and those that will not. If a breast cancer is found treatment will be offered and there is a possibility of undergoing treatment for a breast cancer that would not have been life threatening.

This contrasts with NHS breast screening information in the United Kingdom. 'About 3 in every 200 women screened every 3 years from the age of 50 to 70 are diagnosed with



▲ Cervical Cancer and Cervical Screening panel at the Cartwright Symposium: Beth Quinlin, Julie Radford-Poupard, Astrid Koornneef, Dr Naomi Brewer, Dr Hazel Lewis

a cancer that would never have been found without screening and would never have become life-threatening. This adds up to about 4,000 women each year in the UK who are offered treatment they did not need. Overall, for every 1 woman who has her life saved from breast cancer, about 3 women are diagnosed with a cancer that would never have become life-threatening'4.

It is our understanding that Breast Screen Aotearoa are currently updating their information for people considering screening.

Copies of presentations from the symposium are available from: http://www.womens-health.org.nz/ cartwright-anniversary-seminar-the-futureof-cancer-screening-in-new-zealand/

### NOTICEBOARD

#### **MELANOMA SUMMIT**

6-7 NOVEMBER, AUCKLAND

The Summit theme is "Connecting Melanoma Expertise in New Zealand" and features internationally recognised experts and workshops on prevention, diagnosis, clinical management and research http://melnet.org.nz/news/melanoma-summit-2015

#### **NEW ZEALAND SEXUAL HEALTH SOCIETY** 'HIDDEN DEPTHS' CONFERENCE

15-17 OCTOBER, TAUPO

This conference aims to explore the 'Hidden Depths' of sexual and reproductive health, both for service users (particularly our young people) and service providers, focussing on the key themes of Equality, Quality of Care and Accountability. www.shs2015.co.nz

### WHITE RIBBON DAY

25 NOVEMBER November is White Ribbon Month Events will be taking place around New Zealand. http://whiteribbon.org.nz/

#### **NZ DEMENTIA SUMMIT 2015**

5-6 NOVEMBER, WELLINGTON

The Summit is an opportunity to have a say about the future of dementia care in NZ. Health professionals, service providers, government officials, educators, researchers and people affected by dementia come together to share their experience, knowledge, and expertise. http://www.nzdementiasummit.org/

#### MENTAL HEALTH AWARENESS WEEK

5-11 OCTOBER

This year's theme is GIVE - your time, your words, your presence. Events taking place across the country. www.mhaw.nz

#### ASTHMA FOUNDATION RESPIRATORY CONFERENCE

5-6 NOVEMBER, WELLINGTON A view of the whole picture of respiratory

health will show where best to put time, effort and resources in order to make the biggest gains. The conference will highlight the goals and outcomes from the National Respiratory

Strategy being launched on 4 November. http://asthmafoundation.org.nz/newsand-events/2015-new-zealand-respiratoryconference/

### **HINZ CONFERENCE**

19-22 OCTOBER, CHRISTCHURCH

The HiNZ Conference is New Zealand's premier event for health informatics. This year's theme is COLLABORATE. This conference attracts a diverse audience including clinicians, health sector managers, academics, educators, government, IT professionals and industry

### **NEW ZEALAND HEALTHCARE SUMMIT**

28 & 29 OCTOBER, AUCKLAND

This year's event will include new patient models of care that form positive policies and guidelines, and a focus on health priorities including; diabetes / obesity, ageing, mental, Maori health, and other major health priorities. It will also look at prevention versus cure.

http://www.activebusinesscommunications.com/ healthcare/index.php



Women's Health Update is produced by Women's Health Action Trust with funding provided by the Ministry of Health. To receive copies of **Women's Health Update**, make suggestions about future contents or send items for publication please contact: Women's Health Action Trust, PO Box 9947, Newmarket, Auckland 1149, NZ. Ph (09) 520 5295, Fax (09) 520 5731, email: info@womens-health.org.nz

Women's health information - www.womens-health.org.nz Breastfeeding Friendly Workplaces - www.bfw.org.nz