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EDITORIAL – *Editor: Ian Freckelton AO KC*

Disability Law Reform in Australia: Principles, Pragmatism and Politics – Ian Freckelton AO KC

This editorial reviews two landmark contributions to disability reform in Australia, both published in 2023 – the 12 volume report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the important Commonwealth Government of Australia report on the operation of the 10-year-old National Disability Insurance Scheme. It contends that each leaves Australia with major steps that need to be taken to enable persons with disability to live in a fairer, safer and more inclusive environment in which their human rights are genuinely respected. The reports contain many challenges where a balance needs to be orchestrated between implementation of principled reform and what is financially feasible. If Australia’s governments are to adopt the recommendations in the reports, politics will need to be set aside and collaboration between Federal and State governments will be essential. Attitudes and practices will have to change in government and the general community, laws, protocols and even institutions will need to be reformed, accountability mechanisms will need to be tightened, and considerable sums of money will have to be spent. 785

HEALTH LAW REPORTER – *Editor: Cameron Stewart*

Conscientious Objection and Institutional Objection to Voluntary Assistance in Dying: An Ethico-legal Critique – Ian Kerridge, Cameron Stewart, Jackie Leach Scully, Mary Chiarella, Julie Hamblin, Adam Johnson, Christopher Ryan, Linda Sheahan and George Skowronski

This column examines conscientious objection and institutional objection in Australian voluntary assistance in dying. It reviews the current legislative regimes and then examines these practices from an ethical perspective, and raises particular concerns and suggestions with how conscientious objection and institutional objection should be operationalised. 806

LEGAL ISSUES – *Editor: Joanna Manning*

Access to Justice: The Quest for a Right of Appeal in New Zealand’s Health and Disability Commissioner Complaints Scheme – Joanna Manning

Given the absence of a civil damages action for personal injury in New Zealand, its Health and Disability Commissioner’s (HDC) complaints process occupies a pivotal role in its medico-legal arrangements. Much hope was invested in it, but as currently configured, the regime is incapable of delivering justice or fulfilling its legislative purpose in a good number of cases. Many hundreds of complaints per annum, in which there is a strongly arguable case of deficient conduct or more than a mild departure from acceptable standards and in which a serious outcome has resulted, are not fully investigated; and there is no mechanism to appeal an adverse HDC decision that a party considers substantively unfair. Recent criticism of these issues by courts, the Chief Ombudsman, and commentators

has mounted, and a petition to Parliament seeking legislative reform to create a right to appeal from adverse HDC decisions resulted in referral of the issue to the Commissioner to consider in an upcoming review, but hoped-for reform will not happen quickly. 822

MEDICAL ISSUES – *Editor: David Ranson*

Legislating the Cause of Death: “What’s in a Name ...” – *David Ranson*

In recent years legal rules to regulate causes of death have begun to appear. One example of this relates to the term “excited delirium” which has been subject to challenge by medical and legal professionals. Human rights activists have pushed against its usage by law enforcement and medical death investigators. The passing of the *California Assembly Bill 360* restricting the use of the term is an example of this. Legislatively mandating, or banning causes of death poses an interesting challenge for death investigators. The lack of uniform guidance on how deaths should be classified across different jurisdictions and the variations in linguistic and causation-based language in cause of death statements may have influenced this development. Legislation that seeks to enforce ways of documenting the cause of a death, which is in effect an expert medical opinion, presents significant future challenges in expert testimony. 839

ARTICLES

Between Public and Private: Electronic Health Record-sharing, Health Privacy Principles, and Hepatitis C – *Sean Mulcahy, Emily Lenton, Kate Seear, Kylie Valentine, Dion Kagan, Adrian Farrugia, Michael Edwards and Danny Jeffcote*

People with (a history of) hepatitis C have concerns about privacy and the confidentiality of their health information. This is often due to the association between hepatitis C and injecting drug use and related stigma. In Australia, recent data breaches at a major private health insurer and legislative reforms to increase access to electronic health records have heightened these concerns. Drawing from interviews with people with lived experience of hepatitis C and stakeholders working in this area, this article explores the experiences and concerns of people with (a history of) hepatitis C in relation to the sharing of their health records. It considers the potential application of health privacy principles in the context of hepatitis C and argues for the development of guidelines concerning the privacy of health records held by health departments and public hospitals. Such principles might also inform reforms to legislation regarding access to health records. 847

What Legal Frameworks Should Govern Use of Genetic Test Results by Private Health Insurers in New Zealand? – *Hanne Janes*

The rising cost of private health insurance and constraints within public health systems are global concerns. Genetic testing presents a transformative opportunity for health care to enhance health outcomes and optimise resource allocation through personalised medicine, early diagnosis, targeted treatments, managed care, and improved drug development. However, ethical and policy issues arise, including privacy, discrimination and equitable access to testing. Balancing these against potential health benefits poses a complex challenge. While some advocate for restricting health insurers from using genetic data, others argue that well-regulated private insurance can ensure affordability, improved health outcomes, and innovative care adoption. This article explores examples of improved health outcomes through genetic testing, identifies areas of risk related to insurers’ use of genetic data, evaluates the adequacy of New Zealand’s legal framework, and emphasises the need for ethical and equitable policy solutions. The broader issues of data governance, biases in algorithms, and implications of artificial intelligence and machine learning warrant separate exploration. 862

Personalising Social Ills: An Analysis of Race-based Genomics and Personalised Medicine – *Josephine Y Lee*

The mapping and sequencing of the human genome at the turn of the new millennium marks a pivotal reassessment of genomic science in its potential to replace traditional “one-size-fits-all” medicine with a personalised approach. The use of racial proxies in the development of pharmacogenomic products risks conflating genetics with race under the guise of alleviating health disparities. This article argues that the current genomic approaches to realising personalised medicine do not deliver on the promise for optimised health for all and may result in irreversible harm, including psychological, social and medical harm, to racial minority groups. In light of recent epigenetic findings, the article provides a reconceptualisation of the genome and race, which is necessary to understand enduring racial disparities and the cumulative effects of racial discrimination. It then addresses the need for regulatory oversight of the approval of race-based pharmacogenomic products.

884

Family Veto in Organ Donation – *David Ernest*

A current inconsistency in organ donation is the ability for a family to veto a valid consent for organ donation by a deceased individual; yet the family is unable to veto a valid refusal. Reasons proposed for accepting or rejecting family veto include concerns regarding distress (individual’s family vs potential recipients), impact on organ donation rates, and regard for the deceased individual’s autonomy. Advance care directives (ACDs) provide an ethical and legal framework for documenting medical treatment decisions which allow an individual to provide directives and to appoint a medical treatment decision-maker to act on their behalf. I argue that consent for organ donation as an ACD under the *Medical Treatment Planning and Decisions Act 2016* (Vic) addresses the arguments in support of family veto. This may be an effective ethical and legal framework for managing family veto to meet the needs of the individual, family and community more effectively.

899

Supportive/Substitute Decision-making and Capacity in Victoria: Compliance with Australia’s Obligations under the CRPD? – *Rohan Wee*

The *Convention on the Rights of Persons with Disabilities* (CRPD) restates human rights through the lens of disability. One of the key rights relates to equality before the law. This has been interpreted as requiring the abolition of substitute decision-making regimes. As a signatory, Australia has agreed to implement the rights set out in the CRPD. In Australia, the laws relating to substitute decision-making and legal capacity vary from State to State. This article examines how the laws in Victoria compare to Australia’s CRPD obligations and, hence, whether Victoria is compliant with or in breach of the CRPD. It concludes that, while on the surface Victoria is in breach of Australia’s CRPD obligations, Victorian legislation is making significant efforts to operationalise a human rights approach to decision-making.

907

Expert Evidence of “Risk Assessments” and the Preventive Detention of “Dangerous Prisoners” – *Russ Scott, Ian Coyle and Ian Freckelton AO KC*

The *Dangerous Prisoners (Sexual Offenders) Act 2003* (Qld) provides for the preventive detention of a prisoner if there is “acceptable, cogent evidence” to a “high degree of probability” that the prisoner is a “serious danger to the community” because of an “unacceptable risk” that the prisoner will commit a “serious sexual offence”. In preventive detention cases courts rely on the expert opinion of psychiatrists and psychologists who often use actuarial risk assessment instruments. In *Black v Attorney-General (Qld)* [2022] QCA 253 the Queensland Court of Appeal considered a decision to detain an offender who had a history of possessing and trading child sexual exploitation material but who

had not previously been proved to have committed a contact offence against a child. This article analyses the reasoning of the Court of Appeal and critically examines the reliability of probabilistic risk assessment tools and the validity of expert evidence about risk in the preventive detention context. 917

BOOK REVIEW

Trust in Medical Research: What Scientists Must Do to Enhance It, by Warwick Anderson – Reviewed by Professor Ian Freckelton AO KC 962

OBITUARY

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