



IAB Presidential address: “Searching for Justice”

1 | INTRODUCTION

Let me begin by thanking Professor Graeme Laurie, Dr Nayha Sethi, and the rest of the organizing committee, for their vision, attention to detail, and their commitment to making the 13th World Congress of Bioethics challenging, rich and diverse. Thank you also to all the presenters who made this Congress so engaging, especially the first-time attendees. As always, the Congress was both a great pleasure and an inspiration. This *Special Issue* captures some of the highlights.

As President of the International Association of Bioethics, it is my job to offer a “state of bioethics” address. With an interdisciplinary field as varied and prolific as bioethics, that is no easy task. I decided to start by re-reading previous presidential addresses.¹ These provide a fascinating overview of the development and progress of bioethics since 1996. A broad range of topics has been covered, but I was most struck by the repeated calls for bioethics to focus more on global justice and poverty, and less on technological advances and autonomy.

- In 1997 Daniel Wikler predicted that in the near future “high-tech medicine will lose its pride of place at the centre of bioethics concern... our focus will be on health, just as much as healthcare.”²
- In 2007 Alexander Capron referred to the 10/90 gap in bioethics, “too much of the energy of our field is spent on the most esoteric problems and too little is spent addressing the ethical outrages... that kill and cripple tens of millions of people.”³
- Ruth Macklin asked in 2010 “why [is] only a very small percentage of the [mainstream] literature in our field devoted to ...injustice in health status, access to health care and adequate nutrition.”⁴
- Nikola Biller-Andorno said in 2011 “not surprisingly, genetics and neuroscience have received a lot of bioethics attention, much more than issues such as poverty or sustainable development.”⁵

I interpret these references to justice to refer broadly to social justice – a focus on the role of cultural, legal and financial structures in the

distribution of privileges, opportunities, and resources amongst individuals and populations. Without doubt there is excellent work in bioethics that takes justice as its primary focus. During the Congress we have heard powerful and challenging critiques appealing to justice – especially in presentations on public health ethics, feminist bioethics, disability rights, resource allocation, and international research. The persistent concern, however, seems to be that there is not *enough* work on justice, especially the issue of global justice. If Presidents of IAB have been calling for this shift in focus for twenty years, we should give further thought to why progress in this area has been so slow. I will assume for the sake of argument that justice is both an important and a neglected element in bioethics. I want to explore three potential explanations for this neglect. These are:

1. biases in research funding leading to a focus on technological innovation;
2. role ambiguity concerning academia, advocacy and activism; and
3. tension between the applied nature of bioethics and the role of justice critiques in challenging the status quo.

2 | FOLLOWING THE FUNDING

Bioethics as a discipline has continued to grow over the last 20 years, resulting in more research opportunities, PhDs, and post-docs. But as academia shifts from hard to soft money, we are increasingly dependent on research grants – for salaries, promotion and prestige, or to support junior staff.⁶ I think there is a prevalent perception within bioethics that grant applications looking at innovative technologies such as PGD (prenatal genetic diagnosis), enhancement, neuroscience or data mapping for example, are more competitive than projects investigating social justice and poverty. Perhaps this is because early research work in bioethics was often ELSI (ethical legal and social implications) studies associated with specific genetic technologies. And perhaps this perception is reinforced in the form of “partnership grants”, which many national research funding agencies use to incentivize collaboration with industry.⁷ Finding industry partners for technology-related grants seems immeasurably easier than finding an industry partner for justice-related research (at least one with cash to contribute to the research). So the concern is that as bioethicists follow the grant

¹These are published in the biennial Congress Special Issues of *Bioethics*.

²Wikler, D. (1997). Presidential address: Bioethics and social responsibility. *Bioethics*, 11(3–4), 185–192.

³Capron, A. M. (2007). Imagining a new world: Using internationalism to overcome the 10/90 gap in bioethics. *Bioethics*, 21(8), 409–412.

⁴Macklin, R. (2010). The death of bioethics (as we once knew it). *Bioethics*, 24(5), 211–217

⁵Biller-Andorno, N. (2011). IAB presidential address: Bioethics in a globalized world: Creating space for flourishing human relationships. *Bioethics*, 25(8), 430–436.

⁶Kaplan, K. (2010). Academia: The changing face of tenure. *Nature*, 468(7320), 123–125.

⁷See for example the Australian Research Council Linkage Program, Retrieved from <http://www.arc.gov.au/linkage-projects>

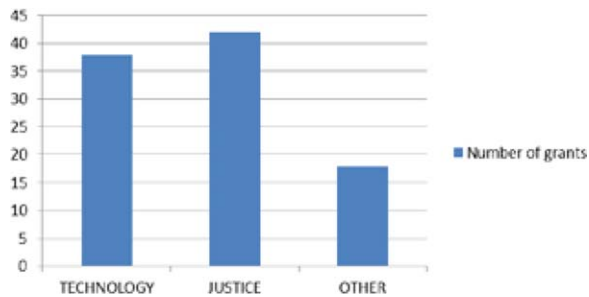


FIGURE 1 Number of grants [Colour figure can be viewed at wileyonlinelibrary.com]

money, we may be diverted from a focus on justice; or worse. ... led down a path of politically safe, industrially expedient, research.”⁸

But is this funding bias real or perceived? To investigate this further I conducted a quick survey of the Australian Research Council database for all grants funded between 2001–2016 including the term bioethics; and classified the 98 results as relating primarily to new technology, justice or other.⁹ The “technology” category included, for example, neuroscience, biotech, enhancement, ART, genetics, genomics, innovative therapy, embryos, stem cells. The “justice” category included welfare, relationships, resources, rights, humanitarianism, transparency, terrorism, public participation, patient safety. “Other” included ethical theory, business regulation, integrity and governance. These classifications were not cross-checked by a second reviewer and I am sure some would be open to debate.

I was however surprised by the results, which at least give us some cause to challenge the presumption that grant money favours technology-related research over justice-related research. There were slightly *more* grants in the justice category (42) than in the technology category (38); see Figure 1.

Second, I broke the funding down per grant, hypothesizing that the technology-related grants may receive on average more funding than the justice grants. Again, I was surprised. Figure 2 shows that for all funding awarded for bioethics by the Australian Research Council between 2001–2016, almost equal amounts were awarded for justice-focused grants (Aus\$11,732,270) and technology-focused grants (Aus\$11,710,223). Figure 3 shows that the average funding awarded for technology-focused grants was marginally higher than justice-focused grants.

For those concerned about a side-lining of justice in bioethics research, these results may be encouraging. That said, most of the grants classified as justice-related focused on the Australian context and were not grants looking at global justice issues. Low and middle

⁸Dreger, A. (2015). *Galileo's Middle Finger: Heretics, Activists, and the Search for Justice in Science*. London: Penguin Press: p. 258.

⁹I selected the Australia Research Council simply because it was a relatively large funding body with a website and funding system that I was familiar with. My allocation to “justice”, “technology” or “other” was made based on the content of the project description (approximately fifty words per project), and the nominated “fields of research”. I made a judgment as to the primary focus of the study. Many of the “technology” projects included a sub-theme looking at justice; and many of the “justice” projects included some consideration of new technologies.

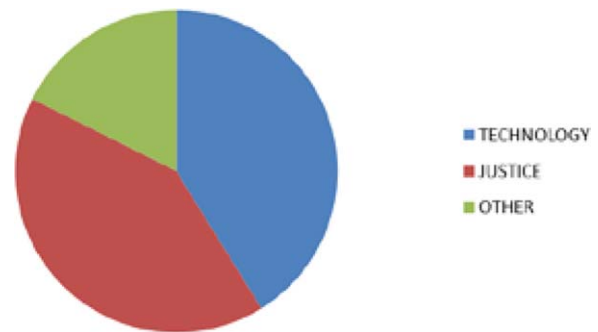


FIGURE 2 Total grant funding [Colour figure can be viewed at wileyonlinelibrary.com]

income countries, with the highest morbidity and mortality burden, lack resources to provide comprehensive basic health care, let alone research grants for bioethics. So issues of global justice are likely to be relatively neglected. The data I have presented is only one piece of the funding picture. Some funding for bioethics comes directly from industry and it can be hard to track and quantify that impact on our work and to weigh that influence against grants from global charity funders such as the Wellcome Trust. My point here is that, despite the difficulty in getting an accurate picture of funding patterns, the perception that ‘justice’ grants are less competitive than ‘technology’ grants may well be false and this perception itself may act as a barrier.

3 | ACADEMIA, ADVOCACY AND ACTIVISM

A second potential barrier is debate around the appropriate role of bioethicists and in particular whether they should engage in activism and/or advocacy work. Advocacy involves public support for or recommendation of a particular cause or policy; and activism goes one step further and involves taking action to effect social change – protesting, campaigning, trying to shift public perception and policy.

Peter Singer, one of the founders and the first President of IAB, has argued that “Bioethics... should not dedicate itself to advocacy for anyone. Its only commitment... is to pursue knowledge and understanding with integrity and respect for the views of other scholars in the field. It should serve neither those with money and power nor those without it—or rather, it serves all of us best by preserving its independence and freedom of opinion, encouraging open debate and

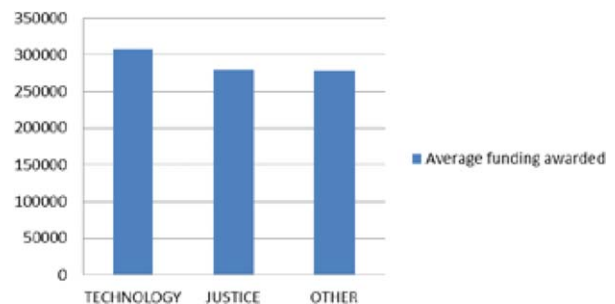
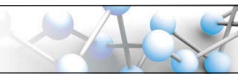


FIGURE 3 Average funding awarded [Colour figure can be viewed at wileyonlinelibrary.com]



the free exchange of ideas.”¹⁰ By contrast, Florencia Luna’s opening keynote of this Congress demonstrated bioethics as advocacy. She discussed the disproportionate impact of Zika virus on poor, rural, isolated women, who are denied access to both contraception and to abortion for affected fetuses.¹¹ She said “these women have no voice; we need to be their voice.” I hear Luna’s work as a strong call for advocacy. Going one step further, Alice Dreger has controversially called out bioethicists for being too conservative and resistant to engaging in advocacy. “Patient advocacy is actually the opposite of bioethics, because bioethicists are the people who increasingly set up and justify the systems we patient advocates have to fight.”¹² Of course this is a generalization, but it helps illustrate the contentious nature of the job of bioethics.

The grey zone between academic work, advocacy and activism is particularly relevant for bioethicists working on issues related to justice because it can be hard to write about injustice without getting caught up in advocacy work. To many, especially those working on justice, Singer’s purist idea of academia may seem utopian. Even in choosing what topics to investigate, bioethicists allocate their intellectual and financial resources and it seems reasonable to think this prioritization should be informed by the relative importance of the problems. This contested debate around advocacy may serve as a barrier to work on justice, if bioethicists, particularly younger scholars, feel wary of stepping outside a prescribed role (or a perception of such a role). I am therefore pleased to see an increasingly explicit debate the place of advocacy and activism in bioethics.¹³

4 | PRAGMATISM VERSUS JUSTICE

The third issue I want to consider is a conflict for bioethicists between, on the one hand, providing practical advice that can be implemented within the status quo; and, on the other hand, advocating for justice in a way that fundamentally challenges the status quo. Bioethics is a branch of practical or applied ethics. That doesn’t mean that every piece of work in bioethics has to be applied, but as a community of bioethicists part of our job is to help solve real problems and advise on ethical practice, to guide clinicians, scientists and policy makers. These clinicians, scientists and policy makers need to work within the current broad social, cultural, political and economic framework. This is in tension with accounts of justice that often fundamentally challenge the status quo. There is a deep tension between a focus on justice,

particularly global justice, and a call to provide practical solutions to bioethical problems.

This tension only holds for people who think the background socio-political global structure is manifestly unjust. Yet it is my impression that many bioethicists hold this view. Indeed the reason that work on global justice is deemed so important is because the current global structures are so strikingly unjust.

The practicality of a bioethicist’s advice is inversely related to the degree to which that advice challenges the status quo. We saw a compelling example of this in the opening plenary session of the 11th Feminist Approaches to Bioethics World Congress, where Professor Kate Hunt spoke of the Football Fans in Training (FFIT) program in the UK.¹⁴ Weight management interventions, either commercial or those provided by the National Health Service, are still predominantly attended by women. This is in part due to the perception that it is not masculine to care about one’s weight or health. Cultural views of masculinity empathising risk-taking, self-sufficiency, and toughness have been shown to act as barriers to men seeking help for physical and mental health symptoms, at the detriment to men’s overall health and life expectancy.¹⁵ FFIT was developed as a program that would align weight management and health with concepts of masculinity – a love of football, loyalty to the club, and a male only program. Men taking part in the program are “trained” by club community coaches, at their team’s home stadium, with other male club fans. The program has been remarkably successful. It works because it aligns the concept of health with elements of these men’s core identity, rather than trying to challenge their core identity. But in doing so it perpetuates sexist stereotypes about men and women. I am not on-balance criticizing the program on these grounds; but rather trying to show that there is a tension between developing something that succeeds, largely because it cleverly fits into the cultural status quo, versus really fundamentally challenging the status quo on the grounds of justice. In relation to health-seeking behaviour, traditional gender norms undermine men’s interests; but more generally traditional gender norms serve men’s interests by entrenching their dominance in social and financial power. Anyone who thinks patriarchal power structures are unjust will feel at least a little unsettled by the means – reinforcing gender norms – used to achieve the success of the FFIT program.

Work on non-ideal theory is important to bioethics as this provides a framework for balancing the demands of justice and practicality. Non-ideal theory is about what social justice requires of us in our actual circumstances. What can normative theories of justice offer us in an imperfect

¹⁰Singer, P. (2001). Response to Mark Kuczewski. *American Journal of Bioethics*, 1(3), 55–56.

¹¹Luna, F. (2017). Public health agencies’ obligations and the case of Zika. *Bioethics*, 31(8).

¹²Dreger, A. (2012). *The Dex Diaries, Part 7: How to Be a Bioethicist*. Retrieved from <http://www.fetaldex.org/diary07.html>

¹³The role of advocacy was a major theme at the 2016 Australasian Association of Bioethics and Health Law Conference in Melbourne. Retrieved from <https://aabhl.org/article/aabhl-2016-conference-melb-24-26-nov>; See also the Canadian Impact Ethics Blog, Retrieved from <https://impactethics.ca/> that seeks to use “the tools of ethics to shock, press, crack, and chip society into a better place.” See also Baylis, F., & Dreger, A. (Eds) (forthcoming). *Bioethics in Action*. Cambridge University Press.

¹⁴Wyke, S., Hunt, K., Gray, C. M., Fenwick, E., Bunn, C., Donnan, P. T., ... Treweek, S. (2015). *Football Fans in Training (FIT): A randomised controlled trial of a gender-sensitised weight loss and healthy living programme for men – end of study report*. Southampton (UK): NIHR Journals Library, Jan. (Public Health Research, No. 3.2.) Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK273998/> <https://doi.org/10.3310/phr03020>

¹⁵Seidler, Z. E., Dawes, A. J., Rice, S. M., Oliffe, J. L., & Dillon, H. M. (2016). The role of masculinity in men’s help-seeking for depression: A systematic review. *Clinical Psychological Review*, 49, 106–118; Camlin, C. S., Ssemundo, E., Chamie, G., El Ayadi, A. M., Kwarisiima, D., Norton Sang, J., ... Havlir, D. (2016). Men “missing” from population-based HIV testing: Insights from qualitative research. *AIDS Care*, 28, Suppl 3, 67–73.



world, encumbered by partial compliance and unfavourable circumstances? How much pragmatic compromise is ethically acceptable?¹⁶

Let me give you a further case that was discussed at both the FAB and IAB Congresses, and I am sure will receive attention at the 2018 Congress in New Delhi – the Indian surrogacy industry. If we think about the ethical concerns regarding commercial surrogacy in India, and the potential solutions offered, we clearly see the tension between a pragmatic response and a genuinely just solution.

India became a major hub for surrogacy, due to a ready supply of potential surrogates, a high standard of clinical care and access to medical technology, and the relatively cheap cost for commissioning parents. The Indian surrogacy industry is thought to be worth more than \$2.5bn annually, with an estimated 5,000 surrogate babies born per year.¹⁷ Many surrogates defend the practice on the grounds that surrogacy is preferable to the other employment options available.¹⁸ However for many commentators the concern is not that surrogacy is an irrational choice for women in India, but rather that it is a choice that women should not have to make. Justice-related critiques are that international commercial surrogacy allows private infertility companies to exploit disadvantaged, vulnerable women in India; that the legitimacy of surrogates' consent is questionable, because they may be directly coerced by their husbands (or other family members) and/or indirectly coerced by the lack of opportunities for meaningful, reasonably paid work; and that surrogacy commodifies babies or commodifies women's reproductive labour.¹⁹

In response to these concerns, here is some advice that bioethicists might offer and, during the Congress, have offered. All of these proffered solutions attempt to advocate for the welfare of potential surrogates. But they vary in their degree of ambition. The first few examples work largely within the status quo and the later examples fundamentally challenge the status quo.

4.1 | Potential responses to commercial surrogacy concerns:

1. Institute more robust informed consent process to minimize potential coercion
2. Limit the number of embryos transferred
3. Support financial empowerment of surrogates
4. Ban commercial surrogacy on the grounds of justice
5. Ban all forms of exploitive labour

¹⁶Murphy, L. (2000). *Moral Demands in Nonideal Theory*. Oxford: Oxford University Press.

¹⁷Shetty, P. (2012). India's unregulated surrogacy industry. *The Lancet*, 380 (9854), 1633–1634.

¹⁸Gupta, D. (2011). Inside India's surrogacy industry. *The Guardian*. December 6th. Retrieved from <https://www.theguardian.com/world/2011/dec/06/surrogate-mothers-india>

¹⁹Baylis, F., & Downie, J. (2014). Introduction. *International Journal of Feminist Approaches to Bioethics*, 7(2), 1–9; Ballantyne, A. (2014). Exploitation in Cross-border Reproductive Care. *International Journal of Feminist Approaches to Bioethics*, 7(2), 75–99; Whittaker, A. (2014). Merit and money: The situated ethics of transnational commercial surrogacy in Thailand. *International Journal of Feminist Approaches to Bioethics*, 7(2), 100–120.

6. Ensure gender equality and equal opportunities

Recommendations 1–3 seek to work within the existing commercial surrogacy framework to improve conditions for surrogates.²⁰ But some bioethicists do not think recommendations 1–3 go far enough. Indeed, in 2015 India announced a ban on surrogate services for foreign couples, a significant proportion of the market;²¹ and in 2017 the Indian government announced plans to ban all commercial surrogacy.

The problem with banning commercial surrogacy, or even commercial surrogacy for foreign couples, is that it will reduce women's employment options in India. A full account of justice would look at surrogacy in relation to other employment options for Indian women. Interviews with surrogates suggest they previously had jobs such as farm and domestic labour; many claim they could hardly survive on these incomes and are anxious that demand for surrogacy might decrease.²² "We pray that this clinic stays open" said one surrogate.²³ On the grounds of consistency we should advocate for the prohibition of all form of exploitive labour including domestic work and sweatshops, rather than focus on the highly emotive topic of surrogacy.

But even if it were somehow achievable to "ban sweatshops", the nature of women's employment is not simply a question of labour laws. It is fuelled by sexist views about the role of women. According to the International Labour Organization, there has been a decline in Indian women's participation in the labour force from 31% in 2004 to 25% in 2011. This is despite 7% growth of the Indian economy, and increasing levels of female education during this period.²⁴ Some economists believe the explanation lies in the persistence of India's traditional gender norms, which seek to isolate women from non-related men, and restrict mobility outside their homes.²⁵ These norms limit women's capacity for self-determination, restrict their economic freedom, and constrain their activity in the public sphere. Taking this into account we might advocate, in the name of justice:

- Combatting cultural stereotypes that associate a women's worth with fertility and that glorify female acts of altruism.
- Ensuring free access to education for girls
- Protecting women from sexual violence and child marriages

²⁰Kirby, J. (2014). Transnational gestational surrogacy: Does it have to be exploitative? *American Journal of Bioethics*, 14(5), 24–32.

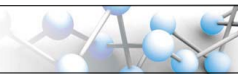
²¹Howard S. (2015). Proposed ban on foreigners using Indian surrogacy services sparks protests. *British Medical Journal*, Nov 2, 351:h5854. <https://doi.org/10.1136/bmj.h5854>

²²Pande, A. (2011). Transnational commercial surrogacy in India: Gifts for global sisters? *Reproductive BioMedicine Online*, 23(5), 618–625.

²³Doshi, V. (2016). "We pray that this clinic stays open": India's surrogates fear hardship from embryo ban. *The Guardian*. Retrieved from <http://www.theguardian.com/world/2016/jan/03/india-surrogate-embryo-ban-hardship-gujarat-fertility-clinic>

²⁴Verick, S. (2013). *Women's labour force participation in India: Why is it so low?* International Labour Organization. Retrieved from http://www.ilo.org/wcmsp5/groups/public/-asia/-ro-bangkok/-sro-new_delhi/documents/genericdocument/wcms_342357.pdf

²⁵Pande, R., & Mooreaug, C. T. (2015). Why aren't india's women working? *New York Times*. August 23 Retrieved from <http://www.nytimes.com/2015/08/24/opinion/why-arent-indias-women-working.html>



These last suggestions get us closest to a robust conception of social justice. But without doubt, they provide the *least* practical response to the question of international commercial surrogacy in India. The problem for bioethics is that it seems perverse on one hand to justify surrogacy on the grounds that it is not as bad as other forms of exploitative labour; and naïve to advocate for banning surrogacy when this is going to leave surrogates worse-off (assuming no other forms of labour replace it).

What I have tried to show is a tension between the likelihood of anyone acting on the advice of bioethicists (and this translating into even a marginal improvement in the surrogate's circumstances) and the extent to which the advice adequately takes account of justice. This tension is a barrier to work on justice because those bioethicists committed to making a practical contribution to policy may shy away from analyses of the root causes of injustice.

In conclusion, understanding the barriers facing bioethicists working on justice can provide an agenda for change. Conceptual work on the relationship between advocacy, activism and academia and on non-ideal theory can help to build a coherent framework that facilitates bioethicists doing the messy work of justice in our imperfect world.

I greatly look forward to the 2018 World Congress of Bioethics in New Dehli, where I am sure questions of justice will be centre stage.

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