



# Contemporary challenges in children's health: law, ethics and policy

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Welcome to this special issue of Monash Bioethics Review, which focusses on pressing legal and ethical issues in children's health in the 21st century. As co-directors of the Melbourne Health Law and Ethics Network (<https://law.unimelb.edu.au/centres/hlen>), we noticed a number of emerging issues in children's health that were yet to receive focused attention. Healthcare decision-making for children is being transformed, with demands for the autonomy of young people to be recognised and promoted in ways that were never envisaged in the past. The respective roles of parents, health practitioners, children and (in some cases) courts in making complex treatment decisions has been subject to considerable debate in recent years.

Added to this mix are the major advances in medical science and technology, which are disrupting the way in which human health is promoted, illness is diagnosed and treated, and death is faced—including by children. Innovations in genomics, big data, medical devices, digital technologies and pharmacological treatments are throwing up questions that clinicians and regulators are struggling to answer. At the same time, a greater social emphasis on human rights and the ethics of care means that simply continuing with traditional approaches to children's health is no longer adequate. Health concerns raised by particular groups, including transgender children, also require specialised attention. Customary approaches to health law and ethics are primarily developed for cases involving adults, and do not easily translate to children. New perspectives are needed to guide regulatory responses and clinical practice through this complex set of children's health issues.

There is little focused academic work on these topics, and it is this significant gap in the literature that this special issue seeks to address. The chapters in this special issue are devoted to the analysis of issues relating to the health of the child from pre-conception to birth, early childhood and adolescence. Each chapter consists of descriptions of novel regulatory and ethical quandaries arising in children's health,

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critiques of current legal and ethical frameworks, and unique suggestions for new regulatory, policy and clinical directions.

Making progress on this raft of issues arising in children's health requires a multidisciplinary approach. This special issue combines insights from legal scholars, ethicists and clinicians and draws on the expertise of internationally renowned authors in the field of children's health law and ethics as well as early career researchers and students in developing fields of expertise.

In the first manuscript, Professor Ian Freckelton discusses how the health needs of children have been utilised by the medicinal cannabis lobby. The article covers many aspects of the use of children to promote medical cannabis, discussing the ethics of the media, and politicians/entrepreneurial doctors utilising parents' testimonials about the effects of medicinal cannabis as part of the cannabis law reform movement.

Dr Carolyn Johnston examines the #WeAreNotWaiting movement, which supports parents of children with childhood diabetes to build their own real time blood sugar motoring devices using web connected device. This article considers whether this type of do-it-yourself intervention is in the best interests of the child and, if not, whether intervention in parental decision making is justified to prevent harm to the child.

In our third article, Dr Georgina Dimopoulos and Associate Professor Michelle Taylor-Sands critically examine the *Re Imogen (No 6)* decision made by the Family Court of Australia, which held that an application to the Family Court is mandatory if a parent or medical practitioner disputes a diagnosis of gender dysphoria in a child or adolescent. The article argues that the conclusion of the Family Court represents an unjustified incursion into the right of *Gillick* competent transgender children and adolescents to make decisions about their own bodies and identities.

In our next manuscript, Professor John Tobin, looks at whether the medical interventions for children born with variations in their sex characteristics represents a violation of their human rights. The manuscript identifies the points of complementarity between a human rights approach to this topic and medical ethics approach, but ultimately argues a rights-based approach offers unique insights that can help resolve this debate.

In the fifth manuscript of this special issue, Dr Hilary-Bowman Smart and Associate Professor Michelle Taylor-Sands discuss the use of non-invasive prenatal testing (NIPT) to detect adult-onset conditions. The authors argue that prospective parents should be given access to NIPT for an adult-onset condition, even when they have no intention to terminate the pregnancy. In arguing of this position, the authors draw on a view of pregnancy that conceptualises the foetus as a part of the gestational parent, as opposed to the more common 'container' model of pregnancy. They suggest that foetal information is best conceptualised as shared information between the gestational parent and future child.

Moving from the beginning to the end of life, our sixth manuscript examines the 2014 Amendment to the Belgian Euthanasia Act, which allows children under 12 to become candidates for euthanasia. In this paper, Joanna Murdoch argues the amendment is problematic and vulnerable to abuse. She contends that specifically

for children under 12 years, paediatric palliative care that risks, but does not intend, death is more ethically justified than euthanasia.

Our final manuscript looks at the use of rapid genomic sequencing (RGS) in critically ill children, and asks what type of parental consent is ethically appropriate for this test. Members of the Centre of Ethics for Paediatric Genomics, Dr Christopher Gyngell, Dr Fiona Lynch, Dr Danya Vears, and Professor Zornitza Stark, argue that exiting legal and ethical frameworks that govern genomic sequencing need to be updated in light of the unique features of RGS, particularly the potential for delays in consent to result in harm to the child.

We hope readers enjoy this special issue, and that we have helped bring attention to some overlooked contemporary challenges in children's healthcare.

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