

<p><b>Institution: Lancaster University</b></p>
<p><b>Unit of Assessment: Theology and Religious Studies</b></p>
<p><b>Title of case study: Ethics and the Care of Premature Babies</b></p>
<p><b>1. Summary of the impact</b>          Research by Professor David Archard on the moral and legal status of children has improved health policy and care for extremely premature babies through its contribution to the Nuffield Council on Bioethics report <i>Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues</i>, released in late 2006. During 2008-13 the report's guidelines have come to be followed across the NHS in the clinical care of extremely premature babies and are regarded by doctors as the best available advice. Through its contribution to the Nuffield report, Archard's research has helped to bring improved and more consistent health care provision to extremely premature babies and their families across the UK.</p> <p><b>2. Underpinning research</b>          From 2004 to 2006, Archard (Professor of Philosophy and Public Policy at Lancaster Sept 2003-June 2012) published a monograph and articles on children's rights and moral standing, addressing the principles underpinning child welfare law and policy.          The monograph (Archard 2004a) is the second, substantially expanded edition of <i>Children: Rights and Childhood</i> which lays the foundation for further work in which Archard develops the policy applications. Archard (2004b) argues that it is wrong deliberately to bring into existence an individual whose life will be of very poor quality. Archard (2006a) argues that a child's best interests should be a primary but, realistically, not the only consideration in how he or she is treated. He argues for giving 'at least equal consideration to the interests of any adults affected by policies and actions promoting the child's welfare' (2006a, sec. 7).          This research has had transformative impact on medical practice and policy through its contribution to the Nuffield report <i>Critical Care Decisions in Fetal and Neonatal Medicine</i> (Nuffield Council on Bioethics 2006). This is so both indirectly, because the research led to Archard's invitation to become Member then the Deputy Chair of the relevant Working Party (2004-6), and directly, through Archard's joint authorship of Chapter 2 of the report 'Decision making: the ethical issues' (with Alastair Campbell, now Emeritus Professor of Medicine, University of Bristol) as well as Archard's broader input into the entire report.  <u>Context</u> of the report. Major improvements in medical care have given extremely premature newborns – those born before 29 weeks – better survival chances yet often very limited life spans and/or major abnormalities, chronic illnesses or disabilities. These cases present difficult decisions to families and health professionals: whether to resuscitate such babies, or replace intensive with palliative care. In the Netherlands the 2004 Groningen Protocol established criteria to guide doctors in the active ending of life of severely ill newborn babies. This, and increasing media attention to the issue, led the Nuffield Council to commission the <i>Critical Care Decisions</i> report. Its overall aim was to provide a sound ethical basis for critical care decisions. As such Archard's input as a moral philosopher was crucial.          In <u>Chapter 2</u>, Archard and Campbell argue that 'the best interests of a baby must be a central consideration in determining whether and how to treat him or her' (<i>Critical Care Decisions</i> 2.21) and that it is against a baby's interests to be kept alive if this causes the baby intolerable suffering. Parents' interests carry some weight, but the baby's interest in avoiding an intolerable life has more weight (2.29-2.30). These conclusions are based on Archard (2004a, 2004b, 2006a) and they underpin the report's key conclusion, rarely openly stated before, that intensive treatment should not always be given to seriously ill and extremely premature babies who are unlikely to get any better and/or for whom death is inevitable, if the suffering caused by continuing active treatment outweighs its benefits to the baby.          This principle, applied to current outcomes of treatment for premature babies of different ages, underpins the report's week-by-week guidelines on giving intensive care to babies born at 25 weeks and above, 24, 23, 22 and before 22 weeks.          In Chapter 2 Archard and Campbell also argue that deliberate ending of life and</p>

## Impact case study (REF3b)

withdrawing/withholding treatment are not morally equivalent, because while the latter is sometimes permissible given the importance of the baby's best interests, the former contravenes doctors' obligations and damages doctor-patient relationships (2.35). These arguments underpin another key conclusion of the report, against active ending of neonatal life even when that life is intolerable.

**3. References to the research**

1. Archard, David (2004a) *Children: Rights and Childhood*, second enlarged and revised edn., London: Routledge. ISBN-10: 0415305845; ISBN-13: 978-0415305846. 2\* evidence: peer-reviewed monograph with leading academic publisher; widely cited, 593 times since first edition; many favourable reviews (of second edn.), comments including: 'An exhaustive and meticulously comprehensive examination of children's rights from both a moral and a legal perspective ... a fine ... text' (*Metapsychology* June 2005).
2. Archard, David (2004b) Wrongful Life. *Philosophy* 79 (3): 403-420. DOI 10.1017/S0031819104000348. 2\* evidence: peer-reviewed journal article; highly respected philosophy journal ranked A in the Australian Research Council's 2010 journal list.
3. Archard, David (2006a) Children's Rights. In *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, URL: <http://plato.stanford.edu/archives/sum2011/entries/rights-children/> (substantive content change, Winter 2006, to version first archived 2002). 2\* evidence: The Stanford Encyclopedia is widely recognised as the world-leading encyclopaedia of philosophy, with regularly updated entries commissioned from leading international experts; all entries and substantive updates are refereed by the distinguished Editorial Board before publication. At 18,000 words Archard's entry constitutes a substantial research piece.
4. Archard, David (2006b) The Moral and Political Status of Children. *Public Policy Research* 13 (1): 6-12. 2\* evidence: this is the policy-oriented journal of the Institute for Public Policy Research, the UK's leading progressive think-tank; most articles are commissioned to bring academic research to a policy audience. Archard's commission reflects his high standing in this area.
5. Nuffield Council on Bioethics (2006) *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues*, London: Nuffield Council on Bioethics. ISBN: 1 904384 14 5. Available to download at: <http://www.nuffieldbioethics.org/neonatal-medicine> 2\* evidence: The definitive set of guidelines on medical care of extremely premature babies, favourably received by the medical community and welcomed by Parliament in Early Day Motion 122.

That the general quality of Archard's ethical work is at least 2\* is further evidenced by his invitation on its basis to become Member then Deputy Chair of the Nuffield Working Party on *Critical Care Decisions*.

**4. Details of the impact**

Archard's research underpins the recommendations in Chapter 2 of the *Critical Care Decisions* report and informs its overall recommendations on palliative care and involving parents in decision-making.

Before the report was published, clinical care of extremely premature babies in 222 UK neonatal units, and information given to parents, varied greatly at different hospitals. The report's guidelines have led to much more consistent practice. Although non-mandatory, the guidelines have during 2007-2013 become universally used as the framework for practice across the NHS, as one neonatal consultant attests: 'when it comes to premature babies ... most decisions are based on guidelines from the Nuffield Council on Bioethics' (*Telegraph* 29/04/2012). Indeed, the 2011 BBC2 documentary *23 Week Babies: The Price of Life* called the report 'the Bible' on prematurity. The report's guidelines have shaped clinical practice so pervasively by providing the basis for successive further sets of medical guidelines. This happened as follows.

At the end of 2006 the report was favourably received by the medical community (*The Lancet* editorial of 25/11/2006 called the report 'thoughtful, sensitive, and sensible') and other bodies including the Church of England House of Bishops. Early Day Motion 122, tabled by MP Kevin

## Impact case study (REF3b)

Barron and signed by over 46 MPs in the 2006-7 British Parliamentary session, declared: ‘this House welcomes the report by the Nuffield Council on Bioethics on critical care decisions...’

The Nuffield report presented its recommendations as a basis on which organisations that govern the medical profession should develop guidelines on the care of extremely premature babies. In response:

- In Oct 2008 the British Association of Perinatal Medicine (BAPM) published a framework for clinical practice for *Management of Babies Born Extremely Preterm*. Citing the Nuffield report (Ref. 3, p. 1, p. 4), the framework’s week-by-week guidelines (pp. 2-3) reflect those of the Nuffield report. The framework is generally followed across the NHS (as attested, e.g., in the *Daily Mail* 10/09/2009).
- In 2008 the Neonatal Taskforce was established, made up of practitioners across the NHS and members of special care baby charity Bliss, supported by the Department of Health. The Taskforce published the first NHS-wide comprehensive framework for improving neonatal services (*Toolkit for High Quality Neonatal Services*, 2009; Ref. 4). The Toolkit states: ‘Recommendations for the care of babies born at the threshold of viability, such as those produced by BAPM, should inform local guidelines’ (Ref. 4, p. 88).
- In 2009 Bliss was granted Department of Health funding to produce guidance for parents to support decisions around the management of extremely premature birth. This resulted in a booklet for families, *Making Critical Care Decisions for Your Baby* (2010, updated, 2011), now used across the NHS for involving parents in decision-making. As Bliss acknowledge (at [www.bliss.org.uk/improving-care/professional-development/making-critical-care-decisions-for-your-baby/](http://www.bliss.org.uk/improving-care/professional-development/making-critical-care-decisions-for-your-baby/)), the production of this booklet follows the Nuffield report’s recommendations for ‘partnerships of care’ with parents (*Critical Care Decisions* 8.54). These recommendations are informed by Archard’s principle that parents’ interests, not only the baby’s, carry weight.
- The Royal College of Obstetricians and Gynaecologists (RCOG) welcomed the *Critical Care Decisions* report in a 11/2006 press release: ‘These guidelines will help maternity and neonatal staff to make difficult decisions in consultation with parents, and to provide the best care available to those that need it’ (Ref. 5). The RCOG established a working party whose 2010 report *Termination of Pregnancy for Fetal Abnormality* incorporates the Nuffield guidelines on prematurity (Ref. 5, p. 6).
- The positive impact of these successive guidelines is shown by the 2009/10 EU benchmarking report by the European Foundation for the Care of Newborn Infants (EFCNI) (Ref. 6, pp. 84-90). EFCNI highlights the UK as one of only two European countries with a national policy on premature infants (the Toolkit – enabled by the Nuffield report) and one of three countries representing best practice in neonatal care (Ref. 6, esp. p. 89 and 94-95).
- Today, the Nuffield report’s conclusions remain widely endorsed in the medical community: e.g., a 2010 *Lancet* editorial found that ‘a recent study ... underline(s) the validity of the 2006 Nuffield Council on Bioethics recommendations on resuscitation and care of extremely premature babies’ (*The Lancet* 1/5/2010).

The Nuffield report has received extensive media coverage. When it first appeared coverage followed in the BBC News, CBC News (Canada), *New York Times*, *Irish Times*, Sky News, Australian Broadcast Corporation and all UK daily newspapers. To today the report is still regularly discussed in articles in many UK broadsheets and tabloids (*The Mail*, e.g. 10/09/2009, the *Mirror*, e.g. 09/09/2009). The March 2011 BBC2 documentary *23 Week Babies: The Price of Life* (which dubbed the report ‘the Bible’ on prematurity) drew 1.9 million viewers.

The report receives extensive attention in the virtual sphere. The Nuffield web-pages on *Critical Care Decisions* are widely viewed: e.g., in 2011 they drew 2,323 visits, plus 1116 downloads of the full report and 669 downloads of the summary. Likewise Jan-Jul 2012 saw 1393 visits and 516 report downloads. This shows the level of public interest in the report and its beneficial effect on public understanding of care for extremely premature babies.

Through its contribution to the Nuffield report, Archard’s research has helped to enable healthcare teams, especially maternity and neonatal staff, to improve care for extremely premature babies, to involve parents in difficult decisions, and to develop a unified approach to such care and decision-making. Archard’s research has thus helped UK health authorities to offer better provision across the UK’s 162 neonatal units and 46 neonatal intensive care units, improving public services in

**Impact case study (REF3b)**

health and medicine. Archard's research has thereby contributed to benefits in well-being for the many families and their babies who are directly affected by neonatal services – extremely premature babies constitute around 1% of newborns in the UK today (so, of 655,357 newborns in 2006/7 as a sample year, this means 6553 babies). The reach of these benefits of Archard's research extends, then, to thousands of babies and their families and hundreds of hospital staff.

**5. Sources to corroborate the impact**

1. The *Critical Care Decisions* report and summaries of its key conclusions are at: [www.nuffieldbioethics.org/neonatal-medicine](http://www.nuffieldbioethics.org/neonatal-medicine) (This includes a list of working party members.)
2. Evidence of widespread media reference to the Report is at: [www.nuffieldbioethics.org/neonatal-medicine/neonatal-medicine-media-coverage](http://www.nuffieldbioethics.org/neonatal-medicine/neonatal-medicine-media-coverage)
3. The BAPM framework is at [www.bapm.org/publications/documents/guidelines/Approved\\_manuscript\\_preterm\\_final.pdf](http://www.bapm.org/publications/documents/guidelines/Approved_manuscript_preterm_final.pdf)
4. The *Toolkit for High Quality Neonatal Services* is at: [http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_107845](http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107845)
5. The RCOG press release and report are at: <http://www.rcog.org.uk/news/nuffield-councils-critical-care-decisions-fetal-and-neonatal-medicine-ethical-issues>  
<http://www.rcog.org.uk/termination-pregnancy-fetal-abnormality-england-scotland-and-wales>
6. EFCNI's European benchmarking report is at <http://www.efcni.org/?id=1571>
7. Further information on the report's impact is in the Nuffield's annual reports of 2006 (pp. 10-15), 2007 (p. 23), 2009 (p. 10), 2011 (p. 12), all available at: [www.nuffieldbioethics.org/content/annual-reports](http://www.nuffieldbioethics.org/content/annual-reports)

Additional sources who can be contacted:

7. Professor of Neonatal Medicine, UCL EGA Institute for Women's Health.
8. A statement from the Programme Manager, Nuffield Council on Bioethics, is available. It contains the impact assessment of *Critical Care Decisions* carried out by the Nuffield Council on Bioethics.
9. A statement from the Communications Officer, Nuffield Council on Bioethics, is also available. It testifies to the impact of the *Critical Care Decisions* report (visits to the webpage, numbers of downloads, plus media coverage).