

Institution: Queen's University Belfast		
Unit of Assessment: 30 – Philosophy		
Title of case study: Making Ethically Difficult Medical Decisions For Children		
Period when the underpinning research was undertaken: 2012 to 2018		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
David Archard	Professor	01/06/2012 – 01/02/2018
Period when the claimed impact occurred: 2015 to 2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>Great Ormond Street Hospital for Children (GOSH) is a world leading hospital for children pioneering many innovative and life-saving treatments. Because decisions about these treatments can be ethically complex, the hospital's Clinical Ethics Committee (CEC) provides a rapid response service to assist clinicians both in the hospital and further afield. Since 2015 Professor Archard has served as the only moral philosopher on this committee. In that role he has (a) provided academically robust and research informed ethical input to decision making on individual cases, and (b) helped improve the operation of the clinical ethics service by taking a lead role in the CEC's annual Away Days.</p>		
2. Underpinning research		
<p>Professor Archard's appointment to the Clinical Ethics Committee was made in recognition of his internationally leading role, as evidenced in his body of published work, in philosophical and ethical research on children's medical treatment – including work on children's rights, on the concept of best interests, and on the rights and obligations of parents.</p> <p>Archard's contribution to the CEC has been materially informed by his ground breaking research (carried out at QUB between 2012 and 2018) on three topics, each of which plays a role in many of the ethically complex decisions faced by the Committee:</p>		
<ol style="list-style-type: none"> 1. The weight that should be given to a child's own views, particularly where these differ from those of his or her parents and/ or medical staff. Archard has carried out original work on what it is to give a child's views weight where these views do not count as decisive (Ref 3.4). He has also argued against the view that children's input into decisions that concern them is important solely because this helps medical staff determine what is in the child's best interests. Archard has been developing and defending an alternative account according to which children who have a view have a right to express that view because they have a right to be involved in processes determining their own future (Ref 3.3). 2. The extent to which a child's best interests should be decisive, and what it means for a course of action to be in a child's best interests. While the concept of best interests plays a significant role in legislation and regulation concerning children, it is contentious and has been criticised as being poorly defined (Ref 3.5). There is also a potential conflict between aiming to do what is in a child's best interests and giving appropriate weight to his or her views. In his work Archard has both sought to explicate the 'best interests' principle and provided an original analysis of ways to manage this conflict (Ref 3.3). 		

3. The nature and extent of parents' rights to make decisions about their child's medical treatment. Archard's work on the family has addressed this question in some detail, and feeds into arguments about the limits of parental rights particularly when it comes to medical treatment.

In addition to his detailed work on ethics and decisions about children's medical treatment, Archard has also carried out research on the nature of 'moral compromise' (Ref 3.1) and the proper role of moral philosophers in collective decision-making as part of a public body. This research, and related work on complicity in non-ideal collective decision-making (Ref 3.2), has directly informed his work on the CEC where members from a wide range of different specialisms, as well as lay members, must work together to come to a decision on morally contentious issues.

3. References to the research

1. D. Archard, 'Moral compromise', *Philosophy*, 87:341 (July 2012): 403-420 — doi:10.1017/S0031819112000265
Contribution to a leading peer-reviewed journal
2. D. Archard, 'Dirty hands and the complicity of the democratic public', *Ethical Theory and Moral Practice*, 16:4 (August 2013): 777-790 — DOI 10.1007/s10677-012-9387-y
Contribution to a leading peer-reviewed journal
3. D. Archard, 'Children, adults, best interests and rights,' *Medical Law International*, 13:1 (March 2013): 55-74 — DOI: 10.1177/0968533213486543
Contribution to a leading peer-reviewed journal
4. D. Archard, 'Children, Adults, Autonomy and Well-Being,' in A. Bagattini and C. Macleod (eds.) *The Nature of Children's Well-Being: Theory and Practice* (Dordrecht: Springer, 2014): 1-14. ISBN: 978-94-017-9252-3
Chapter in invited volume with international contributors
5. D. Archard, 'Family and Family Law: Concepts and Norms', in Elizabeth Brake and Lucinda Ferguson (eds.) *Philosophical Foundations of Children's and Family Law* (Oxford: Oxford University Press, 2018): 59-72. ISBN: 9780198786429
Chapter in invited volume with international contributors

4. Details of the impact (indicative maximum 750 words)

Great Ormond Street Hospital is a world leading children's hospital where doctors face difficult decisions on a daily basis in trying to extend or save the lives of children. They also face ethical dilemmas: Should innovative yet unproven treatments be used as a last resort? How should we treat neonates born prematurely with significant problems? What palliative care should be offered to terminally ill children? The Clinical Ethics Service (CES) at GOSH provides a unique facility for families, patients and clinicians to address these issues as they arise in the course of ongoing treatment. The CES is considered a world-leading exemplar of how informed, considered ethical review of medical treatment should be conducted, and has influenced clinical ethics practice in other UK healthcare institutions and children's hospitals throughout the world. (Ref 5.1).

In 2015 Professor Archard was appointed to the CES's Clinical Ethics Committee (CEC) on the basis of his established international reputation as an applied ethicist who has written extensively on childhood, parenthood, children's and parent's rights, and the nature of the family (Refs 5.2 & 5.3). As a member of the Committee's Rapid Response team, which meets to consider urgent, ethically challenging cases, he has ensured that its work is informed by authoritative, relevant ethics research, including his own. He has played a material role in helping the Hospital manage the numerous ethical challenges it faces each year. That has, in

turn, had a significant effect, in many cases a life-changing effect, on the many sick children and their families involved in cases considered by the Committee.

“[Archard] has made a huge difference to the work of the Trust, helping with the nuanced balance between the Rights of the child being treated; the Rights and duties of parents and their decision-making with medical teams. This has been especially needed as rarer and more innovative treatments are increasingly being tried with children who would otherwise die.” (Director of Bioethics and vice-chair GOSH Clinical Ethics Committee, Ref 5.2)

By bringing his expertise on the extent of parents’ rights, considerations of how to interpret the ‘best interests’ requirement, and the child’s voice to the Committee, Archard has helped the Hospital navigate cases where families, children, and hospital staff disagree about what should be done:

“[Archard] has a focus on the rights of the child, formulated from a philosophical perspective... This knowledge forms a basis to a pragmatic approach to cases brought to the team for ethical consideration. Examples of cases ... have been conjoined twins, and whether separation should be carried out, long term ventilation for an infant with a severe neuromuscular disorder for which there is no definitive treatment, and innovative treatments such as gene therapy for a child with a progressive genetic ocular disorder leading to blindness and the use of CAR-T cells in children with immunological and haematological disorders.” (Member of GOSH Clinical Ethics Committee, Ref 5.4)

Recognition of his central role within the GOSH CEC is evidenced by his prominent appearance in the BBC2 documentary *The Conjoined Twins: an Impossible Decision*, which followed the CEC’s work on a case that had drawn much public attention (Ref 5.5).

In addition to contributing to decision-making about specific cases, Archard has helped develop the capacity of the Committee through his leading role in its annual Away Day, which is designed for members of the Committee to reflect on the past year’s activity and to improve future practice. Archard was the sole organiser and lecturer for the 2016 Away Day, and played a significant role in both the 2017 and 2018 Away Days,

“His teaching and training, along with his quiet words of wisdom to senior team members have been utterly invaluable, together with his presence at complex ethical reviews with clinical teams and parents.” (Director of Bioethics and vice-chair GOSH Clinical Ethics Committee, Ref 5.2)

Archard has taken a lead on the monthly educational sessions that are held before the main Committee meetings and that discuss key issues, including the notion of ‘moral distress’, and how to communicate difficult moral decisions to parents and the wider public. This work has been instrumental in building the Committee’s capacity to address the challenging ethical issues it faces on a regular basis, and to ensure that the Committee’s future decisions are informed by up to date and rigorous academic research in ethics, beyond the cases in which Archard has been directly involved,

“[Archard]’s teaching and contribution has led to those of the team involved in these cases to have a more rigorous approach in formulating ethical advice.” (Member of GOSH Clinical Ethics Committee, Ref 5.4)

As a result of his experience with the GOSH Clinical Ethics Committee, Archard was invited to lead development of the Nuffield Council on Bioethics’ Briefing Note *Disagreements in the Care of Critically Ill Children* (Ref 5.6). These Briefing Notes are specifically designed to guide and influence policy-making, and are written for politicians, key stake-holders, and the media. The Note, published by the UK’s national ethics think-tank, sets out the major causes of such disagreements, the ethical, social and legal issues raised, and suggests ways forward to navigate them.

5. Sources to corroborate the impact (indicative maximum of 10 references)

1. Great Ormond Street Hospital, *The Child First and Always: First Clinical Ethics Service Report*, July 2017, available at <https://www.gosh.nhs.uk/wards-and-departments/departments/clinical-specialties/clinical-ethics-service-information-health-professionals/about-clinical-ethics-service/>
2. Letter, dated 25th July 2019, from Director of Bioethics and vice-chair GOSH Clinical Ethics Committee.
3. Letter, undated, from GOSH Chaplain, Deputy Director of the Paediatric Bioethics Service and Lay Member of CEC.
4. Letter, undated, from member of GOSH Clinical Ethics Committee.
5. BBC2 Documentary August 5th 2019 *The Conjoined Twins: an Impossible Decision* <https://www.bbc.co.uk/programmes/m0007f81>
6. Nuffield Council on Bioethics Briefing Note *Disagreements in the Care of Critically Ill Children*: <http://nuffieldbioethics.org/project/disagreements-care-critically-ill-children>