

<b>Institution: Keele University</b>
<b>Unit of Assessment: C20 Law</b>
<b>Title of case study: Human Reproduction: ethics and law</b>
<p><b>1. Summary of the impact</b></p> <p>Stephen Wilkinson's research on medical ethics and law (including joint work with Sally Sheldon) has:</p> <p>(1) Influenced policy formation processes (e.g. through being submitted in evidence to parliamentary committees and enquires, and via bodies such as the Nuffield Council on Bioethics).          (2) Challenged conventional wisdom, stimulating debate among stakeholders, and enabled improved public understanding. Mechanisms for this include participation in popular media outlets and in public and stakeholder engagement events.</p>
<p><b>2. Underpinning research</b></p> <p>(a) Research carried out between 2003 and 2009 (jointly by Sheldon and Wilkinson, and also individually by Wilkinson) generated novel arguments not only for permitting what came to be known as the creation of 'saviour siblings' but also for the extension of this practice to cases in which the recipient is not a sibling, cases in which the tissue in question is a solid organ rather than merely umbilical cord blood, and cases in which the condition is not life-threatening.</p> <p>(b) Work carried out (by Wilkinson) between 2006 and 2010 generated novel arguments for permitting 'social' sex selection (using embryo selection techniques) in the UK within the context of a particular regulatory regime.</p> <p>(c) Work carried out (by Wilkinson) between 2006 and 2010 enabled improved understandings of the concept of 'eugenics' in contemporary debates about genetics and reproductive technologies, and of the many and varied arguments for and against 'screening out' embryos with genetic disorders or disabilities. In addition, this work presented a set of arguments against the specific legal prohibition (in the HFE Act 2008) on selecting in favour of (e.g.) 'deaf embryos'.</p> <p>This was scholarly 'desk' research employing the methods of analytic philosophy to answer policy questions in bioethics and medical law.</p> <p><b>Dates:</b> Wilkinson's research on organs and tissue dates back to 1995. His work on human reproduction dates back to 2000. The work with Sheldon specifically on 'saviour siblings' was undertaken between 2003 and 2009, with the majority of this occurring in 2003-4.</p> <p><b>Key Researchers:</b> Wilkinson was employed by Keele University from 1994 to 2012 as Lecturer, Senior Lecturer, and Professor. Sheldon was employed by Keele from 1994 to 2006 as Lecturer, Senior Lecturer, Reader, and Professor.</p>
<p><b>3. References to the research</b></p> <p>1) <b>WILKINSON, S. (2003)</b> <i>Bodies for Sale: ethics and exploitation in the human body trade</i> (London, Routledge) [264 page monograph].</p> <p>2) <b>SHELDON, S. &amp; WILKINSON, S. (2004a)</b> Hashmi and Whitaker: an unjustifiable and misguided distinction?, <i>Medical Law Review</i>, 12, pp. 137-163. DOI: <a href="http://dx.doi.org/10.1093/medlaw/12.2.137">http://dx.doi.org/10.1093/medlaw/12.2.137</a></p> <p>3) <b>SHELDON, S. &amp; WILKINSON, S. (2004b)</b> Should selecting saviour siblings be banned?, <i>Journal of Medical Ethics</i>, 30, pp. 533-537. DOI: <a href="http://dx.doi.org/10.1136/jme.2003.004150">http://dx.doi.org/10.1136/jme.2003.004150</a></p> <p>4) <b>WILKINSON, S. (2008)</b> Sex Selection, Sexism, and 'Family Balancing', <i>Medical Law Review</i>, 16, pp. 369-389. DOI: <a href="http://dx.doi.org/10.1093/medlaw/fwn013">http://dx.doi.org/10.1093/medlaw/fwn013</a></p> <p>5) <b>WILKINSON, S. (2010)</b> <i>Choosing Tomorrow's Children: the ethics of selective reproduction</i> (Oxford, Oxford University Press) [265 page monograph].</p>

## Impact case study (REF3b)

**6) SHELDON, S. & WILKINSON, S. (2010)** Saviour Siblings, Other Siblings and Whole Organ Donation in : NISKER, J., BAYLIS, F., KARPIN, I., MCLEOD, C., & MYKITIUK, R. (eds), *The 'Healthy' Embryo: Social, Biomedical, Legal and Philosophical Perspectives* (Cambridge: Cambridge University Press), pp.251-264.

All the research for the above was carried out at Keele (i.e. both authors were at Keele) except for SHELDON & WILKINSON (2010) which was 50% Kent and 50% Keele. The authors are listed alphabetically with 50% credit assigned to each.

### Evidence of Quality

**1)** was supported by an AHRB Research Leave Award, *The ethics of selling human bodily parts, products, and services*. 2000-1. £8,086. Extracts from this work, as well as **2), 3), and 4)** are reprinted in a leading medical law textbook: Emily Jackson, *Medical Law: text, cases, and materials* (2<sup>nd</sup> edition), Oxford: Oxford University Press, 2010. Journal articles **2), 3), and 4)** were all subject to the journals' anonymous peer review systems, and the first, to two waves of independent review by the publishers. Chapter, **6)**, was an invited contribution to a grant-funded programme of work entitled 'The Healthy Embryo', funded by The Canadian Institutes of Health Research, Institute of Human Development, Child and Youth Health. **5)** was subjected to two waves of independent review by the publishers. It was supported by the following grants. (1) AHRC Research Leave Award. *Ethical Arguments against Selective Reproduction: a philosophical analysis*. 2006-7. £25,682. (2) Wellcome Trust Research Leave Award. *The role of the concept of 'eugenics' in contemporary debates about the regulation of genetic and reproductive technologies*. 2005-6. £32,867. It has thus far been the subject of at least nine favourable book reviews, including the *Medical Law Review*.

### 4. Details of the impact

Wilkinson's research impacts fall into two main categories: (a) targeted interventions in policymaking processes, which seek to influence and/or inform law and policy; (b) public and stakeholder engagement, which seeks to stimulate and improve the quality of debate.

#### Influencing and Informing Policymaking

Since the mid-2000s, Wilkinson has sought to influence and improve policymaking by providing information and evidence to those involved in policy formation processes (including but not limited to law reform). Some key examples are listed below.

(a) Sheldon and Wilkinson's work on 'saviour siblings' influenced the **Human Fertilisation and Embryology (HFE) Act 2008**. Research carried out between 2003 and 2009 generated novel arguments not only for permitting what came to be known as the creation and selection of 'saviour siblings' but also for the extension of this practice to cases in which the recipient is not a sibling, cases in which the tissue in question is a solid organ rather than merely umbilical cord blood, and cases involving non-life-threatening conditions.

As well as enabling a challenge to 'conventional wisdom', this work influenced the wording of the HFE legislation. One important issue debated in Parliament was whether or not the use of 'saviour siblings' should be restricted to medical conditions which are life-threatening or life-shortening. Sheldon and Wilkinson submitted written evidence to the Joint Committee on the Human Tissue and Embryos (Draft) Bill and Lord Jenkin of Roding claimed in the House of Lords that this was the basis on which his committee came to its view on this matter. He stated – "We [the Joint Committee] came to the conclusion that it really would be unduly restrictive to refuse permission for a saviour sibling to be used in those circumstances. We based this on the evidence of two distinguished academics, Professor Sheldon and Professor Wilkinson. If anyone wants to read it, it is in their memorandum at pages 454 and 455 of the evidence" [source 1]. In addition, Sheldon and Wilkinson's evidence is discussed alongside that of the Human Fertilisation and Embryology Authority [HFEA] in the written report of the Joint Committee on the Human Tissue and Embryos (Draft) Bill [source 2].

(b) Wilkinson submitted written evidence (based on his earlier research on selective reproduction) to the **July 2013 Parliamentary Inquiry into Abortion on the Grounds of Disability** [source 3]. He is mentioned eight times in the report.

(c) Wilkinson is mentioned six times in **the Nuffield Council on Bioethics' high-profile 2011 report, *Human Bodies donation for medicine and research*** [source 4]. Wilkinson (2003) is favourably cited, and the Nuffield Council testify that Wilkinson provided thoughtful and challenging critiques of the draft ethics chapters, leading to the Working Party re-working and/or strengthening the arguments made.

(d) Wilkinson's research on the ethics of organ donation and sale led to membership of the **Ethical Advisory Sub-Group of the Organ Donation Task Force** (established by the Department of Health). The remit of this group was to advise the main Task Force on the ethical bases of different consent systems and the ethical acceptability of different systems. The work of the Sub-Group was reported in the Organ Donation Task Force's report: *The Potential Impact of an Opt Out System for Organ Donation in the UK* (November 2008).

(e) In 2012, Wilkinson acted as the 'ethics expert' at a public dialogue event in Newcastle-upon-Tyne, organised for the HFEA by Dialogue by Design, a consultancy that specialises in running public and stakeholder engagement processes. The consultation in question was entitled **Medical Frontiers: debating mitochondrial replacement**, which the HFEA ran on behalf of the UK government. His role included giving three short talks on the ethical questions, and being on hand to help members of the public understand particular issues. These events eventually fed into the HFEA's 2013 policy recommendations on mitochondrial replacement, which have been broadly accepted by the UK government.

### **Stimulating and Improving Debate**

Wilkinson's work on 'social' sex selection stimulated debate amongst the public and stakeholders and has enabled improved public understanding via a series of appearances in popular news media. The key findings of this work were widely reported in the media and were made available via short pieces on the *BBC News* and *This is Staffordshire* websites. In 2010, these pieces in turn led to considerable media interest with interviews given to more than ten UK local radio stations, as well as to BBC Radio 5 Live, the World Service, LBC, BBC Radio Scotland, the BBC TV News Channel, and BBC 1 TV's *The One Show* which at that time had an audience of around four million viewers. He also appeared on a 30-minute panel discussion on Voice of Russia Radio in 2010 to discuss Sex Selection.

In 2011-12, Wilkinson held a Wellcome Trust Dissemination Award (£34,000). This grant funded the following activities:

(a) **Two stakeholder engagement seminars (2011)**. Participants included representatives or members of the following groups: (a) Activist, Campaigning, or Educational Organisations with special interests in genetic and reproductive technologies (e.g. Genewatch, Human Genetics Alert, ProChoice Forum, Progress Educational Trust); (b) Health Care Professionals (and allied Researchers) especially those in Reproductive Medicine; (c) Policy and Regulatory Bodies with remits or interests in genetic and reproductive technologies (e.g. HFEA, Nuffield Council on Bioethics); and (d) Stakeholder Organisations representing people with disabilities, people with particular genetic disorders, or actual/prospective recipients of infertility treatment services.

(b) **The creation of a set of accessible and freely available dissemination essays (2013)**. On 3rd July 2013, four dissemination essays by Wilkinson and Garrard were published by Keele University under the collective title *Eugenics and the Ethics of Selective Reproduction* [source 5], and released in hard and electronic copy. Written for a public audience, they have enabled dissemination of Wilkinson's research to hundreds of people in the NHS and organisations interested in these ethical debates, such as Progress Educational Trust who are using the essays

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as a source of information in their work promoting ethically sound research and practice in relation to genetics.

The ideas articulated in the essays have also been disseminated to the public through the media:

(a) The essays gained significant and detailed coverage in the **international media** in July 2013 including in *The Independent* (2 page article and front page banner) [source 6] (78 reader comments in July 2013) to which *The Guardian* wrote a response piece [source 7], and which led to a debate on *Mumsnet* with 423 comments in July 2013 [source 8]; *The Telegraph* (20 reader comments in July 2013); and Arab Emirates' *Top News*. It was picked up internationally on-line and through syndication in Canada, Germany, Poland, Portugal, Spain, UAE, and Vietnam (for example an article was published on Vietnamese Health and Parenting Website *kien thu'c phu nu* on 11<sup>th</sup> July 2013 [source 9]). There was also extensive coverage in specialist medical publications including: *Medical Xpress*; *The British Medical Journal*; and by the PGH Foundation. On 3<sup>rd</sup> July 2013 Wilkinson participated in radio interviews and debates about the issues raised in the essays on several BBC radio stations, including: Radio 4 *Today*, Radio London, 5live, and the World Service.

(b) **Blog / Online Publications.** The publication of *Eugenics and the Ethics of Selective Reproduction* also led to requests for Wilkinson to write blog posts and online articles. Wilkinson wrote pieces for *ETHOX* [source 10], the *Wellcome Trust Blog*, and *Bionews*, which has 18,000 readers per week. These outlets aim to improve ethical standards, supporting health professionals and general education of the public.

**5. Sources to corroborate the impact**

Source 1: HL Debs 4 Dec 2007 : Column 1663

Source 2: Joint Committee on the Human Tissue and Embryos (Draft) Bill (Session 2006-7), *Human Tissue and Embryos (Draft) Bill – Volume 1 – Report*, 1<sup>st</sup> August 2007, London: The Stationery Office. And in the Final 2008 Bill, Section 1ZA(1)(d)

Source 3: Parliamentary Inquiry into Abortion on the Grounds of Disability, July 2013

Source 4: Nuffield Council of Bioethics (2011) *Human Bodies donation for medicine and research*.

Source 5: Wilkinson, S. and Garrard, E. (2013) *Eugenics and the Ethics of Selective Reproduction*. Keele University, Keele.

Source 6: *The Independent*, 3<sup>rd</sup> July 2013 'Medical ethicist: Ban on sex selection of IVF embryos is not justified'.

Source 7: *The Guardian*, 6<sup>th</sup> July 2013 'Sex selection has the potential to skew future generations'.

Source 8: *Mumsnet Talk* on Mumsnet.com., July 2013 'To say why not use IVF to choose the sex of a baby?' [http://www.mumsnet.com/Talk/am\\_i\\_being\\_unreasonable/a1794177-To-say-why-not-use-IVF-to-choose-the-sex-of-a-baby](http://www.mumsnet.com/Talk/am_i_being_unreasonable/a1794177-To-say-why-not-use-IVF-to-choose-the-sex-of-a-baby)

Source 9: Vietnamese website *Kien thu'c phu nu* 10<sup>th</sup> July 2013: 'So thích con trai con gái trong mat người phương Tây': <http://doisong.vnexpress.net/tin-tuc/gia-dinh/so-thich-con-trai-con-gai-trong-mat-nguoi-phuong-tay-2846602.html>

Source 10: Wilkinson, S. (July 2013) Should we reconsider the UK ban on sex selection? *Ethox Blog*, The Ethox Centre. <http://www.ethox.org.uk/ethox-blog/should-we-reconsider-the-uk-ban-on-sex-selection>

**Corroborators:**

Nuffield Council on Bioethics

Dialogue by Design

Progress Educational Trust