

WHEN DOCTORS AND PARENTS DISAGREE: ETHICS, PAEDIATRICS AND THE ZONE OF PARENTAL DISCRETION

When Doctors and Parents Disagree: Ethics, Paediatrics and the Zone of Parental Discretion, by Rosalind McDougall, Clare Delany and Lynn Gillam (eds), Federation Press, 2016, 272 pages: ISBN 9781760020590. Softcover \$79.95.

The past 60 years has seen enormous changes in the way in which decisions regarding the medical care of children are approached. From an era of medical paternalism where “doctor knew best”, decision making has emerged into an era where parent and care givers have become an integral part of the decision-making process and the internet has seriously eroded the doctor’s monopoly on information relevant to decisions whether or not to treat, or between various treatment options.

Not uncommonly doctors face situations where, despite discussion and the provision of information, the doctor and the parent disagree as to what treatment should be given, or whether any treatment should be given at all.

The way in which doctors are equipped to deal with these type of dilemmas traditionally involved resort to deceptively simplistic admonitions to “do no harm” or to do “what is best” for the child. However, in clinical practice, such phrases are apt to beg more questions than they answer. How does one determine what is “best” for the child? How should the harm which might result from the parents’ refusal to agree to treatment to be weighed against the harm which might result from the treatment if it were to proceed? Without a framework, questions of this type are apt to multiply and lead to inconsistent results even among similar clinical situations.

This is the area in which the authors of *When Doctors and Parents Disagree* suggest a framework to enable clinicians to address treatment decision in an orderly way. For legal practitioners the approach is familiar: in determining whether to grant an interlocutory injunction, the court does not proceed by asking what is the “best” outcome but by asking a structured series of questions reaching an outcome that is one of many which are “good enough” rather than “best”.

The framework rests upon the concept of a “Zone of Parental Discretion” (ZPD). By considering a series of structured questions the doctor attempts to determine whether the parental decision falls within the zone that can be accepted even if it is sub-optimal or whether the decision falls outside the zone and meaning that attempts must be made to override it. After explaining the framework the subsequent chapters include thought provoking discussions of issues including the concept of “harm”, the components of a child’s wellbeing and the theoretical underpinning of the “rights” of parents to make decisions for their children and the impact of the information age upon the role of clinicians particularly in relation to children with rare conditions. The book includes a series of case studies which assist the reader to see the framework can apply in different scenarios.

While the book is primarily aimed at assisting doctors in clinical practice, the cases it discusses often have the potential to evolve into a legal dispute, meaning it is likely to be of interest to lawyers. By way of example, one case study involves a decision by the parents of a 10-year-old child with cerebral palsy, severe intellectual handicap and difficulty swallowing, to refuse to permit the insertion of any form of feeding tube. Although her swallowing difficulties have led to undernourishment, her parents are afraid that a feeding tube will ultimately result in her becoming too heavy for them to care for at home and will mean she loses the pleasure of oral feeding. Despite being grossly undernourished the child appears happy and giggly on consultation.

Under the ZPD framework, the key critical question is whether the parents’ decision is likely to cause a serious setback to the child’s interests when compared to the suggested alternative. In this case that involves weighing the multiple risks and benefits to the child’s interests including, at least, the risks involved in the insertion of the feeding tube, the likely compromise, her ability to be cared for at home by her parents, the resultant lack of ability to be with her siblings, the loss of pleasure of oral feeding against the risks of current and ongoing undernutrition. If the parents’ decision is likely to cause a serious setback to the child’s interest as opposed to the outcome where the feeding tube is inserted, then it falls outside the zone of parental discretion. However, before deciding whether to

attempt to override the decision, the doctor would then need to consider what potential harm the process of attempting to override the parent's decision would itself cause and whether it outweighs the harm of not overriding it.

Ultimately, of course, no conceptual framework can overcome the fact that many ethical decisions are difficult and are often matters about which minds might reasonably differ. Nevertheless, the framework suggested seems likely to mean that factors that might otherwise be overlooked or given insufficient weight are considered in a systematic way prior to determining the appropriate approach to treatment.

The book is a useful resource in a difficult area of practice in both the medical and legal professions. It will also be of assistance to courts exercising statutory or *parens patriae* jurisdiction in disputes between parents and doctors over the treatment of children or even adults under an incapacity.

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