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Editorial**

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Contemporary Legal and Ethical Challenges in Children’s Health: Reproduction, Technology, Capacity, Medicine and Violence – Editorial

MALCOLM SMITH*

This special issue of the *QUT Law Review* focuses on contemporary legal and ethical problems in the sphere of children’s health and reproduction. The special issue arises from a multidisciplinary colloquium hosted at the Queensland University of Technology in July 2017, by the Australian Centre for Health Law Research (‘ACHLR’). This colloquium was attended by a diverse group of experts in the field, including legal scholars, legal practitioners, bioethicists and health practitioners. It was encouraging to see a number of attendees from the colloquium submit papers to this special issue, as well as a range of other leading scholars in the field. The focus on children’s rights is timely in the current Australian social and political climate and the research undertaken by the contributors to this special issue is significant in terms of conceptualising the rights of children, and analysing the extent to which the law prioritises their welfare and protects their interests.

The first paper in this edition has particular significance in the aftermath of the Royal Commission into Institutional Responses to Child Sexual Abuse, which has generated substantial public dialogue in Australia about the measures that should be adopted to safeguard children and protect them from abuse. The paper by Eunro Lee, Jane Goodman-Delahunty, Megan Fraser, Martine B Powell and Nina J Westera, focuses on the evidence procedures adopted in child sexual assault trials. This important study analyses the views and experiences of a range of practitioners working within Australia’s criminal justice system. Through empirical research, the researchers uncover a snap-shot of the measures adopted in such cases and how these measures might help facilitate the giving of evidence by child sexual abuse complainants. This paper provides important insight into the effectiveness of such measures and, ultimately, the impact that they have on children in this process. As the authors note, ‘[t]o advance the health and wellbeing of child sexual abuse victims and to prevent secondary trauma, empirical assessment of the effectiveness of special measures plays a vital role in determining what is working, what is not, and what additional steps or interventions may be helpful’.¹ This research therefore has significant importance in terms of considering the extent to which future evidence practices in trials concerning child sexual abuse can help safeguard the welfare of children.

The theme of best interests continues in Fiona Kelly’s paper, which considers how Australian law and regulation promotes the openness of genetic information relating to donor conceived children. Kelly’s paper presents the findings of her empirical research, which involved the collection of qualitative data from a sample of single mothers by choice. Kelly analyses the lived experiences of her participants in terms of their concerns about their children’s health and wellbeing as a result of being donor conceived. Kelly seeks to uncover the extent to which

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¹ Eunro Lee, Jane Goodman-Delahunty, Megan Fraser, Martine B Powell and Nina J Westera, ‘Special Measures in Child Sexual Abuse Trials: Criminal Justice Practitioners’ Experiences and Views’ (2018) 18(2) *QUT Law Review* Page 27.



Australian law and regulation might promote the health and welfare of donor conceived children, by facilitating access to, and disclosure of, genetic information. To achieve this, Kelly’s paper maps the legal and regulatory frameworks that exist in Australia as they relate to the openness of genetic information for donor conceived children. She considers the extent to which these frameworks promote the welfare of children, based on her analysis of the empirical data. One of Kelly’s findings is that there are gaps in the regulatory frameworks in this regard and that, although the single mothers by choice involved in the study were very open about the circumstances of their children’s conception, law and regulation did not always support this objective. She uncovers that, in some Australian jurisdictions, there are significant gaps in the regulatory frameworks that can compromise this aim, and thereby potentially fail to prioritise the health and wellbeing of donor conceived children.

The third paper in this special issue, which I co-authored with Michelle Taylor-Sands, Harriet Fraser, and Michelle King, considers the issue of non-medical sex selection and how this was addressed as part of the consultation process undertaken by the National Health and Medical Research Council (‘NHMRC’). The paper analyses a range of submissions made to the NHMRC by members of the public, during its review of the ethical guidelines that relate to assisted reproductive technology.² A large part of the NHMRC’s review process focused on the issue of non-medical sex selection – a topic that has also been heavily debated in the bioethical literature. The accessibility of submissions made during this process, all of which were publicly available on the NHMRC’s consultation website, provided a unique opportunity for us to consider and analyse the views contained within those submissions. Our aim was to consider the extent to which the views expressed in the submissions correspond to the arguments put forward in the scholarly literature. Interestingly, we found that some of the concerns and arguments against non-medical sex selection, which are heavily voiced in the bioethical literature, were not given the same prominence in the submissions made by members of the public. Noting that the NHMRC was reluctant to depart from its moratorium on non-medical sex selection following the review process, we conclude that although non-medical sex selection continues to raise significant bioethical concern, if there is a shift in public perception concerning the ethical acceptability of NMSS, this might be significant in shaping future debate, and ultimately, future regulation on the topic.

The fourth paper in this special issue, by Bernadette Richards and Travis Wisdom, is also of significance at the time of publication of this special issue, given that the Australian Human Rights Commission is undertaking a project to consider how best to protect the human rights of people born with variations in sex characteristics, in terms of the performance of non-consensual medical interventions.³ Richards and Wisdom analyse the decision of *Re: Carla (Medical Procedure)* (‘Re Carla’),⁴ which concerned an application to the Family Court of Australia, made by the parents of a five-year-old intersex child. The circumstances of the case were that the parents sought the Court’s approval to consent to irreversible surgery for the removal of the child’s gonads, as well as ‘any further or necessary and consequential

² The current version of these guidelines, published in 2017, incorporate a number of changes that were made as a result of the consultation and review process: National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive in Clinical Practice and Research* (2017).

³ For further information about this project, see Australian Human Rights Commission, *Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions* (30 September 2018) <<https://www.humanrights.gov.au/our-work/sexual-orientation-gender-identity-intersex-status/projects/protecting-human-rights-people>>.

⁴ [2016] FamCA 7.

procedures to give effect to her treatment' as recommended by the child's medical team. The authors are critical of the decision to authorise medical intervention, as well as the Court's conclusion that court oversight in future cases of this kind is unnecessary. By contrasting the decision in *Re Carla* with earlier authorities, the authors cast doubt on the Court's conclusions. Richards and Wisdom build an argument throughout their paper to support the proposition that irreversible medical interventions for children who are born with variations in sex characteristics, should not be left solely in the hands of parents and medical practitioners. Instead, the authors argue, such decisions should fall within the realms of a multi-disciplinary review panel. Again, underpinning the analysis and proposals made in this paper, is the prioritisation of the best interests of the child – a theme that emerges throughout this special issue.

The final paper in this special issue, by Carolyn Johnston and Lynn Gillam, examines legal and ethical issues arising in the context of type 1 diabetes paediatric care, focusing specifically on emerging technologies in this space. Again, this is a timely piece of work when considered in light of the decision of the federal government to subsidise CGM devices for all persons under the age of 21 with type 1 diabetes, funded by way of the National Diabetes Services Scheme (NDSS).⁵ Moreover, in September 2018, the Hon Greg Hunt MP announced that the Australian Government is investing more than \$6 million to better support children living with diabetes, with the launch of a new schools program for children with type 1 diabetes.⁶ As more sophisticated technology becomes available for the management of type 1 diabetes and the administration of insulin, this technology poses significant ethical and legal challenges in the sphere of paediatric health care. This important paper focuses on situations that fall outside of the 'standard care' care setting. The authors outline a number of scenarios faced by paediatric clinicians that pose particular legal and ethical problems and explore how the ethical and legal duties might play out. Through these scenarios, the authors explore issues that are likely to emerge more frequently as the technology becomes more accessible and advanced. These scenarios include, for example, circumstances where a doctor encounters families using medical devices for the management of their child's type 1 diabetes that the clinical team think is not appropriate for the particular child's circumstances, or where the family contacts a doctor with whom they have no prior relationship with, and is external to the paediatric treating team, to share information with that external clinician about their child's diabetes management and care. This paper provides important legal and ethical guidance for clinicians working in this space.

The contributors to this special issue have all played an important part in making significant contributions to the literature in their respective fields, and I thank them for the excellent work they have submitted to make this special issue a success. I am grateful for the support of ACHLR in hosting the colloquium that led to this special issue, as well as the reviewers who helped with providing constructive and valuable feedback on each of the papers. I would also like to thank the team behind the QUT Law Review for facilitating this process, which has resulted in the successful publication of the special issue. Lastly, I would also like to thank Professor Ben Mathews for his support in developing this special issue. I hope that these papers will provide value to the Journal's readership.

⁵ Australian Government, Department of Health, *Australian Government Subsidy of Continuous Glucose Monitors* (1 March 2018) <<http://www.health.gov.au/internet/main/publishing.nsf/Content/MC15-004873-continuous-glucose-monitors>>.

⁶ See The Hon Greg Hunt MP, Minister for Health, 'More Support for Children Living with Type 1 Diabetes' (Media Release, 4 September 2018) <<http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2018-hunt115.htm>>.