



The Tragic Death of a Young Woman and an Exercise in ‘Ethics Washing’ by the Nuffield Council on Bioethics

Last Tuesday evening (12 September 2023) a nineteen-year-old young woman, ST, died after a protracted dispute about her treatment and care¹. The NHS Trust in charge of her care had argued that she lacked mental capacity to make decisions because she disagreed with her doctors. This was despite two experienced psychiatrists finding that she was not mentally ill and that she did have decision-making capacity.

As is often the case in these disputes, there were reporting restrictions which prevented ST speaking about her situation while she was alive. Even now, in their grief, her parents are prevented from naming her publicly. This freedom has been taken from them by the Court of Protection. The NHS Trust involved also cannot be named.

In the Court proceedings, which are publicly available, the term “a treatment plan of palliative care”² was used to mean a plan in which ventilation would be given but the dialysis on which she was dependent would be withdrawn. This was despite her declared wish for this to continue. Dialysis can indeed be very burdensome but it is for the patient to weigh the burdens of treatment. It was because of her wish to continue to receive life sustaining treatment that the Trust wished to have her declared non-competent.

The thoughts and prayers of the staff of the Anscombe Bioethics Centre are with ST and her family at this time.

On a related note, today, Monday 18 September, the Nuffield Council of Bioethics has issued a report on the causes of disagreements over the care of critically ill children (those under 16). The Report has been commissioned by the Secretary of State for Health as required by the Health and Social Care Act 2022, s.177.

The Nuffield Council is part-funded by the taxpayer. It is not clear whether this Report also received additional funds from the Department of Health and Social Care. In any case, the Report does not include any statement of Conflict of Interest in relation to the Council’s paymasters, but “extend[s] thanks to officials at the Department of Health and Social Care for their willingness to have open and constructive conversations throughout whilst respecting our independence.” (p. 2) There is no record of what these “constructive conversations” concerned or what parts of the report were altered in the light of them.

¹ *Lethal Paternalism: The Case of ST*, Anscombe Bioethics Centre Press Release (4 September 2023): <https://www.bioethics.org.uk/news-events/news-from-the-centre/press-release-lethal-paternalism-the-case-of-st/>

² [2023] EWCOP 40, para 2,4, 18, 19 <https://caselaw.nationalarchives.gov.uk/ewcop/2023/40>

The requirement that there be a review of disagreements between parents and healthcare professionals was included in the Act as a compromise because the government blocked an amendment proposed by Baroness Finlay of Llandaff³. That amendment would have shifted the balance to give parents a greater say in these disagreements, and would have discouraged Trusts from taking them to Court pre-emptively. It is thus extraordinary that the Nuffield Council should cite as a reason against the “significant harm” test, that this “has sparked considerable debate, however, the result has been inconclusive and legal change has not occurred” (p. 48). The reason legal change has not occurred is precisely because the government prevented it from occurring, the same government which is now commissioning this review.

Most of the positive recommendations of this report are weak but unobjectionable. They are requests for more research or for information for parents or healthcare professionals or for greater efforts at communication. However, there is nothing here that would require NHS Trusts or the Courts fundamentally to change their attitudes towards parents who disagree with doctors. The recommendation, for example, that palliative care not be conflated with “symptom control when the end of life is imminent” (p. 30), rings hollow given the repeated use of the term “palliative care” (more than two dozen times) by the NHS Trust in the ST case to refer to what was in fact the withdrawal of life-sustaining treatment. The Nuffield Council had no criticism for the way that Trusts in these legal cases have used the language of “palliative care”.

In general, in the Report, there is very little discussion of the role of Trusts in disagreements (in distinction from healthcare professionals), even though it is the Trust, rather than the professionals that take legal action. (It is worth noting the Report’s acknowledgement (pp. 48-50) of how distressing and costly, both financially and emotionally, it is to go to court, with little notice or advice.) It is also noteworthy that healthcare professionals found that “support from the Trust was both less forthcoming and less useful” (p. 41). Nor is there discussion in the document of the role that healthcare resource allocation plays, or is perceived to play, in the decisions of Trusts.

Typically, “best interests” decisions are presented as though the NHS was not subject to any resource constraints whatsoever. However, such constraints play a subtle upstream role in what treatments are thought reasonable. The report does not acknowledge that in most if not all cases that come to court, the Trust is seeking to withdraw costly treatment and in all cases, the treatment is currently funded by the NHS. The pretence that resource allocation plays no role, leads Trusts to rely instead on the claim that providing costly life-sustaining treatment would in these cases be contrary to the child’s best interests. It should be the role of an ethics Centre to examine the subtle pressures that frame such best interests discussions but such allocation considerations are entirely lacking from the Nuffield Council Report.

Faced with issues of institutional culture and a massive imbalance of power, knowledge, and resources, between NHS Trusts and parents, the recommendations of the Nuffield Council are extremely weak. They do not include the bite of statutory obligation and in this regard are fundamentally different to the constructive proposals that were in Baroness Finlay’s proposed amendment.

³ Health and Care Act 2022, amendment 172: <https://bills.parliament.uk/bills/3022/stages/16122/amendments/91480>

The Nuffield Council Report's discussion of the proposed legal changes is extremely thin. There is no acknowledgement that, in taking decisions away from parents without having demonstrated the likelihood of "significant harm", Courts are currently perpetuating an injustice. It was an injustice towards Archie Battersbee, for example, that his mother to whom he was evidently devoted, was not permitted to speak for him⁴. The problem of the perception of the Children's Guardian noted by the Nuffield Council (p. 51), is not due to parents not understanding the role, but is due to their recognition that this role usurps the rightful position of the parents. The right of children to be cared for and represented by their own parents is not absolute but, in justice, it requires evidence of the danger of significant harm before this role is taken from a parent and given to a social worker. The Nuffield Council opines that the "best interests" test is "well understood due to being developed through numerous legal judgements" (p. 48). However, it is precisely the unsatisfactory nature of this contentious cycle of legal judgements that shows the need for a different approach.

There are other problems with the document. In its outline of ethical principles, the presentation of the "sanctity of life" is a caricature: that "human life should be preserved at all costs" (p. 14). This statement does not represent the "sanctity of life" as defended within any serious intellectual tradition, certainly not that of the Catholic Church. It is rather, the error of "vitalism"⁵. No references are provided for the Report's definition of the sanctity of life. Similarly the discussion of quality of life fails to distinguish between the legitimate use of quality of life in weighing the relative burdens and benefits of treatment and the dangerous misuse of quality of life as a motivation for intentional ending of life by omission. Nothing in the Nuffield Council Report protects children from non-voluntary passive euthanasia imposed by healthcare professionals over the objections of parents.

The Nuffield Council accepts that these disagreements stem from and lead to a weakening of trust, but do not acknowledge that the greatest threat to trust is a lack of transparency, a problem exacerbated by reporting restrictions. There is no acknowledgement of the distress caused to parents by prohibiting even the naming their child in public. Those few whose names are known (Ashya King, Charlie Gard⁶, Alfie Evans⁷, Isaiah Haastrup, Tafida Raqeeb, Pippa

⁴ *Comment on the Latest High Court Judgement on Archie Battersbee*, Anscombe Bioethics Centre (20 July 2022): <https://www.bioethics.org.uk/news-events/news-from-the-centre/press-release-a-comment-on-the-latest-high-court-judgement-on-archie-battersbee/> *Press Statement on Archie Battersbee – "Very Likely Dead" is not Dead Enough*, Anscombe Bioethics Centre (17 June 2022) <https://www.bioethics.org.uk/news-events/news-from-the-centre/press-statement-on-archie-battersbee-very-likely-dead-is-not-dead-enough/>

⁵ See for example Keown, J. 'The Legal Revolution: From Sanctity of Life to Quality of Life and Autonomy'. *J. Contemp. Health L. & Policy* 14 (1997): 253. <https://scholarship.law.edu/cgi/viewcontent.cgi?article=1334&context=jchlp> Anscombe Bioethics Centre, *The Ethics of Care of the Dying Person* (11 July 2013): <https://www.bioethics.org.uk/media/z0dhvfb/the-ethics-of-care-of-the-dying-person.pdf>

⁶ *Press Release: Charlie Gard – The End of Legal Proceedings*, Anscombe Bioethics Centre (24 July 2017): <https://www.bioethics.org.uk/news-events/news-from-the-centre/press-release-charlie-gard-the-end-of-legal-proceedings/>

⁷ *Press Statement – Alfie Evans: A Brief Statement of the Fundamental Ethical Principles*, Anscombe Bioethics Centre (2 February 2018): <https://www.bioethics.org.uk/news-events/news-from-the-centre/press-statement-alfie-evans-a-brief-statement-of-the-fundamental-ethical-principles/>

Knight⁸, Alter Fixsler⁹ and Archie Battersbee¹⁰), stand for very many more who have never been named. It is striking that the Nuffield Council neglects to name even those whose names are in the public domain. It keeps the veil of silence.

The Nuffield Council is not transparent about the funding received for this Report, or about the views and interests of the Department of Health and Social Care in regard to this issue, or the role played by conversations with the Department in specific sections of the Report. In relation to the proposed amendment of Baroness Finlay, which lies at the origin of the review, the Nuffield Council limits itself to a brief summary of some arguments for and against, giving more weight to the latter and including some prominent quotations. It acknowledges diversity of opinion but, in its recommendations, it does not even suggest that the case for possible legal change might usefully be the subject of further research. After the most cursory of discussions, the door is simply shut.

It would have been better had this review been conducted by the Department of Health and Social Care. At least then the political interests that lie behind its conclusions in regard to legal change would have been overt. As it is, this exercise in “ethics washing” does no credit either to the Nuffield Council or to the Department.

END

Notes to Editors:

- Any part of the above can be quoted as coming from our Director, Professor David Albert Jones.
- For more information on the Anscombe Bioethics Centre, see our website: www.bioethics.org.uk.
- For interviews or comment, contact: media@bioethics.org.uk or 07900925708.

⁸ *Press Release: Catholic Bioethics Centre Highlights Deeply Flawed Court Decision to Withdraw Treatment From Five-Year-Old Child*, Anscombe Bioethics Centre (4 February 2021): <https://www.bioethics.org.uk/news-court-decision-to-withdraw-treatment-from-five-year-old-child/>

⁹ *Press Statement – The Alta Fixsler Case: Subsidiarity and the Importance of Circumstances*, Anscombe Bioethics Centre (5 August 2021): <https://www.bioethics.org.uk/news-events/news-from-the-centre/press-statement-the-alta-fixsler-case-subsidiarity-and-the-importance-of-circumstances/>

¹⁰ *Press Release on the Passing Away of Archie Battersbee*, Anscombe Bioethics Centre (4 August 2022): <https://bioethics.org.uk/news-events/news-from-the-centre/press-release-on-the-tragic-passing-of-archie-battersbee/>



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