

Guest Editorial

An Enduring and Difficult Issue from a Multidimensional Perspective

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This special section has been put together to combine perspectives on an enduring and difficult issue—the ethical principles governing the care of severely neurologically impaired newborns and infants and the best-interest standards that ought to govern our judgments about them. The cast of authors includes pediatricians, neurosurgeons, ethicists, philosophers, and lawyers, and many individual authors are legitimately able to wear more than one hat (including that of a parent). Together we get a singularly comprehensive view of a problem that besets clinicians, courts, and bioethical theorists throughout the world.

The first article, “Ashley, Two Born as One, and the Best Interests of a Child” (Grant Gillett), suggests two principles: (1) a potentiality principle that recognizes the rightness of every child being given the opportunity to develop in his or her own way to the extent possible in the light of a conception of individual human potential and (2) a *psychosomatic harmony principle* that recognizes the unity that is the embodied subjectivity of a human being.

The second article, “Separation of Craniopagus Twins: A Clinical, Legal, and Ethical Conundrum” (Reuben Johnson and Philip Weir), picks up the difficult problem of conjoined twins and the varying ways of managing that problem that have been developed. The particular focus is on twins conjoined at the head, cases in which issues of survival from surgery and the livability of the human life that otherwise obtains have to be weighed very carefully. A keen clinical judgment about best interests and biomedical realities along with concerned, attentive engagement with the twins themselves must be skillfully melded together to resolve such cases in a way that all can live with.

Jeanne Snelling tackles the fraught medicolegal debates about children’s rights and best-interest judgments in “Minors and Contested Medical-Surgical Treatment: Where Are We with Best Interests?” Her dual health science and legal qualifications allow an in-depth and considered treatment in which rights are related to best interests in an intricate and nuanced way.

“The Ethical Grounds for the Best Interest of the Child” (Lynne Bowyer) reminds us of the philosophical basis of our intricate interrelatedness as Beings-in-the-world-with-one-another and therefore of the fact that we cannot legitimately consider the children we are discussing as monads or even rational, liberal individuals for the purpose of realistic clinical ethics and medical jurisprudence. That salient corrective allows us to address the actual issues that arise here in a way that has

a grip on the world in which our healthcare has to be organized and adapted to meet our needs.

Nikki Kerruish accentuates that point from the perspective of both a working pediatrician and a bioethicist as she considers the need for delicate and ethically informed counseling and support in relation to the issues addressed in her article, "Growth Attenuation Therapy: Views of Parents of Children with Profound Cognitive Impairment." This demanding area of practice requires deep compassion and realistic acumen in terms of the demands created by a very damaged child.

Informed and caring sensitivity to the emotionally and clinically demanding negotiation required in neonatal care is evident in Dominic Wilkinson's "Ethical Dilemmas in Postnatal Treatment of Severe Congenital Hydrocephalus." Here we encounter a cohort of patients whose potentiality is severely reduced, whose parents and clinical teams are tested to their limits of tolerance, and whose situation requires that our humanity and wisdom be raised to a level not often attained so that all those involved can emerge intact from the tragic journeys involved. Wilkinson brings compassion and deep insights to this arena as a practicing clinician and accomplished ethicist.

The final article, "Parents of Adults with Diminished Self-Governance: Unique Responsibilities" (Jennifer DeSante, David DeGrazia, and Marion Danis), rounds out the symposium and takes us beyond childhood and into the challenges that will continue to face neurologically impaired children and those who care for them.

Altogether, this symposium has been a pleasure and an education to convene and will, I hope, form a valuable ethical resource for healthcare professionals and academics alike.