Children’s Competence to Consent to Medical, Surgical and Dental Treatment

Partners in Healthcare?

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Abstract

Commonly it is believed that children need to be 16 years old before they have the right to give, or refuse, consent to medical, surgical or dental treatment. This is an understandable misconception in New Zealand, as the Care of Children Act 2004 provides for children of that age to consent, but is silent on the rights of those under 16 years. Yet, in New Zealand, the English House of Lords case of *Gillick v West Norfolk and Wisbech Area Health Authority and another*, which established that competent children under 16 years may give consent, has been followed. Given this uncertainty in the law, this thesis examined: (i) what are children’s, parents’ and health professionals’ experiences of the consent processes; (ii) what factors influence children’s competence; (iii) how do health professionals assess children’s competence and what criteria, if any, do they use; and (iv) how does the law in New Zealand influence the consent processes for children seeking healthcare, and are any changes required to the law, legal policy and health professionals’ practices?

This qualitative research focused on the competence of children under the age of 16 years and the consent processes within and across different healthcare environments – hospitals, private practices, schools and community youth services. It included 59 participants having experience of medicine, dentistry and surgery, comprising of: seven children, six parents, seven hospital doctors, six GPs, three hospital dentists, three private dentists, two dental therapists, eight nurses and 17 stakeholders.

The research found that there are many interlinking factors influencing the development of children’s competence to participate in the consent processes for healthcare, relating to the physical environment in which health professionals consult; children’s internal characteristics; their relationships with parents and health professionals; and the support they receive. Intertwining to either promote or constrain children’s competence are factors such as children’s preferences, experience, maturity, attitudes, values, skills and health; parents’ and health professionals’ knowledge, skills and attitudes; and time, privacy, policies, guidance and law. Thus, when health professionals assess children’s competence they need to consider many factors. Although their processes are organic rather than formal, they all agreed that children’s competence can be measured through the level of children’s interest/independence in their health; their ability to engage with them and explain details about their health; children’s intelligence and understanding; their ability to ask and answer questions; and their development and maturity. Age was found to be a misleading indicator of children’s competence. Nonetheless, health professionals’ practices in taking consent for children under the age of 16 years is inconsistent, with some relying upon parental consent, rather than trusting the consent of competent children. As a result children’s competence may not be promoted or respected, and children may fail on occasions to receive necessary and desired health treatment.

Recommendations from this study include reviewing professional policies and guidance to ensure greater consistency; developing a “toolkit” for health professionals to use to assess children’s competence; introducing courses/seminars for children, parents and health professionals to raise awareness and knowledge of the law; and amending or introducing a new law to better embed the rights of competent children to consent, or refuse, treatment.
Acknowledgements

When reflecting on the completion of this thesis two words spring to mind: “privilege” and “gratitude.”

It has been an immense privilege to have the opportunity to research into this area of law at the University of Otago, under the excellent supervision of Associate Professor Nicola Taylor, my primary supervisor, and Professor Mark Henaghan, my secondary one. I have had such enjoyment and satisfaction from this research, thanks to Nicola and Mark’s energy, encouragement, insights, patience and support. A special thanks goes to Nicola for her availability through emails and Skype calls, guiding me through this process and diligently editing.

I thank also the University, whose scholarship made this undertaking financially possible, and the library staff, whose hard-work in efficiently sending me materials to Wellington made it possible to easily undertake this study from home.

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<th>Full Form</th>
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<tr>
<td>ACYA</td>
<td>Action for Children and Youth Aotearoa</td>
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<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
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<td>ALCSA</td>
<td>Age of Legal Capacity (Scotland) Act 1991</td>
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<td>BMA</td>
<td>British Medical Association</td>
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<td>Caleb</td>
<td>Caleb Moorhead</td>
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<td>Children</td>
<td>Children under 16 years</td>
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<td>Children’s Charter</td>
<td>Charter on The Rights of Tamariki Children &amp; Rangatahi Young People in Healthcare Service in Aotearoa New Zealand</td>
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<td>COCA</td>
<td>Care of Children Act 2004</td>
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<tr>
<td>Code</td>
<td>Code of Health and Disability Consumers’ Rights 1996</td>
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<tr>
<td>Commission</td>
<td>Human Rights and Equal Opportunity Commission</td>
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<td>Committee</td>
<td>Ngāi Tahu Research Consultation Committee</td>
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<td>Contraception Act 1977</td>
<td>Contraception, Sterilisation and Abortion Act 1977</td>
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<td>CRC</td>
<td>Committee on the Rights of the child</td>
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<td>CYS</td>
<td>Community Youth Service</td>
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<td>DCR</td>
<td>Dialectical Critical Realism</td>
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<td>Dee</td>
<td><em>Auckland District Health Board v Dee</em></td>
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<td>Dental Council</td>
<td>Dental Council of New Zealand</td>
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<tr>
<td>DHB</td>
<td>District Health Board</td>
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<tr>
<td>England</td>
<td>England/Wales</td>
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<td>Ethics Committee</td>
<td>University of Otago Human Ethics Committee</td>
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<td>FLRA</td>
<td>Family Law Reform Act 1969</td>
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<td>GA</td>
<td>General Anaesthetic</td>
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<td><em>Gillick</em></td>
<td><em>Gillick v West Norfolk and Wisbech Area Health Authority and another</em></td>
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GMC  General Medical Council
Government New Zealand Government
HDC  Health and Disability Commissioner
HDCA Health and Disability Commissioner Act 1994
Healthcare environments Hospital, private practice, school and community youth service
LCCA Legal Capacity of Children Act
Liam Liam Williams-Holloway
MacCAT-T MacArthur Competence Assessment Tool for Treatment
Marion’s case Secretary, Department of Health and Community Services v JWB and SMB
Medical Council Medical Council of New Zealand
Medical Treatment Medical, dental and surgical treatment and procedures
Mental Health Act Mental Health (Compulsory Assessment and Treatment) Act 1992
MG UNCRC Monitoring Group
NGO Non-Government Organisation
Nursing Council Nursing Council of New Zealand
NSW New South Wales
NZBORA New Zealand Bill of Rights Act 1990
OCC Office of the Children’s Commissioner
PGT Predictive Genetic Testing
Programme Three-day Initial Programme for Diabetes
PPPR Act Protection of Personal and Property Rights Act 1988
PSD Public Service Department
Re E Re E (a minor)(wardship: medical treatment)
Re L Re L (medical treatment: Gillick competency)
Re P
Re P (medical treatment: best interests)

Re R
Re R (a minor) (wardship: consent to treatment)

Re S
Re S (a minor) (consent to medical treatment)

Re W
Re W (a minor) (medical treatment)

SA
South Australia

SCLC
Scottish Child Law Centre

SDS
School Dental Service

SHHD
Scottish Home and Health Department

SLC
Scottish Law Commission

SMS
School Medical Service

Stakeholders
Key Stakeholders

The Standard
Dental Council’s Informed Consent Practice Standard

Tetanus case
Case 01HDC02915

Tovia
Tovia Laufau

The Trust
Hereford Primary Care Trust

UNCRC
United Nations Convention on the Rights of the Child

Vaccination programme
Public Health School Vaccination Programme

Young People
Young People 16 years and over
Chapter 1

Introduction

The first appointment we had at [X hospital] was with a surgeon in a very small room that had three surgeons, well actually, one surgeon and two registrars, three nurses, me and Samantha. So there was a bunch of adults, staring down at her, a surgeon looking at x-rays and making decisions, doctors often talking across the room at each other and definitely talking at adult level, and a child sitting in the middle. (Wilma, mother)

Samantha was 10-years-old when she was first admitted to hospital with bone cancer in her leg. The treatment she was given saved her life, and following three operations, she was able to walk again, pain free. However, in that lengthy process how did the health professionals and her mother, Wilma, help her understand what was happening? How were treatment decisions made, and how was consent obtained? To what extent was Samantha supported to participate in those processes, and was she respected as a child and a patient, with her own feelings, views, and aspirations?

The issues that these questions raise are the focus of this thesis, exploring how parents, health professionals and the law respect and support children’s competence to contribute to, and make, health decisions. The research questions underpinning this inquiry are aimed at considering micro and macro level, medico-legal policy and practice issues about children’s consent. They are as follows:

1. What are children’s, parents’ and health professionals’ experiences of the consent processes?
2. What factors influence children’s competence?
3. How do health professionals assess children’s competence and what criteria, if any, do they use?
4. How does the law in New Zealand influence the consent processes for children seeking healthcare and are any changes required to the law, legal policy and health professionals’ practices?

I. Significance of Researching Children’s Competence and Consent to Medical Treatment

A. The Law

In New Zealand the laws for young people over the age of 16 years and children under that age differ for giving, or refusing, consent to medical, surgical or dental

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\(^1\) See Chapter 8, page 145 where Samantha and Wilma narrate more fully their experiences during their research interview for this doctoral study. The names of the children and parents in this thesis are pseudonyms to preserve their anonymity and some of the genders of the children have been changed.
treatment/procedures. Section 36(1) of the Care of Children Act 2004 (COCA) gives young people the same statutory rights as adults, to either consent to, or refuse medical treatment. However, the law for children consenting to, or refusing, medical treatment (other than abortion, contraception and other sexual health matters) is more uncertain, as the COCA fails to provide for them. The gap it leaves requires to be filled by other statutes, regulations and case law, such as the Code of Health and Disability Services Consumers’ Rights 1996 (Code), the New Zealand Bill of Rights Act 1990 (NZBORA), and the 1986 English decision of Gillick v West Norfolk and Wisbech Area Health Authority and another (Gillick). Nevertheless, this is still problematic. Whilst the Code contains both a presumption of competence and rights for everyone to consent to, or refuse, treatment, it is a regulation under the Health and Disability Commissioner Act 1994 (HDCA), and as such cannot confer a power or right beyond the authority of the HDCA, or alter the general law. Similarly, there is uncertainty in the NZBORA’s scope of filling the gap left by COCA, for although section 11 includes the right of everyone to refuse medical treatment, which presumably also applies to children, this assumption has not yet been tested in court. Thus, it is necessary to turn to the common law. In 1986 the English House of Lords (now Supreme Court) in the landmark case of Gillick decided that children with sufficient understanding and intelligence to enable them to understand fully what is proposed, have the right to make their own decisions, and can consent to medical treatment. This was a groundbreaking decision for the rights and autonomy of children. It not only recognised their evolving competence, but also challenged the right of parents to make decisions for them. Worldwide countries adopted Gillick into their law, and New Zealand was no exception, albeit in a rather ad hoc manner.

The most authoritative recognition of Gillick in New Zealand was by the Court of Appeal in Re J (An Infant): B and B v Director of Social Welfare (Re J) that involved a three-year-old whose parents refused to consent to a blood transfusion due to their religious beliefs. The Court not only recognised Gillick as applicable in New Zealand, but also confirmed that parental rights are never absolute, rather reflecting their responsibilities towards their children. Similarly, the High Court in Hawthorne v Cox, subsequent to the passing of the COCA, acknowledged consistency between Gillick and COCA of the

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2 See abbreviations, page xvii. In this thesis I have abbreviated medical, surgical and dental treatment or procedures to “medical treatment.” There is no distinction in the law of consent between them. Also, I define ‘young people’ as those aged 16 years and over and ‘children’ below the age of 16 years, although I recognise for example the Care of Children Act 2004 (COCA), s 8; United Nations Convention on the Rights of the Child (UNCRC), art 1; and the Children’ s Act 2014, s 5(1) define ‘child’ as being under the age of 18 years. I make this demarcation due to the distinction in the COCA between the rights of those aged 16 years and over and those under the age of 16 years.

3 COCA, s 38, provides for girls of any age consenting to, or refusing, an abortion, and by repeal of section 3 of the Contraception, Sterilisation and Abortion Act 1977 (the Contraception Act 1977), children of any age can obtain sexual health advice and contraception.

4 Gillick v West Norfolk and Wisbech Area Health Authority and another [1986] 1 AC 112 (HL).

5 PDG Skegg and Ron Paterson, Health Law in New Zealand (Thomson Reuter, New Zealand, 2015) at 239.

6 See Chapter 3 page 30 where I refer to Auckland Healthcare Service Limited v Liu 11/7/96 HC Auckland M812/96 in which the Court indicated that section 11 of NZBORA is not determinative of children refusing medical treatment.

7 Gillick, above n 4 at 113 and 189 per Lord Scarman.

yielding nature of parental involvement in children’s decision-making, as they develop and mature.\(^9\) However, the clearest recognition of children’s competence and their right to consent was by the Family Court in \textit{Re SPO}, when it decided that a 15-year-old boy could consent to vaccinations, despite his mother’s refusal.\(^10\) Yet, despite this recognition of \textit{Gillick}, at three differing levels of judicial authority, an element of doubt remains as to the respect courts will give to children’s competence and their right to consent, due to the judiciary failing to consistently consider or apply \textit{Gillick}.\(^11\)

To gain a deeper understanding of \textit{Gillick’s} applicability within the New Zealand legal system, I have undertaken an international comparison of the laws of Australia, England/Wales (England) and Scotland.\(^12\) Australia has a close connection to New Zealand, while England is the home of \textit{Gillick} and has long influenced our law, and uniquely Scotland incorporated \textit{Gillick} into statute.\(^13\) Differing attitudes and histories emerge. The main feature of Australia’s experience is the complexities that developed from requiring the court’s approval of children’s competence for non-therapeutic treatment, in particular for gender dysphoria. The complexities in English law arose as a result of restricting the scope of \textit{Gillick}, by distinguishing children’s right to consent from their right to refuse. In these countries, significant lines of legal precedents developed. On the other hand, Scotland has virtually no case law, regulating children’s right to consent to medical treatment in the \textit{Age of Legal Capacity (Scotland) Act 1991} (ALCSA). While the ALCSA does not specify the right to refuse, Scotland has not distinguished this right from that of consent. The generally accepted view of section 2(4) of the ALCSA is that it includes both rights.\(^14\)

Turning to the process and criteria for assessing competence, New Zealand law gives little guidance. No universally accepted process or list of criteria exists, although the Code and Professional Guidance from health regulatory bodies, such as the Medical Council of New Zealand (Medical Council) and Dental Council of New Zealand (Dental Council), provide direction on the importance of informed consent. Therefore, this research explores how health professionals assess children’s competence and their processes for taking consent.

\textbf{B. Research}

It is important to consider how children’s competence evolves, and is promoted and respected in different healthcare environments – hospitals, private practices, schools and

\(^9\) \textit{Hawthorne v Cox} [2008] 1 NZLR 409 at [57] and [61] per Heath J.


\(^11\) Chapter 3 considers New Zealand’s application of \textit{Gillick} in detail. See also Skegg and Paterson, above n 5 at 241.

\(^12\) Chapter 4.

\(^13\) \textit{Age of Legal Capacity (Scotland) Act 1991}, section 2(4).

community youth services (healthcare environments), due to there being sufficient certainty in the law entitling children to give consent. Children frequently encounter situations where they need to consult with health professionals for minor, everyday matters, or sometimes for potentially life threatening conditions. Concerning in New Zealand are the significant health issues amongst children, for example, relating to obesity, asthma and cancer.

My study focuses on two areas: competence and consent; in particular, how children’s competence is promoted and assessed, and how consent is obtained. This is the first study of its kind in New Zealand that traverses specialist areas of health – medicine, surgery and dentistry, and in a range of healthcare environments. Worldwide there is a dearth of research focusing on the issue of children giving informed consent to health treatment. Most international studies focus on specific health conditions, such as cancer, or range of health conditions, or alternatively, consider only hospital care. As Kilkelly and Donnelly noted, “little has been done to identify whether children are involved in decision-making in the private sector.” In their study therefore they recruited a range of health professionals, as I have done. Participating in my study were 29 health professionals, comprising of six GPs, six private and hospital dentists, seven hospital doctors/surgeons, eight nurses, and two school dental therapists. While the aim of Kilkelly and Donnelly’s study was to explore the extent to which Irish children were listened to in the healthcare settings, I took my research one step further, examining the processes by which health professionals assess competence and obtain consent. This has

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15 Ministry of Health “Obesity Statistics: Child Obesity Statistics” (1 August 2018) <www.health.govt.nz>. The New Zealand health survey 2016/2017 found that 12% of children aged two-14 years were obese with a further 21% overweight.

16 Asthma and Respiratory Foundation “Key Statistics” (2016) <www.asthmafoundation.org.nz>. One in seven children and one in six adults suffer from asthma. Respiratory disease is New Zealand’s third most common cause of death and accounts for one in 10 of all hospital stays.

17 Kirsten Ballantine and the New Zealand Child Cancer Report Working Group The incidence of childhood cancer in New Zealand 1990-2014: A report from The New Zealand Children’s Cancer Registry (National Child Cancer Network, Auckland, 2017) at 2. Cancer is the second most common cause of death after road traffic accidents for children aged one to 14 years, and it is estimated that one in 500 children will be diagnosed with cancer before the age of 15 years.


19 For example Bryony A Beresford and Patricia Sloper “Chronically Ill Adolescents’ Experiences of Communicating With Doctors: A Qualitative Study” (2003) 33 Journal of Adolescent Health 172; Bridget Young and others “Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents” (2003) 326 British Medical Journal 305.


22 One of which practiced in a private practice, school and community youth service.
enabled me to compare across and within healthcare specialties and environments the criteria health professionals consider when assessing competence, and their processes for obtaining consent. In doing so, greater understanding is achieved of how, and to what extent, children’s competence is promoted and respected.

At the heart of this small-scale qualitative study were seven children and six parents who narrated, and gave their perspectives, on a range of health experiences, involving cancer treatment, surgeries, GP and dental consultations, and the public health school vaccination programme (vaccination programme). Through their intimate first-hand accounts, rarely seen insights emerged of how children were supported and constrained in their discussions with health professionals; understanding of their health conditions and treatment; contribution to treatment decisions; and in the giving of consent.

Finally, 17 key stakeholders (stakeholders) also contributed to this study. The range of their roles was diverse, including advising and training health professionals; policy development; and supporting children and their families through lifelong/chronic health conditions. Their experiences and perceptions assisted in not only explaining the rationale behind some of the consent processes, but also giving valuable insights into the potential effects of changing the law.

C. Theory

Historically, children were viewed as vulnerable and ignorant; and childhood was seen as a preparatory phase for adulthood, when children would become competent and independent. These views have been challenged by theories. It is now understood that competence is not age-related, but instead evolves through participation and ‘scaffolding’ from those with more experience.23 Childhood Studies, Sociocultural Theory and the Capability Approach support these propositions, which individually and in combination advance our understanding of children’s competence and agency. They understand the development of children’s competence to be dynamic and relational in nature. The Capability Approach builds upon Childhood Studies and Sociocultural Theory by recognising that when children achieve capabilities they have the ability and right to make decisions according to their views, values, priorities and goals. Together these theories provide a comprehensive framework for the proposition that competent children have the right and freedom to make health decisions.

II. Personal Background

Having practiced law in Scotland for 13 years between 1994 and 2007, I became familiar with the ALCSA that provides for children of any age to consent to medical, surgical and

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dental treatment when they are capable of understanding its nature and consequences.  
In particular, during my role as Principal Solicitor at the Scottish Child Law Centre (SCLC) between 2001 and 2006, I was involved in educating, training and advising health professionals in the practical application of this provision. I found that despite the ALCA being passed in 1991 many were unaware, or held misunderstandings, of its terms and implications. Unsurprisingly, I found also that children were even less informed, and at times were actively prevented from being made aware of their rights. For example, one head teacher cancelled our visit to his school upon learning that we would be informing the children of their right to seek medical advice on contraception.

Through the SCLC I began working with children and local authorities to educate them on children’s rights, by conducting workshops in schools, writing leaflets, and in one local authority, contributing to the redesign of the medical consent form for school vaccinations.

Upon relocating to New Zealand, and requalifying as a lawyer and barrister in 2008, I became immediately intrigued about section 36 of the COCA, which provides only for young people to consent to treatment. Many questions sprung into my mind, such as, why is this the position, what is the law for under 16-year-olds, why is Scots Law different, and what does this all mean for children, parents and health professionals? Thus, I embarked upon this doctoral project part-time in 2013, upon completing the Postgraduate Diploma in Child Advocacy at the University of Otago, whilst also continuing to work as a family lawyer until 2016, and then subsequently as a legal instructor. My aims in undertaking this research were to find answers to those questions and to give the participants, particularly children, a voice. My objective was to determine whether the current law in New Zealand needs amendment to better respect the competence and rights of children to consent, and if so, how.

III. Structure of the Thesis

The two key concepts of this thesis are children’s competence and consent in different healthcare environments. Chapter 2 discusses the legal foundation for children giving consent to health treatment, by initially considering Gillick, followed by the United Nations Convention on the Rights of the Child (UNCRC) and the Charter on The Rights of Tamariki Children & Rangatahi Young People in Healthcare Service in Aotearoa New Zealand (Children’s Charter).  

The processes used by health professionals to recognise and assess children’s competence are also set out. Chapter 3 explains the statutory and case law in New Zealand governing children’s consent to, and refusal of, medical treatment. The legal landscape is complex, comprising several statutes and regulations, together with case law that inconsistently considers Gillick. The international legal context is then addressed in Chapter 4, where the laws of Australia, England and

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24 Section 2(4).
25 The Children’s Charter implements the UNCRC principles in a healthcare context.
Scotland are examined. This international comparison enables the unique development of each country’s legal approach to be compared and contrasted, providing understanding of their strengths and weaknesses of how they have defined and regulated children’s competence and rights to consent to, or refuse, treatment.

Chapter 5 reviews the research literature relevant to issues of children’s competence and consent, focusing on the factors that influence the development and demonstration of children’s competence to participate in, and provide, consent to health treatment.

Chapter 6 outlines the theoretical basis for the evolution and acquisition of children’s competence. The history of childhood is traced to highlight the changing status of children over time. The chapter then sets out the theoretical framework I draw upon to support children’s evolving competence and their right to consent. This involves consideration of Childhood Studies, Sociocultural Theory and the Capability Approach, which strongly combine to provide the lens for regarding children as competent social actors when contributing to, or making, health decisions.

Chapter 7 outlines the methodology and methods used in this small-scale qualitative study with 59 participants. The following four chapters present my research findings.

In Chapter 8, the experiences of the seven children and six of their parents in the consent processes are set out. Using their own words, and conveying their feelings about treatment processes highlight the real significance of hearing directly from them, as they are at the sharp end of medical, surgical, nursing and dental services. Chapter 9 examines the various healthcare environments, and the factors within these that either promote or constrain children’s competence. The criteria that health professionals consider when assessing competence are also considered. Chapter 10 examines the practices and attitudes of health professionals in obtaining consent in these healthcare environments. Health professionals’ understanding of the current legal framework is then examined in Chapter 11, considering also participants’ perspectives on children’s right to consent and whether changes to the law on consent are needed.

The thesis concludes in Chapter 12 with a discussion of my findings in the context of the law domestically and internationally, current research evidence and theoretical issues. Their implications for policy, practice and reform of the law are also considered.
Chapter 2
Recognising and Assessing Competence

I. Introduction

Children will encounter situations throughout their lives when they will need medical or dental advice. As they develop, mature and become more independent, they are likely to take more responsibility for their health, and may wish to consult alone with health professionals, or form different opinions from their parents about treatment. Through this transition children will develop competence, but what does this term mean, and how is it recognised and assessed by health professionals? This chapter lays the foundation for defining competence, by considering how children are identified and assessed as being competent, or having capacity, to provide consent, in law and in medical practice.\(^\text{26}\) It firstly examines the leading authority of *Gillick*,\(^\text{27}\) a landmark judgment establishing the right for competent children to consent to medical treatment. Secondly, the chapter discusses the UNCRC, which protects and promotes children’s rights to participate in all matters that affect them, including those related to their health. Finally, the processes or methods health professionals use for assessing children’s competence are considered.

II. *Gillick v West Norfolk and Wisbech Area Health Authority and Another*

Central to the issues of children consenting to medical treatment and their competence is the seminal English House of Lords case of *Gillick*.\(^\text{28}\) *Gillick* arose from a challenge by Mrs Victoria Gillick to a circular issued by the Department of Social Security in 1980. As the Catholic mother of several daughters, she was concerned that the advice given to doctors in this circular, to provide contraception to girls under 16 years, without their parents’ consent, would adversely affect their welfare, and also unlawfully interfere with parents’ rights and responsibilities.

The Court at first instance rejected her claims on the basis that parents’ legal relationship with their children is more accurately described as a responsibility or duty, rather than a right.\(^\text{29}\) As such, giving advice on contraception was not an unlawful interference with her parental rights. Moreover, doctors prescribing contraception without parental consent was not considered unlawful if the girl “was a normally intelligent girl who was

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\(^{26}\) In the context of providing consent, competence and capacity are used interchangeably. For example, see Alison Douglass *Mental Capacity: Updating New Zealand’s Law and Practice* (The Law Foundation, New Zealand, 2014) at viii; Paul S Appelbaum “Assessment of Patients’ Competence to Consent to Treatment” (2007) 357:18 The New England Journal of Medicine 1834 at 1834. The definition of competence is further developed in Chapter 5, Literature Review.

\(^{27}\) *Gillick*, above n 4.

\(^{28}\) Chapter 3 considers the statutory and case law in New Zealand in detail.

\(^{29}\) *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1984] 1 All ER 365.
reasonably capable of assessing the advantages and disadvantages of the proposed treatment and giving effective consent to such treatment. Mrs Gillick challenged this decision, appealing to the English Court of Appeal. The Court, finding firmly in favour of the sanctity of parental rights, held that parents’ decisions are prima facie in their children’s best interests, and they alone have authority to make them, unless restricted by statute or overridden by a court. Children were viewed as being incapable of providing lawful consent for contraception or abortions, as the law did not recognise their decisions.

On further appeal by the Department of Health and Social Security, the House of Lords, by a majority of three to two [Lords Fraser, Scarman and Bridge; dissenting Lords Templeman and Brandon], overturned the Court of Appeal’s decision. Now commonly known as “Gillick competence”, a child who has sufficient understanding and intelligence to enable her to understand fully what was proposed has the right to make her own decisions and can consent to medical treatment. In issuing the leading judgment, Lord Fraser accepted that children must have a degree of control over medical interventions. He gained perspective on the issue by setting it in the context of what other responsibilities children have in law, such as being sued, giving evidence on oath and a girl consenting to sexual intercourse. He considered that it would be:...

... verging on the absurd to suggest that a girl or boy aged 15 could not effectively consent, for example, to have a medical examination of some trivial injury to his body or even to have a broken arm set ... Provided the patient ... is capable of understanding what is proposed, and of expressing his or her own wishes, I see no good reason for holding that he or she lacks the capacity to express them validly and effectively to authorise the medical man to make the examination or give the treatment which he advises.

Lord Scarman concurred, outlining the factors that required to be satisfied for children to consent: “understand(ing) the nature of the advice” and having “sufficient maturity to understand what is involved.” However, he expanded upon these by indicating that there are wider considerations of “moral and family questions, especially her relationship with her parents; long-term problems associated with the emotional impact of pregnancy and its termination; and ... risks to health of sexual intercourse.” A doctor must be satisfied that children can “appraise these factors before he can safely proceed upon the basis that she has at law capacity to consent.”

30 Gillick v West Norfolk and Wisbech Area Health Authority and another [1984] 1 All ER 365 at 373 per Woolfe J.
31 Gillick v West Norfolk and Wisbech Area Health Authority and another [1985] 1 All ER 533 at 557 and 559 per Everleigh LJ.
32 At 540, 547 and 550 per Parker LJ and 554, 556 and 557 per Fox LJ.
33 Gillick, above n 4 at 113 and 189 per Lord Scarman.
34 At 169 per Lord Fraser.
35 At 169 per Lord Fraser.
36 At 189 per Lord Scarman.
37 At 189 per Lord Scarman.
38 At 189 per Lord Scarman.
Additionally, the Court gave recognition to children’s increasing autonomy, by acknowledging that as a child grows older she becomes increasingly independent and, correspondingly, parental authority diminishes. In considering the relationship between children’s and parental rights to consent, Lords Fraser and Scarman had slightly differing views. Lord Fraser’s viewed parental authority as remaining, but dwindling, as children grow older. He postulated that in current times and with social customs it is unrealistic to expect that absolute parental authority continue until a child is 18 years of age. Whilst Lord Fraser did not “doubt that any important medical treatment of a child under 16 would normally only be carried out with the parents’ approval”, he did not believe that a parent had a right to veto this treatment. His concerns, however, lay in both the protection of children and the inclusion of parents, believing that doctors should be entrusted with discretion to “act in accordance with … what is best in the interests of … his patient.”

Similarly, Lord Scarman focused on the “extent and duration” of parental rights, acknowledging that while these do not disappear until children reach the age of majority, they are derived from a parental duty to protect children, for so long as that is required. He said “the common law has never treated such rights as sovereign or beyond review and control” and described them as “yielding” to competent children’s right to make decisions on medical treatment. He also considered that age limits are arbitrary, as they fail to recognise children’s individuality and natural development:

The law relating to parent and child is concerned with the problems of the growth and maturity of the human personality. If the law should impose upon the process of “growing up” fixed limits where nature knows only a continuous process, the price would be artificial and a lack of realism in an area where the law must be sensitive to human development and social change.

Thus, the subtlety differentiating the dicta of Lords Fraser and Scarman is that while Lord Fraser considered that the doctor has the final say on what is best for children, Lord Scarman considered that children could decide for themselves, provided they have sufficient understanding and intelligence.

39 At 172 per Lord Fraser.
40 At 171 per Lord Fraser said “It is, in my view, contrary to the ordinary experience of mankind, at least in Western Europe, in the present century, to say that a child or young person remains in fact under the complete control of his parents until he attains the definite age of majority, now 18 in the United Kingdom, and that on attaining that age he suddenly acquires independence. In practice most wise parents relax their control gradually as the child develops and encourage him or her to become increasingly independent. Moreover, the degree of parental control actually exercised over a particular child does in practice vary considerably according to his understanding and intelligence and it would, in my opinion, be unrealistic for the courts not to recognise these facts. Social customs change, and the law ought to, and does in fact, have regard to such changes when they are of major importance.”
41 At 173 per Lord Fraser.
42 At 173 per Lord Fraser.
43 At 174 per Lord Fraser.
44 At 184 per Lord Scarman.
45 At 184 per Lord Scarman.
46 At 186 per Lord Scarman.
Whilst Lord Templeman dissented, he also recognised children’s evolving competence, growing autonomy, and capacity to consent based upon “the nature of the treatment and the age and understanding” of children.

In 1986, this decision was groundbreaking, as it established the legal precedent for children’s competence to consent to medical treatment being defined in relation to their abilities, rather than their age. The judgment was not specific on the factors upon which to assess competence, but those distilled involve having the maturity and intelligence to understand the nature, consequences, advantages and disadvantages of the treatment, and also to think abstractly, such as how their decisions could affect others, in particular, their parents. Sadly, however, the progress of, and certainty in, the law since Gillick in further defining competence and recognising children’s rights to consent has been limited.


A. Introduction

Following two earlier Declarations on the Rights of the Child 1924 and 1959, the UNCRC was a further significant milestone in recognising children’s legal status and protecting their human rights. By viewing them as “not simply objects of adult concern, but … as citizens with rights”, it contains 54 articles that can be grouped together into three categories of rights: protection, participation and provision (also known as survival and development rights). Underpinning these rights are four guiding principles: non-discrimination/equality (article 2); the best interests of the child as a primary consideration in matters affecting them (article 3); the right to life and development to their fullest potential (article 6); and participation by expressing their views and having these considered (article 12). These principles must be respected both in the interpretation and implementation of all other rights, as well as rights in themselves.

B. Ratification, Implementation and Review

Worldwide, all countries, except the USA (which is a signatory), have ratified the UNCRC. The New Zealand Government (the Government) became a signatory to the UNCRC on 1 October 1990 and formally ratified it on 6 April 1993, thereby obligating

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47 At 201 Lord Templeman based his decision on public policy arguments. He believed that as it was a statutory criminal offence for a man to have sexual intercourse with a girl under the age of 16 years, and consent was not a defence, a girl of this age could not be sufficiently mature to give consent for contraception. He doubted that a girl under 16 years of age had the knowledge and understanding of all the issues to make a “balanced judgment.”

48 At 201 per Lord Templeman.

49 This will be seen in Chapter 3 when examining New Zealand’s laws, and also in Chapter 4 when considering the laws of Australia, England and Scotland.


itself to comply with these rights and principles for all children and young people under the age of 18 years.\textsuperscript{52} Ratification of the UNCRC requires the Government and its agents, such as judges, health professionals, social workers, police and teachers, to ensure compliance with its provisions when making laws and policies, and in decision-making. Families who are responsible for children’s day-to-day care are expected also to uphold children’s human rights.

In 2004, New Zealand enacted the COCA, which was influenced to a degree by the UNCRC. Whilst the COCA gives some respect to children’s participation and protection rights,\textsuperscript{53} it is “still very adult-focused”, particularly when considering children’s right to participate in medical decisions, as this still “turns on an arbitrary age, not on their level of maturity.”\textsuperscript{54}

Nonetheless, signatories have scope for improving their implementation of the UNCRC through reporting and monitoring processes. Each country submits reports every five years, examined by the Committee on the Rights of the child (CRC), an internationally elected body of independent experts. The CRC then questions Government and Non-Government representatives attending the review, after which the CRC provides observations and recommendations to promote each country’s implementation of the UNCRC. New Zealand last reported to the CRC in 2016. In New Zealand, the Ministry of Social Development is responsible for the Government’s reporting, and Action for Children and Youth Aotearoa (ACYA) leads the non-government reporting. The Office of the Children’s Commissioner (OCC) may also report separately.\textsuperscript{55} The UNCRC Monitoring Group (MG) is responsible for monitoring the Government’s implementation of the UNCRC and is convened by the OCC. The MG also includes representatives from agencies, such as the Human Rights Commission, UNICEF New Zealand, Save the Children New Zealand and ACYA.\textsuperscript{56} On 21 October 2016 the CRC issued its concluding observations on New Zealand’s fifth periodic report, including urgent measures to be adopted relating to violence, abuse and neglect; standard of living; and children belonging to minority or indigenous groups.\textsuperscript{57} This review process is child-centred, as it is without any other compromising considerations, such as those of parents or the family as a unit. Further, it provides opportunities for government and non-government organisations to reflect upon the application of the principles and provisions of the UNCRC and focus on how law, policy and practice can improve. The OCC has a

\textsuperscript{52} Three reservations were entered relating to the non-provision of benefits to children unlawfully in the country (article 28), the adequacy of measures to protect children in employment (article 32), and the mixing of juvenile and adult prisoners (article 37).
\textsuperscript{53} For example, COCA s 6 gives children the right to express a view in matters that affect them, and s 7 provides for the child being appointed a lawyer. However, even this latter provision is not an absolute right, as it is at the discretion of the court whether a lawyer is appointed, rather than it being at the instigation or request of the child. COCA s 4 protects children’s welfare and best interests as the paramount concern, and s 5 defines the welfare principles upon which to base such decisions.
\textsuperscript{54} Bill Atkin “Harmonising Family Law” (2006)37 VUWL 465 at 479. COCA, s 36 provides for only young people over 16 years to have the right to consent to, or refuse, medical treatment.
\textsuperscript{55} Office of Children’s Commissioner www.occ.org.nz
\textsuperscript{56} Office of Children’s Commissioner www.occ.org.nz
\textsuperscript{57} Committee on the Rights of the Child Concluding observations on the fifth periodic report of New Zealand CRC/C/NZL/CO/5 21 October 2016 at paragraph 4.
statutory mandate to raise awareness and understanding of the UNCRC in New Zealand. It does this through working with, for example, Government agencies, to include the UNCRC in law and policy, and with those working directly with children and young people to assist them to implement the UNCRC into their practices.

Providing useful assistance for organisations and individuals on how best to improve practices and policies for better compliance with UNCRC are three models of child participation: Hart’s Ladder; Shier’s ladder; and Lundy’s Model. Hart and Shier’s ladders provide a hierarchy of participation, with adults involving children increasingly in decision-making, as they move up the rungs; whereas Lundy’s model is dynamic and egalitarian. Lundy’s model compartmentalises article 12 of the UNCRC into children’s right to express views, and separately their right to have those views given due weight, with adults being obligated to provide the appropriate environment for the upholding of these rights through four elements: space; voice; audience; and influence. Other rights supporting article 12 are contained in the model: non-discrimination (article 2); best interests (article 3); guidance (article 5); information (article 13) and safety (article 19). These are also responsibilities adults must fulfill to uphold children’s participation rights by considering the practical elements of space, voice, audience and influence to best promote children’s engagement and uphold the rights of article 12. Common to all of these concepts/models are respect for children’s preferences in the degree of their participation, and also in the recognition of adults’ roles and responsibilities to support children’s participation.

C. Application of UNCRC to the Health Context

Whilst there is no specific article in the UNCRC providing for competent children to give consent for health treatment, there are clear rights and principles that support their participation in informed consent processes. Children’s participation is safeguarded through article 12 (participation) and article 2 (non-discrimination). Article 12 assures that all children have the right to express their views, if they are capable of forming them, in all matters that affect them, and further that regard must be given to those views when

58 Children’s Commissioner Act 2003 s 12(1)(d).
59 Roger A Hart Children’s Participation From Tokenism to Citizenship (1992) UNICEF International Child Development Centre, Italy at 9-12. The first three rungs of Hart’s ladder are non-participation: manipulation, decoration and tokenism. Children have little or no opportunity to form their own views or express them and are given little or no choice. They need to understand who sought their involvement, appreciate the purpose and the reasons for it, and can contribute freely in a meaningful way. This occurs at rung four “assigned but informed’, where although adults control the project by choosing its nature and making decisions, children volunteer, understand it and the reasons for their involvement, and have a meaningful role. Their contribution increases at level five, ‘consulted and informed’, as their views are considered. At level six children share in decision-making with adults, taking more initiative in doing so as they move to levels seven and eight.
60 Harry Shier “Pathways to Participation: Openings, Opportunities and Obligations” (2001) 15 Children and Society 107 at 110-115. Shier’s ladder has five rungs, omitting Hart’s first three rungs of non-participation. Moving through the levels, children’s involvement and influence increase, together with adults’ responsibilities to support them and share in the process. The minimum requirement for endorsing UNCRC occurs after having fulfilled level three.
decisions are made. A pre-requisite for children being able to form and express their views is having adequate information on their wellbeing and health, a right protected in article 17. Also supporting their participation is respect for their privacy (article 16). Together, these rights mean that all children have the right to contribute to discussions and decision-making on health issues.

Supporting these rights is article 5, encouraging parents to provide “in a manner consistent with the evolving capacities of the child appropriate direction and guidance.” The legal relationship of parent and child is thus recognised: as children develop competence; the degree of parental involvement diminishes.

Children’s protection and provision rights in health are also protected through the overarching principle and right of best interests (article 3), together with the right to life (article 6) and to receive the highest attainable standard of health and facilities for any treatment (article 24). Additionally, the UNCRC clearly respects the role of parents in protecting and caring for their children by acknowledging their responsibilities. Together, these articles promote children’s health and welfare through appropriate treatment decisions being made.

These participation and protection rights are not necessarily contradictory, for involving children in informed consent processes can meet both children’s right and need to participate.

D. Charter on The Rights of Tamariki Children & Rangatahi Young People in Healthcare Service in Aotearoa New Zealand

New Zealand has recognised the UNCRC in the healthcare context in the Children’s Charter. The Children’s Charter is a consensus statement between Children’s Hospitals Australasia and the Paediatric Society of New Zealand, implementing the UNCRC by reflecting protection, participation and provision principles and rights. It contains three underlying principles: children’s best interests are the primary consideration; children’s participation is respected; and recognition of the family’s importance to children, together with 11 rights. In considering each right, a holistic approach is taken towards

62 See articles 5, 7, 9, 10 and 18.
63 Wangmo and others, above n 18 at 18.
64 Children’s Charter at 6.
65 Every child and young person has a right to:
1. Consideration of their best interests as the primary concern of all involved in his or her care.
2. Express their views, and to be heard and taken seriously.
3. The highest attainable standard of healthcare.
4. Respect for themselves as a whole person, as well as respect for their family/whānau and the family’s/whānau individual characteristics, beliefs, tikanga, culture and contexts.
5. Be nurtured by their parents and family/whānau, and to have family/whānau relationships supported by the service in which the child or young person is receiving healthcare.
6. Information, in a form that is understandable to them.
7. Participate in decision-making and, as appropriate to their capabilities, to make decisions about their care.
8. Be kept safe from all forms of harm.
the overall wellbeing of the child (physical, spiritual, family and mental), and the child is recognised as both an individual and as part of a family. Children’s own assessment of their best interests, in line with their capacity, is respected also, in addition to the views of their parents and health professionals. Children also have the right to participate in decision-making, placing responsibilities upon health professionals to effectively communicate and provide understandable information. Although the Charter does not have legal status, in the sense that it is neither enforceable nor binding, it is an agreed statement of good practice founded on legal principles.

Thus, it is evident that together Gillick, the UNCRC and the Children’s Charter recognise children’s competence and the importance of parents’ roles in supporting their participation. Commonly, children will work in partnership with parents, but may seek greater autonomy from them, as their competence evolves. When this occurs, health professionals’ assessment of their competence is of central importance, as it is attaining of sufficient competence that gives them the right to consent.

**IV. Assessing Competence**

**A. Introduction**

No single test or process exists for assessing competence:

There is no all-purpose test of capacity to give or refuse consent. Even in the specific context of medical procedures, the courts have not adopted one test to the exclusion of all others.

In fact, some have likened the search for a universal test to a search for a Holy Grail. Nevertheless, toolkits do exist for assessing adults’ decision-making capacities, so could these be used or adapted for assessing children’s competence, and if so, are they reliable?

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9. Have their privacy respected.
10. Participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability.
11. Continuity of healthcare, including well-planned care that takes them beyond the paediatric context.

66 Right 1 at 9.
67 Rights 1 at 9.
68 Right 7 at 13.
69 At 13-14.
70 Right 6 at 12-13.
71 Ursula Kilkelly and Mary Donnelly, above n 21 at 40-1; Belinda Garth, Gregory Murphy and Dinah Reddihough “Perceptions of participation: Child patients with a disability in the doctor–parent–child partnership” (2009) 74 Patient Education and Counseling 45 at 50.
72 Skegg and Paterson, above n 5 at 216.
B. Toolkits for Adult Competence Assessments

Capacity toolkits, such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), are used to assess adults whose competence may be compromised by psychiatric conditions.\(^{74}\) They provide a standardised structure to the health professional-patient consultation, aiming to ensure a comprehensive, but flexible, assessment. For adult competence assessments, MacCAT-T is the most universally recognised tool, and is internationally regarded as the “gold standard.”\(^{75}\) It measures four aspects of decision-making:\(^{76}\)

1. understanding the disclosed information about the nature of the disease and the proposed intervention;
2. reasoning in the process of deciding about the proposed intervention, with a focus on abilities to compare alternatives in the light of their consequences;
3. appreciation of the effects of the intervention (or failure to undergo the intervention) on patient’s own situation; and
4. expressing a choice about the intervention.

Taking around 20 minutes to administer and score, the Mac-CAT-T toolkit is of use in particularly difficult cases, or ones that are likely to proceed to court,\(^ {77}\) rather than being of practical daily use.

In New Zealand, Douglass, Young and McMillan created a toolkit for adult competence assessments based on criteria similar to those of Mac-CAT-T:\(^ {78}\)

- understand the nature and purpose of a particular decision and appreciate its significance for them;
- retain relevant, essential information for the time required to make the decision;
- use or weigh the relevant information as part of the reasoning process of making the decision and to consider the consequences of the possible options, (and the option of not making the decision);
- communicate the decision.

Its aim is to provide:\(^ {79}\)

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\(^{75}\) Douglass, above n 26 at 160.


\(^{77}\) Appelbaum, above n 26 at 1837.

\(^{78}\) Douglass, above n 26 at 238.
… a consistent and systematic approach to assessing capacity within the New Zealand healthcare setting. It covers: key practice points, how to carry out a capacity assessment, and an overview of the relevant law.

C. Applicability of Toolkits for Children’s Competence Assessments

Arising from the limited knowledge of assessing children’s competence to consent to medical treatment, Hein and others evaluated the MacCAT-T tool in the context of predictive genetic testing (PGT) in the Netherlands. They aimed to evaluate the feasibility of assessing children’s competence using a standardised tool by modifying the MacCAT-T and ascertaining whether there were “cut-off ages for competence to consent.” Participating in the study were 17 paediatric patients between the ages of six and 18 years who were eligible for PGT due to their risk of autosomal dominantly inherited cardiac disease. Experts set a reference standard of competence, assessing 12 children (71%) as being competent, compared to using the MacCAT-T tool that assessed 16 children as competent (94%). The experts judged five children as being incompetent, aged six, seven, nine and two 11 year olds, whereas MacCAT-T judged all children as competent, except one seven year old. Hein and others considered that these results might demonstrate the limitation of the tool with children younger than nine years, but thought “individual competence assessment might create an opportunity in exceptional cases to allow a competent child under the age of 12 to co-decide over significant medical interventions.” Whilst acknowledging that further research on the reliability and feasibility of the Mac-CAT-T tool for assessing children’s competence was required, they believed that their results showed that children aged 12 years and over were consistently assessed as being competent in a complex area of PGT. Thus, for children aged 12 years and over they recommended a dual consent procedure, including both children and parents.

The implications of their proposals are that children aged 12 years and over would be presumed competent, and those younger presumed incompetent, with the tool being used in borderline situations. Although Hein and others strived “to underpin a just age

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79 At 237.
80 Hein and others, above n 76 at 971.
81 At 973.
82 At 975. The average age was 10.9 years, with eight children being 10 years and under and nine children 11 years and over.
83 At 974-5.
84 At 976.
86 At 976.
87 At 1151.
88 Imra Hein and others “Informed consent instead of assent is appropriate in children from the age of twelve: Policy implications of new findings on children’s competence to consent to clinical research” (2015) 16:76 BMC Medical Ethics 1. The legal context may have influenced the researcher, as in The Netherlands the age of medical consent is 12 years. Anticipating the question of what happens when there are disagreements between children and their parents, the researchers indicate that in the Dutch experience such situations are rare, but where unresolved, the child’s consent can be overridden were harm will ensue.
for alleged competence” and “an accurate assessment instrument … to substantiate competence judgment”\(^8\), they acknowledged that in “the treatment context, there are no conclusive age-limits for competence established empirically.”\(^9\)

D. Organic Competence Assessments by Health Professionals\(^1\)

Competence assessments are an intrinsic part of every clinical interaction,\(^2\) occurring naturally or organically during conversations with patients. With adults and young people a specific assessment is only required if health professionals have some indication of decision-making capacity being compromised, due to the presumption of competence. However, with children there is no such presumption, and therefore an assessment is required in every situation,\(^3\) although a formal assessment, such as by a psychologist, would only be likely in complex situations.\(^4\)

In the context of adult assessments, it is recognised that greater accuracy and consistency will be achieved if health professionals are aware of the legal criteria and questions to ask.\(^5\) Whilst no universal criteria for the assessment of children’s competence exist,\(^6\) when reviewing commentary by health professionals, common factors emerge, some relating to the context of assessments, and others to children’s abilities and understanding.\(^7\)

Firstly, the context of assessments recognises that the child’s situation, environment and relationships influence their competence, such as, whether they are in pain or anxious, are accompanied by supportive parents and have trusting relationships with health professionals.\(^8\) Several responsibilities lie with health professionals to enhance children’s competence by:\(^9\)

1. Creating an environment conducive to consulting, for example by providing privacy or allowing the support of a third party;
2. Sharing information on treatment, options and their consequences tailored to children’s developmental levels, such as by breaking down the process;
3. Giving children time to decide; and

\(^8\) Hein and others, above n 76 at 976.
\(^9\) Hein and others, above n 88 at 5.
\(^1\) I have used the term “organic assessment” to define competence assessments conducted in the natural course of clinical consultations, without the use of a toolkit.
\(^2\) Appelbaum, above n 26 at 1837.
\(^3\) Ministry of Health, Consent in Child and Youth Health: Information for Practitioners (Ministry of Health, Wellington, 1998) at 14.
\(^5\) Appelbaum, above n 26 at 1837.
\(^6\) Pierre André Michaud and others "Assessing an Adolescent’s Capacity for Autonomous Decision-Making in Clinical Care” (2015) 57 Journal of Adolescent Health 361 at 362
\(^7\) For example, John Pearce “Consent to Treatment During Childhood: The Assessment of Competence and Avoidance of Conflict” (1994) 165 British Journal of Psychiatry 713.
\(^8\) Mike Shaw “Competence and consent to treatment in children and adolescents” (2001) 7 Advances in Psychiatric Treatment 150 at 152.
\(^9\) Larcher and Hutchinson, above n 94 at 309.
4. Engendering a supportive and understanding relationship, within which children can express their views, values and reasons.

Through this engagement a trusting partnership can develop, unlocking children’s understanding and decision-making capabilities:100

… if viewed as partners, minor adolescents often display “hidden abilities,” that is a much better gauge of their situation than adults would otherwise anticipate. This is especially true when the young person has a chronic disorder with which he has learned to live and thus is capable of making good decisions in an autonomous way.

The environment of medical consultations provides the foundation for children to develop and demonstrate their competence. Crucially, children’s understanding, maturity, intelligence and decision-making abilities relate to the specific health decision, rather than in a global sense:101

Formal assessment of competence requires examination of how a young person deals with a particular decision rather than the application of standardised tests, but some analysis of the young person’s capacity to understand and assess risks is essential. … [C]ompetence is both task-specific and context-dependent.

Although assessment of these factors can occur naturally through conversation, being aware of specific questions that children must understand will assist the assessment, such as:102

- What is the illness/condition and what are its effects?
- What treatments/investigations are necessary and why?
- When does this need to be done?
- What does the treatment mean to me, and how will it affect my life?
- What happens if I do not have the treatment?
- What are the alternatives and their effects?
- What are the practical consequences for me and my family, on school and friends? 103

This final question appears to be aimed at assessing children’s cognitive development of their capacity for abstract thinking and their maturity, as it involves their perceptions of themselves, how their decisions could affect others and is future focused,104 including having a sense of time.105 However, there needs to be clarity upon what is required to

100 Michaud and others, above n 96 at 363.
101 Larcher and Hutchinson, above n 94 at 310.
102 At 309.
103 Similar questions are suggested in Ministry of Health, Consent in Child and Youth Health, above n 93 at 14: does the patient understand why they need the intervention; does the patient understand what the intervention involves and what it is for; does the patient understand the probable benefits and risks and what the alternatives are?
104 See Chapter 2 page 9. This is similar to the wider considers given by Lord Scarman in Gillick, above n 4 at 189.
105 Pearce, above n 97 at 714: “The central issue concerns the child’s stage of cognitive development. In order to give valid consent, children must have reached the stage of maturity where they have a clear
meet these criteria and their implications, such as, whether children only need to show their ability to consider the impact upon their family, but can still make independent decisions, rather than requiring to reach decisions that least affects their family.

When distilling criteria upon which to base children’s competence assessments, subjective elements may be present that are not applied to adults. For example, whilst it is necessary for both adults and children to articulate reasons for their choices, Larcher and Hutchinson consider that children’s choices should be “compatible with a life plan,” which appears to relate to one that does not compromise a long and healthy life. Further, linked to this is the criterion that the choice is required to be “reasonable, right or responsible.” Yet, these criteria are outcome-based, whereas adults’ assessments are process focused, having the right to make unreasonable choices. Nevertheless, those assessing children’s competence should remain objective and:

… also be aware of the potential biases that are linked with his or her own prejudices that may interfere with the ability to provide a neutral assessment of the adolescent’s decision-making capacity. This bias may arise for example from the provider’s own judgment of what can be considered as competence and the final outcome of the decision process.

Thus, it appears that children are being asked to show a greater degree of competence than adults, as they are potentially asked to evaluate the needs of others, predict the future and evaluate their reasons based on their life plan in order to be competent. The difficulties with introducing subjective criteria are that it predicates inconsistencies and uncertainties, and justifies health professionals judging children as incompetent if children hold a different opinion. Whilst competence must be assessed on a case-by-case basis, the application of objective universal criteria would assist in reducing such inconsistencies, aiding children’s and parents’ understanding of health professionals’ assessments, while ensuring that children are being assessed fairly, as “it is important not to set a higher standard for competence than would be expected for adults.”

Dr Applebaum, psychiatrist, for example, has distilled “legally relevant criteria” for assessing adults’ decision-making capacities, identifying for each, tasks that patients require to fulfill, and assessment approaches and questions health professionals should

concept of themselves in relation to other people, including an ability to recognise their own needs and the needs of others. … [T]he competent child will be able to understand these issues (risks and benefits of having or not having treatment) in relation to the passage of time and be fully aware of what might happen in the future as a result of having or foregoing the treatment.”

106 Larcher and Hutchinson, above n 94 at 308.
107 At 308-9. The other criteria are an ability to understand, possess actual understanding and have the ability to choose.
108 Appelbaum, above n 26 at 1836. Larcher and Hutchison, above n 90 at 308-9 suggest that children’s understanding requires to be actual understanding, whereas adults need only show an ability to understand, being a lower standard. This distinction is not made in the toolkits described in this chapter, which indicate actual understanding is assessed.
109 Michaud and others, above n 96 at 365.
110 Shaw, above n 98 at 152.
111 Appelbaum, above n 26 at 1836. The criteria are: understanding the relevant information; able to reason about treatment choices; appreciate the consequences; and communicate a choice.
follow. It provides a clear and easy process, highlighting also the relational nature of competence between patient and health professional.\footnote{112}{At 1836. See Appendix A.}

\section{Chapter Summary}

\textit{Gillick}, the UNCRC and the Children’s Charter each recognise children as individuals and rights-holders, with growing competence and independence, whilst acknowledging also the importance of family support. Likewise, when health professionals engage with children they too have responsibilities to be alert to children’s competence, promoting their participation, understanding and decision-making. It is within the context of these relationships that children’s competence and autonomy develop and are promoted. However, health professionals’ obligations go one step further, requiring to assess children’s competence to ascertain whether consent should be taken from the competent child. Most health professionals will undertake this informally, or naturally, within clinical interactions. Nonetheless, having criteria to base such assessments upon will enhance their accuracy and consistency and if transparent should increase children and parents’ understanding. Whilst competence has been defined simply, as having the ability, or capacity, to perform a task, it is task specific, and therefore the criteria vary amongst contexts.\footnote{113}{In terms of competence to make specific medical decisions, competence can be further defined as having the:} \footnote{114}{\ldots capacity to understand the material information, to make a judgment about the information in light of their values, to intend a certain outcome, and to communicate freely their wishes.}

These criteria can be expanded on, clarifying that (i) understanding relates to “the disclosed information about the nature of the disease and the proposed intervention”,\footnote{115}{At 70.} and also the “nature and purpose of a particular decision and [to] appreciate its significance”,\footnote{116}{At 71.} (ii) making a judgment involves weighing up the advantages and disadvantages of the options, considering the consequences and making a decision; and (iii) communication relates to the reasoning and the decision.\footnote{117}{Hein and others, above n 76 at 973; Douglass, n 26 at 238; Larcher and Hutchinson, above n 94 at 309.}

Children may be required to satisfy further criteria, such as, demonstrating an understanding of how the decision affects their parents or relationships with them.\footnote{118}{For example, Larcher and Hutchinson, above n 94 at 309 and \textit{Gillick}, at 189 per Lord Scarman.}

The above criteria relate to the process of decision-making, and although children may need to satisfy additional criteria from those applied to adults, they do relate to children’s maturity and emotional intelligence. Clear and objective criteria, based upon the process
of decision-making, rather than outcome, are required to promote consistency, certainty and understanding of assessments. This will be of particularly importance, for example, where children consult/consent without their parents, or where there are differences of opinions between health professionals, parents and children.

The themes of competence and consent are explored further in the following two chapters, which respectively examine how New Zealand law regulates the issue of children consenting to, or refusing, medical treatment, followed by the law internationally, in Australia, England and Scotland.
Chapter 3

New Zealand Legal Context

I. Introduction

Consent is the gatekeeper to medical treatment, permitting not only physical bodily contact, but also respecting patients’ autonomy, dignity, right to self-determination and privacy.119 Without consent, health professionals risk being sued for negligence,120 or prosecuted for assault.121 Thus, it is of importance to all concerned - children, their families and health professionals - that there is clarity in the law on how, and from whom, consent is obtained.

The focus of this and the following chapter is how the law regulates consent to, and refusal of, medical treatment for children, including any established criteria for assessing children’s competence. This chapter begins by considering New Zealand’s statutory law and the extent to which children’s rights to consent/refuse are specified. It then examines the development of the case law, considering how it has responded to gaps left by the statutory framework. The final section explores the nature and role of professional guidance and policies advising health professionals of their obligations in terms of the law.

II. Legislation

New Zealand does not have a specific statutory provision that regulates children consenting to, or refusing, medical treatment. Instead this is governed in a disconnected way, between the COCA, NZBORa and the Code. Moreover, there is a lack of clarity in the scope of children’s rights to consent to, or refuse, medical treatment within COCA, requiring the sections to be pieced together, with some inferences being made.122 This section interprets these statutes to elicit as much clarity as is possible.

A. Care of Children Act 2004

The COCA, which reformed and replaced the Guardianship Act 1968, gives more
prominence to children’s rights. It acknowledges children as active participants by, for example, recognising “certain rights of children” and giving them the right to express their views on matters that affect them. However, in the context of consent to medical treatment, the rights of children are limited, essentially relying upon arbitrary age rather than maturity. Only three groups of young people are given statutory rights to consent to, or refuse, medical treatment: those over the age of 16; those who are married, in a civil union or living with another person as a de facto partner; and girls of any age for an abortion. COCA is silent on the rights of children to consent to, or refuse, general medical treatment. So what did Parliament intend? How did it anticipate that the rights of children would be regulated, and what did it believe those rights to be? I will answer these questions by firstly interpreting COCA and then looking behind it to Hansard to examine the debates.

Turning firstly to the purposes in section 3, COCA aims to both protect children and promote their development, independence and autonomy. When combining this with the duties, powers, rights, and responsibilities of a guardian under section 16, COCA envisages parents and children working together in partnership, each having varying degrees of contribution when making decisions on important matters affecting children. Although section 16(1)(c) does not specify that the degree of parental involvement should be based upon children’s evolving competence and maturity, it is something akin to Gillick and that of evolving capacity in the UNCRC, and has been interpreted in that way.

Further exploring section 16, examples of “important matters affecting the child” are set out in section 16(2)(c), which includes medical treatment, but excludes “routine” medical treatment.

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123 Mark Henaghan Care of Children (LexisNexis NZ Limited, Wellington, 2005) at 1.
124 COCA, s 3(1)
125 COCA, s 6(2). However, see Henaghan and Ballantyne, “Bill Atkin: A Fierce Defender of Children’s Rights and Proponent of Child-Focused Legislation” (2015) 46 VUWLR 591 at 593 where they note Professor Atkin’s view that the Care of Children Bill, which was then passed as the COCA, was more adult-focused than child-centred, as children’s views could be undermined.
126 Atkin, above n 54 at 479.
127 COCA, s 36(1)
128 Children over 16 years can marry with their parents’ consent (Marriage Act 1955, s 18), or enter a civil union (Civil Union Act 2004, s 19(2)).
129 COCA, s 36(2). Potentially this could give children under the age of 16 years the right to consent or refuse medical treatment. For example, a hospital doctor (HD1) participating in this study spoke of treating a 13-year-old girl in an adult ward as she was living with her boyfriend, was pregnant and was “living in an adult world.”
130 COCA s 38.
131 COCA, s 3(1) “The purpose of this Act is to (a) promote children’s welfare and best interests, and facilitate their development, by helping to ensure that appropriate arrangements are in place for their guardianship and care; and (b) recognise certain rights of children.”
132 COCA, s 16(1) “The duties, powers, rights, and responsibilities of a guardian of a child include (without limitation) the guardian’s (a) having the role of providing day-to-day care for the child … and (b) contributing to the child’s intellectual, emotional, physical, social, cultural, and other personal development; and (c) determining for or with the child, or helping the child to determine, questions about important matters affecting the child.” (emphasis added).
133 Article 5.
134 COCA, s 16(1)(c); Atkin, n 54 at 479; Westlaw New Zealand, “Commentary - routine medical treatment” at CC36.04 www.westlaw.co.nz.
treatment. Routine is not defined in the COCA, but applying the commonly understood
definition of “routine” to medical treatment, this could encompass commonly
experienced complaints, such as colds, infections, vaccinations, warts, cuts, sprains,
dental check ups, and fillings. However, the range is imprecise and subjective.

Thus, parents have a responsibility to consider their children’s growing competence to
make decisions on medical treatment, other than routine matters, for which it may be
assumed they are capable of making themselves. Professor Skegg suggested that this
qualification was added to reflect children’s increasing competence or evolving capacities,
assuming that “it was accepted that children could often consent on their own to
routine treatment, without the need for assistance from their guardians.” However,
another, perhaps more cynical reason, is that this exception has been singled out to avoid
separated parents filing guardianship applications when in conflict for routine medical
treatment, adding time and expense to the court system, and causing further stress to
children.

Moving to section 36, which deals with consent procedures generally, young people (over
16 years) have clear rights to both consent to and refuse treatment. Yet section 36(3) is
very unclear and non-specific as to whom it covers:

If the consent of any other person to any medical, surgical, or dental treatment or
procedure (including a blood transfusion) to be carried out on a child is necessary or
sufficient, consent may be given—
(a) by a guardian of the child.

By implication this could cover under 16-year-olds, meaning that a guardian can consent,
but does it cover all under 16-year-olds, or only those who are not competent? The

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135 “A sequence of actions regularly followed” English Oxford Living Dictionaries
<www.en.oxforddictionaries.com>. See also Westlaw, above n 134 at CC36.04 where routine medical
treatment is defined as “Medical treatment for minor health problems such as acne, colds, cuts or sprains,
or vaccinations would probably be characterised as “routine” but there might be questions whether a 15-
year-old seeking advice or contraception from a Family Planning clinic was accessing routine treatment.”

136 Westlaw, above n 134 at CC36.04. ‘The guardian does not have the power to make a decision on behalf of
the child if the proposed treatment is “routine”’.

137 Skegg and Paterson, above n 5 at 246.

138 Both parents are children’s guardians and as such must “act jointly” in guardianship matters under s
16(5) COCA. In the event that they are unable to agree an application can be made to court under s 46R. If
parents became aware of the other’s opposition to medical treatment this should be resolved by agreement
or through court. However, Skegg and Paterson, above n 5 at 255 have questioned the requirement to act
jointly in even non-routine matters as s 16(5) provides for consultation of guardians being required
“wherever practicably, with the aim of securing agreement” and consent may be given by a guardian (s
36(3)).

139 COCA, s 36(1) “A consent, or refusal to consent, to any of the following, if given by a child of or over
the age of 16 years, has effect as if the child were of full age:
(a) any donation of blood by the child:
(b) any medical, surgical, or dental treatment or procedure (including a blood transfusion, which, in this
section, has the meaning given to it by section 37(1)) to be carried out on the child for the child’s benefit
by a person professionally qualified to carry it out.”
section states ‘if consent of any other person … is necessary’ (emphasis added), implying that that there may be situations where the consent of another person is unnecessary. One interpretation could be that parental consent is only necessary when children lack competence to give their own consent. Support for this view is gained from earlier statutes and case law.¹⁴⁰ Nevertheless, one argument against this interpretation is that given the specific statutory provision for over 16-year-olds and also for girls under 16 years consenting to, or refusing, an abortion, it is reasonable to believe that if this had been Parliament’s intention it would have been clearly stated. Moreover, section 38(2) (consent to abortion) overrides section 36, implying that the two are inconsistent to a degree. The more likely interpretation is that children have not been given a statutory right to consent and therefore “New Zealand statute has made it a guardian’s power.”¹⁴¹

Support for this view is found in Hansard, where the Parliamentary debates regarding the Care of Children Bill (“the Bill”) are recorded. During the third reading of the Bill, the Hon Bill English (National—Clutha-Southland and Leader of the Opposition) stated:¹⁴²

Clause 35 [now section 36] states that there is an exception to the general rule that a child under 16 cannot consent to a medical procedure, and that a parent must give consent. The exception is when a girl is having an abortion. That is the one exception to the rule, as outlined in clause 35.

This is the only reference during the Bill’s passage through Parliament of the Minister’s understanding of the law for children under the age of 16 years giving general medical consent. Mr English reveals a glimpse of the lack of depth of Parliament’s understanding of the law when he states in reference to Clause 35:¹⁴³

I know for a fact that the debate on the clause was conducted largely in ignorance of the law by the MPs who were voting on it. The debate demonstrated that many MPs thought the current law prevented a medical or other health professional from advising parents when a girl under the age of 16 had an abortion. Of course, the current law does not do that.

Instead, Opposition parties’ focused on preserving what they regarded as the traditional family and parents’ rights.¹⁴⁴ Of particular concern to them was the clause enabling a girl

¹⁴⁰ See for example Mental Health (Compulsory Assessment and Treatment) Act 1992 considered below at page 28 and Re J, above n 8 that confirmed that parental rights are never absolute but reflect their responsibilities towards their children, and R v Laufau and Laufau HC, Auckland T.000759 2 August 2000 where the Court considered Tovia Laufau’s competence in the context of refusing consent, considered further at page 38-40.
¹⁴¹ Skegg and Paterson, above n 5 at 250.
¹⁴³ At 16715.
¹⁴⁴ For example, see (24 June 2003) 609 NZPD 6539 - Richard Worth (NZ National—Epsom) stated during the Bill’s first reading: “The Minister [Hon Lianne Dalziel (Associate Minister of Justice)] dismisses the concept of the ideal family. That family is, in effect, parents and their children. She dismisses that concept, because she says, “Well, that may be an ideal plan, but that doesn’t really reflect the reality of society”, and that is of course true. I acknowledge that, but it is not a reason for saying that that paradigm is not worth aiming for.” See also (1 July 2003) 609 NZPD 6711 - Hon Dr Nick Smith (NZ National-
of any age to consent to an abortion without informing her parents. Their priorities were parents’ rights and children’s protection, believing that parents’ roles were being substituted by the State, and that parents’ abilities to implement their responsibilities were being eroded. However, supporters of the clause had confidence in health professionals and the system supporting and protecting vulnerable young girls, including their rights to privacy and freedom to make their own decisions. Section 38 was passed with children’s right to privacy intact, but the COCA left ambiguous children’s rights to consent to, or refuse, other forms of treatment.

Uncertainty and confusion are compounded when considering section 13(1), which provides for the COCA acting as a code. One possible interpretation is that the COCA overrides the common law on guardianship matters. If so, the implication could be that decisions on medical treatment, other than routine, are guardianship matters, and therefore, the COCA supersedes the common law on competent children giving consent to medical treatment. The majority of legal experts do not accept this to be the case. Professor Skegg argues that section 13(1) does not cover the common law capacity of children to consent to medical treatment as it “stands entirely apart” from guardianship. In that way guardianship rights and children’s competence can co-exist. Additionally, when considering section 16(1)(c), guardians have the duty, right and responsibility of helping children to determine questions about matters of health, and this specifically recognises children’s independent right to consent.

Further indication of children and parents working in partnership may be interpreted from section 36(5), which preserves the position of other statutes or precedents that enables children to consent in addition to any other person. Interestingly, it does not specifically state that it will not affect any other rule of law that gives children the right to consent independently, or instead, of any other person. Thus, although section 36(5)(b) recognises that children can consent, it lacks clarity of whether they can do so without their parents’ consent.

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145 (2 November 2004) 621 NZPD 16415. For example, Dr Paul Hutchison (National—Port Waikato. However, having been an obstetrician-gynaecologist and having sat on the Abortion Supervisory Committee he was clearly torn between safeguarding the welfare of such girls and protecting his obligation, and their rights, to privacy. He considered that data on the informed consent process would be advisable as it is “unlikely that we will be able to make wise legislation” without it.

146 (21 October 2004) 621 NZPD 16415. For example Hon David Benson-Pope (Associate Minister of Justice) and Metiria Turei (Greens).

147 COCA, s 13(1) “Except as otherwise provided in this Act, this Act has effect in place of the rules of the common law and of equity as to the guardianship and custody of children.”

148 Skegg and Paterson, above n 5 at 248; Henaghan, above n 123, at 20; Ludbrook, above n 122 at 38; and Ministry of Health, Consent in Child and Youth Health, above n 93 at 31.

149 Skegg and Paterson, above n 5 at 248 footnote 189.

150 COCA s 36(5) “Nothing in this section affects an enactment or rule of law by or under which, in any circumstances,—(a) no consent or no express consent is necessary; or (b) the consent of the child in addition to that of any other person is necessary; or (c) subject to subsection (2), the consent of any other person instead of the consent of the child is sufficient.”
Thus, from the statutory provisions of the COCA and from the parliamentary debates it would appear that the rights of children to consent to, or refuse, medical treatment were simply overlooked. This seems quite astounding given the large number of submissions on the Care of Children Bill recommending inclusion of a provision in line with *Gillick*.

... the Ministry of Justice report to the Select Committee considering the Care of Children Bill noted a large majority of the submissions on the Bill recommended that the relevant clause needed revision to remove uncertainty around the ability of children younger than 16 years to give effective consent to medical treatment, and that most of these suggested that the rule in *Gillick* about evolving capacities be adopted. The Ministry’s view on this was that clause 35 (s 36 of the Act) does not prohibit persons under 16 years from consenting in their own right, and that, in determining whether “consent is necessary” or “consent is sufficient” under s 36(5)(b) and (c) common law rules and health legislation apply.

Nevertheless, “[f]or reasons which are not clear the Ministry and Parliament decided not to clarify the position of under-16s,” and COCA missed “the great opportunity to determine the place of *Gillick* in the law.” Parliament had a further opportunity in 2013 to clarify the position during the review of the Family Court system, but failed to do so. Therefore, it is necessary to look beyond COCA for clarification of the law.

### B. Code of Health and Disability Services Consumers’ Rights 1996

The Code recognises the importance of informed consent processes by presuming everyone’s competence, and giving everyone the right to make an informed decision to consent to, or refuse, treatment. However, the Code is a regulation (secondary or subordinate legislation) under the Health and Disability Commissioner Act 1994, and as such, does not fill the gap, or clarify the uncertainty, left by the COCA. As Professor Skegg points out rule 7(2) is “simply for the purposes of Code liability - although it may well have a knock on effect on disciplinary liability. ... Parliament did not intend to confer a power to alter by regulation the general law relating to capacity to give, or to refuse, consent.” Nevertheless, it does establish patients’ rights and health professionals’ duties/responsibilities to follow informed consent processes by providing

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151 Westlaw, above n 134 at CC36.02(8).
152 See also Henaghan and Ballantyne, above n 125 at 596 where they note that as long ago as January 1987 Bill Atkin, submitted to the Social Services Select Committee on Children and Young Persons Bill 1986 that account should be taken of *Gillick* in what became The Children, Young Persons and Their Families Act 1989. Further, at 596-597 they state: “It would have been more helpful if the Care of Children act 2004 had incorporated some guidelines directly based on *Gillick*, such as a requirement for a prescribed sufficient level of understanding by the child. Clear guidelines would have assisted health professionals to determine when, and which, particular children should have the right to be more involved in important medical decisions.”
153 Westlaw, above n 134 at CC36.02(8).
154 Atkin, above n 54 at 479.
155 Code, Right 7(2).
156 Code, Right 7(1).
157 Code, Right 7(7).
158 Skegg and Paterson, above n 5 at 239.
effective communication,\textsuperscript{159} fully informing,\textsuperscript{160} and enabling patients to make informed choices and give informed consent.\textsuperscript{161}

C. \textit{Contraception, Sterilisation and Abortion Act 1977}

Through the repeal of section 3 of the Contraception Act 1977, contraception can be provided to children under the age of 16.\textsuperscript{162} Although it is not stated as a right, the removal of this section enabled children to obtain advice and be prescribed contraception without requiring their parents’ consent.

D. \textit{Mental Health (Compulsory Assessment and Treatment) Act 1992 (Mental Health Act)}

Whilst the Mental Health Act stipulates the age of consent as 16 years, its guidelines\textsuperscript{163} recognise consent from competent children under 16 years, independently of their parents. It further gives indicators for assessing competence based upon understanding and maturity.\textsuperscript{164}

A child/young person under the age of 16 years may give valid and effective consent if they have a sufficient understanding of the significance of the proposed treatment. This depends on the maturity of the individual child/young person, the effect of the relevant disorder at the time, and the seriousness of the matter for decision. If a child/young person under the age of 16 years is able to give consent, the consent of a parent/guardian is not necessary.

E. \textit{Protection of Personal and Property Rights Act 1988 (PPPR Act)}

Similarly, the PPPR Act, despite its remit being over adults, defines capacity in comparable terms to \textit{Gillick} in section 5:\textsuperscript{165}

\begin{itemize}
  \item[(a)] To understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; and
  \item[(b)] To communicate decisions in respect of those matters.
\end{itemize}

This is the only New Zealand statute that defines competence.

\textsuperscript{159} Code Right 5.
\textsuperscript{160} Code Right 6.
\textsuperscript{161} Code Right 7.
\textsuperscript{162} Contraception Act 1977, s 3 was repealed on 7 September 1990 by s 2(1) of Contraception, Sterilisation and Abortion Amendment Act 1990.
\textsuperscript{164} At 77.
\textsuperscript{165} The Health Act 1956, for example, refers to legal capacity but the term and its assessment are not defined.
F. **New Zealand Bill of Rights Act 1990**

Section 11 of the NZBORA gives everyone the right to refuse medical treatment, applying to all New Zealanders, with no age restrictions. There is no doubt that only competent children could be included, as this is consistent with the rule of law in respect of children consenting. Nonetheless, the NZBORA does not override another statutory provision, and there is a limitation on its rights. Section 5 states that “the rights and freedoms contained in the Bill of Rights may be subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society,” and section 6 provides for the preferred interpretation of enactments being consistent with the NZBORA. Including children in the interpretation of NZBORA would not conflict with any other statutory provisions, as there are none that specifically provide for children consenting or refusing consent, and “limitations to the application of section 11 should be set out explicitly in statute and will be read strictly.”

Support for children’s right to refuse is also found in the Code, with right 7(7) giving all patients the right to refuse services and withdraw consent. Whilst there is no New Zealand case law specifically on this matter, there are conflicting indicators from the High Court. The Court in *Auckland Healthcare Service Limited v Liu* appeared to assume that children had no agency, and were therefore unable to consent to, or refuse, medical treatment. On the other hand, the competence of Tovia Laufau to refuse treatment was in issue during the trial of his parents who were prosecuted for failing to provide him with the necessaries of life. When summing up to the jury, Potter J not only directed the jury to apply *Gillick*, but also seemed to assume that children could be competent to refuse consent:

> You will need to consider and decide whether Tovia was capable of making an informed choice not to have medical treatment. ... The important thing about the *Gillick* decision is that it recognises that age is not the only or the major determinant in deciding whether a person is capable of giving informed consent. Age will always be a very important relevant factor, and you will take into account that Tovia was 13 years and 2 months old. Then you will have to consider whether he was capable of understanding what was proposed and of expressing his own wishes in relation to the treatment proposed. Did he have sufficient understanding and intelligence to fully understand what was proposed in the circumstances of the case? From that I think it will become clear to you that the second important component of informed consent is that the person making the decision, in this case it was not consent but choice was indeed informed. Did Tovia have

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166 For example, competence is required in terms of *Gillick*, the Code, and the High Court decision of *Re S* [1992] 1 NZLR 363 at 364. *Re S* involved an application under the Mental Health Act 1969 against detention in which the court held that "everyone" in section 11 means "every person who is competent to consent."

167 NZBORA, s 4.


170 *R v Laufau and Laufau*, above n 140. This case, together with those of Caleb Moorhead and Liam Williams-Holloway, will be considered in more detail at pages 39-42.

171 At [31]-[33].
all the necessary and relevant information about the course of treatment proposed, to
make an informed choice? Was he capable of making an informed choice?

This is a clear application of Gillick by the High Court in the context of children refusing
medical consent and acknowledgement that it is possible for children to be competent to
refuse medical treatment, otherwise it would be a moot point. This is significant, despite
it being in the context of a criminal trial, rather than in the context of a civil law/family
law matter, where the Court can make findings of fact and give a ruling.

As will be seen in the following chapter, precedents post-Gillick from the English Court
of Appeal decided that parental consent could overrule the refusal of competent children.
However, these have not been adopted in New Zealand, and there is indication that they
should not be followed. For example, Ron Paterson, Chief Advisor, Services, Ministry of
Health, advised: 172

In England … the Court of Appeal has suggested that it would be possible to have both
a refusal to consent by a competent teenager and at the same time a valid consent by a
legal guardian. There has been much criticism of this view. It would be possible to avoid
such an unfortunate result in New Zealand by:

• being cautious in assessment of competency and

• where the teenager is found to be competent, relying on s. 11 of the Bill of
Rights, to come to the conclusion that parents/guardians lose the right to give
or withhold consent to treatment of that teenager.

The right to refuse consent is the most controversial and debated issue, not only because
of the degree of ambiguity in the law, but also due to the emotive and ethical issues of
whether children should have treatment forced upon them, or alternatively are left to
suffer, and in its extreme, die without it. Whilst some commentators focus on whether
children are competent, rather than their age, with the corollary of competence being
both the right to consent to, and refuse, treatment; 173 others believe that the necessary
degree of competence to refuse treatment is greater than that required to consent, as it
involves rejecting health professionals’ advice, 174 or requires consideration of moral and
family questions. 175 Viewing the issue from a practical perspective, and giving priority to
parental authority, Skegg and Paterson voice their concerns that children having the right
to refuse medical treatment “would not be without problems”, and “[i]f children acquire
the right to effectively prohibit treatment when they first become capable of giving
consent, there would be room for endless disputes about whether a particular child had
capacity to consent to a particular procedure in the particular circumstances. This would

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172 Ministry of Health, above n 93 at 48.
173 Norrie, above n 14 at 436; Sarah Elliston “If You Know What’s Good for You: Refusal of Consent to
Medical Treatment by Children” in Sheila McLean (ed.) Contemporary Issues in Law, Medicine and Ethics
175 Graeme W Austin, “Righting a Child’s Right to Refuse Medical Treatment” (1992) 7 Otago L. Rev. 578
at 595.
make it much more difficult to rely on a guardian’s consent in, say, the case of an articulate 12-year-old.\textsuperscript{176}

III. Case Law

A. The Extent to which New Zealand Case Law Recognises Gillick Competence\textsuperscript{177}

There has not been a thorough examination of the issues of children’s competence and their rights to consent to, or refuse, medical treatment, although some courts have referred to, followed and applied \textit{Gillick}.\textsuperscript{178} This has led to inconsistency and uncertainty of not only the existence, and extent, of children’s rights, but also the criteria upon which competence is assessed.\textsuperscript{179}

Starting precariously from the standpoint of \textit{Gillick}, the High Court assumed children had no right to consent. Hillyer, J in \textit{Re X ( sterilisation: parental consent)} gave a generalised and sweeping statement, that “[o]f course when a child is under the age of 16 years or intellectually handicapped, such [parental] consent is required.”\textsuperscript{180} However, Hillyer, J made this obiter statement, with no reference to, or consideration of, \textit{Gillick}, as competence was not in issue, the 15-year-old girl being severely intellectually handicapped. Likewise, Tompkins J in \textit{Auckland Healthcare Service Limited v Liu} failed to consider the competence of a 12-year-old boy (Joseph) and the ratio of \textit{Gillick}, when the Court indicated children less than 16 years have no rights of consent or refusal.\textsuperscript{181}

\textsuperscript{176} Skegg and Paterson, above n 5 at 253.

\textsuperscript{177} \textit{Gillick} has been applied in a variety of contexts outside of medical treatment by the New Zealand courts. For example: in \textit{Tao v Woodridge} [2015] NZFC 6212 children aged four and five were deemed to be not \textit{Gillick} competent to decide whether they attend Seventh Day Adventist Church with their father; \textit{Moore v Moore} [2015] 2 NZLR 787 children aged six and four were not yet \textit{Gillick} competent to decide upon whether to participate in the Jehovah Witness faith. In \textit{Moore} at [137]-[146] the court had regard to whether they had reached a stage in their development where they were able to make an informed choice by weighing up the pros and cons; \textit{Powell v Riley} FC Auckland FAM-2013-004-1204 26 November 2013 at [57], an application was made under COCA, s 103 for return from New Zealand to Australia of a young person aged 15 years and 5 months who could “readily be described as having \textit{Gillick} competence”; and \textit{ARB v KLB} [2011] NZFLR 290 the court applied \textit{Gillick} to determine whether a young person nearly 14 years was competent to choose her dental and medical practitioner. It appears that the Court undertook a competence assessment. At [17] Judge Moss interviewed her to “not only ascertain her opinion but also the underlying basis for the formation and expression of that opinion … relating to both her capacity and to her opinion, and the extent to which she was in a position, independently, to form a view.” At [18] Judge Moss had regard to her intelligence, her “particular skill in abstract and analytical thinking”, her ability to form “opinions herself which she was able to express articulately” and had a high level of ability to think for herself and express herself clearly but gently.” She was able to list the qualities she sought in each health professional, and at [23] the court concluded that she was capable, with parental support, of choosing their identity.

\textsuperscript{178} For example, \textit{Re J}, above n 8; \textit{Hearthorne v Cos}, above n 9; \textit{Re SPO}, above n 10.

\textsuperscript{179} Tim Grimwood, “\textit{Gillick} and the consent of minors: contraceptive advice and treatment in New Zealand” (2009) 40 VUWLR 743 at 744 believed that “if the \textit{Gillick} situation arose in New Zealand the courts would be working in a very grey and ill-defined area.”

\textsuperscript{180} \textit{Re X ( sterilisation: parental consent)} [1991] NZFLR 49 at 57.

\textsuperscript{181} \textit{Auckland Healthcare Service Limited v Liu}, above n 6 at 7. The child and his parents refused to give consent to the surgery on the grounds of their religious beliefs. Tompkins J at 7 confirmed the decision of \textit{Re J},
although recognising Joseph’s right to express his views on whether he had retina surgery. The Court appeared again to assume that he had no right to either consent or refuse treatment: 182

… a child under the age of 16 is unable to give effective consent and in my view similarly is unable to exercise the right that would otherwise be conferred by s 11 of the Bill of Rights Act. Whilst of course full weight should be given to Joseph's views, I do not consider that s 11 of the Bill of Rights Act can be determinative.

Taking a similar approach in Auckland Healthcare Service Limited v T, 183 Paterson J took account a 12-year-old girl’s views, considering her “both positive and mature”, but also “somewhat confused, … notwithstanding her maturity, having regard to her age” 184 In failing to apply Gillick, or specifically address her competence, the paramount concern of the Court, in this application for guardianship, was her welfare and best interests, when she and her parents refused to give consent for treatment on the grounds of their religious beliefs.

Nevertheless, on 6 March 2002 there was clear recognition of both a competent child’s right to consent and of Gillick by the Health and Disability Commissioner (the Commissioner) after reviewing a complaint by a 14-year-old boy’s mother, Case 01HDC02915 (tetanus case). 185 The boy had been taken by a school staff member to his medical practice after being injured at school and required a tetanus vaccination. The issue related to whether he could give consent for it. The Commissioner indicated: 186

The common law concerning consent by minors (persons below the legal age of majority) to medical treatment is well established as a “competency based” assessment: Gillick v West Norfolk and Wisbech Area Health Authority. This means that Mr B’s ability to consent to receiving an immunisation against tetanus is not determined on the basis of his age alone. Rather, Dr C was under a duty to consider whether Mr B was able to make an informed choice and give informed consent to the tetanus and diphtheria immunisation.

In considering the question of the boy’s competence, the Commissioner took account of “his ability to understand the information given to him about the risks of his condition and the consequences of any decision, as well as the relative seriousness of the situation.” Establishing that the boy had understood the information given, and was competent to give consent, the Commissioner stated: 187

Mr B was 14 years old at the time of this incident. A young person of that age is well

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182 Auckland Healthcare Service Limited v Liu, above n 6 at 7.
184 At 671.
185 Case 01HDC02915, 6 March 2002.
186 Case 01HDC02915, above n 185 (pages and paragraphs are unnumbered).
187 Case 01HDC02915, above n 185.
able to understand basic medical information and give consent to a vaccine injection. There is no evidence that Mr B did not understand any of the information that Dr C provided to him. Mr B understood that he was receiving an injection to “fight off tetanus” and that tetanus was a “disease” which “was not a good thing” to have because “you get real sick”. Mr B knew that the injection would hurt, after Ms D [nurse] told him so.

Similarly, the potential of children’s competence was recognised in another complaint to the Commissioner, involving an 11-year-old girl who underwent dental extractions. However, due to the orthodontist failing to first inform and then obtain consent prior to the extraction, her understanding and competence were not determined.188

Nevertheless, despite the Commissioner’s recognition of children’s potential competence and right to consent, there has been a lack of transparency, process and consistency. For example, six months after the tetanus case, the Commissioner decided on 18 September 2002 that a 10-year-old girl was not competent to consent to the vaccinations for polio and measles, mumps and rubella (MMR) when a complaint was made that her GP had administered, or authorised administration of, them without obtaining the informed consent of her mother.189 There were no details of the information provided to the girl, of her understanding, or how the commissioner reached his conclusion. It appears that incompetence was presumed, probably due to her age and the nature of the decision:190

In light of Miss A’s young age (10 years) and the nature of the decisions (consent to immunisation), there were reasonable grounds for Dr B to believe that she was not competent to make an informed choice and give informed consent.

This lack of transparency was particularly unfortunate, as the issue in question was whether lawful consent had been given to the GP, as neither the child, a parent or guardian had consented.191

Similarly, there was no acknowledgment of competence, its evolving nature, or the reasons for the incompetence of a six-year-old child who underwent more than 40 appointments over more than five years.192 The Commissioner found that the dentist had failed to provide the girl’s legal guardians, or their representative (the Grandmother), with sufficient information on the proposed orthopaedic treatment to obtain informed consent. The reason for this lack of recognition of competence may be an assumption of obvious incompetence, given the girl’s age, combined with the complexity of the treatment, but there is nothing explicit to clarify the position, or any acknowledgement of how her competence would have evolved throughout the lengthy period of treatment, as she matured and developed experience.

188 Case 14HDC00736, 31 March 2015 at [44]. This involved three baby teeth being removed.
189 Case 01HDC12269, 18 September 2002.
190 At 2
191 The child was cared for by her Grandmother. She was taken to the GP by her Aunt, who gave him a letter from the Grandmother stating that she was a guardian and gave permission for the child to be seen by him. However, the Grandmother was not a legal guardian and the mother complained as she had not consented and was opposed to her children receiving them.
192 11HDC01103, 28 March 2014.
 Nonetheless, there should be little doubt about the right of competent children to give consent after the Family Court in Re SPO accepted and applied *Gillick*.\(^{193}\) The issue before the Court was whether a 15-year-old boy could consent to vaccinations, despite his mother’s refusal. The court in considering his competence had regard to the following: the information he had received from the public health nurse; discussions he had had with his GP and older brother;\(^ {194}\) his earlier experience of having, and consenting to, the first of three vaccinations; and confirmation of his full understanding, through a letter he filed, and submissions from his lawyer.\(^ {195}\)

Despite these factors confirming competence, this decision has been criticised for lacking sufficient consideration of it, specifically not examining “the boy’s actual understanding of the treatment or his capacity to understand in terms of *Gillick*, just that he had received relevant information.”\(^ {196}\) It is questionable in the context of the facts what additional evidence would have been necessary, as vaccinations are a relatively simple procedure. It would seem excessive to require either a medical practitioner or the child to attend court for the Judge to be satisfied of his competence. However, those steps may be appropriate in more complex matters, as is commonplace in Australia for example, when courts consider children’s competence to consent to transgender treatment.\(^ {197}\)

The Family Court in *BAS v CHE*\(^ {198}\) took such an approach in an application seeking a direction to fit a severely, intellectually disabled and autistic 13-year-old girl with a Mirena to suppress menstruation. Prior to the hearing, the Court directed her paediatrician to report to the Court upon whether the girl was competent to give her consent, and if not, whether she was likely to develop such competence. The conclusion of both matters was in the negative, the doctor confirming that she was not competent “to make reproductive choices because of her limited capacity to understand the concepts of menstruation, fertility and how her body works” and would be unlikely to ever achieve competence.\(^ {199}\) In accepting the paediatrician’s view, Judge O’Dwyer placed weight upon the length of his relationship with the girl, her family and social worker, together with his account of earlier assessments by other professionals:\(^ {200}\)

He [the paediatrician] bases that, in my view importantly, on his assessment since 2006, but also the previous assessment of Dr Hall, who was the developmental paediatrician between 2004 and 2006, the opinion of Dr Judith McDougall, the clinical psychologist, and his ongoing assessment of S through his contact with her social worker Ms Staples and also her caregivers, and also information available to him from her school.

Despite the courts and Commissioner providing some confidence in the adoption of *Gillick*, and of competent children’s rights to consent, the situation lacks certainty and

\(^{193}\) *Re SPO*, above n 10.
\(^{194}\) At [27].
\(^{195}\) At [9].
\(^{196}\) Grimwood, above n 179 at 746.
\(^{197}\) This is considered further in the next chapter.
\(^{198}\) *BAS v CHE* [2012] 28 FRNZ 847.
\(^{199}\) At 849.
\(^{200}\) At 849.
The question arises whether the common law capacity of some minors to consent to medical procedures can be relied upon in New Zealand. More than half a century after the New Zealand legislature first intervened in the area the question has still not been settled beyond all shadow of doubt.

The primary reason for this uncertainty is the lack of explicit statutory provision, resulting in case law attempting to fill the gap, but doing so in an ad hoc manner. On some occasions the higher courts have little opportunity to develop the law. For example, in *Chief Executive of the Ministry of Social Development v Young Person X* “there was inadequate information as to when, how and by whom the ultimate decision to begin treatment would be made” in respect of a 15-year-old who had expressed desire to begin medical treatment to transition from male to female. Likewise, there was no opportunity for the Court to consider John’s competence, a nine-year-old boy, in *Auckland District Health Board v Dee*, albeit for a different reason. John had been diagnosed with HIV at four months old, but he was unaware of this fact. No indication is given in the judgment of the reasons for this, and why he would be told at the age of 11/12 years, although it can be inferred that his parents and health professionals agreed he was too young. Projecting into the future, the Court pre-empts to a degree, how it is likely to deal with John’s refusal, should that eventuate, confirming such refusal would not be decisive.

The Court supported this view with reference to two English cases, the first *An NHS Trust and another v Mr and Mrs A and others*, in which J, a 14-year-old boy, was held to be incompetent, although ‘intelligent thoughtful and articulate’ and having ‘received a very considerable amount of information about HIV and AIDS from a variety of sources.’ The issue was that J did not accept that he was suffering from HIV, and as such, he could not assess his state of risk. The Court accepted unreservedly that J had HIV and was at risk of AIDS and other serious illnesses. The second case, to further illustrate “the nature and extent of this Court’s jurisdiction,” was *Re W (a minor) (medical treatment)* (*Re W*), in which the refusal of a 16-year-old girl was not accepted by the Court, as she was deemed to lack capacity, due to suffering from anorexia nervosa. Notably, although the Court in *Dee* placed importance upon being aware, and taking into account, of John’s views, it does not reflect upon the implication to his competence when he becomes aware of his condition, nor the bearing that this would have upon the issue of consent to,
or refusal of, treatment.\textsuperscript{209}

Similarly, the courts have had little opportunity to clarify the law at other times, due to the children involved being clearly too young to be Gillick competent in the context of the decision.\textsuperscript{210} Nevertheless, on other occasions, courts have missed opportunities to give more clarity or certainty, particularly on the assessment of competence. In some cases courts may have assumed children’s incompetence, but it is more likely that the issue was simply overlooked, as there is no reference to competence, Gillick, or even to children’s views. For example, in \textit{Waikato District Health Board v FF and MM} a seven-year-old boy was diagnosed with a rare and severe form of epilepsy when he was a few months old.\textsuperscript{211} An application was made by the Health Board seeking orders to enable him to receive medication. The question for the Court was whether the proposed treatment was in the child’s best interests. Likewise, in \textit{The Chief Executive of the Ministry of Social Development v Bates} there was no indication of whether the competence of a 10-year-old girl had been assessed or consideration given to her evolving capacity.\textsuperscript{212} Her parents had not appropriately addressed her medical condition of congenital nephrotic syndrome that causes significant loss of protein and swelling in the face or lower legs, and gives rise to higher risks of infections. The child’s views were not considered, as lawyer for child had been unable to meet with her. Her mother’s evidence was that her daughter was opposed to treatment, but the doctor conveyed that during treatment there was “no noticeable objection.”\textsuperscript{213} Given that the doctor was able to so report, the Court could have made inquiry of what information she had received, of her understanding and whether she was competent.

Thus, the New Zealand courts have considered, followed and applied Gillick in an ad hoc manner, resulting in children’s potential competence and right to consent sometimes being overlooked. When courts have considered competence, account is taken of the information children have received, their understanding and abilities to weigh up risks, their age, experience and acceptance of their health conditions.

\textbf{B. The Scope of Parents’ Rights to Give or Refuse Consent}

The most authoritative precedent on the nature and limits of parental authority was from the Court of Appeal in \textit{Re J}.\textsuperscript{214} In delivering the judgment Gault, J not only recognised Gillick as applicable in New Zealand, but also confirmed that parents have responsibilities towards their New Zealand, as well as rights, stating:\textsuperscript{215}

\begin{itemize}
\item [\textsuperscript{209}] At [16].
\item [\textsuperscript{210}] For example, \textit{Auckland District Health Board v E} [2013] NZFLR 451; \textit{Waikato District Health Board v L} [2008] 27 FRNZ 596; \textit{Auckland District Health Board v Z} [2007] 26 FRNZ 596; \textit{Paddy v L} [1994] NZFLR 352; and \textit{Director-General of Social Welfare v M} [1991] 8 FRNZ 498, where each child was four years old or younger and required treatment or surgery against their parents’ refusal on religious or cultural grounds.
\item [\textsuperscript{211}] \textit{Waikato District Health Board v FF and MM}, HC Hamilton CIV 2008-419-001471, 5 December 2008.
\item [\textsuperscript{212}] \textit{The Chief Executive of the Ministry of Social Development v Bates}, [2014] NZFC 5554.
\item [\textsuperscript{213}] At 47.
\item [\textsuperscript{214}] \textit{Re J}, above n 8. This case involved a three-year-old whose parents refused to consent to a blood transfusion due to their religious beliefs.
\item [\textsuperscript{215}] At 145. Subsequent High Court authority have followed this approach: \textit{L v A} (2003) 23 FRNZ 583 followed \textit{P v K} (2003) 23 FRNZ 677; and \textit{Hawthorne v Cox}, above n 9 followed \textit{Auckland District Health Board
The upbringing of children extends to making decisions for them as to health and medical treatment. That is a right long recognised under the common law in any event: *Gillick v West Norfolk AHA* [1986] 1 AC 112 though, as that case makes clear, it was never absolute. As was pointed out particularly by Lord Scarman … the scope of parental rights is reflective of parental duties towards children.

Continuing this child-centred view of guardianship, the High Court in *Hawthorne v Cox*, confirmed the yielding nature of parental involvement in children’s decision-making as they develop and mature:

The dual focus on determination and assistance in s 16(1)(c), coupled with the general policy shift towards a more child-centred approach to guardianship, reflects the concept applied in *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112; [1985] 3 All ER 402 (HL). … Put in those terms, the Act is consistent with the philosophy underpinning *Gillick*, namely that a parent's interest in the development of his or her child does not amount to a “right” but is more accurately described as “a responsibility or duty”. The terms of s 16 itself reflect that proposition.

The extent of parental authority and how it is balanced with children’s rights to participate and consent/refuse are issues with which the courts have grappled. This was highlighted in the three high profile cases of Liam Williams-Holloway (Liam), Tovia Laufau (Tovia) and Caleb Moorhead (Caleb), who all died when their parents refused treatment.

### 1. Liam Williams-Holloway

Liam died from a cancerous tumour on his jaw in 2000 aged five and a half years old, following his parents refusing conventional treatment, preferring alternative methods in Mexico. They evaded Court orders for wardship, custody and a warrant to enforce the custody order by going into hiding for four months, orders that the Court had granted in an effort of protect Liam’s welfare, best interests and right to life. In making Liam subject to a wardship order under the Guardianship Act 1968, the Court followed the evidence from medical experts that with intensive chemotherapy Liam would have a 50% chance of survival, but without it, he would die. The case attracted significant media attention, which was later controlled by a Court order, restricting further publicity. After four months, with no success of locating Liam’s parents, the Court discharged the

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\(^{216}\) *Hawthorne v Cox*, above n 9 at [57] and [61] per Health J. This case involved an application for a 16-year-old girl to be placed under the guardianship of the Family Court and did not consider medical decisions or competence of children under the age of 16 years.

\(^{217}\) Martin Johnston and Francesca Mould, “Little Liam’s battle ends” The *New Zealand Herald* (New Zealand, 28 October 2000) at 1.


\(^{219}\) At 806.

\(^{220}\) At 804.

\(^{221}\) Healthcare Otago Limited v Williams-Holloway, above n 218.
orders upon an application by Healthcare Otago, as “the likelihood of conventional medical treatment being able to provide benefit to Liam [had] diminished to the point where the application of further public funds towards this end cannot be justified.”

When Liam died he was described by the media as having become “a national symbol of the tug-of-war between conventional medicine and controversial alternative therapies, and that “[h]is plight also plunged the nation into debate on the rights of parents to decide treatments for their children.” This divergence of views is reflected to some extent by oncologist, Rob Corbett, who was reported as being of the view that their decision was “illogical”, and that Liam died because of his parents’ choice, and the then Children’s Commissioner, who sympathised with his parents, stating: “His mum and dad did the best they could. They did what they felt compelled to do, and that’s what any parent would do.”

2. **Tovia Laufau**

Contrastingly, in 1999/2000 Tovia’s parents were charged, prosecuted and found guilty of failing to provide him with the necessaries of life, when Tovia, aged 13 years, died from a cancerous tumour (osteosarcoma) on his knee, after he refused to attend hospital. The jury decided that Tovia had not been competent to make his own decision, and thus it was the responsibility and duty of his parents to ensure he received potentially life-saving treatment. Giving evidence as a defence witness, Dr Peter Watson, from the Centre for Youth Health in South Auckland, stressed the shared responsibility amongst health professionals and families in managing young people’s needs, believing that in this case the health system had failed him. He is reported as saying:

This young man and other young people before him and subsequently in the future, I believe, have and will suffer - not only suffer but also die - from the failure of the health system to recognise the unique needs of young people in our hospitals and provide appropriate services for them. I think it is also a tragedy for this family and would hope that no other family ever has to be put through this experience when there is such an evident failure of the health system.

Dr Watson is reported also as saying that ‘the medical world was full of jargon’ and that:

… it was critical for families to understand exactly what was being said at stressful times when bad news about complex issues was being given, especially when it was in a foreign language and in a "foreign" environment.

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222 At 813. At 814 the Court acknowledged the efforts of health professionals to work and compromise with Liam’s parents.

223 Johnston and Mould, above n 217 at 1.

224 At 1.

225 At 1.

226 Crimes Act 1961, s 151.


228 At 1.
Nevertheless, when sentencing Tovia’s parents, Potter J emphasised the sanctity of life, and the responsibility of parents to protect children’s lives, at times overruling their objections, when they lack maturity to make life or death decisions: 229

The duty the law imposes on parents and caregivers is greater and stronger than the wishes of their children, no matter how sincerely and strongly they might be expressed, and no matter how strong may be the wish or will of the parents to accede to the child’s bidding. It is one matter for an adult person with full mental faculties to exercise a right to elect not to undergo medical treatment. It is quite a different matter for the parents or caregivers of a child who carry the legal duty and responsibility to ensure that child has the necessaries of life, to determine that the child shall not have medical treatment when medical treatment is necessary to protect his life.

However, illogically, although the State condemned Tovia’s parents after his death, it had not sought any protective court orders for Tovia. Professor Henaghan believed that this may have been due to doctors probably not wanting to risk public backlash in light of the public’s response to Liam’s situation. 230

3. Caleb Moorhead

In 2002, public sympathy swung away from the rights of parents and towards children’s protection, with the death of Caleb. The media attention centred on the preventable damage to Caleb and the extreme beliefs of his parents, 231 raising general questions of whether in such cases doctors should be making applications to court. 232 Caleb’s parents were found guilty of manslaughter, and sentenced to five years imprisonment, for killing him by failing to provide him with medical treatment in the form of vitamin B12, due to their religious beliefs. 233 Their conduct was at the extreme end of negligence, justifying the severe conviction.

Yet the efforts of the State to protect Caleb were not commensurate with public opinion. More significant efforts had been made to protect Liam, by way of court orders, than either Tovia or Caleb. Whilst the ripples of public opinion may have resulted in a reluctance to proceed to court for Tovia, it is unlikely that this was the situation for Caleb. Clearly, an application to protect Caleb should have been made. There was no difference in the stance of Caleb’s parents and that of parents who refuse blood products for their children, due to their religious beliefs. There is an established line of New Zealand case law protecting children’s lives in such situations by overriding parental

229 R v Laufau, HC, Auckland, T 000759 2 October 2000, at [15].
231 For example Tony Stickley “Parents of baby Caleb found guilty of manslaughter” The New Zealand Herald (online ed New Zealand, 5 June 2002).
232 Bridget Carter and others “Science, religion and a dying baby” (The New Zealand Herald (online ed New Zealand, 6 June 2002).
rights, the leading authority being Re J. Nonetheless, each case must stand on its own facts to evaluate the welfare and best interests of children, as Baragwanath, J acknowledged in Auckland District Health Board v Z.

... an unblinkered approach must be taken by the Court in accepting its solemn responsibility in such cases. While continuation of life is of great importance it is not necessarily conclusive; quality of life must also be considered. There must be a meticulous evaluation of the interests of the child, viewed broadly, and of that alone.

One aspect of those broad interests is the importance of the family, and parental support, through the treatment process, as was identified by both Tompkins, J in Re Norma and Baragwanath, J in Auckland District Health Board v Z. Tompkins J, in considering whether to order chemotherapy against the cultural practices and beliefs of the family, stated:

A child's welfare is also bound up with his or her family. If a course of action is likely to cause serious distress and disruption within a family, that too is a factor that must bear on the welfare of the child and therefore weigh with the Court.

Therefore, in terms of the law, the matter is relatively clear when parents’ decisions are contrary to what health professionals regard as protecting children’s welfare:

1. The paramount concern of the court is the welfare and best interests of children, including the protection of their right to life.
2. Parental rights to refuse medical treatment and their right to follow their religion are curtailed when it compromises this right.
3. However, courts will consider all the facts and circumstances before making their decision, including any likely adversity to children resulting from treatment being ordered.

The complexity for judges is in the weighing up of competing factors in the assessment of children’s welfare and best interests. Also, for health professionals, there is a layer of

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234 Re J, above n 8. The Court balanced the child and parents’ respective rights, concluding that the paramount concerns are the welfare of the child and his right to life, which limits parental authority to refuse medical treatment on the grounds of their religion. At 146 per Gault J: “The parents’ right to practice their religion cannot extend to imperil the life or health of the child. … Indeed acting in accordance with such a right would be a criminal offence under s 151 of the Crimes Act 1961. … We define the scope of the parental right under s 15 of the Bill of Rights Act to manifest their religion in practice so as to exclude doing or omitting anything likely to place at risk the life, health or welfare of their children. In the present context that is consistent also, in the circumstances of this case, with giving effect to s 23 of the Guardianship Act by recognising the paramount interests of the child.” See also Re Ulutau (1989) 5 NZFLR 631 where this protection extended to a baby in utero.

235 Auckland District Health Board v Z, above n 210 at 602 per Baragwanath, J.

236 Re Norma (1991) 8 FRNZ 498.

237 Auckland District Health Board v Z, above n 210 at [24] per Baragwanath, J.

238 Re Norma above n 236 at 504 per Tompkins J.
complexity in trying to maintain channels of communication and trust with families to prevent the necessity of such court action.\textsuperscript{239}

Thus, as Liam and Caleb were too young to be competent and the court deemed Tovia incompetent, the question remains unanswered as to whether competent children have the right to refuse consent to medical treatment.\textsuperscript{240}

\textbf{IV. Professional Guidance}

Professional regulatory bodies who are responsible for maintaining professional standards and competence, such as the Medical, Dental and Nursing Councils, provide advice to health professionals to which they are responsible in the form of guidance, guidelines or codes. This section considers the guidance they provide on informed consent.

\textbf{A. Medical Council of New Zealand (Medical Council)}

The Medical Council’s advice to its members reinforces their duty to abide by the Code, and that under the Code every patient has the right to make an informed choice and consent to medical treatment.\textsuperscript{241} Further, it reminds doctors of their responsibility to obtain informed consent from the patient before initiating treatment,\textsuperscript{242} including from competent children:\textsuperscript{243}

People under 16 years of age are not automatically prohibited from consenting to medical, surgical or dental procedures so judgement of the patient’s competence to make an informed choice and give informed consent is needed in each instance.

Citing \textit{Gillick} as authority, the Medical Council advises doctors to:\textsuperscript{244}

\begin{quote}
\ldots assess a child’s competency and form an opinion on whether he or she is able to give informed consent. Generally, a competent child is one who is able to understand the nature, purpose and possible consequences of the proposed investigation or treatment, as well as the consequences of non-treatment.
\end{quote}

It concludes that when children are competent, parental consent is not always necessary, and that until there is clear legislation \textit{Gillick} should be followed, which is consistent with

\textsuperscript{239} New Zealand Herald, above n 227 at 1. It appears that from the evidence of Dr Watson a significant factor contributing to Tovia refusing medical treatment was the breakdown in communication and trust.
\textsuperscript{240} Indications of how other jurisdictions have handled this dilemma is given in the following Chapter 4.
\textsuperscript{241} Medical Council of New Zealand “Information, choice of treatment and informed consent” (Medical Council of New Zealand, March 2011) at [5]-[13].
\textsuperscript{242} At [14].
\textsuperscript{243} At [27].
\textsuperscript{244} At [28].
the Code.\footnote{245}

**B. Dental Council of New Zealand (Dental Council)**

The Dental Council updated their ‘Informed Consent Practice Standard’ (the Standard) in May 2018, having first undertaken a consultation process with stakeholders between November 2017 and February 2018.\footnote{246} The Standard provides direction on the criteria for competence, the informed consent process, and children’s rights to consent to, or refuse, dental treatment. It advises that competence assessments relate to patients’ understanding and decision-making processes, relative to the complexity of the treatment.\footnote{247} Further, in emphasising that informed consent is a process rather than simply the act of signing a form, the Standard guides practitioners on the requirements for effective communication, necessary information and giving competent consent freely.\footnote{248} The Standard further confirms that in respect of obtaining consent, it should be sought from competent children, and whilst parents do not require to also provide their consent, practitioners should continue to involve them in the process.\footnote{249}

**C. Nursing Council of New Zealand (Nursing Council)**

Whilst there is no specific mention of children in the Nursing Council Code of Conduct, two of its four values underpinning it are to treat health consumers and their families with respect, and to work in partnership with health consumers. In respect of the latter value this includes giving patients sufficient and understandable information in order that they can make an informed choice.\footnote{250}

**D. District Health Board Policies (DHB policies)**

Some health professionals are subject to another layer of regulation on informed consent through DHB policies. There are 20 DHBs in New Zealand, each with its own Board responsible for strategic direction and monitoring staff performance, and with its own policy.\footnote{251} There are contradictions within and between some policies, with some...
appearing to be inconsistent with the law. For example, Canterbury DHB’s Policy on Informed Consent dated June 2015 refers to the Guardianship Act 1968, despite the passing of the COCA in 2004.\textsuperscript{252} Also, although it states that there is no age for giving informed consent, it directs that parental consent is required, with the child being involved as much as possible and agreement sought where possible.\textsuperscript{253} This policy does indicate that it would be reviewed in June 2016, and whilst it may have been updated, it did not reflect the law of its time, nor has any subsequent policy been made public.

On the other hand, Waikato DHB’s policy dated 1 June 2017 states that competence is not linked to age and that consent of a guardian is not required when children are fully competent to consent to treatment.\textsuperscript{254} Similarly, Capital and Coast DHB’s policy, “Informed consent- adults and children”, considers the legal provisions under the COCA and the Code, advising that competence is not defined by age, although is one relevant factor, together with understanding, maturity and the gravity of the treatment.\textsuperscript{255}

Thus, such policies add further complexity, confusion and uncertainty for health professionals, children and parents when they are not consistent with the law. Nevertheless, it is challenging to provide clear and certain direction, due to the law’s lack of clarity.

\section*{V. Chapter Summary}

The law on children’s rights to consent to, or refuse, medical treatment at best can be described as piecemeal. Regardless of the reasons, Parliament chose not to clarify the position in the COCA. By piecing together the COCA with other statutory provisions, and the common law, they confirm collectively that children do have the right to consent when competent, independently of their parents. Children’s right to refuse treatment is even more uncertain, with there being conflicting indications from courts, and nothing definitive. Nonetheless, by combining the NZBORA, \textit{Gillick}, the Court’s consideration of Tovia’s competence to refuse treatment, and the lack of distinction in the law between consent and refusal, they point to competent children having the right to refuse treatment. However, until there is a statutory provision, or a court decision that specifically considers the right of a competent child to refuse treatment, doubt will remain.

Equally imprecise is the law on assessing competence. \textit{Gillick} established the benchmark for competence, but the courts have applied it in an ad hoc way. There is a lack of logical process or enquiry when approaching cases involving children and medical consent. Courts do not as a matter of course make enquiry into children’s competence. Further,

\begin{footnotesize}
\begin{itemize}
\item\textsuperscript{252} Canterbury District Health Board, “Informed Consent” (June 2015) at 16 <www.cdhb.health.nz>.
\item\textsuperscript{253} At 17.
\item\textsuperscript{254} Waikato District Health Board, “Informed Consent Policy” (1 June 2017) at [5.1] <www.waikatodhb.health.nz>.
\item\textsuperscript{255} Capital and Coast District Health Board “Informed consent-adults and children” (14 July 2010) at 21 <www.ccdhb.org.nz>.
\end{itemize}
\end{footnotesize}
when they do, it is often unclear what factors they believe are relevant for its assessment.

This lack of clarity in New Zealand’s law leads me to explore the position of other countries, specifically the laws of Australia, England and Scotland.
Chapter 4

Children Consenting/Refusing Medical Treatment: An International Comparison of the Laws of Australia, England/Wales and Scotland

I. Introduction

Australia, England and Scotland have either adopted Gillick into statute or through case law. Despite this commonality, each country’s laws have evolved in very different ways. Australian law in this area is mostly regulated by the common law, with much of its focus on ‘special medical procedures’, particularly those for transgender young people. English case law, on the other hand, has differentiated between the rights to consent to, and refuse, medical treatment, developing different competence criteria for each; whilst Scotland enacted Gillick into the ALCSA and has virtually no case law. This chapter will examine each country’s regulation of children’s rights to consent to, and refuse, medical treatment in both statute and case law, highlighting also their criteria for establishing competence.

II. Australian Law

A. Legislation

South Australia (SA) is the only state with legislation providing for children giving consent to medical treatment. Young people of 16 years and over are presumed competent and may make treatment decisions, whilst younger children may consent if three criteria are met: (i) the administering medical practitioner deems them Gillick competent; (ii) the treatment is in their best interests; and (iii) the opinion is supported by the written opinion of at least one other medical practitioner who personally examines the child.

In New South Wales (NSW), although The Minor (Property and Contracts) Act 1970, section 49(2), provides for children of 14 years and over being capable of consenting, the provision does not confer the right to consent, and fails to specify criteria for competence. Rather, it protects health professionals from claims of assault and battery.

256 Consent to Medical Treatment and Palliative Care Act 1995, s 6.
257 Consent to Medical Treatment and Palliative Care Act 1995, s 12 “ A medical practitioner may administer treatment to a child if (a) the parent or guardian consents; or (b) the child consents and (i) the medical practitioner who is to administer the treatment is of the opinion that the child is capable of understanding the nature, consequences and risks of the treatment and that the treatment is in the best interest of the child’s health and well-being; and (ii) that opinion is supported by the written opinion of at least one other medical practitioner who personally examines the child before the treatment is commenced.”
when they rely upon their consent. Yet, in 2008, the NSW Law Commission reported and recommended a new statutory framework, giving competent children and young people the right to consent to, and refuse, health care independently of their parents. It suggested a presumption of competence for over 16-year-olds, and a competence test for those under 16 years based on understanding information relevant to making the decision and its consequences, similar to the criteria in *Gillick*. Despite these recommendations, NSW chose to leave the matter to the common law.

Adding to the legal complexity, all Australian States have legislation that defines a minor as aged under 18 years, after which competence is presumed. This demarcation may produce some confusion for medical professionals. For example, The Queensland Law Handbook, ‘Medical Treatment for Children’, states:

Some medical practitioners take the view that a person of 16 years or older is assumed to have full capacity to consent, and therefore the consent of a parent or guardian is unnecessary. Other doctors and hospitals take a more conservative approach and assume that only a person of 18 years or over can be considered to have such capacity.

However, having adopted *Gillick* into the common law, children under 16 years may be competent to give medical consent. Thus, to gain a sense of how Australia has applied *Gillick*, Australia’s significant cases are now considered, in particular, in the context of gender dysphoria, where there is a significant line of authority.

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258 The Minor (Property and Contracts) Act 1970, s 49(2): “Where medical treatment or dental treatment of a minor aged fourteen years or upwards is carried out with the prior consent of the minor, his or her consent has effect in relation to a claim by him or her for assault or battery in respect of anything done in the course of that treatment as if, at the time when the consent is given, he or she were aged twenty-one years or upwards.”


260 At recommendation 6.

261 At recommendation 5.

262 Age of Majority Act 1977 (Vic) s 3; Age of Majority (Reduction) Act 1971 (SA) s 3; Age of Majority Act 1972 (WA) s 5; Age of Majority Act (NT) s 4 (The name of this Act does not have a year but is in force as at 1 April 1981); Law Reform Act 1995 (Qld) s 17; Age of Majority Act 1974 (ACT) s 5; Minors (Property and Contracts) Act 1970 (NSW); and Age of Majority Act 1973 (Tas) s 3.


264 Secretary, Department of Health and Community Services v JWB and SMB [1992] 175 CLR 218 (‘Marion’s Case’). Complexity is added when considering abortion and contraception, as there are no separate laws governing the right of children to consent to abortion in any Australian state. In some states it is illegal and governed by the criminal law, for example, Criminal Code 1899, ss224-226 (Qld) and NSW Crimes Act 1900, ss82-84, whilst in others abortion is lawful and privacy is protected, such as Abortion Law Reform Act 2008 and Public Health and Wellbeing Amendment (Safe Access Zones) Act 2015 (Vic). Similarly, there are no specific laws relating to prescribing contraception for children, and it is dependent upon the common law *Gillick* competence test. However, there are inconsistencies in practice, for example, in The Queensland Handbook “Children, sex and contraception” it states that “[s]ome doctors will refuse to give contraceptive advice or prescribe oral contraceptives to unmarried minors without parental consent. However, advice and prescriptions for contraceptives are usually available from offices of the Family Planning Alliance Australia.”
B. Case Law on Competence to Consent

1. Secretary, Department of Health and Community Services v JWB and SMB (Marion’s case)\(^{265}\)

This seminal decision of the Australian High Court marked the acceptance of *Gillick* into Australian law, although Marion, the child of this application, would never become competent herself, due to severe intellectual and physical disabilities. Marion’s parents had applied to the Family Court in North Territory for either an order allowing her to have a hysterectomy and an ovariectomy, or a declaration that it would be lawful for them to consent to those procedures. The rationale was to prevent pregnancy and menstruation, and stabilise her changing hormones.\(^{266}\) In delineating the powers between parents and the State, the majority confirmed that a decision to sterilise another person is beyond the scope of parental power in “non-therapeutic” situations, as a “procedural safeguard”,\(^{267}\) as opposed to in “therapeutic” situations. The Court defined therapeutic sterilisation as being a “by-product of surgery appropriately carried out to treat some malfunction or disease”, and by default, “non-therapeutic” must be all other circumstances.\(^{268}\) The Court was reluctant to make this delineation because of

\(^{265}\) *Marion’s case*, above n 264. At 232 per Mason CJ, Dawson, Toohey and Gaudron JJ *Gillick* competence was described as a “threshold”, and at 237-8 per Mason CJ, Dawson, Toohey and Gaudron JJ considered that the *Gillick* approach, “though lacking the certainty of a fixed age rule accords with experience and with psychology.”

\(^{266}\) The Family Court of Australia has jurisdiction to intervene to make orders relating to children’s welfare, in their best interests, under Family Law Act 1975, s 67ZC: “Orders relating to welfare of children

- In addition to the jurisdiction that a court has under this Part in relation to children, the court also has jurisdiction to make orders relating to the welfare of children. (2) In deciding whether to make an order under subsection (1) in relation to a child, a court must regard the best interests of the child as paramount consideration.” Courts have separated ‘special medical procedures’ from ordinary parental rights, and these are the responsibility of the State. Generally, these involve medical procedures or interventions in which the proposed procedure is:

- invasive, permanent and irreversible;
- ‘non-therapeutic’, that being, not for the purpose of curing a malfunction or disease;
- there is a significant risk of making the wrong decision, either as to a child’s present or future capacity to consent or about what are the best interests of a child who cannot consent; and
- the consequences of a wrong decision are particularly grave.

For example non-therapeutic sterilisation of a young person with intellectual disabilities (*Marion’s case*, above n 255); stage two treatment for gender identity disorder (*Re Jamie* [2013] 278 FLR 155); and sex reassignment surgery (*Re Alex* [2009] 248 FLR 312).

\(^{267}\) At 219. The Court, with the exception of Deane J, held that parents could never consent to sterilisation for non-therapeutic purposes. At 305 Deane J would have allowed parental consent for non-therapeutic sterilisation only in a narrowly-defined set of circumstances, namely: (i) where the child is so profoundly intellectually disabled that she will never be able to have a mature human relationship involving informed sexual intercourse, of responsible procreation or of caring for an infant; (ii) where the surgery is necessary to avoid grave and unusual problems and suffering associated with menstruation; (iii) where the surgery is a treatment of last resort; and (iv) where there is medical advice from a multidisciplinary team acting on the basis of appropriate reports.

\(^{268}\) *Marion’s case*, above n 264 at 249 per Mason CJ, Dawson J, Toohey J and Gaudron J.
uncertainty, but considered it necessary to make it “however unclear the dividing line may be.” The Court’s concern over sterilisation, as opposed to other forms of invasive surgery, was:  

... the significant risk of making the wrong decision, either as to a child’s present or future capacity to consent or about what are the best interests of a child who cannot consent, and secondly, because the consequences of a wrong decision are particularly grave.

The Court’s concerns mainly lay in protecting children’s vulnerability from the potential power of both the medical professional and parents:  

Children with intellectual disabilities are particularly vulnerable, both because of their minority and their disability, and ... there is less likelihood of (intentional or unintentional) abuse of the rights of children if an application to a court is mandatory, than if the decision in all cases could be made by a guardian alone.

Their unease of the medical profession lay in two areas: (i) of children’s competence being inaccurately assessed, or assumptions being made, due to disabilities; and (ii) having a purely clinical view of the procedure, rather than viewing it in a wider context of social and psychological consequences. Their concern of parents related to possible conflicting interests.

Although the question of Marion’s competence was not central to this decision, Marion’s case would become the cornerstone of the law on the assessment of children’s competence, and as will be seen when considering Re Jamie, became its limiting factor. However, before examining Re Jamie, the issue of assessing children’s competence was considered in Re Alex. The dilemmas for the Court were the process for assessing competence and who should bear that responsibility.

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270 At 250 per Mason CJ, Dawson J, Toohey J and Gaudron J.
271 At 250 per Mason CJ, Dawson J, Toohey J and Gaudron J.
272 At 250 per Mason CJ, Dawson J, Toohey J and Gaudron J.
273 At 250-253 per Mason CJ, Dawson J, Toohey J and Gaudron J. They desired also to protect the potential right of children to give informed consent.
274 At 253 per Mason CJ, Dawson J, Toohey J and Gaudron J.
275 At 250-1 per Mason CJ, Dawson J, Toohey J and Gaudron J.
276 At 251-2 per Mason CJ, Dawson J, Toohey J and Gaudron J. However, at 253 the Court acknowledged the implication of this for parents, and the need for legislative reform: “In saying this we acknowledge that it is too costly for most parents to fund court proceedings, that delay is likely to cause painful inconvenience and that the strictly adversarial process of the court is very often unsuitable for arriving at this kind of decision. These are clear indications of the need for legislative reform, since a more appropriate process for decision-making can only be introduced in that way.” fl
277 Re Jamie, above n 266.
278 Re Alex [2004] 180 FLRJ 89.
2. **Re Alex (2004)**

Alex was 13-years-old at the time an application was made to the Court to enable her to undergo medical treatment and procedures that would change her gender from female to male. Central to the application was the question of Alex’s competence. The Court, following *Gillick* and *Marion's case*, accepted that for children to be competent to consent, they require “sufficient understanding and intelligence to enable him or her to understand fully what is imposed,” and acknowledged the “significant onus” placed upon health professionals in such assessments.

Nicholson CJ relied upon the evidence of Professor P, a university professor in psychiatry; the treating psychiatrist, Mr T, who prepared the family report; and Dr N, Consultant Psychiatrist and specialist in child and adolescent psychiatry when considering Alex’s competence. Collectively, the experts considered that Alex was knowledgeable; had understanding of the treatment, its side effects and benefits; and was mature and intelligent. Dr N highlighted that although Alex held anger and unresolved feelings, that would have a bearing on her capacity to understand treatment, these “should not be seen as contraindications to medical intervention or as impairing [Alex’s] comprehension.” Although Dr N reached no conclusion on Alex’ competence, he was uncertain whether she understood “the full implications of the treatment.” Both Mr T and Professor P agreed “that it [was] not appropriate at age 13 [Alex] should be wholly responsible for the decision to undergo hormone treatment (emphasis added), it being a factor for Professor P that Alex was not in the care of her mother to share that responsibility.” Further, he believed that Alex would be:

... able to make an informed judgment about the procedure and its risk in the foreseeable future but that the urgency of treatment is such that it should begin a soon as possible.

The Court interpreted this evidence as suggesting “that Alex may have *Gillick* capacity or may reach that standard soon”, but at the present time the Court should make the decision. In concluding that Alex was incompetent to make this decision, the Court stated:

It is one thing for a child or young person to have a general understanding of what is proposed and its effect but it is quite another to conclude that he/she has sufficient maturity to fully understand the grave nature and effects of the proposed treatment.

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279 *Re Alex*, above n 278.
280 At [155] per Nicholson CJ.
281 At [155] per Nicholson CJ.
282 At [157] – [167].
283 At [160] per Mr T and [162] – [164] per Professor P.
284 At 118.
285 At [167].
286 At [160].
287 At [160].
288 At [164].
289 At [165].
290 At [168].
During the proceedings the Human Rights and Equal Opportunity Commission (Commission) made written submissions on human rights principles, concluding that in this case if Alex is found to be competent the Court had no role in making the decision:

... the better view - and the view that is most consistent with Re Marion and the principles of international law outlined above - is that a court has no power to override either the informed consent or informed refusal of a competent child to medical treatment, or, if it does have such a power, it should not as a matter of discretion exercise that power except, perhaps, in extreme circumstances. ... It is submitted that if this Court finds that the child has achieved “a sufficient understanding and intelligence” to enable the child “to understand fully what is proposed”, then this Court has no further role in this matter.

Nonetheless, the Court doubted the accuracy of these submissions by focusing on the nature of treatment and age, concluding:

Much will depend upon what it is that is proposed in each individual case. It seems to me that there is a considerable difference between a child or young person deciding to use contraceptives as in Gillick and a child or young person determining upon a course that will “change” his/her sex. It is highly questionable whether a 13 year old could ever be regarded as having the capacity for the latter, and this situation may well continue until the young person reaches maturity.

The Court took account of Alex’s views, her best interests and finality of proceedings, authorising the hormone therapies, but kept the proceedings on foot to enable them to be re-opened if additional orders/interventions were required.

3. Re Alex (2009)

Further court procedure was necessary, and on 11 July 2007, leave was sought from the Court for special medical procedures - bilateral mastectomies and ongoing psychiatric assessment. At the time of the hearing Alex was almost 17 years old. Evidence was adduced from six witnesses: three medical specialists; a member from Alex’s school; his case manager; and the Departmental officer responsible for Alex’s care under the guardianship order. Alex was present at the hearing, and represented by a lawyer, who conveyed Alex’s views. The Court identified three issues to be addressed in the expert evidence, including “Alex’s views and level of understanding about the nature and effect
of the proposed procedure.”299 Despite this, the Court’s enquiry was based upon Alex’s welfare and best interests, rather than on whether he was now Gillick competent.300 Prior to making her decision, Bryant CJ, took regard of, but accorded relatively little weight to, the submissions made by the Commission in the earlier hearing, which included the issue of whether a child could give informed consent to the contemplated medical procedures.301 Although no evidence was adduced, and no submissions made on this issue, the Court went on to consider it, due to its: 302

… special importance in the circumstances of this case and in light of Alex’s age, the strength of his views and the greater recognition that is being accorded in the international law community to the right of children to exercise agency in decisions affecting them.

In weighing up Alex’s competence, the Court had regard to his experience and impact of treatment since 2004; age and maturity; understanding of the process; weighing up of the advantages and disadvantages of the procedure; initiative in undertaking research on it; consistent and unwavering view of being male; and his developmental capacity for decision-making.303 The Court concluded that Alex was “an intelligent, thoughtful, reflective and creative young person with well developed adaptive skills,”304 and as such it was “not satisfied that Alex is not Gillick competent and therefore unable to himself consent to the surgery.”305 Bryant CJ, however, avoided making a positive finding of Alex being competent, due to an absence of submissions from the parties and Counsel.306 She stated that this “was not an issue identified and thus not one upon which I sought evidence to be adduced.”307 The Court considered that the most appropriate way to proceed was: 308

… to adopt the same approach as that of Nicholson CJ in the earlier proceedings, which is to take the view that the issue of Gillick competence is academic unless I intend to make orders not permitting the procedure. Alex’s maturity and likely Gillick competence however provide further support for the orders I made.

Clearly, given that the Court had identified Alex’s understanding as an issue, his level of competence was, or should have been, argued and decided upon. Instead, the Court, in my view, took a glib, or unnecessary tentative approach to Alex’s competence, which lacked respect for it, avoiding the real issues of whether Alex was competent and

299 At [23].
300 At [44] for example, during the expert medical evidence, Bryant CJ stated “I then articulated my main concern, that being the benefit to Alex of the surgery being performed before he turns 18 years of age.”
301 At [111].
302 At [138].
303 At [141]-[146].
304 At [174] Alex is described as “an intelligent, sensitive, thoughtful and good-humoured young man of considerable maturity and perception.”
305 At [147].
306 At [147].
307 At [138].
308 At [147].
therefore could consent to the proposed treatment.\textsuperscript{309}

Thus, the Court in both \textit{Re Alex} decisions was reluctant to accept that children could possess the requisite level of understanding and intelligence to be competent to consent to such life changing procedures. Naturally, a high level of competence is needed for the serious and complex nature of treatment, but there was nothing in the competence assessments that would have led the Court to conclude that he did not possess the requisite level of understanding, and gave no specific indication of what he lacked. The effect of these decisions was to restrict the parameters of \textit{Gillick}, by considering that some treatments are beyond the competence, and therefore rights, of children to consent.

\section*{4. \textit{Re Jamie} (2013)\textsuperscript{310}}

The extent of parental authority to consent to stages one and two of hormone treatment for gender identity disorder was the subject of appeal in \textit{Re Jamie}, when Jamie was almost 11-years-old.\textsuperscript{311} A Full Court of the Family Court confirmed that stage one treatment was within parental responsibilities and was therapeutic treatment, as defined in \textit{Marion's case}. In giving the leading judgment, Bryant CJ widened the definition of therapeutic treatment to include psychiatric disorders, as “the question is whether the treatment relates to a disease or malfunctioning of organs, including psychological or psychiatric disorders.”\textsuperscript{312} She concluded:\textsuperscript{313}

\begin{quote}

... stage one treatment of childhood gender identity disorder is reversible, is not attended by grave risk if a wrong decision is made, and is for the treatment of a malfunction or disease, being a psychological rather than physiological disease. As such, and absent controversy, it falls within the wide ambit of parental responsibility reposing in parents when a child is not yet able to make his or her own decisions about treatment.
\end{quote}

However, in distinguishing stage two treatment, due to its irreversibility, the Court held that this remained under its authority, unless the child was competent to consent.\textsuperscript{314} In considering competence, Bryant CJ stated:\textsuperscript{315}

\begin{quote}

In my view, it would be contrary to the \textit{Convention on the Rights of the Child}, and to the autonomous decision-making to which a \textit{Gillick} competent child is entitled, to hold that there is a particular class of treatment, namely stage two treatment for childhood gender identity disorder, that disentitles autonomous decision-making by the child, whereas no other medical procedure does. The High Court in \textit{Marion's case}, adopting the formulation
\end{quote}

\textsuperscript{309} At [150] the Court’s concluded that permission was required for a bilateral mastectomy, as this procedure fell outside of the normal exercise of parental responsibility. The Court had regard to “the interventionist nature of the procedure, its irreversibility, [and] the risks that attend any form of surgery (however minor).”

\textsuperscript{310} \textit{Re Jamie}, above n 266.

\textsuperscript{311} The trial judge, Dessau J in \textit{Re Jamie} [2011] FamCA 248 had provided authorization in relation to stage one treatment, which was entirely reversible, but not in relation to stage two, which is normally commenced at 16 years and was only reversible with surgical intervention.

\textsuperscript{312} \textit{Re Jamie}, above n 266 at [98].

\textsuperscript{313} At [107]-[108].

\textsuperscript{314} At [140]. Court intervention may be required if there is dispute over treatment or competency.

\textsuperscript{315} At [134]-[135].
in *Gillick*, held at 237 that a child is capable of giving informed consent when he or she “achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed”. I see no basis for reading this down because the treatment is for childhood gender identity disorder. Indeed, one might think that, of all the medical treatments that might arise, treatment for something as personal and essential as the perception of one’s gender and sexuality would be the very exemplar of when the rights of the *Gillick*-competent child should be given full effect.

Despite this appearance of following *Gillick*, the Court reneged from fully respecting children’s competence and autonomy by creating a further legal barrier, albeit reluctantly. The Court concluded that competence assessments were required to be made by it, even when the treating doctors and parents agreed.\textsuperscript{316} Although Finn J acknowledged the implications of costs and stress to the child and parents, the Court believed it was bound by the High Court decision of *Marion’s Case*, in which:

\[\ldots\] the majority held that court authorisation was required first because of the significant risk of making the wrong decision as to a child’s capacity to consent, and second because the consequences of a wrong decision are particularly grave.”\textsuperscript{317}

Court intervention was further justified when conflict existed, regardless of children’s competence, with the Court considering its role to be more than assessing and determining children’s competence, but also making decision’s in children’s best interests.\textsuperscript{318}

\[d) \text{ If the child is } *Gillick* \text{ competent, the child can consent to the treatment and no court authorisation is required, } \textit{absent any controversy}; \textit{(emphasis added)} \ldots\]

\[f) \text{ If there is a dispute between the parents, child and treating medical practitioners, or any of them, regarding the treatment and/or whether or not the child is } *Gillick* \text{ competent, the court should make an assessment about whether to authorise stage two having regard to the best interests of the child as the paramount consideration. In making this assessment, the court should give significant weight to the views of the child in accordance with his or her age or maturity.}\]

Thus, the court is acting as gatekeeper to stage two hormone treatment. Regardless of whether a child is competent or not the Court retains control: it determines whether children are competent to consent, and if not, it decides whether to consent; and by focusing on the outcome of stage two treatment, it being irreversible, the Court deemed this treatment outside of parental authority.

\textsuperscript{316} At [137]-[138].
\textsuperscript{317} At [137].
\textsuperscript{318} At [140].
5. Re Jamie (2015)¹⁹

A further application was filed to the Family Court on 28 May 2015, when Jamie was 15-years-old, seeking confirmation of her competence to consent to stage two treatment. The court found Jamie to be competent, accepting the unchallenged evidence of Dr T, head of the hospital’s Gender Dysphoria Service; Associate Professor P, child and adolescent psychiatrist; Jamie’s parents; and Jamie, by way of letter. Thornton J, in applying Gillick, took account of her intelligence; understanding over a number of years; consistent views; the questions she asked health professionals; her evolving independence; and her appreciation of the potential consequences, including infertility.²⁰ The Court was satisfied that Jamie was competent “to fully understand the nature and consequences of the treatment described in the application and to make her own decision in relation to that treatment.”²¹ The Court considered that having found Jamie to be competent, there was no requirement to make a declaration of competence to consent.

6. Post Re Jamie

Marion’s case and Re Jamie created confusion and uncertainty on the role and powers of the Australian courts, resulting in variations in approaches. Commonly, applications requested courts to make declarations of competence, and in the alternative, to authorise treatment on the basis of children’s best interests. Some judges simply made findings of competence, then dismissed the application, as occurred in Re Jamie;²² others made orders declaring competence;²³ whilst some also found treatment to be in young people’s best interests.²⁴ It was not uncommon for some judges to cover all bases, by indicating that in the event that they are wrong about their decision on competence,²⁵ or that a finding of best interests is also required,²⁶ then treatment is found to be in young people’s best interests.²⁷ For example, Austin J in Re Jacinta was strongly of the opinion that orders required to be made, as it would be “absurd for the Court to make no orders at all”, leaving health professionals without clear answers.²⁸

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¹⁹ Re Jamie [2015] FamCA 455.
²⁰ At [81]-[82] per Thornton, J.
²¹ At [81] – [82] per Thornton, J.
²² For example Re: Julian [2017] FamCA 621; Re: Mason [2017] FamCA 453; Re Logan [2016] FamCA 87
²³ For example Re: Pat [2017] FamCA 418.
²⁴ For example in Re Tahilia [2017] Fam CA 715 the Court made a declaration of competence and found that such a declaration was in the young person’s best interests.
²⁵ For example, Re Nadia [2017] FamCA 526.
²⁶ For example, Re Jaden [2017] FamCA 269.
²⁷ Re Kelvin [2017] FamCAFC 258 at [51]. Between Re Jamie on 31 July 2013 and 16 October 2017 (shortly before the judgement in Re Kelvin) the Family Court dealt with 63 cases for either stage two or stage three treatment for gender dysphoria, with 62 allowing treatment. The most common outcomes were: declaring a child Gillick competent to consent (26); finding a child is Gillick competent to consent (22); finding competence and making a declaration (7).
²⁸ Re Jacinta [2015] FamCA 1196 at [26].
In 2015 Hon Justice Strickland called for either national or State statutory reform. This call was not responded to, and so in 2017, Watts J in *Re Kelvin* made a stated case to the Full Court - Family Court of Australia (Full Court). The first two questions of six sought clarification on firstly whether the Full Court confirmed its decision in *Re Jamie*, requiring the court’s authorisation for stage two treatment, and secondly whether courts should determine competence, rather than leaving it to health professionals caring for the child. Members of the judiciary, academics, and young people asked a more general question of whether courts have any role to play in young people accessing such treatment, given in almost all cases there is no conflict and no dispute over young people’s competence. For example, after giving his decision in *Re Lucas*, Tree, J made some further observations, describing the role of courts as “administrative sanctioning”, and quoting Lucas’ views, concluded.

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329 Strickland, J “Building bridges: A Multidisciplinary Approach to Family Law To Treat Or Not To Treat: Legal Responses to Transgender Young People Revisited” (paper presented to Association of Family and Conciliation Courts Australian Chapter Conference Sydney, Australia) 14-15 August 2015 at 31.

330 *Re Kelvin* [2017] FamCA 78 at [8]. The six questions in full were:

1. Does the Full Court confirm its decision in *Re Jamie* (2013) FLC 93-547 to the effect that Stage 2 treatment of a child for the condition of Gender Dysphoria in Adolescents and Adults … requires the court’s authorisation pursuant to s 67ZC of the Family Law Act 1975 (Cth) (“the Act”), unless the child was *Gillick* competent to give informed consent to the treatment?

2. Does the Full Court confirm that the Family Court of Australia and not the child’s treating professionals should determine whether a child is *Gillick* competent to give consent to the treatment?

3. If the answer to question 2 is yes, given statements made by the Full Court in *Re Jamie* … if a finding is made that the child was *Gillick* competent to give informed consent to the treatment, should any application for a declaration that the child is *Gillick* competent to give consent to the treatment, be dismissed?

4. In the alternative, if the answer to question 2 is yes, given statements made by the Full Court in *Re Jamie* … if a finding is made that the child was *Gillick* competent to give informed consent to the treatment, should any application for an order authorising the administration of the treatment, be dismissed?

5. If the answer to question 3 is no, given statements made by the Full Court in *Re Jamie*, if a finding is made that the child was *Gillick* competent to give informed consent to the treatment, is the jurisdiction and power of the court enlivened, pursuant to s 67ZC of the Act, to make a declaration that the child was *Gillick* competent to give informed consent to the treatment?

6. If the answer to question 4 is no, given statements made by the Full Court in *Re Jamie*, if a finding is made that the child was *Gillick* competent to give informed consent to the treatment, is the jurisdiction and power of the court enlivened, pursuant to s 67ZC of the Act, to make an order authorising the administration of the treatment? (paragraph 56).

331 For example Felicity Bell “Children with Gender Dysphoria and the Jurisdiction of the Family Court” (2015) 38(2) UNSW Law Journal 426.

332 Of exception was *Re Chelsea* [2017] FamCA 389 in which the court agreed with the second opinion that the 17-year-old was competent.


334 At [68].
… not only is the decision of Re Jamie open to serious doubt, given that it is said that the outcome was required by Marion’s Case, but further, the practical consequences of the decision do not appear to serve any sound policy objective either.

I agree with the view of Tree J in the above case when he states:337

With the greatest of respect to those who discern such a compulsion in Marion’s Case, I regret that it eludes me. Indeed, were I free to decide the matter for myself, I would hold that if the proposed treatment is therapeutic, what Marion’s Case compels is the conclusion that the decision about its administration is within ordinary parental responsibility, and hence no court involvement of any kind is required.

In light of the Court in Re Jamie categorising the treatment as “therapeutic”, it was within the bounds of normal parental responsibilities for parents to consent, where children lacked competence, to consent, and thus no court intervention was necessary. Courts only require to give further consideration to the question of consent for “non-therapeutic” treatment. The implication of Re Jamie’s decision was that stage one treatment was therapeutic, but stage two was non-therapeutic. Inconsistently, the Court in Re Alex regarded the two stages together as “a single treatment plan”, and therefore if that view had been followed, the entire treatment could have been classified as therapeutic.338

Clarification came on 30 November 2017 when the Full Court (five judges) delivered their judgment, answering the first two questions stated by Watts J in Re Kelvin negatively, and therefore the remaining questions were "unnecessary to answer."³³⁹ As a result there is no requirement for courts to act as “a filter” in such cases.³⁴⁰ The Court considered it appropriate to depart from Re Jamie to reflect the current state of the medical knowledge,³⁴¹ and as a consequence no longer viewed this treatment as one which justified court authorisation.³⁴² The result is either competent children, or their parents if not competent, can consent to stage two treatment without an application to the court.

Nevertheless, it is foreseeable that the same legal predicament could result with other

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335 At [54]: “Australia is the only country in the world to have the Family Court process for children under the age of 18 to be able to access cross-hormone treatment. This process is obsolete, there are processes within countries like the USA, or Switzerland, that are more effective, less time consuming and less expensive. I am lucky that I am a patient person who understands that even this system is flawed, it still is a system I must go through. This process of medically transitioning has taken over two years, which is a ridiculous amount of time for any person no matter their age to wait for something so essential to their wellbeing. The suicide rates within the gender community always is at a high due to the external discrimination and marginalisation the community faces. The Family Court process only adds to this in a turmoil. There have been times over the last two years where Dysphoria, frustration and hopelessness has made me feel like I didn’t have control over decision making for my own body and own life. But this frustration and hopelessness is what I have to go through to reach my goal of going on cross-hormone treatment before 18.”

336 At [71].

337 At [66].

338 Re Alex [2004], above n 278 at [186].

339 Re Kelvin [2017] FamCAFC 258.

340 At [119] per Thackray, Strickland and Murphy JJ.

341 At [152] per Thackray, Strickland and Murphy JJ.

342 At [182] per Thackray, Strickland and Murphy JJ.
forms of treatment, as the classification of treatment as “therapeutic” and “non-therapeutic” depends upon “the circumstances surrounding the particular treatment” and “amongst other things, evolving medical science, which, notoriously, occurs at a very rapid pace.”

Further, instead of courts focusing on the children’s processes of decision-making, and rather on the outcome, courts will continue to assess children’s competence to consent to treatment “where there is the significant risk of making the wrong decision and the consequences of a wrong decision are particularly grave.” Yet, if children are unable to assess the risks and understand the consequences then they lack competence, whereas if they can, they are competent and can therefore consent.

C. Summary of Competence to Consent

Thus, although Australia adopted Gillick into its common law, a complex line of authority developed, with courts deciding whether children had competence to consent to treatment, most notable for gender dysphoria. In doing so, it illuminated the criteria used to determine children’s competence. Whilst there was some variation in the criteria used by health professionals and courts, generally they were based around young people’s abilities to: comprehend and retain information about treatment; provide a full explanation at a level commensurate to their maturity and education; describe, and weigh up, the advantages and disadvantages of the treatment; reach an informed decision; and understand that the treatment will not necessarily address all of their psychological and social difficulties. In some cases the court gave a realistic and common sense approach to the degree of understanding needed, rejecting the notion that children’s brains needed to be fully developed to give them the maximum degree of understanding. Instead, children were required to be “fully aware of the consequences and risks” and capable of making a rational and intelligent choice after considering all the relevant information.

Nevertheless, the process applicants were required to undertake was considerable, involving affidavit evidence, reports and oral evidence, usually from several witnesses, such as health professionals, parents, other carers and educators, and sometimes the young people themselves. This process was intended to safeguard children for making wrong decisions, and to ensure health professionals were accurately assessing children’s competence. However, the emotional and financial cost was considerable. As a result of confusion and inconsistencies in court process, clarity was eventually achieved, enabling health professionals to make competence decisions and take consent from competent children.

D. Refusal to Consent

SA stands out as being unusual with the Consent to Medical Treatment and Palliative Care Act 1995, which provides for a person over the age of 16 years to “make decisions

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343 Re Kelvin, above n 339 at [139] per Thackray, Strickland and Murphy JJ.
344 At [179] – [182] per Thackray, Strickland and Murphy JJ.
345 For example Re Desi [2017] FamCA 20.
347 Re Jaden at [51].
… as validly and effectively as an adult.” Nevertheless, the extent of this right has not been tested in SA, in particular whether it includes competent young people’s right to refuse treatment.

In common law, whilst young people’s right to refuse treatment is recognised, it is unlikely to extend to situations resulting in their death, as is supported by two leading authorities.

The first is X v The Sydney Children’s Hospitals Network, involving a young person, who was 17 years and eight months at the time of the appeal to the Court of Appeal in NSW. The issue was whether he should be forced to undergo a blood transfusion against his refusal based on his religious beliefs. After considering the statutory law, and acknowledging the adoption of Gillick, the Court concluded that:

… the applicant was competent, in this practical sense, to determine whether or not to consent to the proposed treatment. The question at the heart of this case is what flows, as a matter of law, from the principle adopted in Gillick and the factual finding with respect to the applicant.

Although the Court recognised the young person’s competence and right to refuse treatment, it instituted the protective jurisdiction of parens patriae, thus overriding his decision.

Similarly ratifying the Courts’ protectionism, the Supreme Court case of Fletcher (an infant by her litigation guardian Rylands) v Northern Territory of Australia, confirmed that a competent minor’s right to refuse treatment could be overridden. The issue was whether a 16-year-old girl suffering from anorexia nervosa would be force-fed against her will, as there was dispute between the health professionals responsible for her care as to her level of competence. The Court found that she was incompetent due to her mental illness, resulting in impairing her “judgement to the point that she did not have the capacity to make decisions about nutrition in a manner that was in her best interests.” In following Gillick, the Supreme Court took account of the following factors when assessing competence: her ability to understand the issues and circumstances; her maturity and degree of autonomy; her age; the complexity and nature of the issue; and the nature and

348 Section 6, above n 256.
350 At [23].
351 At [26]-[44] the Court considered the common laws of Australia, England and Canada that support courts having inherent jurisdiction over competent children who refuse treatment in circumstances that would affect them having a normal, healthy life. Also, in the earlier Supreme Court of South Australia decision in Women’s and Children’s Health Network INC v M, CN & ORS [2013] SASC 16, although the child was clearly incompetent, the Court overrode parental refusal on religious grounds for transfusions of blood and blood products in the course of treating a three-year-old child with leukaemia, instituting parens patriae jurisdiction of the Court in the best interests of the child.
352 Fletcher (an infant by her litigation guardian Rylands) v Northern Territory of Australia [2017] NTSC 62 at [25].
353 At [38].
354 At [38].
effect of any medical condition. However, it appeared that the Court had decided that someone with anorexia nervosa, by its very nature, resulted in incompetence, as in the judgment there was no detailed consideration of how the facts related to these criteria.

Thus, when incompetent children/young people refuse treatment, their parents can consent, and where both competent children/young people and parents refuse, the courts may consent, under parens patriae, to protect children’s welfare and best interests.

E. Professional Guidance on Informed Consent

Some guidance on informed consent is given to doctors and dentists by the Medical and Dental Boards of Australia respectively on good practice of communicating with children, providing information at an appropriate level, encouraging questions, and considering their capacity to make decisions and consent. However, there are no specific criteria recommended for assessing competence. Similarly, the Nursing and Midwifery Board of Australia provides a Code of Professional Conduct for Nurses (Nursing Code) establishing standards, such as the provision of information and explanations to support decision-making and the giving of informed consent. Although there are not specific standards pertaining to children in the Nursing Code, some States have initiatives to support child and family health. For example, the “Health Child and Family Health Nursing Professional Practice Framework 2011–2016” in NSW recognising the importance of health professionals working in partnership with families.

F. Summary of Australian Law on Consent to, and Refusal of, Medical Treatment

Most States in Australia are similar to New Zealand in having adopted Gillick into their common law. However, there are procedural barriers to consenting to “non-therapeutic” treatment, as courts determine competence, rather than these assessments being carried out by treating health professionals. The law has developed in a piecemeal way, with inconsistencies in process emerging, particularly for gender dysphoria treatment. Rather

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355 At [20].
356 At [26].
357 At [31]. Also at [42] per Grant CJ: “... to abide by the infant’s refusal to eat would, on the medical evidence to hand, give rise to an unacceptable risk of permanent injury.”
358 Medical Board of Australia “Good Medical Practice: a code of conduct for doctors in Australia” (17 March, 2014) at 9; Dental Board of Australia “Code of Conduct” (17 March, 2014) at 11-12.
360 NSW Department of Health “Health Child and Family Health Nursing Professional Practice Framework 2011-2016” (2011) at 10 – “The partnership approach involves health professionals and family members working together in pursuit of a common goal. It is based on shared decision making, shared responsibility, mutual trust and mutual respect. Working in partnership with parents requires a major paradigm shift from the traditional role of caring ‘for’ to working ‘with’. The family partnership approach respects parents as advocates, and recognises them as the most significant influence in their children’s lives. The CFHN [Child and Family Health Nurses] respects the client’s ability to understand, learn and manage situations (reference omitted).”
than concentrating on the process of decision-making and competence of children, the courts have focused on the nature of the treatment and outcome, their concerns being the irreversibility of stage two treatment and the consequences of a wrong decision. However, when patients are competent they are able to make decisions. The focus should not be on the outcome, as that is a subjective view, but on whether they meet the criteria for competence, and are capable of making the treatment decision.

Although there is now clarity for gender dysphoria treatment, with the Court reclassifying stage two treatment to therapeutic, courts will continue to be responsible for assessing children’s competence in “non-therapeutic” cases. The concerns stem from a desire to protect children from mistaken competence assessments by health professionals and exploitation of parents. These goals show courts’ mistrust in the child-parent-health professional dynamic, and of the process in making right decisions for children. Yet, it seems hypocritical of the courts to mistrust health professionals in their competence assessments, but then to rely upon them to make their decisions.

South Australia differs by regulating children’s consent by statute, enabling competent children to consent, but only if at least two health professionals deem the treatment to be in their best interests. Therefore, in effect, children only have the right to agree with health professionals. Although, this may appear limiting at first sight, it is liberating in the context of “non-therapeutic” procedures, as these will not require the court’s confirmation of competence, as is required in other States.

Unlike New Zealand, Australian common law has confirmed that competent children do have the right to refuse treatment, although a parent’s consent or the court can override this. As will be seen in the next section, refusing consent is an issue that has concerned the English Courts.

III. Law of England/Wales

A. Introduction

The law of England reflects that of New Zealand in two respects: firstly, young people between the ages of 16 and 18 years have a statutory right to consent, independent of their parents’ consent; 361 and secondly, following Gillick, competent children under the age of 16 years have a right to consent. However, the legal right for children/young people under 18 years to refuse treatment is less certain in England. Unlike section 36(1) of the COCA, there is no statutory right for young people to refuse treatment, and the common law holds that competent children/young people’s refusal will be overridden if the courts consider it to be in their welfare and best interests. Thus, there is no distinction between those under 18 years and 16 years in respect of refusal, and Gillick competence has in effect been reduced to an expression of their views, which are not

361 Family Law Reform Act 1969 s 8(1).
decisive. This section will consider the statutory and common law of England. Firstly, it briefly reflects upon the statutes that regulate consent and refusal, before focusing on the common law, in how it deals with children’s right of refusal, and the criteria for assessing children’s competence. It then turns finally to professional guidance, considering the advice given to health professionals on assessing children’s competence and in taking consent.

B. Statutory Right to Consent to Medical Treatment

The Family Law Reform Act 1969 (FLRA) gives young people the right to consent to surgical, medical or dental treatment. Section 8(2) expands upon the definition of “surgical, medical or dental treatment”, clarifying that this includes diagnosis and ancillary procedures to treatment. However, case law has restricted its scope, excluding blood and organ donations, “as these do not constitute either treatment or diagnosis.”

Lord Donaldson’s concern lay in proceeding with treatment based on either the sole consent of the child or parent when it is not for the benefit of the child.

Section 8(3) further complicates the situation as it states “[n]othing in this section shall be construed as making ineffective any consent which would have been effective if this section had not been enacted.” There is debate on what “any consent” means. For example, Professor Freeman does not believe that this section refers to parental common law rights, as by the age of 16 years these have yielded to the young person. However, Balcombe LJ in Re W takes a different view:

That the section did not operate to prevent parental consent remaining effective, as well in the case of a child over 16 as in the case of a child under that age, is apparent from the words of subsection (3).

It is possible that the section refers to parents consenting for incompetent young people. However, another interpretation is that s8(3) states the legal position of those under 16 years in terms of Gillick, as Professor Freeman suggests:

What is clear is that it is concerned with the preservation of pre-existing rights: in my view the right of a child under 16 to continue to be able to provide a valid consent.

Thus, FLRA, like that of COCA, is not entirely clear. Where it differs is that it left open the question of young’s people right to refuse consent. As will be seen below, the English

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362 FLRA s 8(1) “The consent of a minor who has attained the age of sixteen years to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his person, shall be as effective as it would have been if he were if full age, and where a minor has by virtue of this section given effective consent to any treatment it shall not be necessary to obtain any consent for it from his parents or guardian.”

363 For example, Re W, above n 208 at 78F per Lord Donaldson.

364 At 79/A per Lord Donaldson.


366 Re W, above n 208 at 86B-C.

367 Freeman, above n 365, at 203.
courts have interpreted children/young people’s right to refuse treatment in a restricted way.

C. Statutory Right to Refuse Medical Treatment

The only statutory context in which children have rights to refuse medical examinations or treatment is when they are received into the care, or are under the supervision of local authorities. For example, when they are subject of an interim order, \(^\text{368}\) children may refuse to submit to a medical or psychiatric examination. \(^\text{369}\) However, this refusal may not be determinative, as the court may override that refusal when it “is of the opinion that the examination or other assessment is necessary to assist the court to resolve the proceedings justly.” \(^\text{370}\) In considering whether to so direct, the court will have regard to several factors, including any impact on the child’s welfare. \(^\text{371}\)

D. Common Law Right to Refuse Medical Treatment

Children’s common law right to refuse medical treatment is not absolute. Whilst \textit{Gillick} did not involve the question of children refusing, it has been suggested that Lord Scarman implied that competence to consent carries with it the right to refuse, \(^\text{372}\) when he stated obiter: \(^\text{373}\)

\[\ldots \text{I would hold as a matter of law the parental right to determine whether or not (emphasis added) their minor below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to fully understand what is proposed.}\]

This seems a reasonable assumption to make, as in meeting the threshold of being competent, children need to understand the information and be capable of making

\(^{368}\) \textbf{Children Act 1989, s 38(6)} Where the court makes an interim care order, or interim supervision order, it may give such directions (if any) as it considers appropriate with regard to the medical or psychiatric examination or other assessment of the child; but if the child is of sufficient understanding to make an informed decision he may refuse to submit to the examination or other assessment.

\(^{369}\) \textbf{See also Children Act 1989, s 44(7)} Where any direction is given under subsection (6)(b) [emergency protection order], the child may, if he is of sufficient understanding to make an informed decision, refuse to submit to the examination or other assessment. The court can impose an examination under s 44(8)(b).

\(^{370}\) \textbf{Children Act 1989, s 38(7A).}

\(^{371}\) \textbf{Children Act 1989, s 38(7B)} “When deciding whether to give a direction under subsection (6) to that effect the court is to have regard in particular to—

(a) any impact which any examination or other assessment would be likely to have on the welfare of the child, and any other impact which giving the direction would be likely to have on the welfare of the child,

(b) the issues with which the examination or other assessment would assist the court,

(c) the questions which the examination or other assessment would enable the court to answer,

(d) the evidence otherwise available,

(e) the impact which the direction would be likely to have on the timetable, duration and conduct of the proceedings,

(f) the cost of the examination or other assessment, and

(g) any matters prescribed by Family Procedure Rules.”


\(^{373}\) \textit{Gillick}, above n 4 at 188-9.
decisions, one of which is to reject some, or all, of the treatment. Nevertheless, the English common law during the 1990s restricted the scope of Gillick, both raising the threshold of competence, and determining that the right to consent does not confer the right to refuse. This enabled parents and courts to override children’s refusal, in effect reducing children’s competence to an expression of their wishes, which were then overruled on the grounds of their welfare and best interests. However, there is a glimmer of the tide turning in more recent times, with greater respect being given to children’s competence, and on some occasions children’s decisions to refuse treatment being followed, despite grave consequences.

1. Re R (a minor) (wardship: consent to treatment) (Re R) 374

In Re R, a 15-year-old girl, suffering from a mental disorder, was deemed incompetent by the Court, despite the consultant psychiatrist assessing her as competent between episodes of illness. The Court of Appeal held that due to the fluctuating nature of her illness she was incompetent to give or withhold consent, doubting that she understood the implications of her decision. 375

The Court distinguished Gillick in two respects. Firstly, it decided that children only have the right to refuse treatment when everyone with rights refuse. Lord Donaldson considered that “concurrent powers of consent” exist, with a number of people possessing this right. He declined to hold that parents’ rights terminate when children are competent. 376 By focusing on parental rights and the protection of doctors, he considered that if a competent child refused consent, then consent could be given by anyone authorised in law to give it, describing them as “keyholders” able to unlock the door. 377

Secondly, Lord Donaldson viewed competence as a developmental concept, dependent upon “mental and emotional age, as contrasted with chronological age”, 378 but considered that this test needed to be “modified in the case of fluctuating mental disability to take account of that misfortune.” 379 In order to reach the threshold of competence he considered consistency of competence was needed: one that “will not be lost or acquired on a day to day or week to week basis”; and “a full understanding and appreciation of the consequences both of treatment in terms of intended and possible side effects and, equally important, the anticipated consequences of a failure to treat.” 380 Farquharson LJ agreed, considering Gillick to be inapplicable in situations such as this where competence varied “from day to day according to the effect of her illness.” 381 By taking a holistic approach to the assessment of competence, Farquharson LJ considered that it should not be assessed “at a particular moment in time, isolated from the medical

374 Re R, above n 291.
375 At 26C per Lord Donaldson.
376 Gillick, above n 4 at 189 per Lord Scarman.
377 Re R, above n 291 at 22D-E per Lord Donaldson.
378 At 26A per Lord Donaldson.
379 At 26A per Lord Donaldson.
380 At 26B per Lord Donaldson.
381 At 32 B per Lord Farquharson.
history and background … [but] the whole of the medical background of the case as well as the doctor's opinion of the effect of its decision upon the patient's mental state” should be taken into account.382

2. Re W (a minor) (medical treatment: court's jurisdiction) (Re W)383

The ratio of Re R was confirmed in Re W, when the Court of Appeal exercised its inherent jurisdiction by ordering a 16-year-old girl, suffering from anorexia nervosa, to be transferred into a unit for treatment against her will. Although at first instance Thorpe J found the girl to be competent to make informed decisions, the Court of Appeal considered that he had failed to take sufficient account of a feature of her condition, that being an inability to make an informed choice. Lord Donaldson believed that the condition “creates a compulsion to refuse treatment or only accept treatment which is likely to be ineffective.”384 Belittling the views of children, he further stated:385

Where the wishes of the minor are themselves something which the doctors reasonably consider need to be treated in the minor’s best interest, those wishes clearly have a much reduced significance.

The decision sanctioned the limitless power of the court, confirming that treatment and procedures can be forced upon children in their best interests, even in the context of abortion.386

Hair-raising possibilities were canvassed of abortions being carried out by doctors in reliance upon the consent of parents and despite the refusal of consent by 16- and 17-year-olds. Whilst this may be possible as a matter of law, I do not see any likelihood taking account of medical ethics, unless the abortion was truly in the best interests of the child. This is not to say that it could not happen.

Re W undermined the rights and autonomy of children established in Gillick, by being both protective of the medical profession and paternalistic. Children’s right to refuse was reduced to having a right to express their views, the importance of which increased with age and maturity.387 Despite this, Balcombe LJ acknowledged that at a matter of “logic there can be no difference between an ability to consent to treatment and an ability to refuse.”388 However, he failed to take that logic one step further to conclude that this should result in children having the right to refuse when competent. Rather, he interchanged “competence” with “wishes”, believing that their wishes were only one factor in assessing their best interests.389 Although he gave recognition to children’s increasing competence and autonomy, Balcombe LJ made clear that competence and wishes were not determinative, setting it within the welfare paradigm. In considering when it would be appropriate to disregard the wishes of a 16 or 17-year-old, he believed

382 At 3IC-E per Lord Farquharson.
383 Re W, above n 208.
384 At 81B, per Lord Donaldson.
385 At 81B, per Lord Donaldson.
386 At 79 B-C per Lord Donaldson.
387 At 81C–D and 84 A-B per Lord Donaldson MR.
388 At 88B-C per Balcombe LJ.
389 At 88 C-F per Balcombe LJ.
it unhelpful to define a threshold, although he indicated that this would be reached “in circumstances which will in all probability lead to the death of the child or to severe permanent injury.”

Whilst understandably seeking to protect children, the Court gave no detailed consideration of the required criteria for competence, and specifically in what respect the competence of this young person was lacking. There was simply a broad-brush approach to it basing it upon the mental health diagnoses, rather than upon understanding of treatment and intelligence. The Court could have taken a more objective approach to competence, measuring the facts to criteria, and if finding her to be competent, then separately considering treatment under the mental health legislation. It could be said that the end result is the same, but the means by which that conclusion is reached is significant for the sanctity of the Gillick competence test, and of children’s right to self-determination and autonomy. The effect of the decision was to reduce competence to one of an expression of wishes, which in their best interests, could be overruled.

3. **Re E (a minor)(wardship: medical treatment) (Re E)**

Prior to both of the above decisions, the competence threshold had already been elevated in *Re E*, where the court decided that life or death decisions were outside of children’s understanding, as they are unable to understand the full implications of the process of dying, the manner of death and the extent of family suffering. However,
upon reaching the threshold of 18 years, the age at which the law in England deems people capable of understanding their own death, E refused treatment and was allowed to die.  

4. **Re S (a minor)(consent to medical treatment) (Re S); Re L (medical treatment: Gillick competency) (Re L)**

Likewise, in Re S and Re L, children aged 15½ and 14 years respectively were considered incompetent to refuse blood transfusions, as they lacked the maturity to make such decisions. Yet, both children were not given the opportunity to demonstrate their maturity and competence, as they had not been fully informed of the details of their potential death, due to its distressing nature. On a practical level this would be a difficult conversation for health professionals and children to have, but there needs to be a dialogue, enhancing the others’ understanding, about what the consequences would be if treatment is refused, and similarly, how it would feel to these children to be forced to undergo a blood transfusion against their beliefs and views. Without such exchange of information, neither the children nor health professionals are fully informed. Thus, children cannot be criticised for lacking understanding if they are not provided with necessary information, at an appropriate level, upon which to base their decision. In any event, as Professor Freeman points out, the issue is what they are capable of understanding, rather than their actual understanding.

5. **Re P (medical treatment: best interests) (Re P)**

A more authentic approach to competence is found in Re P, whereby greater respect was given to the young persons’ beliefs, views and competence. John, aged 16 years and 10 months, refused blood or blood products. The Court acknowledged that although young people’s refusal may be determinative as they reach the age of majority, the Court’s role until then is to protect them to ensure they reach that age. Mr Justice Johnson strove to overcome the conflicts between John’s views and competence; the importance of cooperation between doctor and patient; the views and beliefs of John’s parents; and John’s best interests, finding “weighty and compelling reasons why this order should not be made.” However, he concluded, albeit reluctantly, that it was in his best interests “in
the widest possible sense - medical, religious, social, whatever they may be” to override his refusal.\textsuperscript{403} Although there was no detailed consideration of John’s competence, it was implied.\textsuperscript{404}

6. Hannah Jones and Joshua McAulay

The need to consider competing factors when children refuse treatment highlights the unsuitability of a blanket rule. On some occasions, it will be appropriate to follow competent children’s decisions, as the following two cases demonstrate. The first involved Hannah Jones, aged 12 years, who decided not to proceed with a heart transplant, after having considered medical advice.\textsuperscript{405} She had a hole in her heart, caused or exacerbated by leukaemia medication, which she took from the age of five years.\textsuperscript{406} She is reported in the press as having weighed up the risks against the benefits of the operation, believing that the risk was too great for her, and instead preferring to enjoy her remaining time at home with her family and friends.\textsuperscript{407} Initially, Hereford Primary Care Trust (the Trust) filed a court application to force Hannah to undergo the operation. However, upon the Court checking, and receiving confirmation of, her competence, the Trust discontinued its application, allowing Hannah to live at home with her family.\textsuperscript{408} Hannah’s consultant paediatrician is reported as supporting Hannah’s decision, stating that “no one can be forced to have a heart transplant”, leaving it open for her to change her mind.\textsuperscript{409} This is in fact what Hannah did at the age of 14 years, and upon consenting to the transplant, an NHS spokesman is reported as confirming her competence.\textsuperscript{410}

In our discussions with Hannah we are convinced she has the maturity and experience to make decisions for herself about her treatment and truly understands the implications.

Hannah is reported as stating that she was doing what believed was right for her at the age of 12 years, as she overwhelmingly felt that she wanted to be at home.\textsuperscript{411}

The second case, also reported in the English press, involved Joshua McAulay, a 15 year-old, who refused a blood transfusion on the basis of his religious beliefs. His mother supported his decision and the medical practitioners respected it also. The hospital could

\textsuperscript{403} At [12] per Johnson J.
\textsuperscript{404} At [11] per Johnson J.
\textsuperscript{405} BBC unnamed reporter “Girl wins the right to refuse heart” (BBC News, England, 11 November 2008) \(<www.news.bbc.co.uk>\).
\textsuperscript{406} Robert Verkaik, “Girl, 13, wins right to refuse heart transplant” (Independent, 11 November 2011) \(<www.independent.co.uk>\).
\textsuperscript{407} Varkaik, above n 406.
\textsuperscript{408} BBC, above n 405.
\textsuperscript{409} BBC, above n 405.
\textsuperscript{410} Matthew Weaver “Right-to-die teenager Hannah Jones changes her mind about heart transplant” The Guardian (The Guardian, 21 July 2009) \(<www.theguardian.com>\).
\textsuperscript{411} Emily Retter “Hannah Jones at 18: I turned down a heart transplant at 13 but I am so glad I changed my mind” The Mirror (The Mirror, England, 13 July 2013).
have asked the courts to determine the issue, but a spokesman from Selly Oak Hospital said:

There's not one single policy and not one single law regarding transfusions. There's no automatic right to override parental wishes or that of a minor. It's a very complex area that has to be approached on a case by case basis.

E. Competence Assessment and Professional Guidelines

It becomes clear when considering the above cases that the courts at times have struck at the heart of Gillick and its competence test, either by failing to apply competence criteria, or when doing so, have raised the threshold of what children are required to meet. The end result in both scenarios is that competence is reduced to an expression of wishes or views, which are then overruled when they do not accord with what is believed to be in children’s best interests. This subjective approach leads to inconsistencies and uncertainties, which may make it difficult for health professionals to have confidence in their competence assessments.

Nonetheless, the British Medical Association (BMA) and General Medical Council (GMC) provide guidance on assessing children’s competence and the taking of consent. The BMA has developed a “Children and young person tool kit”, designed to assist doctors in identifying key factors when assessing competence, and to assist them in understanding what this means in terms of children and young people’s ability to consent to, and refuse, healthcare. The criteria highlight the need for children to be capable of understanding not only the treatment, but also that they are able to freely use the information to make a choice:

- the ability to understand that there is a choice and that choices have consequences
- the ability to weigh the information and arrive at a decision
- a willingness to make a choice (including the choice that someone else should make the decision)
- an understanding of the nature and purpose of the proposed intervention
- an understanding of the proposed intervention’s risks and side effects
- an understanding of the alternatives to the proposed intervention, and the risks attached to them
- freedom from undue pressure.

413 For example, in An NHS Trust v ABC and A Local Authority, above n 206 at [6] an application was made for declaratory relief to avoid professional risk or criticism. It sought either a declaration that it would be in the interests of a 13-year-old girl to terminate her pregnancy if the Court deemed her incompetent to consent, or if deemed competent “a declaration to that effect so that the position is put beyond doubt and that any later criticisms of the Trust, in taking the steps that they did, can be deflected” (emphasis added).
414 British Medical Association “Children and young person tool kit- assessing competence” (BMA, 30 June 2016) <www.bma.co.uk>.
Similarly, following the wording of *Gillick*, the GMC advises doctors that they must decide whether the young person understands the nature, purpose and possible consequences of having or not having the health care.\(^{415}\) Only those who “are able to understand, retain, use and weigh this information, and communicate their decision to others”, are competent to consent.\(^{416}\) Doctors are advised to assess children’s maturity and abilities to make specific decisions at the time they need to be made, rather than focusing on age, requiring them to re-evaluate competence.\(^{417}\) Also, a collegial approach to competence assessments is recommended for borderline or doubtful situations, taking advice from other health professionals involved in children’s care and from specialists.\(^{418}\)

**F. Summary of Law of England/Wales on Consent to, and Refusal of, Medical Treatment**

In England competent children have the right to consent to treatment, but not to refuse. A higher threshold requires to be reached for children to be deemed competent, in addition to those in *Gillick*, such as: consistent, not fluctuating, understanding; views that have not been unduly influenced by family members; and exclusion of life or death decisions. The shifting nature of competence criteria results in uncertainties, although clearer guidance/criteria are provided to medical professions through their guidelines.

**IV. Law of Scotland**

**A. Introduction**

Scotland is the most straightforward of the four jurisdictions considered, since young people have the same rights as adults,\(^ {419}\) and children’s right to consent to medical treatment is secured in statute.\(^ {420}\) Thus, the common law does not need to be relied upon to define children’s right to consent. However, there is some doubt whether section 2(4) of the ALCSA also covers children’s right to refuse treatment. This section firstly considers the background to the ALCSA, followed by the law on refusal, and finally professional guidelines on assessing competence.

**B. Background to the Age of Legal Capacity (Scotland) Act 1991**

Prior the passing of the ALCSA, the law on the legal capacity of under 18-year-olds was uncertain in several areas of private law, including consent to medical treatment.\(^ {421}\) As

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\(^{415}\) General Medical Council “0-18 years: guidance for all doctors” (2007) at [24].

\(^{416}\) At [24].

\(^{417}\) At [25], [26] and [70].

\(^{418}\) At [73].

\(^{419}\) ALCSA, s1(1)(b).

\(^{420}\) ALCSA, S 2(4).

\(^{421}\) SLC, above n 14 at [1.1]
Thus, clarification of the law was required, and in 1987 the SLC made recommendations for reform. Their initial proposition was that children should be recognised as having the capacity to consent at the age of 16 years. However, they accepted the rigid and unrealistic nature of such a law would fail to take into account the competence of younger children. It thus mooted four possible ways in which flexibility could be added to allow competent children to consent:

1. Where it was “in accordance with approved medical practice to act on the basis of such consent”;  
2. “[F]or specified illness or conditions”;  
3. Where children are “capable of understanding the nature and consequences of the treatment proposed”;  
4. “Where in the opinion of the qualified medical practitioner attending the child, supported by the written opinion of another, (i) the young person was capable of understanding the nature and consequences of the treatment; and (ii) the treatment and procedure to be used was in the best interests of the young person and his continuing health and well-being.”

The SLC invited the public to comment upon, and discuss, the proposals for reform.

422 At [3.65]: “Some doctors are aware of the legal significance of the age of minority and act on the basis of the consent of a girl from the age of 12 or a boy from the age of 14. Others regard 16 as the age of consent and, as we have seen, consent of a parent or guardian is often required as a matter of practice in relation to hospital treatment for patients up to the age of 18.”

423 Circular SHHD (DS(79)2) at [2.7].

424 SLC, above n 14 at [2.9].

425 SLC, above n 14 at at [3.62].

426 SLC above n 14, which was laid before Parliament by the Lord Advocate in 1987, was preceded by a consultative memorandum published in June 1985 that reviewed the law of that time in respect of the legal capacity of pupils (girls under 12 years and boys under 14 years) and minors (girls between 12-18 years and boys between 14-18 years). At [1.2] as the Memorandum was technical and detailed SLC published “a short..."
The majority of those who supported a presumption of competence for young people also believed that there should be “some form of exception to it.”\textsuperscript{427} Notably, some influential members of the medical community, such as medical, nursing and family planning bodies, raised concern of fixing children’s right to consent at 16 years. Amongst their concerns were the view that there was not a problem in the law to fix, as it gave sufficient flexibility and protection to both children and the medical profession, and if it was set at 16 years this may create a barrier to children under that age accessing health services, particularly contraception and sexual health advice.\textsuperscript{428}

Whilst SLC accepted that the law did not appear to present practical problems, it considered that the current law was unsatisfactory, with their concerns being the lack of clarity and inconsistencies in practice: \textsuperscript{429}

\begin{quotation}
It is, in our view, undesirable that such different practices should be adopted on the basis of what is believed, correctly or incorrectly, to be the existing law. For the protection of both the young patient and the doctor, the law in this area should be clear.
\end{quotation}

The most favoured option amongst consultees to provide flexibility in the law was to base it upon children’s capacity to understand. Also, some consultees raised concerns over the competence test requiring a second opinion, or being based on best interests. The former was considered to be “too cumbersome and would not necessarily provide any safeguard for either the doctor or the patient,” and the latter was “too restrictive and unnecessary.”\textsuperscript{430} The SLC agreed, concluding that persons under the age of 16 should have legal capacity to consent where they are capable of understanding the nature and consequences of the treatment proposed. The draft Bill attached to the report proceeded through Parliament unchanged and became law in terms of section 2(4) of the ALCSA:

\begin{quote}
A person under the age of 16 years shall have legal capacity to consent on his own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment.
\end{quote}

Thus, the test reflected \textit{Gillick}, with the attending medical professional assessing children’s understanding.

\textsuperscript{427} SLC, above n 14 at [3.63].
\textsuperscript{428} At [3.64].
\textsuperscript{429} At [3.65].
\textsuperscript{430} At [3.77].
C. Refusal to Consent

Although the ALC SA does not specifically state that children also have the right to refuse treatment, the generally accepted view amongst the judiciary, some academicians, and implied by the SLC, is that section 2(4) should be interpreted as carrying with it the right to refuse. For example, Professor Norrie stated:

…it is submitted that the right to consent necessarily carries with it the right to refuse consent. The very, the only, point of asking patients to consent to medical treatment is to give them the opportunity to refuse that consent. The right to say yes must therefore carry with it the right to say no.

Likewise, Wilkinson and Norrie indicated:

… if the right to consent is an aspect of individual autonomy, then the only point in asking a patient to consent to medical treatment is to give the patient the opportunity to refuse and for that reason the capacity to consent carries with it, it is submitted the right to refuse.

Judicial approval of competent children’s decisions prevailing over those of their parents is found in the only reported Scottish decision of Houston. The Sheriff, referring to section 2(4), stated obiter:

[It] seems illogical that on the one hand a person under the age of sixteen should be granted the power to decide upon medical treatment for himself but his parents have the right to override his decision. I am inclined to the view that the minor’s decision is paramount and cannot be overridden.

Further, although the matter was not fully canvassed, it was conceded that “consent” in section 2(4) covers refusal, to which the Sheriff agreed.

However, the matter has not been put beyond doubt, as there is an absence of Scottish authority on children refusing treatment in general, and in life or death situations in particular, to test it. Commentary by Sheriff Kelbie on Houston notes the uncertainty as to

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431 Houston, above n 14 at 945 per Sheriff J McGowan.
432 See Wilkinson and Norrie, above n 14 at 261.
433 SLC, above n 14 at [3.77]. In rejecting the inclusion of best interests into the capacity provision, the SLC commented that “[i]f it is accepted that a child may consent if he is of sufficient maturity to understand the treatment proposed then that test should apply whether the treatment concerned is for his benefit or not.” Although the SLC did not explicitly consider the question of rejecting treatment, following this line it could be argued that if competent children can consent to treatment that is not in their best interests, so too can refuse.
434 Norrie, above n 14 at 436.
435 Wilkinson and Norrie, above n 14 at 480.
436 John Houston, above n 14.
437 At 945. Also, the Sheriff described the mother’s position as “irrelevant” as the boy was competent, at 945.
438 This supports and answers the dilemma raised by Professor Norrie, above n 14, at 437, in which he ruminates upon conflicting positions of parents and child.
439 Houston, above n 14 at 945.
whether children’s refusal would be upheld in such circumstances. However, it is questionable whether an application to the court by parents seeking a specific issue order to override competent children’s refusal would be competent, a view shared by Wilkinson and Norrie. On the other hand, Griffiths, Fotheringham and McCarthy are of the opinion that provided children are under the age of 16 years, courts retain the right to make orders in relation to parental responsibilities and rights under Children (Scotland) Act 1995, s11(1). Also, the Scottish Executive Health Department has offered guidance that a parent, health professional or anyone with an interest could make such an application.

Although allowing competent children to die may be unpalatable, in my view the logic of Wilkinson and Norrie is preferable in their interpretation of the law. As Scots law accepts that parental rights yield to those of competent children, then as indicated above, children must have an independent right to consent to, or refuse, treatment. If it is accepted that competent children do have the right of refusal, then that is regardless of the outcome. Whilst courts do retain the right to make orders until children are 16 years, those orders would be empty vessels, as they should not override competent children’s decisions. In the event that such an application is incompetent, the only avenues that could be pursued to attempt to override a decision of a competent child, would be under the Mental Health (Care and Treatment) (Scotland) Act 2003, if the circumstance fell within its remit, or perhaps under the nobile officium of the Court of Session, or parens patriae, stemming from the recognition of the sovereign historically, as pater patriae, being the natural and legal guardian of children under full age.

D. Professional Guidance

The Scottish Executive Health Department provides guidance on good practice in taking children’s consent, advising health professionals to use their clinical judgement and take account:

- the age of the patient
- the maturity of the patient
- the complexity of the proposed intervention

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440 At 948.
441 Wilkinson and Norrie, above n 14 at 262.
443 Scottish Executive, Health Department “A Good Practice Guide on Consent for Health Professionals in NHS Scotland” (NHS Scotland, 2006) at 10: “In some circumstances the refusal of consent by or on behalf of a child may be overridden by the courts which in terms of section 11(2) of the 1995 Act [Children (Scotland) Act 1991] may authorise medical treatment. Any person with an interest, which could include a medical practitioner, can apply to the court which will decide the matter on the basis of the best interests of the child. The circumstances in which such an application will be appropriate are likely to be limited but could arise in a life or death situation.”
444 See Law Hospital NHS Trust v Lord Advocate 1996 SLT 848 in which the Court of Session considered these in the context of terminating life sustaining treatment to a vegetative adult.
445 Scottish Executive, Health Department, above n 443 at 8. See British Medical Association, n 414 which is also applicable to Scotland.
• its likely outcome
• the risks associated with it.

E. **Summary of Scots Law**

Young people have the same rights as adults to consent or refuse medical treatment. Children’ right to consent to medical treatment is protected in statute, and although not entirely free from doubt, includes the right to refuse.

V. **Chapter Summary**

New Zealand, Australia (except for SA) and England have no statutory right for children to consent to medical treatment, relying on the common law of *Gillick*. Scotland is unique by having a statutory right that encapsulates *Gillick*. It is likely that this would also be interpreted as including the right to refuse. Although Australia has recognised the right to refuse in its common law, it has limited it, as parents or courts can override children’s decisions. Similarly, in New Zealand and England, it is uncertain whether children have the right to refuse, and if so, to what degree. There is an absence of case law in New Zealand, but in England, the common law has raised the threshold of competence for children refusing treatment, and even when found competent, their decisions can be overruled in their best interests.

For young people in New Zealand, there is a clear statutory right to refuse medical treatment, unlike in England, who treat them in the same way as those under 16 years. In Scotland, young people aged 16 years have the same rights as adults to enter into any transaction.\(^446\) Therefore, cases such as those that have arisen in England, when young people have refused treatment, or in Australia when seeking treatment for gender dysphoria, would not arise in Scotland. It is striking that in Scotland there is a dearth of case law on children consenting to, and refusing, treatment. As a result, the Scottish legal system has not been faced with difficult situations, such as when children refuse treatment, or when parents and children disagree. However, it is probable that given the terms of section 2(4) of the ALCSA competent children’s decisions would be respected.

Table 1 below summarises the similarities and differences of the four jurisdictions considered.

\(^{446}\) ALCSA s1(1)(b).
<table>
<thead>
<tr>
<th><strong>Is there a statutory right for children under 16 years to consent?</strong></th>
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<th>England/Wales</th>
<th>Scotland</th>
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</thead>
<tbody>
<tr>
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<td>No, except for SA</td>
<td>No</td>
<td>Yes</td>
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<th>Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No, but recognised in common law</td>
<td>No</td>
<td>Probably - the statute is likely to be interpreted in that way.</td>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Uncertain but superseded by ALCA. 447</td>
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<th><strong>Is there a statutory right for young people between 16 and 18 years to consent?</strong></th>
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<tbody>
<tr>
<td>Yes</td>
<td>No, except SA</td>
<td>Yes</td>
<td>Yes to any transaction as they have the full capacity of adults.</td>
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<th><strong>Is there a statutory right for young people between 16 and 18 years to refuse?</strong></th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No, but recognised in common law</td>
<td>No, and common law raised competence criteria</td>
<td>Yes, as above.</td>
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<tr>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
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447 Norrie, above n 14, at 436. Also Griffiths, Fortheringham and McCarthy, above n 442 at 113 who described *Gillick* as “an English case but one which has been accepted as highly influential in Scots law.”
This chapter has shown the peculiarities that have developed in the common law of Australia and England in respect of consent to gender dysphoria treatment and refusal of treatment respectively. Although undoubtedly motivated by a desire to protect children/young people, the Australian courts have sought to act as a gatekeeper to treatment, appearing to hold mistrust in parents, health professionals and young people, in the following ways: by limiting parents’ ability to consent to “non-therapeutic” procedures; by enquiring into, and approving, the competence assessments of health professionals; and being reluctant to accept that children/young people are capable of making “non-therapeutic” decisions. In doing so, it has become preoccupied with the definition of “non-therapeutic”, creating uncertainty, inconsistency and complexity in the law. When tracing the path of the common law, it can be seen how, in my view, the common law took a wrong turn in Re Jamie, creating barriers and layers of complexity, by differentiating between stage one, “therapeutic” treatment, and stage two, “non-therapeutic” treatment. This was despite having previously viewed them together as one in Re Alex. It seems illogical to separate them, as both stem from the same health condition and are necessary to complete the treatment.

Age discrimination and disrespect of children, and their autonomous decision-making, appear also to be consequences of the way in which Australian common law has developed. It seems clear in Re Alex and Re Jamie that there was reluctance by the courts to accept that young people could be competent to consent to such treatment. The procedural requirement of applying to court for a decision on competence for stage two gender dysphoria treatment, in particular, and “non-therapeutic” treatment in general, in my view, undermines both the abilities and relationships of health professionals and children, and adds to the costs and stress for families. Although the court may bring an objective perspective to such assessments, and clarify criteria for competence, its involvement lacks proportionality, appearing unnecessary, particularly when, in all but one gender dysphoria case, the courts followed health professionals’ views, confirming young people’s competence. Such consequences could have been avoided, if in Re Jamie, the Court had either respected Jamie’s competence, or held that the treatment was therapeutic, and his parents could consent. The law’s uncertainty and confusion reached the point that clarification was necessary through a stated case in Re Kelvin, which was a more expedient and direct process than attempting to pass legislation. Applications are now no longer required for either an order permitting parents to consent, or to determine children’s competence, for stage two gender dysphoria treatment.

Similarly, in England, a line of authority developed by differentiating between the rights to consent to, and refuse, treatment. In doing so, it elevated the competence threshold, resulting in some children/young person being deemed incompetent. Nevertheless, cases such as Hannah Jones and Joshua McAulay have paved the way for the possibility of children being sufficiently competent to make life or death decisions. Moreover, what Hannah Jones’ situation highlighted is that a decision reached by a child/young person may not be final, and should always be open for review, placing responsibilities upon parents and health professionals to maintain good lines of communication and information.
Features common to laws of New Zealand, Australia and England are the inconsistent court processes and application of *Gillick*. On some occasions, applications for orders allowing medical treatment are viewed as guardianship matters, in which children’s views are considered, but where neither *Gillick*, nor competence, are considered. In other cases, although *Gillick* is considered, and competence determined, there is a lack of transparency from courts on what criteria are used and in what respect(s) children lack competence.

Greater predictability in the law could be achieved by respecting the ratio of *Gillick*. Competence to consent relates to intelligence and understanding to make a specific decision. If children possess those, and can make the decision, they are competent, and as such have the right to give, or conversely refuse, consent. Competence gives children the right to decide, not simply to agree with health professionals’ or parents’ decisions. By distinguishing between the rights of consent and refusal, it unnecessarily complicates matters. Focus needs to be on the process of making the decision, rather than on the outcome. If the law’s attention is diverted to outcome, then subjective judgments will be made about children’s decisions, leading to inconsistencies and uncertainty. The law needs to clearly separate competence from outcome. If the law and society do not approve of that outcome, and seek to protect children, there needs to be a separate process, such as by making an application for additional guardianship, under parens patriae jurisdiction, or the mental health legislation, if applicable.

However, what are the views of health professionals, parents and children who are at the sharp-end of the law? The next chapter reviews the research literature on children’s competence and the consent processes.
Chapter 5

Literature Review

I. Introduction

In the legal sense competence to consent is viewed in black or white terms - either a person meets the threshold to provide valid consent or does not. However, taking a broader perspective, it is much more complex. Firstly, competence can exist in degrees, or at certain stages in informed consent processes. For example, children may show competence to participate in discussions, but are not able to make decisions. Secondly, children’s competence does not exist in isolation, but is relational. It is promoted or constrained by the relationships between children, parents and health professionals, and their attitudes, values, personal attributes and communication skills, together with their intersection with the environment - physical surroundings, availability of time, or nature of the health condition.

This chapter reviews the international research evidence on the factors influencing children’s competence to participate in discussions and decision-making, and in the giving of consent. It firstly highlights the range of factors involved, moving then to discuss those relating to each key participant: health professionals, parents and children. Finally, the chapter reviews studies on health professionals’ practices in taking consent, to examine what, if any, barriers exist in the consent processes for children.

II. Factors Influencing Competence

A. Range of Factors

Competence is affected by a multitude of factors, some of which relate to children’s individuality and others to external factors. Alderson argues that children’s social context is a powerful influence on their competence and divides this into i) inner/personal attributes, such as gender; ethnicity; temperament and ability; degree of independence and optimism; comfort in taking risks; and their hopes, fears and values;448 and ii) external factors, including home and family; the hospital environment; medicine; media; attitudes towards childhood; and the law.449 The range and interplay of these sets of factors are two reasons why it is unsound to make presumptions about children’s competence.

To shed light on the diversity of factors affecting children’s communication with health professionals, Beresford and Sloper researched the experiences of 63 chronically ill children.448 Priscilla Alderson “In the genes or in the stars? Children’s competence to consent” (1992) 18 Journal of medical ethics 119 at 120. 449 At 122-123.
children, aged between 11-16 years, suffering from the chronic health conditions of cystic fibrosis, diabetes, epilepsy, juvenile chronic arthritis, or Duchenne muscular dystrophy. They found that a multitude of factors influenced children’s abilities to have open discussions, such as a lack of time or privacy; feelings that there may be negative consequences if they divulge personal/sensitive information; their parents dominating conversations; their age; and the doctor-parent dynamic excluding them. Age was relevant in the sense that children of different ages were inhibited in various ways, for example, the status of health professionals impacted upon younger children more, whereas the lack of privacy constrained older ones. Children’s age was confirmed by several studies to be an unreliable indicator of how involved children were in consultations. Instead, Lambert and others found four factors influencing the degree of children’s participation in communication: their preferences; attitudes and skills of health professionals; attitudes of parents in recognising children’s needs to be part of conversations; and the hospital environment, such as the workload of professionals. It is the interweaving of these factors that influence children’s competence. They are now considered under the headings of health professionals’ roles, parents’ roles and children’s views and experiences.

B. Health Professionals’ Roles

1. Health Professionals’ Communication Styles and Attitudes

Health professionals’ roles are central to children’s involvement in consultations, specifically their communication styles, attitudes, values, assumptions and time. For instance, health professionals who regard children as partners are more likely to communicate with them in an inclusive way, as they respect their abilities and contributions, rather than those who view them as vulnerable and in need of protection. Paternalistic attitudes can result in not only children’s exclusion from discussions, information and decision-making, but also cause them to have less meaningful encounters with health professionals, as the following two studies discovered. In Garth, Murphy and Reddihough’s research, the nine participating paediatricians acknowledged the importance of including children, describing the strategies they used, such as using understandable language. However, of significance was the purpose for which these health professionals involved children, as commonly they engaged with them more in preliminary discussions, to develop a rapport and to gather information, rather than providing them with information or making decisions.

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450 Beresford and Sloper, above n 19.
451 At 175-6.
452 At 174-177.
453 At 176.
454 For example, Young and others, above n 19 at 308; Coyne and others, above n 20 at 3; Lambert, Glacken and McCarron, above n 20 at 3098.
455 Lambert, Glacken and McCarron, above n 20 at 3099.
456 Coyne and others, above n 20 at 3. However, this was not the only factor. Four factors promoted children’s participation in treatment discussions with health professionals in hospital: familiarity with the hospital and procedures; children’s age; relationship with health professionals; and time.
458 Garth, Murphy and Reddihough, above n 71 at 48.
than to enhance children’s understanding and involve them in decision-making. The study found that, at times, children were excluded from conversations by parents and paediatricians gatekeeping information to protect them from stress, having regard also, to children’s preferences. This had the effect of controlling the degree to which children were involved in treatment discussions and decision-making.

Similarly, van Dulmen found in 302 outpatient encounters that children’s contributions were limited to 4%, almost exclusively for the purpose of “social talk and laughter and the provision of medical information.” Paediatricians sourced information from children (26%) more than they provided information to children (13%), which “would seem to be a contradiction, in that children are considered capable of providing information, yet not sufficiently capable of receiving information.” However, the average age of the children participating was low (5.3 years), which may have contributed to these findings, as the study found also that the level of communication increased with age. Nevertheless, if younger children are not encouraged or expected to participate by health professionals and parents, it can result in social conditioning, or “passive obedience”, where children feel inhibited, or are otherwise unable to contribute, thus constraining their competence. The rationale in some situations may be due to the seriousness of children’s health, such as in cancer, where there is a lack of treatment choice, and the adherence to protocol is paramount. For example, Ruhe and others found, during their qualitative research in eight paediatric oncology centres, that doctors and parents controlled information. They did this by filtering and pacing its disclosure, to times when they perceived children prepared to receive it, and also by influencing decisions, by providing persuasive explanations. Whilst children’s cancer treatment was curative, both health professionals and parents believed that they should make treatment decisions, but when palliative, children had more say.

In the case of disease progression almost all parents and physicians stated that the child’s point of view becomes more important than theirs. Thus, they related that as long as cure is possible, decisional priority lies with adults, but in palliative situations, the roles are inverted and a priority shift takes place.

However, some health professionals would give children choices for minor procedures in

\[459\] At 48.
\[460\] At 49-50.
\[461\] At 48.
\[463\] At 567.
\[464\] At 565.
\[465\] At 567.
\[466\] At 564.
\[467\] At 565.
\[468\] Coyne and others, above n 20.
\[469\] Ruhe and others, Putting patient participation into practice in pediatrics-results from a qualitative study in pediatric oncology” (2016) 175 European Journal of Pediatrics 1147 at 1149-1151.
\[470\] At 1149-1150.
\[471\] Wangmo and others, above n 18 at 14. Children may seek to have greater influence over palliative decisions than curative ones, viewing the decision in terms of the quality of their life, and it being their right to “fight or not to fight.”
curative situations, provided these did not affect the overall efficacy of the treatment, for example, whether to insert a port-a-cath.472 Yet, there is no indication that health professionals’ judgement, of whether or not to involve children in such decisions, was based upon children’s competence. It was rather defined by outcome or consequence. Other factors that influenced children’s participation, beyond the categorisation of curative/palliative in cancer, were (i) from adults’ perspectives: the parenting culture; health professionals’ attitudes; time pressure;473 and children’s age, health, emotional state, maturity and preferences;474 and (ii) from children’s perspectives: adults’ behaviour and the state of their illness.475

In the wider health context, beyond that of cancer treatment, Runeson, Enskar and Elander found a similar range of factors were significant to whether health professionals involved children in treatment decisions. Through obtaining the views of 350 Swedish health professionals (doctors, nurses, assistant nurses, play therapists and psychologists) the following issues were significant: children’s protests; age and maturity; parents’ roles; attitudes of staff; time; and whether alternatives were offered.476 These, in combination, influenced whether health professionals reconsidered their decisions to proceed with treatment when children refused, by for example, agreeing to administer medication in the child’s chosen method, or whether they forced treatment upon children. The complicity of health professionals and parents, at times, resulted in children being forcibly treated. For example, her parents and nurses held down a protesting two and a half year old, while a catheter was inserted, and a four-year-old boy’s father held him down while a blood sample was taken, whilst he screamed hysterically.477 Although older children were less likely to be forced to undergo treatment, the research found children aged eight and nine being forcibly treated.478 Children are more likely to co-operate if they have been emotionally prepared, understand the necessity and purpose of treatment and have a sense of control.479 Alderson contends that consent is not simply an act of signing a form, but a collective process, in which there is an exchange of information and consideration of options, to “arrive at a medical and moral agreement that satisfies both parties.”480 This applies equally to minor procedures, such as the insertion of nasogastric tubes or catheters, as it does for major surgery.

Naturally, health professionals are experts in their fields, advising and guiding families, but the exchange of information, particularly listening to children’s views and

472 Coyne and others “Children’s participation in shared decision-making: Children, adolescents, parents and healthcare professionals’ perspectives and experiences (2014) 18(3) European Journal of Oncology Nursing 273 at 278; Ruhe and others, above n 469 at 1149-1153.
473 Coyne and others, above n 472 at 278.
474 Ruhe and others, above n 469 at 1149-1153.
475 Coyne and others, above n 472 at 278.
476 Ingrid Runeson, and others “Professionals’ perceptions of children's participation in decision making in healthcare” (2001) 10 Journal of Clinical nursing 70 at 73.
477 At 73. The father refused to allow him anaesthetic ointment.
478 At 76.
479 At 103.
perspectives, is crucial to the best decisions being made.\(^{481}\) If assumptions are made on children’s views or best interests, and the focus is solely on treating health conditions, children may miss opportunities to contribute to discussions and decision-making. Powerful examples of this emerged in Alderson’s research in two children’s heart surgery units in England, when she considered the implications to children of decisions being made for them, rather than with them. 95 families were involved in her study, who were asked about their children’s illnesses and treatments, and how much they thought they were, or could have been, informed and involved in medical and nursing decisions. Accounts differed, with some families participating in joint decision-making with doctors,\(^ {482}\) whilst some parents were given little or no opportunity to have a discussion with the doctor, but simply asked to sign the consent form.\(^ {483}\) Patrick’s story illustrates what can happen when children are not consulted. Aged 10 years, Patrick was unable to stand straight, but could run in a hunchbacked way, and play football, which he loved. Following surgery to straighten his legs he became upright, and looked normal, which the surgeon regarded as a success. However, to Patrick it was a disaster, as he could no longer run.\(^ {484}\)

Several studies have found significant variability in health professionals’ practices of including children. Coyne discovered, for example, that nurses were using their personal perceptions of children’s cognitive abilities, rather than using specified criteria to decide whether to involve children, such as children’s understanding relative to the treatment.\(^ {485}\) This led to practices of involving only older children, of at least 13 years, preventing younger children from having a voice and developing their decision-making skills and experience.\(^ {486}\) Examples of this are vividly conveyed in Alderson’s study when she examined children’s ability to reach informed and wise surgical decisions.\(^ {487}\) Some of the 120 participating children, aged between eight and 15 years old, told of how they were not consulted in significant, body altering procedures, such as leg lengthening, and instead, surgeons made decisions.\(^ {488}\) Some adult participants were protective towards children, believing that it was not worthwhile informing them, as it was too much responsibility to make surgical decisions, or beyond children’s competence,\(^ {489}\) and that children would refuse treatment.\(^ {490}\) However, uninformed and excluded children feel ignored and forced into the surgery;\(^ {491}\) whilst informed children, who are able to talk about their anxieties and understand its purpose, are more likely to co-operate and be

\(^{481}\) Garth, Murphy and Reddihough, above n 71 at 50 where the children confirmed the importance of listening and having clear and open communication.
\(^{483}\) At 37.
\(^{484}\) At 104.
\(^{486}\) At 68-69. The impact of health professionals’ perspectives on children’s age is examined further at page 83.
\(^{487}\) Alderson, Children’s Consent to Surgery, above n 20.
\(^{488}\) Alderson, Children’s Consent to Surgery, above n 20 at 23.
\(^{489}\) Alderson, Children’s Consent to Surgery, above n 20 at 147-148.
\(^{490}\) Alderson, Children’s Consent to Surgery, above n 20 at 97.
\(^{491}\) Alderson, Children’s Consent to Surgery, above n 20 at 15-22.
less fearful. For some procedures, such as leg-lengthening, it is possible to give children time to understand and decide upon their options, as it can be undertaken until around the age of 30 years, although the clinical outcome may be greater if done earlier. However, being pressurised into the decision, or entering surgery unprepared, may come with psychological difficulties. Involving children, and giving them time to consider their options, respects their bodily integrity, individualism and growing competence.

It is essential to include children in treatment decisions to gain their views, perspectives, and concerns, particularly prior to treatment, but also during it when children are finding it invasive and/or distressing. This is not uncommon for children when undergoing dental treatment. The only study exploring the informed consent process during dental treatment is that of Smith and others who considered the degree to which children were involved when receiving stainless steel crowns. They found that children’s right to choose was not always respected, and consent not always sought, when they filmed 22 children undergoing this treatment. For example, although all the children were told that they could raise their hand to request that the dentist stop drilling, this was not respected for one child; whilst another received a local anaesthetic against his wishes, and without his mother’s consent, despite initially being advised that it would not be required. The first example highlights the on-going nature of consent, and the second is an extreme example of the dentist proceeding without consent. It is the exchange of information and working in partnership with both children and their parents that truly makes consent processes informed. Health professionals are in a position to inform and enable children to participate in discussions, decisions and in the self-management of their health. Whilst they may seek consent in the legal sense from parents, “[c]onsent is about sharing knowledge and control over decisions.”

Thus, health professionals’ attitudes towards children’s involvement affect the purpose and level of communication, the information they provide, and the extent to which they involve them in decisions. Where their focus is on protecting children from stress, or on the treatment outcome, they are less likely to involve children in these processes. Meaningful participation is therefore important in the development and attainment of competence.

492 Alderson, Choosing for Children: Parents’ Consent to Surgery, above n 20, at 103.
493 At 28.
494 Lee A Smith and others “Children’s Rights in their Oral Health Care: How Responsive are Oral Health Professionals to Children’s Rights (2018) 26 International Journal of Children’s Rights 354. The study involved six dental practitioners, each undertaking one to 14 treatments, involving children aged between four years and 11 months and nine years and two months.
495 At 364-365.
496 At 367.
497 For example, nurses teaching children to care for their wounds after surgery. Alderson, Children’s Consent to Surgery, above n 20 at 20.
498 Alderson, Children’s Consent to Surgery, above n 20 at 16.
2. **Significance of Health Professionals’ Perspectives on Age**

Health professionals’ perspectives on children’s age and maturity can influence their style of communication and the extent to which they involve children in discussions.\(^{499}\) Commonly, children’s involvement increases with age and cognitive level,\(^{500}\) but even then there are inconsistencies in practice, as Coyne and others found. In their study, only a few children, generally over the age of 13 years, reported positively on participation in discussions, and of those, only two reported situations where they felt able to question procedures.\(^{501}\) Additionally, health professionals tended to make decisions for children throughout the age range (seven to 18 years), with the consequences that some children felt health professionals did not view them as being capable; others felt annoyed that their experience of their health was not respected; and some had to insist on being involved.\(^{502}\) Highlighting this final frustration, was an 18-year-old, who reported having to assert, and re-assert, himself, on whether he received his treatment by way of injection or cannula.\(^{503}\) Coyne and others surmise that:\(^{504}\)

> Such experiences suggest that much younger children would require considerable courage to assert their right for inclusion and therefore may experience difficulties in having their voices heard.

Yet, consistently since the seminal work of Weithorn and Campbell, more than 25 years ago, age has been shown to be an unreliable indicator of competence.\(^{505}\) Their study demonstrated that children aged 14 years were as competent as adults in making informed treatment decisions in hypothetical situations, and those aged nine years, although less competent in their understanding and reasoning for decisions, were able to make reasonable treatment choices, equal to those of the older participants aged 14, 18 and 21 years.\(^{506}\) Thus, if preconceived perceptions of children’s capabilities based on age are eliminated, children have the opportunity to develop and demonstrate their competence. Alderson’s research highlighted how children’s competence can be enhanced to a level comparable to that of adults, when a psychologist recounted a three-year-old demonstrating understanding of the nature and purpose of his liver biopsy, from careful explanations by his mother, who was a nurse.\(^{507}\)

Factors having greater influence on children’s competence than age are receiving understandable explanations from health professionals, children’s experience and maturity.\(^{508}\) This is particularly relevant to severely ill children with lifelong/chronic

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\(^{499}\) Coyne, above 485 at 68-69. See also Coyne and others, above n 20 at 30.

\(^{500}\) Coyne and others, above n 20 at 48.

\(^{501}\) At 30.

\(^{502}\) At 43-44.

\(^{503}\) At 30-31.

\(^{504}\) At 31.


\(^{506}\) At 1595-6.

\(^{507}\) Alderson, above n 448 at 122.

\(^{508}\) For example, P Alderson, K Sutcliffe & K Curtis “Children as Partners with Adults in their Medical Care” (2006) 91(4) ArchDisChild 300; Wangmo and others, above n 18 at 11-20; Michael Rost and others
health conditions, such as cancer or diabetes, who can be cognitively ahead of their peers in their understanding of their health and its treatment, due to their experience and frequent interactions with physicians and parents. Children from as young as four years begin to understand the principles of managing their diabetes, for example, and can take responsible moral and ‘wise’ decisions in their best interests, as Alderson, Sutcliffe and Curtis found. They concluded that competence develops through experience, rather than according to age.

Similarly, Rost and others confirmed age was an unreliable indicator of children’s competence, when conducting quantitative research on shared decision-making in paediatric oncology, although participation in treatment decisions did increase with age. Most children participating in this study were capable of understanding their diagnosis at six and a half years; their prognosis at nine years; causes of cancer at nine and a half years; response to treatment at six years; and were able to make treatment decisions at 11.5 years. Parents rated their children’s capacities to understand diagnosis and prognosis information higher than physicians. Of more relevance to their competence than age were the family dynamic and children’s personality and maturity. As Alderson poignantly states “[c]ompetence is a way of relating to others, not simply an individual skill.” Thus, the manner in which health professionals communicate and build relationships become central to children’s competence.

Whilst age is not a reliable indication of competence, it is relevant to children’s communication needs and desire for information, as Gibson and others found in the context of cancer. Children aged four to five years relied on their parents to communicate with health professionals, also preferring to receive information from them, rather than directly from health professionals. On the other hand, children from six to 12 years preferred to communicate directly with health professionals, and those from 13 years favoured taking the lead over their parents. Likewise, these two older groups of children preferred receiving information directly from health professionals, but for children aged six to 12 years the level of information was important, with some needing

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509 Wangmo and others, above n 18 at 17.

510 Alderson, Sutcliffe and Curtis, above n 508 at 302. They interviewed 24 children between the ages of three and 12 years.

511 At 302.

512 Rost, and others, above n 508 at 562. Overall 44 out of 137 children (32%) were involved in decision-making. They belonged to these age groups: three out of 50 children from zero to four years (0.06%), six out of 36 children from 5 to 9 years (17%), 23 out of 38 children from 10 to 14 years (60.5%), and 12 out of 13 from 15 to 17 years (92%).

513 At 559.

514 At 562. Rost and others questioned the reasons behind this finding and note research in this area is lagging behind.

515 Wangmo and others, above n 18 at 17.

516 Alderson, above n 448 at 122.

517 Gibson and others, above n 18. Their study included 38 children/young people, divided into three age brackets: “young children” aged four-five years; “older children” aged six to 12 years; and “young people” aged 13-19 years.

518 At 1403.
health professionals to read their body language better, to gauge, for example, when they were comfortable/uncomfortable in discussing matters; when they were feeling overwhelmed; when they wanted more; and also to encourage them to ask questions.\textsuperscript{519} Teenagers were able to demonstrate greater independence and responsibility by seeking and retaining information.\textsuperscript{520} However, regardless of the age group, when children were well informed they felt more involved in the consent process, whilst insufficient information caused them anxiety.\textsuperscript{521} Although this study categorised children into age brackets, the researchers recognised that these are not fixed, with transitions depending upon the individuality and children’s development,\textsuperscript{522} and health professionals’ and parents’ roles.\textsuperscript{523}

3. \textit{Triadic Communication}

Health professionals’ abilities to manage the triadic dynamic are key to children’s success in participating in consultations when their parents accompany them. This involves health professionals being mindful of not only children’s abilities and views on participating, but also encouraging parents to support their children’s involvement.\textsuperscript{524} This dynamic can be challenging, as Van Staa found, when researching into the communication preferences and competence of adolescents (12-19 years). Hospital staff described managing triadic communication:\textsuperscript{525}

\begin{quote}
\ldots as balancing on a slack rope. Many felt incompetent to restrict parents’ involvement and to activate adolescents. Though professionals set the stage in hospital consultations, they seemed unaware of their power to turn the tables.
\end{quote}

Health professionals’ concerns lay in interfering in the parent-adolescent relationship and in parents’ established role as primary communicator or participant.\textsuperscript{526} Emphasising this was a finding in Coyne’s study, where some nurses felt that in order to involve children in decision-making, they needed both parents’ approval and children’s request:\textsuperscript{527}

\begin{quote}
\ldots nurses may experience difficulty involving children in decision-making and may not encourage involvement of children unless explicitly requested by the child and approved by the parent.
\end{quote}

While health professionals may sense that parents are in control of their children’s involvement, children may feel that health professionals take the lead and set the agenda.

\textsuperscript{519} At 1402.
\textsuperscript{520} At 1405.
\textsuperscript{521} At 1402.
\textsuperscript{522} At 1405.
\textsuperscript{523} At 1403.
\textsuperscript{524} Imelda Coyne and Pamela Gallagher “Participation in communication and decision-making: children and young people’s experiences in a hospital setting (2011) 20 Journal of Clinical Nursing 2334 at 2341; Runeson and others, above n 476 at 76.
\textsuperscript{525} AnneLoes van Staa “Unraveling triadic communication in hospital consultations with adolescents with chronic conditions: The added value of mixed methods research (2011) 82 Patient Education and Counseling 455 at 459.
\textsuperscript{526} At 460.
\textsuperscript{527} Coyne, above n 485 at 68.
in discussions. When health professionals are unable to successfully balance the triadic dynamic, this can contribute to children’s subordination in consultations. Nevertheless, although the triadic nature of interactions in consultations may be such that it constrains children’s involvement, there may be dyadic conversations occurring between parents and children at home, resulting in parallel, or distinct, discussions from those between parents and health professionals. Garth, Murphy and Reddihough questioned whether with age these merge into a triadic relationship, or remain dyadic, moving to one between health professionals and children.

4. Parents’ Roles

Parents’ roles and relationships with their children are also central to the development, and demonstration, of children’s competence. Parents can either enhance or limit their children’s abilities to participate in discussions with health professionals, understand their health/treatment and contribute to decisions. For example, in preparation for consultations, parents can be supportive by rehearsing questions and giving children the confidence to interact with health professionals. Conversely, they may be inhibitive by dominating conversations, taking control, answering for their children or asking them to be quiet. These traits may be due to their need to discuss matters with health professionals, or it may be an established dynamic.

Several studies demonstrated the multiple roles parents play: facilitating communication between their children and health professionals; acting as agents by sourcing information; shielding children by controlling information; educating; and interpreting.

In the researcher role … the gathered knowledge may have helped parents in one of their most important roles, connecting the physician and the adolescent through explaining the adolescent’s symptoms to the doctor, describing options to the adolescent,

References:

528 Van Staa, above n 525 at 459. This applied to children under 16 years.
529 Coyne and Gallagher, above n 524 at 2340.
530 Garth, Murphy and Reddihough, above n 71 at 50.
531 At 50-51.
532 Beresford and Sloper, above n 19 at 175.
533 At 175; See also Eileen Savage and Peter Callery “Clinic consultations with children and parents on the dietary management of cystic fibrosis” (2007) 64 Social Science and Medicine 363 at 368.
534 Coyne and others, above n 20 at 33.
535 Beresford and Sloper, above n 19 at 175.
536 Ruhe and others, above n 469 at 1153; Wangmo and others, above n 18 at 14.
537 For example, Coyne and Gallagher, above n 524 at 2340; Coyne and others, above n 20 at 3; Young and others, above n 19 at 306.
538 Young and others, above n 19 at 307. Participating were 13 children and young people aged between eight and 17 years who suffered from cancer or a brain tumour. This study also showed that there is no correlation between children’s age.
539 Ellen A Lipstein and others “I’m the One Taking It”: Adolescent Participation in Chronic Disease Treatment Decisions (2013) 53 Journal of Adolescent Health 253 at 256.
and asking the doctor questions the adolescent has posed.

Parents’ roles may change over time, particularly, where children have long-term health conditions. For instance, around the time cancer is diagnosed, gatekeeping is particularly prevalent, but can change over the course of treatment, with parents becoming more open. Nevertheless, for some, their desire to be protective, strong and positive for their children may result in them continuing to control discussions and information. Wangmo and others found that health professionals supported families in excluding children, or in filtering upsetting information, by respecting family dynamics. Overall, however, the study found that parents and health professionals were willing to include children in discussions, be open and build trust, in order that children could voice their concerns and understand their treatment and its side effects. This helped them to cope with their imaginations, which can be sometimes worse than the reality.

A number of factors have emerged as influencing whether parents encourage their children to participate in decision-making: the nature of health conditions; parents’ perceptions of the seriousness of decisions; their desire to protect their children; and their children’s preferences. Angst and Deatrick explored how the nature of the health condition/decision affected parents’ roles in involving their children in health care decisions. They compared two different health areas, the first, cystic fibrosis, a lifelong/chronic health condition, and the other, a distinct surgical procedure. The first group of 20 children who suffered from cystic fibrosis were required to make daily decisions relating to their therapies, medication and diet; whereas the other group of eight children with scoliosis, required to make an isolated decision to correct a curvature, distinct from the everyday management of a chronic condition. One might have predicted that the first group would be more involved in daily decisions than the latter group, having developed experience of managing their condition. However, the study found that generally children with cystic fibrosis were not involved in decisions, as parents and children followed the advice of health professionals without question, believing that there were few decisions to make. Similarly, these children were not involved in the daily decisions of their care, as this had not occurred to most parents. Three factors influenced parents’ views of their children’s involvement. Firstly, they had to recognise that there were options, or decisions, to be made. Secondly, their perception of the consequences - if serious, they were less likely to involve their children for fear of

540 Young and others, above n 19 at 306.
541 At 306.
542 Wangmo and others, above n 18 at 16.
543 At 14.
544 At 15. This was expressed in terms of children’s need to know, linking it to their health and welfare, rather than in terms of a right.
545 At 15.
546 Denise Angst and Janet Deatrick “Involvement in Health Care Decisions: Parents and Children With Chronic Illness” (1996) 2(2) Journal of Family Nursing 174; Garth, Murphy and Reddihough, above n 71 a
547 The age range of the first group was seven to 11 years, the average being nine years, and the second ranged from nine to 19 years, the average being 12.5 years.
548 At 181.
549 At 183.
a wrong decision compromising their children’s health. Thirdly, parents were more likely to involve their children if they had positive previous experiences of doing so.\textsuperscript{550} Children’s age was not a factor influencing whether parents involved their children.\textsuperscript{551} Many parents wanted their children to be involved in the decision-making process by receiving information, being included in discussions, and being “treated as children first.”\textsuperscript{552} Although most children (45%) liked being uninvolved, a significant proportion (35%) wanted greater involvement.\textsuperscript{553}

Comparing this with surgical decisions, all parents considered that they were involved in decisions,\textsuperscript{554} and that their children’s involvement evolved over time, through information and encouragement from them and health professionals.\textsuperscript{555} Most children made decisions jointly with their parents and health professionals, and had varying degrees of influence. For example, two children’s involvement and persistence were instrumental in persuading their parents to consent,\textsuperscript{556} and in one family, the 13-year-old made the final decision, as his parents felt that he was the one undertaking it.\textsuperscript{557} All parents and children felt involved in the process. The children/young people appreciated their views being heard on their desire for surgery and its timing.\textsuperscript{558}

Thus, in this study children were more involved in making surgical decisions than those with a lifelong/chronic condition. This may stem from both the belief, or understanding, that few options were available to them, and also from the perception that decisions are only made in respect of major procedures, rather than in the context of day-to-day health management.

Hence, parents play vital roles in the development of children’s competence. They support their children’s participation in consultations, for example, by preparing them and bridging any communication gaps. They enhance children’s understanding and decision-making abilities by researching and discussing the issues, and also by giving them emotional support and confidence. The other side of the coin is that they can equally constrain children’s participation and competence by dominating the relationship with health professionals. Listening to children, valuing their contributions and supporting them in their participation are therefore important roles for both parents and health professionals.\textsuperscript{559}

\textsuperscript{550} At 184.
\textsuperscript{551} At 184.
\textsuperscript{552} At 185.
\textsuperscript{553} At 185.
\textsuperscript{554} At 186. Three viewed themselves as primary decision-makers, with the others considering that the health professionals made the decision, to which they could agree or disagree.
\textsuperscript{555} At 187.
\textsuperscript{556} At 188.
\textsuperscript{557} At 188.
\textsuperscript{558} At 188.
III. Children’s Views and Experiences

A. Introduction

Children’s perspectives in much of existing research are represented through their parents, rather than from them directly. Yet, children have unique experiences, perspectives and preferences, which when listened to, give insights into how they think and feel about their interactions with health professionals and the management of their treatment. This section reviews the research literature that has involved children. It reveals the many factors influencing children’s participation, such as whether health professionals view them as part of a family unit, rather than also as individuals; whether they are given opportunities or encouragement to be involved; the extent of treatment choices; and the seriousness of decisions. This section begins with the research that emphasises the individual and changing nature of children’s participation, preferences and experiences, before moving to consider cancer treatment, highlighting the issues children may face, and the degree of competence they can possess.

B. Individualism

Children are individuals, distinct from their family unit, although naturally they receive essential support from their parents and families when receiving healthcare. Thus, their experiences may not coincide with those of their families, as Rasmussen, Water and Dickinson found when considering the factors that affect children’s experiences of hospitalisation. Through the narratives of six New Zealand children, they discovered some struggling with asserting their agency, such as one child, who spoke of being scared and overwhelmed having a room full of people looking at her and talking about her. In contrast, however, the mother of a nine year old girl, Teresa, who had died of cancer several months prior to the interview, told of how her daughter loved to participate in her own care and how most nurses encouraged her autonomy and individualism. She said, “care happened when Teresa … was allowed to be Teresa, rather than an anonymised child with cancer.”

Children’s preferences are important for health professionals to recognise, as some children may seek to be included more, but find this difficult to exercise. Kilkelly and Donnelly’s study showed that their preferences and experiences might not always coincide, as a range of external factors influenced their experiences. For example, children were able to participate more when: treated in a specialist hospital, rather than in a general one; were older; and consulted with health professionals who effectively...

561 Rasmussen, Water and Dickinson, above n 559 at 8. Six children participated aged six years, two nine-year-olds, 10 years and two described as “adolescents.”
562 At 7.
563 At 7.
564 Kilkelly and Donnelly, above n 21 at 38.
565 At 40.
communicated. In contrast, children struggled to effectively contribute when: health professionals communicate ineffectively; children did not know them; they were ignored, disbelieved, or not listened to by health professionals; there was insufficient time; and they felt inhibited, from fear of causing ‘trouble’, by asking questions.

Further insight into children’s communication experiences were discovered by Lambert, Glacken and McCarron, who coined the “visible-ness” spectrum, being “the degree to which children were, or wanted to be, included in the communication process.” Their study confirmed that age and experience did not equate to being at the forefront of communications, as some older and/or more experienced children preferred, and experienced, being in the background. Nevertheless, children were in “constant motion” along this spectrum, depending upon their preferences, the roles of health professionals and parents, and the healthcare environment.

Similarly, children’s inclusion in decision-making exists on a continuum, varying with individual preferences and existing at different levels, rather being ‘all or nothing.’ For example, Coyne and others discovered that children tended to distinguish between “small” and “serious” decisions, when they considered the experiences and views of 55 hospitalised children aged seven to 18 years with acute and chronic health conditions. Nearly half of the children (23) believed they would make only small decisions, leaving serious decisions to health professionals, and/or parents, because they know best, some doubting their abilities to make the right decision. Others felt that decisions should be shared, whilst some wanted to make their own decisions, believing that it was their right to have the final say over their bodies. Nonetheless, even those who preferred to be independent still expected that they would be encouraged and supported by their parents and health professionals. Significantly, only one child expected that health professionals would assess their competence to make serious decisions.

The authors concluded that age was not a determining factor in children’s desire to contribute to decisions, as children throughout the age range (seven-18 years) were willing to participate, with most believing it to be their right, as it concerned their health and bodies. Instead, it was dependent upon factors, such as parents’ and health

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566 At 42.
567 Coyne and others, above n 20 at 33 and 49.
568 Lambert, Glacken and McCarron, above n 20 at 3096. Their study found that children were ‘overshadowed’, marginalised, unheard and least visible in communications at one end of the spectrum, whilst those at the other end were at the ‘forefront’, being most vocal, with health professionals communicating directly with them.
569 At 3098. The study involved interviewing and observing 49 children aged between six and 16 years, with a variety of medical and surgical conditions in a hospital in the Republic of Ireland.
570 At 3099.
571 Coyne and others n 20 at 57.
572 At 23. 17 were aged between seven-nine years, 29 between 10-13 years and 9 between 14-18 years.
573 At 40-41.
574 At 41-42.
575 At 42.
576 At 42.
577 At 42.
professionals’ views and support, and children’s confidence in decision-making.\textsuperscript{578} Consistent with the findings of Kilkelly and Donnelly, children’s preferences and their experiences may not coincide, as they may experience difficulties in participating due to:\textsuperscript{579}

\ldots the lack of choice, lack of time for discussion and preferences being ignored. They generally felt that health professionals make the decisions without eliciting their views or presenting alternatives and then present them with a ‘fait accompli.’

In navigating the triadic dynamic (children-parents-health professionals), children may need to negotiate with their parents that they are ready to assume decision-making responsibilities, and gauge whether their parents are prepared to relinquish some control.\textsuperscript{580} As Coyne and others concluded, involvement in decision-making “is not a simple matter that occurs overnight; rather, it can involve a delicate negotiation process between parents and children.”\textsuperscript{581}

Thus, research indicates that most children prefer to be involved in consultations and decision-making, to some degree, but their experiences vary, due to a number of factors, such as, their parents’ views and support, health professionals’ communication skills, the healthcare environment and the seriousness of decisions.

\textbf{C. Cancer}

This section explores children’s participation and competence in the context of cancer treatment, a particularly grave health condition, with few treatment options. Research reveals that many children demonstrate maturity and realism about the seriousness of their cancer diagnosis and the lack of treatment choices.\textsuperscript{582} However, although they trust their parents and health professionals to make the right decisions, and recognise health professionals’ expertise, they can also feel frustrated at the loss of control from not being informed and included in discussions and decisions.\textsuperscript{583} Some may experience feelings of anger, inadequacy and challenge the treatment as a consequence.\textsuperscript{584} Understandably, some parents and health professionals may seek to protect children from adverse information at times,\textsuperscript{585} intending to avoid causing them fear or upset,\textsuperscript{586} but as Ellis and Leventhal found, children do not want information to be withheld.\textsuperscript{587} Most children in their study preferred to receive information directly from health professionals, but also

\textsuperscript{578} At 42.
\textsuperscript{579} Coyne and Gallagher, above n 524 at 2340. This confirmed the findings of Runeson and others, above n 476.
\textsuperscript{580} Coyne and other, above n 20 at 42.
\textsuperscript{581} At 42.
\textsuperscript{582} Coyne and others, above n 472 at 276; Wangmo and others, above n 18 at 15.
\textsuperscript{583} Ellis and Leventhal, above n 18 at 281.
\textsuperscript{584} Coyne and others, above n 472 at 278.
\textsuperscript{585} Ellis and Leventhal, above n 18 at 280 and 283.
\textsuperscript{586} At 280.
\textsuperscript{587} At 283. They explored the information needs and decision-making preferences of 50 children aged between eight and 17 years, and 60 accompanying parents.
favoured their parents to be present. When moving into their teenage years though, more sought to exclude their parents, with 42% of children/young people aged between 13 and 17 years preferring to have private discussions with health professionals. This study found also that there was a cumulative effect, in the sense that, the more information children possessed, the stronger their desire and need became for further information, which then resulted in them being more involved in the consent process. This applied across the age range of eight to 17 years. When decisions needed to be made, those aged between 13 and 17 years had a greater sense of it being their right to make these about later phase I, II and palliative chemotherapy than younger children, and more often than their parents felt they should. Nevertheless, most children/young people and parents preferred health professionals to decide, being content to follow their advice. When they were asked the reasons they had agreed to treatment, most children (90%) and parents (98%) indicated, it was due to trusting the health professionals. Ellis and Leventhal concluded that although children preferred to be fully informed about their disease and its treatment, “with the exception of terminally ill teenagers, children do not want to make decisions about their treatment.” However, the same could be said of parents, as most delegated that responsibility to the doctor.

Similarly, Coyne and others found that teenagers struggled the most with the limited involvement in decision-making. In their study, children aged between 12 and 16 years preferred to be informed, and to contribute to major, as well as minor, treatment decisions. Their dissatisfaction and frustration stemmed from the lack of choice, and being unable to influence the outcome. On the other hand, younger children (seven-11 years) reported satisfaction with their level of involvement in decision-making.

Several studies, including the above two, demonstrated that adults, in particular health professionals, make major cancer treatment decisions. This may be due to parents and children feeling ill-equipped to make these decisions immediately after diagnosis, and/or from a lack of treatment choice, as refusal is not an option. Adults may be uncertain whether children would agree to it, or may lack understanding of children’s competence.

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588 At 281. Only 18% were in favour of their parents and health professionals having private discussions. This compared with 77% of parents who sought private conversations.
589 At 281. Most parents agreed (73%).
590 At 282-283.
591 At 282.
592 At 281-2.
593 At 281.
594 Wangmo and others, above n 18 at 283.
595 At 283.
596 At 281-2.
597 Coyne and others, above n 472 at 275. “Major medical decisions included investigations, decision to treat, administration of cancer therapies, selecting a treatment protocol, and delivery of medical and nursing procedures. Minor decisions were decisions about how care/procedures would be delivered.”
598 At 278.
599 At 278.
600 See also Bianca M. Wiering and others “Sharing decisions during diagnostic consultations” an observational study in pediatric oncology” (2016) 99 Patient and Education Counseling 61 at 64.
However, this mistrust in children’s maturity and realism may be misplaced, as children can be accepting of adults overruling their views in the final decision. Most children simply seek to work in partnership with parents and health professionals, when treatment is curative (as opposed to palliative), as they value their opinions being taken seriously and decisions being taken together. These desires become stronger as treatment progresses, with children and parents becoming more knowledgeable. They may seek to redress the power balance with health professionals as a result. Families aim to live their lives as normally as possible, whilst also having the same goal as health professionals, of children’s survival. Thus, tensions can develop between families and health professionals over decisions relating to healthcare management, such as the timing of treatment, diet, and whether a nasogastric tube is inserted, as families seek to regain more control over their lives. However, health professionals’ agenda is to strictly follow the protocol in order to maximise its effectiveness and to standardise treatment. The children participating in De Vries and others’ research felt that they had no choice, and that their refusal would not be respected, even for minor procedures, such as the insertion of nasogastric tubes. Despite this research giving insights into why, at times, there were clashes in decision-making, it did not question the model of best interests, as the standard for reaching decisions. Thus, children’s competence, or their potential autonomy, was not addressed. The study’s focus was on the factors health professionals and parents take into account when considering children’s best interests, highlighting their different perspectives. They found that the way in which decisions in cancer treatment were taken had the effect of depersonalising children and subordinating them and their families to health professionals’ superior knowledge. In an effort to recognise the views of parents and children, with a view to making joint decisions with health professionals, De Vries and others proposed a model called “communicative ethics.” Although De Vries and others avoided discussing power or rights, this process is designed to give greater respect to the views and rights of families, acting as a vehicle to redress the balance of power, moving from a purely paternalistic approach towards a more rights-based approach.

It can be seen, therefore, that even in cancer treatment, where there are few treatment options, children’s preferences, needs and sense of their rights, are to be involved and to work in partnership with adults. They prefer to know the reality of the situation and to have some say in their treatment. Whilst they may not wish to have the responsibility of curative decisions, this increases when palliative. However, children’s response to cancer, and the degree to which they choose to be involved, will vary from child to child, and from time to time during their cancer journey. Respecting their individualism by adopting

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602 Wangmo and others, above n 18 at 17.
603 At 17.
604 De Vries and others, above n 601 at 7.
605 At 6.
606 At 5-6. Families and health professionals may have different perspectives on the degree of flexibility of protocols in cancer treatment.
607 At 6.
608 At 5-7.
609 At 8.
“an individualised flexible approach so that children can have an active, shared or passive role as and when they prefer” is key.610

D. Value in Children’s Participation and the Implications of their Exclusion

The benefits children derive from participating relate to their wellbeing, the development of their competence and relationships with adults, and compliance with treatment. Commonly children experience positive feelings when they are included in communications and decisions, such as feeling valued, respected and less anxious,611 as they are treated as individuals, who are “intrinsically worthwhile.”612 For example, most of the children participating in Kilkelly and Donnelly’s study were happiest when health professionals spoke to them directly, either in addition to, or instead of, their parents.613 They specifically appreciated being involved, and having an element of control, through being able to: accurately describe their symptoms; develop greater understanding of their health; build rapport with health professionals; have their fears allayed; and felt happier to co-operate with treatment.614 However, their participation was not to the exclusion of their parents, as they understood the importance of the roles of, and partnership with, parents.615

Underpinning children’s inclusion are the trusting relationships that children build with adults who are open and honest with them.616 Children appreciated knowing the truth, as it makes them feel less anxious, and helps them cope with the reality of their illness and treatment, rather than feeling isolated in their imagination, as Wangmo and others found in their cancer research.617 In this sense, the importance of children participating is expressed in terms of their need to know, rather than in terms of their right to know.618 Nonetheless, the two are not mutually exclusive, as children may also seek to participate to have their agency respected, as Coyne and others’ study revealed, when they considered children’s experiences of acute or chronic illnesses. The children in their study valued health professionals listening, and providing information directly, to them. They viewed these in terms of their rights to have their opinions about themselves and their bodies respected,619 together with helping them prepare for treatment and alleviating their fears.620

610 Coyne and others, above n 472 at 278.
611 For example, Lambert, Glacken and McCarron, above n 20 at 3097; Garth, Murphy and Reddihough, above n 71 at 48; Victoria A Miller and Abbas F Jawad “Relationship of Youth Involvement in Diabetes-Related Decisions to Treatment Adherence” (2014) 21 Journal of Clinical Psychology Medical Settings 183 at 187; Coyne and others, above n 472 at 278.
612 Wangmo and others, n 18 at 17.
613 Kilkelly and Donnelly, above n 21 at 41.
614 At 41.
615 At 40-1; Garth, Murphy and Reddihough, above n 71 at 50; Wangmo and others, above n 18 at 17.
616 Alderson, Choosing for Children: Parents’ Consent to Surgery, above n 20 at 129.
617 Wangmo and others, above n 18 at 15. This confirms earlier studies such as the results found in the context of surgery by Alderson, Choosing for Children: Parents’ Consent to Surgery, above n 20, at 129.
618 Wangmo and others, above n 18 at 17.
619 Coyne and others, above n 20 at 35.
620 At 2.
Research has found that the greater children/young people participate in their healthcare management, for example, through information sharing, negotiation, expressing their opinions and being presented with options, the greater their compliance with treatment. For example, Miller and Jawad’s study found that the value was in children and parents’ partnership:

Working through problems and decisions with parents provides youth with the opportunity to learn decision-making skills and have a voice in the process, with the parent still present as a source of support and guidance.

Conversely, research indicates that when children are marginalised in their interactions with health professionals, such as, by being only asked one or two specific questions; being physically excluded from consultations; having their treatment preference ignored; and having things done to them, with brief or no explanations, they experienced a range of negative emotions. These include feeling “disappointed, sad, confused, angry, worried, shocked, betrayed, lonely, ignored and rejected”, with the consequences that they feel “forgotten and depersonalised, as if they are an inanimate object with no feelings.” They are unable to express their concerns, or have their agendas addressed, as a consequence. These negative emotions are likely to compound children’s inability to participate, thus reducing their competence.

IV. Consent

Studies focusing on the consent processes have discovered inconsistencies in health professionals’ practices: some health professionals fail to take explicit consent, proceeding on an assumption; some take consent only from parents; whilst others take consent jointly from parents and children. For example, most oncologists participating in Dutch research, explicitly sought consent from either parents or children to commence cancer treatment in only two out of 43 consultations. This was despite the consent of parents and children over the age of 12 years being legally required. Three explanations were given for this finding: oncologists assumed parents wanted their children to receive it; the success of treatment reduced the need to discuss the risks and benefits; and refusal is considered to be not an option, as it could result in legal...

621 Miller and Jawad, above n 611 at 187. This sample of 89 children/young people aged between eight and 19 years with type 1 diabetes, and their parents, was part of a larger study involving 226 participants suffering from asthma or cystic fibrosis.

622 Miller and Jawad, above n 611 at 188.

623 Coyne and Gallagher, above n 524 at 2337.

624 At 2340.

625 At 2337.

626 Coyne and others, above n 20 at 52. See also Coyne, n 485 at 66.

627 Lambert, Glacken and McCarron, above n 20 at 3097.

628 Michaud and others, above n 96 at 363.

629 For example, Wiering and others, above n 600 at 64; Alderson, Children’s Consent to Surgery above 20 at 148-149; Kilkelly and Donnelly, above n 21 at 67.

630 Wiering and others, above n 600 at 64.

631 At 64. The study took place in the Netherlands where the age of consent is 12 years.
Taking consent only from parents was the norm for health professionals participating in Alderson’s study in the context of surgery. Commonly, children’s competence to consent was only considered at 16 years, with many believing that children legally required to be this age, or perceived that younger children were unable to take a long-term view, and/or that they should not bear such responsibility. Similarly, Kilkelly and Donnelly found differences in practice across health disciplines, with some taking consent from parents only, whilst others, particularly in specialist hospitals, secured joint consent from parents and children. The reasons for those taking children’s consent were to secure their co-operation, in the interests of the treatment proceeding successfully, and for it not to constitute an assault. The researchers recognised that this was an area deserving of further attention, particularly with a view to forming joint protocols for consistency of practice to safeguard children being treated with the highest standards.

In other healthcare environments, such as vaccinations in schools, parents give prior written consent, with children consenting orally at the point of vaccination. There is no difficulty with this consent process when parents and children agree. However, when there are differences of opinion, health professionals may feel unable to rely upon competent children’s consent, as Wood and others found when they considered the practices of vaccinating girls between the ages of 12-13 years with the HPV vaccination. Of the 25 health professionals participating, only three considered that there was no ethical dilemma to rely on the consent of a Gillick competent child, where there was no written parental consent. All three were involved in the development, rather than the implementation, of the vaccination programme. Most research participants held significant concerns about vaccinating without parental consent, although they accepted that guidelines on Gillick competence were relevant. These concerns included how Gillick competence could be assessed within a school setting; whether nurses had the skills to assess it; and potential damage that might be caused to schools’ relationships with parents. Their reservations of assessing Gillick competence

632 At 64.
633 Alderson, Choosing for Children: Parents’ Consent to Surgery, above n 20, for example at 37 and 38; and Children’s Consent to Surgery, above n 20 at 147.
634 Alderson, Children’s Consent to Surgery above n 20 at 147-149.
635 Practice areas of health professionals included GPs, dentists, nurses, play specialists, psychologist, anaesthetist, ear, nose and throat (ENT) consultant, radiographer, social worker, accident and emergency doctor and dermatologist.
636 Kilkelly and Donnelly, above n 21 at 67.
637 At 67.
638 At 68.
639 Fiona Wood and others “What constitutes consent when parents and daughters have different views about having the HPV vaccine: qualitative interviews with stakeholders (2017) 37 Journal of Medical Ethics 466 at 468.
640 14 were involved in the development of the vaccination programme and 11 in its implementation.
641 Fiona Wood and others, above n 639 at 468.
642 At 468.
643 At 468.
644 At 469.
were professional limitations/abilities, time restrictions, the girls’ ages, and professional risk. Nonetheless, one nurse felt that risks could be mitigated by “careful documentation of the Gillick assessment and consent-taking process,” and, despite reservations, all participants confirmed that they would respect the girls’ refusal to consent, for proceeding against their will was generally considered to be assault. However, almost all regarded such refusal as being an emotional response, and a lack of maturity, rather than viewing it in terms of being competent to refuse. Only one participant alluded to such competence. Wood and others recommended that guidance be provided for health professionals, including advice that girls who are Gillick competent can give consent, despite parental refusal. In Sweden a wider perspective on competence was adopted when Gottvall and others undertook similar research involving 30 school nurses who administered the HPV vaccine. The study explored the relational aspects of the consent process, suggesting that nurses should engage in an interests-based negotiation/mediation type process with parents, children and the school when there are disagreements, rather than focusing on rights. Contradictions emerged from the research. Firstly, all nurses considered that parental consent was required for 11-year-old girls, both in terms of the law, and their maturity, considering them too young to make such decision themselves, and therefore it was a parental responsibility. Yet, many believed that by the age of 15 years, girls should have the choice, and that the law was a barrier. They were willing to assist 15 and 16 year olds to be vaccinated without their parents’ knowledge when parents refused their consent. Secondly, although nurses respected the girls’ refusal, despite parental consent, they did not respect their consent when parents’ refused. The barrier of taking girls’ consent, for some, was the concern of excluding parents when it should be a joint process through discussion, as was their common practice. The rationale for this practice was to provide a transparent and democratic process, promoting “dialogue that could strengthen the autonomy of both child and parent, without necessarily destroying the family bonds.” Naturally, the ideal situation is that consensus will be reached

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645 At 469.
646 At 469.
647 At 469.
648 At 469. “RS: Well if we decide that they can make that decision to have it, then you have to partly accept the decision that they do not. I think you have just got to put it on hold and say, well perhaps we can revisit this again at another time. I don’t think you can actually physically force the girl to have it.”
649 At 470. These findings and recommendations are consistent with those of an earlier English study by Rebecca Stretch and others “A qualitative study to assess school nurses’ views on vaccinating 12-13 year old girls against the human papillomavirus without parental consent” (2009) 9 British Medical Council Public Health 254 in which 15 administering nurses participated.
651 At 51: “… a child younger than 18 years old needs the consent of a parent or guardian for medical interventions. However, the law also states that as the child grows older and becomes more mature, his or her wishes should be taken more into consideration.”
652 At 55.
653 At 56.
654 At 59.
655 At 58.
656 At 59.
657 At 60.
through communication, education and understanding, which health professionals can promote. However, where this cannot be achieved, there needs to be a mechanism for breaking the deadlock. The crux of the issue in such situations is whether the autonomy and competence of children will prevail over parental authority. Transparent criteria for the assessment of children’s competence, together with clear policies and legal provisions, could assist in resolving such matters.

V. Chapter Summary

Children’s competence develops, and is demonstrated, through children’s participation during the stages of the informed consent process, with health professionals and parents playing crucial roles in supporting children’s participation and competence. Competence or incompetence cannot be assumed, due to its complex relational nature. Research confirms that basing competence solely on age is an unreliable indicator, and thus during each consultation children’s competence needs to be supported. The relationship most children prefer to have with health professionals and parents is a partnership, as they value being listened to, and their contributions considered, when medical decisions need to be made. However, they prefer not to bear the responsibility of such decisions, until they move into their teenage years, when they seek more autonomy. When children are viewed as partners they feel respected, valued and less stressed, and can develop high degrees of knowledge and competence over their health, particularly when suffering from long-term conditions, such as diabetes and cancer, as they are managing their health on a daily basis, and frequently engaging with health professionals. As such, they can develop maturity, and be cognitively ahead of their peers in their understanding of their health.

Health professionals in general, and hospital nurses in particular, can play key roles in advocating for children, by ensuring that they are active partners in decisions about their healthcare. This can be challenging, due to work pressures and the lack of structure/criteria for assessing competence. As a result, practice becomes inconsistent, as it is based on their personal perceptions of children’s competence. Certainty and clarity of the law, policies and criteria would assist in providing more consistency in practice. For example, Coyne and Gallagher, recommended that:

Hospital policies and ward guidelines on information sharing and decision-making need to be developed. Such guidelines should emphasise the importance of giving children sufficient time to communicate and of not prejudging children’s capabilities by their age.

658 For example, Ellis and Leventhal, above n 18 at 280; Coyne and others, above n 472 at 275.
659 For example, Lambert, Glacken and McCarron, above n 20 at 3097; Garth, Murphy and Reddihough, above n 71 at 48; Miller and Jawad, above n 611 at 187; Coyne and others, above n 472 at 278.
660 For example, Alderson, Sutcliffe and Curtis, above n 508 at 302; Rost, and others, above n 499 at 559-562.
661 Wangmo and others, above n 18 at 17.
662 Coyne, above n 485 at 69.
663 Coyne, above n 485 at 68-69.
664 Coyne and Gallagher, above n 524 at 2340-1.
Chapter 6

Children as Social Actors

Theories are the Living Centre of Research.\textsuperscript{665}

I. Introduction

Childhood is socially constructed and has varied according to the prevailing social norms, attitudes, values, laws, politics, and culture throughout history, and is thus not universally defined.\textsuperscript{666} Prior to the 18\textsuperscript{th} century, childhood was regarded as a preparatory stage to adulthood, with little value being attributed to it. However, from the 18\textsuperscript{th} century, although childhood was separated from adulthood, providing children with a protected place, it was one in which they were viewed as dependent, vulnerable and ignorant. It was not until the 20\textsuperscript{th} century that children’s agency was recognised. By creating a separate space for childhood, children became visible, emerging from the family unit. Consideration could then be given to their lives, development, relationships and views.

Theories influence our attitudes towards children, enhancing our understanding of their status as citizens and rights-holders. This chapter begins by tracing the history of childhood, and how children’s status and our views of their competence have changed over time. The chapter then draws on Childhood Studies, which views children in the context of their lives, such as the culture, historical period and politics. It gives respect also to children’s individuality, by valuing their perspectives and views of their lives, providing a foundation for children’s agency and advocacy. Moving then to Sociocultural Theory, this continues to advance our thinking of children as social actors, with agency, rather than perceiving them as incompetent and vulnerable. It provides also deeper understanding of how children learn, acquire skills and make decisions through the support or ‘scaffolding’ from adults. Finally, adding to these principles of social agency, competence and scaffolding is the Capability Approach. This moral theory not only respects children’s human dignity, agency, abilities and individuality, but also promotes their freedom to make life choices based on their values.


II. **History of Childhood**

A. **Seventeenth to Nineteenth Centuries**

Controversially, Philippe Ariès claimed that childhood was invented in Europe in the 17th century, since “[i]n medieval society the idea of childhood did not exist.” 667 Earlier societies had recognised, however, that children were different to adults, and as such, had classified them. For example, in the time of Emperor Justinian in the Roman Period, childhood was separated into three periods: 668

*Infantia*, when children were incapable of speech, *tutela impuberes*, when, prior to puberty, children required a tutor, and *cura minoris*, when, after puberty, young persons had not yet reached their majority and required the care of a guardian.

The intent of Ariès’ observation was that society lacked sentiment for children, with a lack of awareness of their “particular nature.” 669 During this period “childhood was, relative to the nineteenth century, undervalued”, 670 although parents did nurture and care for their children. The goal was to produce functional citizens, and thus childhood was simply a preparatory phase for adult roles: 671

The overriding impression derived from ancient sources is that childhood was not seen as important for itself, but as part of a process towards producing a good citizen. … Moreover, it was common to consider children, not as individual human beings, but in terms of the services they could render their parents, partly in continuing the line, but also as supports in old age, and in carrying out essential rituals at the time of the parents’ death.

As soon as children were independent, they entered adult life, 672 which Ariès considered occurred at the age of seven years. 673 Nevertheless, in doing so they did not have the same role and status as adults, but found their place in the adult world, with “no boundary fence separating off the world of adults from that of children.” 674

Significant developments occurred in how childhood was perceived during the 18th century that led to its recognition as a distinct phase of life: 675

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669 Ariès, above n 667 at 128. For example children were depicted as small adults in art and played the same games as adults.
671 At 23.
672 Ariès, n 667 at 26.
673 At 21.
674 Cunningham, n 670 at 27.
675 At 58.
Some people began to see childhood not as a preparation for something else, whether adulthood or heaven, but as a stage of life to be valued in its own right.

Influencing this change in perspective were several factors, the most significant of which was the increase in secularism. Greater importance was laid upon children’s education, development and growth, moving away from their spiritual welfare.\(^676\)

... the evidence is powerful that a change of some magnitude occurred, one which may be summarised as the shift from a prime focus on the spiritual health of the child to a concern for the development of the individual child.

Significant in changing attitudes towards children was John Locke.\(^677\) He believed that child-rearing principles must be adapted to the individual, recognising that not all children are the same, having differing abilities and temperaments.\(^678\) Following Locke, the romantic poet Jean Jacques Rousseau perpetuated the appreciation of childhood in its own right. In his landmark work *Émile* (1762), Rousseau emphasised that children should be raised in accordance with nature, experiencing love and happiness, and learning through play.\(^679\) Combining these influences with improvements in domestic living conditions, such as, through greater privacy and comfort, family dynamics changed.\(^680\) Parents showed more affection and attention towards their children and their individuality.\(^681\)

Unfortunately, the economic reality of the Industrial Revolution rather overshadowed this Romantic Period, with children being exploited and abused for labour.\(^682\) Once more children entered the adult world, unprotected, and the concept of childhood was somewhat lost. Nevertheless, within the landscape of industry, three factors led to the reconstruction of childhood and the protection of children.\(^683\) The first was recognition that the nature of child labour was different from that of adults’, as children do not enjoy the same status in the employer-employee relationship. Secondly, following on from the first, were the parallels between children and slaves, and thirdly, were concerns for the breakdown of the ‘natural order’ that threatened the patriarchal society, as the demand for child and female labour increased.\(^684\)

In Britain, responding to these concerns, and preceding the passage of protective legislation, were debates that recognised the differences between adults and children. In

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\(^{676}\) At 59.


\(^{678}\) Hendrick, at 35.

\(^{679}\) At 65.

\(^{680}\) At 58-59.

\(^{681}\) At 59.

\(^{682}\) At 32.

\(^{683}\) At 35.

\(^{684}\) At 35.
1833 a Royal Commission declared childhood to end at 13 years, based upon psychological evidence and in recognition of children’s independence and competencies. This was the first step in Britain towards a socially constructed, and universal notion of, childhood. Ultimately, this led to state intervention by regulating employment and protecting children from the dangers of working. For example, the Factory Act 1833 was passed in Britain, prohibiting the employment of under nine year olds and restricting the working day to eight hours for children aged nine to 13 years. Likewise, enactment of the Education Acts in the 1870s and 1880s were pivotal in separating and institutionalising children by making, for example, schooling compulsory. Driving such changes, between 1830 and 1920, were concerns for “the child's soul”, “the future manpower needs of the state”, and “to save children for the enjoyment of childhood.” Protecting and educating children met not only their interests and rights, but also those of the State, in producing functional adults. However, in doing so, this positioned children as vulnerable, ignorant and in need of protection.

It was recognised that the child was not ready for life and that he had to be subjected to a special treatment, a sort of quarantine, before he was allowed to join adults.

Similarly, in New Zealand, from 1873, the government regulated the employment of children and placed greater importance upon their education. Traditionally, Māori children had been educated in whare wānanga, with missionaries establishing schools from 1816 to teach them literacy and practical skills. However, from 1800, the English influence had growing significance for New Zealand culture, family life and institutions, including the parliamentary, legal and education systems. The Education Act 1877 established free, secular and compulsory education for children between the ages of seven to 13 years, and children were entitled to attend from five to 15 years. Nonetheless, children continued to work, as their wages were important to poor and rural families, and as such, their attendance at school was irregular.

In health, separation of children from adults occurred also, with the growing specialisations of children’s medicine. Children’s hospitals opened, such as in Paris in 1802, followed by others in the mid-1800s in Germany, London, New York and Philadelphia. New Zealand followed with the first hospital wards for children opening in the 1880s. Health and development were then linked to education through, for

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685 At 35.
686 At 35.
687 For example, in Scotland schooling was compulsory for children between five and 13 years under the Scottish Education Act 1872, and in England for children between five and 10 years under the Elementary Education Act 1880.
688 Cunningham, above n 670 at 137.
689 Ariès, above n 667 at 412-3.
690 Children required to be over 10 years, were unable to work for more than eight hours in a day and prohibited form working at night. The Te ARA-the Encyclopedia of New Zealand <www.TeAra.govt.nz>.
691 Cunningham, above n 670 at 174-5. These early hospitals were initially only for the isolation of child patients, and it was not until the end of the 19th century that they specialised in treating children, leading to paediatrics as a distinct branch of medicine.
example, assessments of their physical and mental abilities, as a means of ascertaining whether they were able to participate in mainstream schooling. This had the effect of “categorising children by intelligence, and … measuring their physical development against newly-conceived norms.”693 Thus, the expectations of children’s development and capabilities were predetermined through generalisations, and measured by standardised testing.

B. Twentieth to Twenty-First Centuries

During the first half of the 20th century, childhood became increasingly defined by education, health and welfare, with significant refinements through the emerging fields of psychology and psychiatry.694 This provided new insight into children’s lives, such as their thinking, development, relationships and parenting. In particular, the work of Cyril Burt and Susan Isaacs gave greater understanding into children’s individual differences and their development, leading to an appreciation of children having the “same mechanisms of thought” and comprehension as adults.695 The effect of this knowledge was to view children in a more holistic way, taking account of their minds, personalities and emotions, as well as their physical welfare.

In the second half of the 20th century, there was growing cognisance of relationships between adults and children, children’s individuality, and the need to consider children in their social context. One catalyst for these changing perspectives was the surfacing, or re-surfacing, of physical abuse, and then later, sexual abuse.696 Some social scientists began reflecting on this power dynamic between adults and children, and by taking a child-centred approach, gained new insights into children’s individuality and their social lives.697 These two strands (children’s individuality and their social lives) were the foundations for promoting children’s rights, and for the emergence of Childhood Studies in the 1970s (or the Sociology of Childhood as it was formerly known). Both disciplines recognised that children were active and capable participants in the shaping of their lives.

Exemplifying this in England was Gillick in 1986. In New Zealand, movement in attitudes towards children’s status occurred also, albeit later, with the passing of the COCA in 2004, which replaced the Guardianship Act 1968. Children’s legal status shifted from being regarded as possessions, with their guardians having rights of control over them,698 to one in which parents have diminishing, or at least variable, authority.699 In Māori tradition children are regarded somewhat differently, having never been

693 Cunningham, above n 670 at 175.
694 Hendrick, above 677 at 43.
695 At 43.
696 At 48.
697 At 48.
698 For example, under section 3 “custody” was defined as the right to possession and care of a child and “guardianship” meant the right of control over the upbringing of a child.
699 Section 16(1)(c). Also, their views are respected and some rights recognised. For example, section 3(1)(b) recognises certain rights of children and section 6(2) respects their right to express their views and have those considered.
considered as property, but rather as taonga (precious or treasures) and rangatira mo oppopo (tomorrow’s chiefs). Māori children are not only children of their parents, but also of their extended family, whānau, hapu and iwi. Commonly, whānau is translated as “family”, but its meaning is more complex, since it encompasses the common values, understandings and relationships that bind the family together, including physical, emotional and spiritual dimensions. Children are protected and cared for, and decisions taken, collectively.

In the modern age, “media environments” and parents’ desire for “emotional gratification” are additional influences on children’s status and parent-child relationships. Children are exposed to consumerism through various forms of media. This has been linked to a lessening, or even a collapse, of parental authority, through parents increasing their spending on children, as a means of giving them a better childhood and having closer relationships with them. Consequently, it is thought that the demarcation between adults and children is becoming less defined, and children are seeking to gain their independence and enter the adult world earlier.

What has happened in the second half of the twentieth century is that parental authority has declined, and children have demanded and received an earlier access to the adult world; they have not been willing to accept the attempt to prolong childhood to the late teenage years. In some ways this represents a return to a historical norm in which childhood did not extend beyond fourteen at the maximum.

Postman has gone as far as suggesting that childhood is disappearing, due to the impact of media, such as television. Television has the ability to connect with people regardless of their age and intellect, and as a result is indiscriminate between adults and children. Children are exposed to matters that traditionally would be confined to only adults, such as fashion, current affairs, violence and sexual relationships. One consequence is a blurring of boundaries, with childhood and children losing their innocence, by choosing to act in an adult-like manner, and society responding in a corresponding adult way. One of the most serious examples of this involved an act of extreme violence in England, when two 10-year-old boys, Jon Venables and Robert Thompson, tortured and murdered Jamie Bulger in 1993. Venables and Thompson were tried and convicted in an adult court. It brought to the fore the polarisation of perspectives: on the one hand, viewing them as evil and responsible, justifying their treatment as adults; and on the other, acknowledging their vulnerability and need for protection, as they were still children. However, as Wyness points out, this perception of

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701 Children’s Charter at 5.
703 Hendrick above n 677 at 49.
704 At 49.
705 Cunningham, above 670 at 185. An example of this is the ruling in Gillick.
706 Postman above n 702 at 286.
707 At 290.
childhood disappearing, or being in crisis, is “based on the misplaced idea that childhood is inferior to adulthood”, inferiority referring to children lacking “the full range of roles and responsibilities demanded of adults.” Instead, he argues that the crisis is the understanding of childhood, which requires serious revision, as the boundaries between adults and children are being contested. However, rather than viewing this as a challenge to authority, it can be considered positively in the sense that children are becoming less reliant on adults and more capable. Despite this shift in the power dynamic between parents and children, it is probably still weighted in adults’ favour as they have economic, political and “age-patriarchy.” For example, Hood-Williams argues that childhood remains “a firmly exclusionary status” and that children “remain subject to authority relations.” Parents continue to demand obedience over children’s space, bodies and time, with this positional power more distinctly defining the boundaries between childhood and adulthood.

III. Childhood Studies

A. Introduction

Childhood Studies emerged over 30 years ago, initially called ‘the sociology of childhood’ due to its academic base being in sociology and social anthropology. It then evolved into Childhood Studies, with the inclusion of other fields of research, such as education, health and law. It challenged the dominant theory of its time, child psychology, which regarded children’s development as pre-determined, moving through a sequence of stages from the immature and irrational, to the mature and rational, achieving complex thinking in adulthood. Jean Piaget was the most influential exponent of children’s cognitive development, believing that the child in isolation, as defined by the stage of development, determined learning. Childhood Studies, on the other hand, positioned children’s learning in the context of social relations and culture, being subjects, active in their own lives, learning and development.

708 Michael G. Wyness, Contesting Childhood (Falmer Press, London, 2000) at 1. See also Cunningham, above n 670 at 180.
709 Wyness, at 1.
712 Hendrick above n 677 at 50; Hood-Williams, above n 702 at 165-169.
713 Mayall, above n 710 at 3.
714 E. Kay Tisdall and Samantha Punch “Not so ‘new’? Looking critically at childhood studies (2012) 10:3 Children’s Geographies 249 at 249.
716 At 10.
718 Smith, above n 717 at 17.
Childhood studies ... positions children as participating subjects, knowers and social actors, rather than the objects of socialisation.

Thus, this theory provides a different interpretative framework or paradigm within which to analyse and research childhood, by drawing together three elements: acceptance of children as social actors in shaping their lives; the permanence of childhood as a social structure; and its variance according to the historical period and culture. As such, childhood is described as a social construction. By thinking more widely about the concepts that create this social construction, such as environmental space and time, Childhood Studies can further adapt to new situations, giving deeper understanding to children’s lives, capacities and development.

Nevertheless, there remains a place for developmental child psychology, as otherwise the reality of the many changes in children’s lives is sidelined, such as their physical, emotional and intellectual development, their maturity, interests, perspectives and skills. By giving attention to both fields, respect is given to children’s present lives, as well as to their future ones.

Childhood Studies, in common with Sociocultural Theory and the Capability Approach, gives respect to children’s individuality, competence and agency. In the next section, the key principles of Childhood Studies are firstly considered, before turning to children’s agency and individuality, followed by an exploration of how Childhood Studies could further evolve as a theory through the use of dialectical critical realism (DCR). DCR separates ontology from concepts, such as agency and law, which gives greater understanding of children’s lives.

**B. Key Features of Childhood Studies**

Childhood Studies views children in various contexts of their lives, having regard to both the external settings, such as culture, history and politics, and also children’s internal features, for instance, their age, gender and beliefs. Within this framework two key features emerge: the social construction of childhood; and recognition of children’s status through their agency and rights.

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719 James and Prout, above n 677 at 3.
720 At viii.
721 At xii.
724 At 54.
725 Alderson, above n 665 at 20.
727 Woodhead, above n 726 at 19.
Firstly, the notion of social construction recognises that children develop in the context of social relationships, which themselves are influenced by cultural, politics, history and social practices and beliefs. Every aspect of children’s lives, such as the ways in which they are parented and educated, their recreation and health are influenced and defined by societies’ beliefs and understandings of the time. Further, childhood and children’s status are political, due to the power imbalance between adults and children. Children lack the economic and political power, and as such, to a large extent, depend upon adults to represent their views and protect their interests.

This leads to the second feature of Childhood Studies, children’s agency and rights. Pre-requisites to children’s agency are being able to form, and express, views. Views tend to be used in a fairly generic way, but are broader than simply their opinions, as they include matters such as values, priorities and aspirations. Pufall and Unsworth capture the depth of children’s voice when they define it as “that cluster of intentions, hope, grievances, and expectations.” Through such expression emerges their individuality.

Agency is an extension of being a social actor, as it is the process by which their voice is heard. The concepts of actor and agency are central to contemporary Childhood Studies. Mayall defines these concepts as follows:

A social actor does something, perhaps something arising from a subjective wish. The term agent suggests a further dimension: negotiation with others, with the effect that the interaction makes a difference – to a relationship or to a decision, to the workings of a set of social assumptions or constraints.

However, simply identifying the existence of children’s agency is insufficient. The enquiry needs deeper exploration to understand the reasons why children can sometimes demonstrate agency, and at other times, not.

The observation that children can exercise agency should be a point of analytical embarkation not a terminus.

From consideration of these features of Childhood Studies, the importance of adults’ roles and relationships with children unfold. Adults’ attitudes, values and understandings, and their relationships with children, affect children’s development, opportunities, experiences, status and the implementation of their rights. When adults value children’s

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728 As highlighted in above in ‘The History of Childhood’ section of this chapter, childhood and the status of children are understood and defined differently at various periods in history.
729 For example COCA, s 6.
732 Mayall, above n 710 at 21.
views and abilities, it enhances children’s competence and respects their rights. Conversely, when adults hold a paternalistic view, seeing children as vulnerable, ignorant and in need of protection, or are motivated by exerting their power and status, children’s rights and competencies will be constrained.

Childhood Studies considers “matters such as competence, not as fixed and measureable facts, but as shifting, contingent, social experiences, co-constructed between children and adults.” It is within relationships, and through negotiating the power dynamic, with their parents, siblings and teachers, for example, that children learn and develop behaviours, skills and values. They learn where the boundaries lie, recognising that adults have authority over them, although these will change over time, as children acquire increased knowledge, experience and independence.

Thus, competence is relational, and not simply a skill that children acquire alone, or develop at a specific stage of their development. It relies on interactions with adults. In the health context, for example, children’s competence is promoted by parents preparing children for consultations, and supporting them in discussions, and by health professionals communicating effectively with them. With adults fulfilling these roles, children have the opportunity to effectively enter into discussions. These relationships are of the paramount importance to the development and demonstration of children’s competence.

C. Evolution of Childhood Studies

Although Childhood Studies began to flourish from around 1990, with many studies giving children the opportunity to participate, Alderson considers that greater attention needs to be placed upon children’s real existence or being (ontology), as distinct from concepts and thoughts (epistemology): Researchers … tend to reduce being into thinking, ontology into epistemology, things into thoughts, to mistake their perceptions and reports for reality, or to deny that there is an independent, essential reality. This reduction and loss of reality into ideas, termed the epistemic fallacy … is at the heart of social science and childhood studies.

In order to separate ontology from concepts Alderson turned to DCR, “a philosophy of how knowledge about people and their social structures may be construed, interpreted, described and fitted together.” She argued that DCR could support Childhood Studies research by, for example, “moving beyond describing and documenting, to include

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734 Alderson, above n 665 at 10.
735 Mayall, above n 710 at 29.
736 Alderson, above 665 at 13-14.
737 At 20.
738 Alice AA Sawyerr and Christopher A Bagley Equality and Ethnic Identities (Sense Publishers, Rotterdam, 2017) at 27.
analysing, making connections, explaining and working to resolve contradictions.” By doing so, children’s actual existences can be seen.

However, Qvortrup observed that whilst there has been a trend towards research at a micro level, which enables children’s voices to be heard more than is possible in large-scale survey based research, generalisations cannot be made from them. Whilst Qvortrup favours research at a macro-level, such as considering how political and economic conditions or structures affect large groups of children, he does acknowledge that “there are many ways of collecting information about children’s lives and childhood. No one method alone can produce all knowledge needed.” Alderson agrees that there is merit in both approaches. By separating the infrastructure from the individual child, it informs and raises awareness of the inequalities children experience, perhaps also raising its importance on a political level. However, without including children themselves, research risks being ill-informed. Alderson’s point is that adults should step into the shoes of children, and see their reality, rather than making assumptions. This debate would appear to be similar to that of the value of qualitative versus quantitative research, the former giving greater insight into the personal experiences of individual children, and the latter enabling trends and generalisations to be seen. There is a place, of course, for both, with one helping to inform the other. This is of particular relevance, and importance, when reviewing laws and policies, which are developed by one generation, but affect another. As each generation has a different set of perceptions, experiences, values and goals, it is of importance that there is involvement of both.

A further use of DCR is to separate the ontological entities of structure and agency, as it has the effect of illuminating the relational characteristic of childhood. It does this by emphasising how the structures, such as laws, policies and practices, control or regulate childhood, and also how they intersect with both adults’ and children’s agency, in the forms of their characteristics, views, experiences and goals. This process of separation is a useful process in the context of children providing medical consent, as it can be seen whether laws, policies and practice meet the needs, and reflect the reality, of children and their competence.

Additionally, by applying DCR, it may give more credibility and validity to research, and therefore, in turn more influence. This view arises from Alderson’s concern that by separating the study of childhood from mainstream social science and society, it has less impact upon policy, practice and public thinking, and she questions whether in reality the

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739 Alderson, above n 665 at 20.
740 At 20.
742 At 31.
743 Alderson, above n 665 at 104-105.
744 Mayall, above n 710 at 30.
745 At 30.
746 At 39.
747 Alderson, above n 665 at 18.
issues studied can be separated from the adult world. This issue is of significance to the question of how children's right to provide medical consent should be regulated - whether based on reaching a specific age, or upon competence. The former has the effect of defining this right by status, excluding those who have not reached it, rather than upon ability or competence. By Childhood Studies being more reflective and critical of its own research practices, and of the issues it researches, it will develop into being a more critical social science. This is achievable from not only identifying what is happening, but also asking why, and in turn, what needs to change, in order to make the situations better for children.

Thus, Childhood Studies positions children in context, viewing them as competent and active participants, in the shaping of their lives. This theory recognises that children contribute to their own learning, development, relationships and decisions, by using their experiences and expressing their views. This occurs, however, in a relational context, relative to their parents and other adults, who can support them. Through children and adults working together, children can on a personal level express, and exercise, their individuality and independence, and on a macro-level can influence practices, policies and laws. This theory provides a strong foundation for examining children’s competence to participate in managing their healthcare, and in considering how best to reflect this in practice, policy and law. As demonstrated by the research literature considered in the previous chapter, children learn about their health and treatment by being involved, whilst being supported by adults. By placing children at the centre of this process, and understanding their perspectives, their competence can evolve, and child-sensitive practice can develop. Woodhead sums up Childhood Studies as offering:

... an integrative framework for elaborating a 'child-centred' research that is holistic in approach, and built around children's agency, their rights and their well-being, which is especially sensitive to the relationships between researcher and researched and which is inclusive of diversities related to age, gender, ethnicity, place and time.

IV. Sociocultural Theory

A. Introduction - Key Features

Adding to our understanding of children’s participation and development of competence is Sociocultural Theory. This emerged in the 1980s and 1990s from the thinking of Lev Vygotsky, a Russian child psychologist, described as the father of sociocultural theories. He viewed children’s learning and development as a social process set in a cultural and historical context, rather than a universal one that all children follow.
There is no one pathway for development (such as the Piagetian progression towards rationality), rather development depends on cultural goals.

Central to Sociocultural Theory is recognition of children’s agency as a relational and active process. Children learn and develop through participating in activities and engaging with others in “a reciprocal partnership where adult and child jointly construct understanding and knowledge.” Children are of course not limited to learning from only adults, as they spend much time with other children, such as siblings, friends, and from those sharing similar experiences.

B. Scaffolding

Sociocultural Theory recognises the importance of the social, dynamic and relational nature of children’s learning and development through the support of those more skillful. Children acquire skills, not simply from observing others, but also from practicing and being challenged. In becoming adept at existing skills, they build upon these to develop more complex ones, with assistance:

Children advance to higher stages of development by being stimulated and guided at the outside limits of their skill by others. Child development is the result of children’s competence being challenged and extended with help. The help is gradually withdrawn and children become able to perform more and more on their own.

The type of support through directing, guiding and supporting children’s learning and development has become known as “scaffolding”. This is a metaphor that arose from Vygotsky’s theory, and was coined by Wood, Bruner and Ross.

Scaffolding involves:

… process that enables a child or novice to solve a problem, carry out a task or achieve a goal which would be beyond his unassisted efforts. This scaffolding consists essentially of the adult "controlling" those elements of the task that are initially beyond the learner’s capacity, thus permitting him to concentrate upon and complete only those elements that are within his range of competence. … It may result, eventually, in development of task competence by the learner at a pace that would far outstrip his unassisted efforts.

It occurs through people around the child, such as parents, siblings and teachers, modeling and instructing how tasks can be performed, so that the child can learn new ways to approach or understand situations, and enables the child’s capacities to evolve. As the child becomes more experienced, a transition occurs, with the support

754 At 21.
755 At 28.
756 At 22.
757 At 25.
760 Children’s evolving capacities are reflected in UNCRC Article 5 and COCA s 16.
being gradually withdrawn, and the child’s contribution increasing, until the child can manage alone: 761

… children’s interests are best promoted when they are given opportunities for graduated decision making that enable gradual assumption of independence so that full autonomy is not exercised until there is some experience with the decision or task.

This process can apply to specific skills, such as reading or swimming, and to general ones that can be applied in many contexts, for instance, critical thinking. Through practice and experience children build their own sets of knowledge, skills and views, making it unwise to generalise about children’s abilities and responsibilities based only on age. Rather than age being a threshold for measuring children’s abilities and responsibilities, it is simply a biological marker. The plasticity of our perceptions of children’s abilities based on age is highlighted by Anne Solberg’s study, which discovered that the more responsibility children took in the home, by carrying out work and being alone, the older they became in the eyes of their parents. 762 Thus, when children are permitted to engage in activities, and assume responsibilities, it has a dual effect of: (i) developing children’s internal attributes, such as their experience, maturity and intelligence; and (ii) adults’ perceptions of these changes.

Nevertheless, the law tends to set thresholds for ages at which children are permitted to do activities, or when they can/must accept responsibility. For example, they can attend primary school at five years in New Zealand, 763 and be responsible for certain serious crimes from the age of 10 years. 764 Yet, age is an arbitrary concept, highlighted, for example, by the wide age range at which children assume criminal responsibility throughout the world. 765

Hence, Sociocultural Theory is relevant to the issues of children developing competence to consent to medical treatment, and to how that is reflected in practice and law. At a micro-level, children need supportive adults, giving them opportunities to practise skills, such as, contributing in consultations, understanding information about their health/treatment, and making decisions. As they practise these skills, and develop experience, they become capable of undertaking more complex tasks, and also more autonomous in the process. Research demonstrates how, for example, children living with lifelong/chronic health conditions become knowledgeable and skilled at managing their health. 766 Although principally parents and health professionals will provide such

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762 Anne Solberg “Negotiating Childhood: Changing Constructions of Age for Norwegian Children” in Allison James and Alan Prout (eds) Constructing and Reconstructing Childhood (RoutledgeFalmer, 1997) at 134 and 141.
763 Education Act 1989 section 3.
764 Crimes Act 1961 section 22(1).
766 For example, Alderson, Sutcliffe and Curtis, above n 508 at 302; Rost, and others, above n 499 at 559-562.
support, children in hospital, for example, are surrounded by others enduring similar experiences, who can also provide a learning environment. As a consequence, children develop knowledge, skills and maturity beyond those of their peers, who are not in the same situation. Also, at a macro-level, policies and law need to reflect the unique ways in which children develop competence. Age-based policies and laws fail to reflect children’s individuality and can undermine and underestimate children’s competence.

V. Capability Approach

A. Introduction

The Capability Approach was developed by Amartya Sen and Martha Nussbaum over the last 30 years, focusing on “participation, human well-being and freedom as central features of [human] development.” This theory is based upon the principles of people flourishing and developing, through promoting their agency and freedom, to live the lives they consider worthy. The Capability Approach extends our thinking and understanding of competence, leading to the freedom to make choices. In this section I will firstly explain the theory and then explore its applicability to children.

B. What is the Capability Approach?

The Capability Approach is a theory that focuses on people’s opportunities. It asks, what can people do and what do they want to be? It has three key concepts: capabilities, functionings and conversion factors. “Capabilities” are defined as the freedom to choose, and act in ways, in accordance with one’s values - by “opening up the maximum number of choices for individuals is equivalent to supposing that they, alone, can judge what is good for themselves.” “Functionings” relate to people’s state of being, their skills and actions that they value. They range from the very basic, such as being nourished and healthy, to the more skillful, such as riding a bicycle and reading. The difference between functionings and capabilities is that the functionings are the achievements, or outcomes, whereas capabilities are the opportunities, or freedom, to choose to live one’s life in the preferred way, using the acquired functionings. However, in order to develop and acquire these, “conversion factors” are required. These are (i) internal/personal, such as intelligence and health; and (ii) external, such as societal, which relate to policies.

768 At 7.
772 Comim and others, above n 767 at 8.
practices, laws and power relationships; environmental; and household - the family’s income and education. Thus, people with the same or similar functionings can have differing capabilities, depending upon their conversion factors. Adult interactions are conversion factors that will either promote or constrain the development, and demonstration, of children’s capabilities and functionings. Children are not passive recipients, as they contribute to the dynamic in the ways they respond to, and influence, that support. This results in a cumulative effect, with the more functionings and capabilities children acquire, the more these evolve; and conversely, the greater the constraints, the fewer functionings and capabilities children can develop. It can be seen how this process is relational and dynamic. Applying this to the health context, children may possess the communication skills and understanding (functionings), but unless, for example, parents prepare them for consultations, and health professionals include them in conversations, assess their understanding, and provide them with the opportunity to give consent (conversion factors), then they are prevented from making choices (capabilities). Likewise, if the law or policies (conversion factors) do not protect their rights, they will be prevented from choosing their preferred course of action.

Figure 1 provides a theoretical model I have developed to depict the process for conversion factors being used to develop functionings, that in turn, convert into capabilities through conversion factors.

**Figure 1: Process of Functionings Converting to Capabilities under the Capability Approach**

### C. Applicability to Children

Central to the Capability Approach is the concept that human development involves the building of people’s functionings to expand their capabilities, so they can live the life they consider worthy. Human development is conceived in terms of having choices and freedom. In order to achieve this, participation and agency are required, concepts

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774 Comim and others, above n 767 at 8.
775 Ballet, Biggeri and Comim, above 770 at 30.
776 At 31.
which are familiar to children’s issues.\textsuperscript{778}

… the CA [Capability Approach] asks how each and every person is doing, and its goal is the empowerment of each? Children are no exception.

Over the years, the Capability Approach has adapted to incorporate children into its thinking. It has progressed from believing children have only future capabilities in adulthood, or minimal/basic ones, such as relating to their survival,\textsuperscript{779} and consequently lack freedom of choice,\textsuperscript{780} to introducing the notion of evolving capabilities.\textsuperscript{781} The challenge for the Capability Approach, and the matter upon which it requires to assert its position, is in respect of children’s capacity for self-determination, as within the theory self-determination is implied.\textsuperscript{782} The question is, what are the boundaries of children’s right to self-determination? Ballet, Biggeri and Comim’s view on this is that the theory’s standpoint requires to be “softened for children, but not abandoned.”\textsuperscript{783} They suggest four perspectives, two of which are compatible with the notion of evolving capabilities, which are considered below. The other two perspectives are acknowledged as oversimplifying the issues.\textsuperscript{784}

Firstly, Ballet, Biggeri and Comim argue that the issue is not that children are unable to make choices, but rather whether they are able to revise and reconsider them. By adults providing them with “choice space”, rather than making choices for them, they can practise and develop their decision-making capacities.\textsuperscript{785} In this sense, children’s evolving capabilities are recognised.

Secondly, if children’s evolving capabilities are viewed from a child-centred and subjective perspective, it reveals that they exercise self-determination and agency throughout their lives. It is the ways in which they do that varies. For example, for one child, walking on their own to the local shops, may be comparable in autonomy and agency to another, more experienced child, taking a trip in an aeroplane.\textsuperscript{786} The degree of self-determination needs to be considered from the child’s perspective, which will evolve with age and maturity.\textsuperscript{787} However, of relevance are more than simply age and maturity, but also the internal and external conversion factors, enabling them to realise their functionings and capabilities.\textsuperscript{788} This is the reason, for example, that young children, who are given clear explanations, are able to demonstrate competence comparable to those of older children or adults.\textsuperscript{789}

\textsuperscript{778} Dixon and Nussbaum above n 769 at 560.
\textsuperscript{779} Ballet, Biggeri and Comim, above n 770 at 22 and 25.
\textsuperscript{780} At 25
\textsuperscript{781} At 28.
\textsuperscript{782} At 25.
\textsuperscript{783} At 23.
\textsuperscript{784} At 26.
\textsuperscript{785} At 27.
\textsuperscript{786} At 27-28.
\textsuperscript{787} At 28.
\textsuperscript{788} At 29.
\textsuperscript{789} For example, Weithorn and Campbell, above n 505 and Alderson, above n 448 at 122.
Peleg advances these points by indicating that:

… it is not children's ability to choose that is debated, but rather the space that society, adults and the law gives children in order to make a choice, and the tolerance for what adults consider to be a mistake.

Therefore, the Capability Approach can provide a theoretical basis for not only recognising the development of children’s competence and their agency, but can also support the argument that once children have attained competence, it gives them the right and freedom to make decisions according to their values and life choices. This is of particular relevance to when children are assessed as being competent to make health decisions, as the implication of being competent is to make the decision and provide consent.

Moreover, the Capability Approach gives recognition to children’s individuality, experience and strengths, and as such can take a child-centered approach. This theory is egalitarian and liberal, focusing on what children are able to do, and what they want to be, recognising their priorities, values and aspirations.

V. Chapter Summary

Individually, and in combination, these theories shift our thinking on children’s status, development and competence. Instead of viewing children as passive, ignorant and vulnerable, there is more understanding of their abilities, and how these develop. By tracing the changing conceptions of childhood throughout history, it has highlighted the differing attitudes and expectations of children. In some ways, childhood has come full circle from where it was in the 17th century, as today’s children also have independence, finding a place in the adult world, before reaching adult age. However, in those earlier times, childhood had not been defined and separated in the ways it has today. By separating children into the category of childhood, it defines them as having distinct qualities from adults, and as a consequence, are treated differently. Adults’ perspectives on these differences are key to children’s abilities to shape their lives, express their views, contribute to decisions and expand their competence.

Childhood Studies has increased our understanding of children’s status and development by positioning children in context. The external influences of their environments and relationships, together with the ways in which children respond to them, demonstrate the relational nature of children’s learning and acquisition of competencies. Sociocultural Theory builds upon this, with the concept of scaffolding, highlighting the importance of supporting children in their development. This process, being both dynamic and relational, demonstrates the evolving nature of the ways in which children’s competence grows: the more responsive the support, the greater children’s competence develops.

790 Peleg, above n 777 at 533-534.
Contributing to, and advancing, our thinking on children’s competence and autonomy, is the Capability Approach, which provides an egalitarian theory, complementing Childhood Studies and Sociocultural Theory. By recognising children’s functionings and capabilities, it gives respect to children’s rights to make decisions, in accordance with their views, values, priorities and goals. It values both children’s present and future situations.

These theories together, provide a comprehensive foundation for appreciating the ways in which children develop competence in the healthcare, and upon achieving it, gain the right and freedom to make health decisions. Through parents and health professionals supporting children, and enabling them to participate, children’s competence and autonomy will develop. Initially, children may be in a position of inexperience and ignorance, at the time of diagnosis or treatment, but that does not define their status or level of potential competence, unless that is the expectation of adults around them.\(^7^9^1\)

\(^7^9^1\) Pia H. Christensen “Childhood and the Cultural Constitution of Vulnerable Bodies” in Alan Prout (ed) *The Body, Childhood and Society* (Palgrave Macmillan, United Kingdom, 2000) at 38.
Chapter 7

Methodology and Methods

I. Introduction

This small-scale qualitative study employed in-depth semi-structured interviews to investigate into (i) the practices and views of a range of health professionals on children’s participation in the informed consent processes; and (ii) the perspectives and experiences of children, parents and stakeholders in those processes. Of particular interest was capturing the health professional-child-parent dynamic, when children consult with health professionals, and consent is obtained. By focusing on children’s competence and the consent processes across health disciplines, this study makes a unique contribution to the understanding of those areas and to the international literature.

In sections II and III of this chapter, I articulate in more detail the aims of the study, and its methodology. In doing so, I explain the theoretical framework of interpretivism, together with the phenomenological and qualitative methods. In section IV, I detail the research sample, considering also the study’s strengths and limitations.

II. Research Aims

The aims of this research is to better understand (i) the development, promotion and assessment of children’s competence to give consent to medical treatment; (ii) the consent processes across different health disciplines and healthcare environments; and (iii) to determine the appropriateness of the current laws that regulate children consenting to, or refusing, medical treatment, and whether reform is necessary. The perspectives from a range of health professionals - doctors, dentists and nurses - are explored within different healthcare environments. Similarly, parents and children’s perspectives and feelings on their experiences of the informed consent processes for treatment within each of these health areas and environments are gathered. This gives them a voice, which is seldom heard. Including parents and children’s views was central and vital to this study, as they are at the sharp-end of the law.

Medico-legal research favours a cross-discipline approach, as it naturally involves a range of professions, health support societies, government and non-government departments and agencies.  

792 Mark Henaghan and Bill Atkin (eds) Family Law Policy in New Zealand (4th ed, LexisNexis NZ, 2013) at xvi-xvii acknowledge the wider context of family law: “No single discipline or process has the right to take control of something as important as family law policy on the family.” My study follows a long history of cross-discipline, socio-legal research by the University of Otago, Children’s Issues Centre, such as “Evaluation of the 2014 New Zealand Family Law Reforms: Phase One Report to the New Zealand Law
III. Methodology

A. Theories and Approaches

The two principal frameworks for research are constructive/interpretative theory and positivist theory. The interpretative theory believes in the subjective meanings of people’s experiences, relying on them making sense of, and having insights into, aspects of their lives. The aim is to obtain rich data, “leading the researcher to look for the complexity of views.” As such, interpretivism tends to use qualitative methods, enabling researchers to understand concepts from the participants’ views. This can occur through interviews, focus groups, documents, and from observing their actions.

Phenomenology, being a qualitative approach, focuses on the lived-in experiences of the participants. It seeks to capture “how people experience some phenomenon – how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others.” Phenomenology is most appropriate when an aim of the research is to obtain rich and personal accounts of an emotional and intimate experience. This approach lends itself to the individual/personal nature of qualitative research through in-depth interviews with the participants.

Alternatively, positivist theory uses a more scientific and objective approach to research, beginning with a pre-determined theory that is tested through the collection of data. The aims are to specify the type of information to be collected in advance of the study, understanding the relationships between variables, and deducing or evaluating causal links. “Systematic procedures” observe, measure and analyse larger quantities of data, commonly through a questionnaire, producing statistical results.

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793 John W Creswell and J. David Creswell, Research Design: qualitative, quantitative and mixed method approaches (5th ed, SAGE, Los Angeles, 2018) at 7. Historically, in his work The Rules of Sociological Method, first published in 1895, David Emile Durkheim, a French sociologist, believed that social phenomena could be researched scientifically and objectively, rather than subjectively according to people’s perceptions. He was a key proponent of positivist theory that favoured quantitative methods. On the other hand, Maximilian Karl Emil Weber believed in research understanding the purpose and meaning that people attach to their actions, supporting an interpretive framework: Max Travers, Qualitative Research Through Case Studies (Online ed, SAGE Publications Ltd, London, 2001) at 9.

794 Creswell and Cresswell, above n 793 at 8.
795 At 8.
796 At 16-17.
797 Michael Quinn Patton, Qualitative Research and Evaluation Methods (4th ed SAGE. 2015) at 115.
798 At 116.
799 At 16-17.
800 At 6.
801 Creswell and Cresswell, above n 793 at 16.
802 At 6.
803 At 20.
804 At 4.
In contrast, the researcher in qualitative studies allows the information to emerge from the participants, seeking “answers to questions that stress how social experience is created and given meaning.” The researcher starts by assuming that there are different ways to view the phenomena and is interested in those different perspectives. In order to fulfil these aims, Cresswell and Cresswell distilled eight general research characteristics of qualitative research: natural setting; researcher as the key instrument for collecting data; multiple sources of data; inductive and deductive data analysis; participants’ meanings; emergent design; reflexivity; and a holistic account. The importance of these, collectively and individually, is the process of data collection, by creating a method and environment in which participants can freely narrate their experiences. Each individual participant is at the heart of such research, and although Cresswell and Cresswell identify “participant’s meaning” as an individual feature, in my view it is also a principle that guides the other characteristics to achieve that aim. The researcher’s focus and methods are designed with the participants’ meanings at the forefront. For example, the researcher provides participants with security and comfort, by entering their natural environment, so they can openly narrate their experiences and views in their own words.

One of the way in which data can be gathered in qualitative studies is through the researcher engaging with the participants in a semi-structured interview, using open-ended questions. Through the building of a rapport, the researcher creates a situational closeness and understanding of the participants, enhanced by empathetic listening and responding. Neutrality and objectivity are preserved, for example, by testing what has been said in an inquiring way, and without being judgemental.

The choice of method is influenced by the aim of the research. I chose a qualitative design, using a phenomenological approach, as my aim was to gain in-depth individual experiences. This allowed the participants to narrate and reflect upon their experiences, also giving their perspectives and views on issues relating to their personal experiences. This was particularly important when interviewing the parents and children, due to the

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805 At 16. See also Mary Alison Durand “Planning your social science research” in Mary Alison Durand and Tracey Chantler (eds) Principles of Social Research (2nd ed, McGraw-Hill Education, Maidenhead, 2014) at 5.
806 Norman K Denzin and Yvonna S Lincoln, The Landscape of Qualitative Research (4th ed, SAGE, Los Angeles, 2013) at 17.
808 Cresswell and Cresswell, above n 793 at 181-182.
809 There are a number of ways in which qualitative research can be conducted, for example, narrative in which the researcher asks the participants to recount their experiences; phenomenological where the researcher describes the participants’ experiences; grounded theory whereby “the researcher derives a general, abstract theory of process, action or interaction grounded in the views of the participants”; ethnography involving observation as well as interviews; and case studies where the researcher takes a prolonged and in-depth approach to an event, activity or process: Cresswell and Cresswell, above n 784 at 14-15.
810 Patton, above n 797 at 57 refers to this as “empathetic neutrality.”
811 Cresswell and Cresswell make point that qualitative and quantitative are not “rigid, distinct categories, polar opposites, or dichotomies [but] [i]nstead, they represent different ends on a continuum.” Thus, a study can have more features of one or the other, with mixed methods at the midway point: Cresswell and Cresswell, above n 793 at 3.
812 At 13-14.
highly sensitive and emotive nature of their health experiences. This method enabled me to capture the description and feelings of their experiences by using their own words. Likewise, when interviewing health professionals, the personal approach to interviews enabled them to reflect upon their practices and processes. Their recollection of situations, where consent was an issue, was invaluable to this research.

Qualitative research is adaptable, able to change direction, with earlier data influencing the collection of future data, for example, by changing/extending intended participants and/or questions. Cresswell and Cresswell term this “emergent design”, while Durant and Chantler refer to it as “theoretical sampling.” Such changes demonstrate the responsiveness of the researcher to the data:

These shifts signal that the researchers are delving deeper and deeper into the topic or the phenomenon under study. The key idea behind qualitative research is to learn about the problem or issue from participants and to address the research to obtain the information.

The flexible nature of qualitative research lends itself to studying phenomena, which although well established, has received little attention in research. Children’s competence and informed consent processes across healthcare environments have received relatively little attention from a legal perspective, and thus flexibility was important to my research. In particular, purposeful sampling was a fundamental feature of this study, which is a characteristic that distinguishes qualitative from quantitative studies, where samples are random. This enables the researcher to select “information-rich cases” that will illuminate the nature and substance of the phenomenon. Their values are in bringing deeper understanding and insights to the study. There are a number of purposeful sampling strategies, including single significant case, comparison-focused sampling and group characteristic sampling. The strategy I employed was comparison-focused sampling. This involved selecting cases and participants to compare and contrast, in order to understand their similarities and differences. It was important to my study that I recruited participants who had either experienced healthcare or were practitioners in different healthcare environments. I sought further diversity within these environments, by for example, seeking hospital doctors with differing specialty, recruiting health professionals practicing within different locations and of differing experience. The aim was to gain deeper understanding of how different health conditions and healthcare

813 At 182.
814 Chantler above n 807 at 47.
815 Cresswell and Cresswell, above n 793 at 182.
816 Initially conducting qualitative research can help to generate hypotheses, which can be tested later with quantitative research: Chantler, above n 798 at 48.
817 Patton, above n 797 at 264.
818 At 264.
819 At 264. Patton lists eight categories of purposeful sampling strategies, classified from 40 possible options: single significant case; comparison-focused sampling; group characteristics; concept or theoretical sampling; instrument-use multiple-case sampling; sequential and emergence-driven sampling strategies during fieldwork; analytically focused sampling; and mixed, stratified and combination sampling strategies.
820 At 267.
environments influence, if at all, the assessment of children’s competence and consent processes.

**B. Research Credibility**

Validity and reliability relate to the accuracy and credibility of studies, which differ between qualitative and quantitative research. In quantitative methods, validity relates to the effectiveness and accuracy of the instruments used to collect the data, and whether these have collected the intended data. Reliability concerns the instruments’ applicability or generalisation of use. Generalisation and replication are key features of quantitative research.

Conversely, individualisation, or uniqueness of the participants and researchers, is the central characteristic of qualitative research, and as such, validity is “based on determining whether the findings are accurate from the standpoint of the researcher, the participants or the readers of an account.” Creswell recommends utilising multiple approaches from eight primary strategies to check the validity and reliability of data: triangulation; member checking; use of rich and thick description; self reflection of researchers’ bias; presentation of negative or discrepant information; spending prolonged time in the field; peer debriefing; and use of an external auditor. The strategies I employed were triangulation through the use of multiple sources and external auditors, the use of rich/thick data, self-reflection and presentation of negative and discrepant information feature.

1. **Triangulation**

Triangulation is “a strategy that adds rigor, breadth, complexity, richness and depth to any inquiry”, by using for example, multiple sources, methods and theories. These strengthen and improve the validity of the research, as they provide greater understanding of the issue; stimulate the researcher to question the views of the participants and reflect upon the issues through earlier knowledge from other perspectives; and provide greater depth from consistent and divergent perspectives.

Triangulation through multiple sources strengthened my study, and was essential to exploring the perspectives of, and the dynamic between, children, parents and health professionals. By considering different areas of healthcare and environments, I was able to undertake comparisons identifying commonalities and differences. Consistency of

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821 Cresswell and Cresswell, above n 793 at 153.
822 At 154.
823 At 199.
825 Patton, above n 797 at 661 identifies four triangulation processes for enhancing credibility: triangulation of qualitative sources; mixed quantitative-qualitative methods; analyst triangulation; and theory/perspective triangulation. See also Denzin and Lincoln, above n 806 at 10.
826 Patton, above n 797 at 660.
findings across types of data increases confidence in patterns and themes, whilst inconsistencies invite questions and reflection about possible reasons.  

Analyst triangulation, or use of external auditors, was another strategy I used, achieved through the supervision of two very experienced researchers, Associate Professor Nicola Taylor and Professor Mark Henaghan. Although I conducted the interviews alone, they were in a position to review the content and processes I employed. Additionally, to some extent, my research was open to scrutiny by the research participants, when I sent them summaries of my research findings upon completing the writing of my findings chapters. Likewise, my peers and members of the public were able to view/consider the research, when I displayed some of my findings by way of a poster presentation, and spoke to attendees, at the Seventh World Congress on Family Law and Children’s Rights in Dublin in 2017.

Triangulation of individual cases, however, was not employed, due to the impracticability of tracing patients and linking them to their healthcare providers. This would have also raised confidentiality concerns for participants, where the child, parent and health professional were linked together.

2. Use of Rich/Thick Data

The use of rich/thick data provides detailed and emotive description of the participants’ experiences, enabling the reader to be transported into their lives. The results become more realistic and richer, adding to the validity of the findings. In this thesis, I faithfully reported the words and feelings of the participants, using their own words as much as possible, to convey their experiences and perspectives.

3. Reflexivity

Reflexivity is of importance to the credibility of qualitative research, which employs in-depth interviews, due to the involvement and impact of the researcher on the data collection and analysis. Reflexivity is a means of enhancing the study’s credibility, as it involves “deep introspection, political consciousness, cultural awareness, and ownership of one’s perspective.” The researcher needs to be reflective about biases, values and personal background.

The influences that I have brought to this study begin with my values of justice and equality, which filtered into my 22 years experience as a child and family law solicitor, in private practice, in Scotland and New Zealand, and also for the charity, The Scottish Child Law Centre. Status, on the other hand, has never held any relevance for me. Rather, of importance are personal attributes, skills and experience, personality and interests. These values lend themselves to having a genuine interest, empathy and respect for

827 At 660.
828 Cresswell and Cresswell, above n 793 at 200.
829 Patton, above n 797 at 70.
others, which I used during interviews. I found it easy to develop a rapport with all the participants, which I feel enabled them to be open with me. Conversely, these values resulted in entering the field with the assumption that children could acquire the skills to be deemed competent to consent to medical treatment. I was aware that this was my starting point, but what I lacked was the understanding and experience of what factors influence the development and demonstration of children’s competence. I have no personal experience of undergoing medical treatment, as a child or through my children. Thus, I had no pre-conceived impressions of the reality of coping with health conditions and treatment. I allowed the participants to educate me on how they felt and viewed their experiences.

I consciously maintained an open mind when listening to and understanding the participants’ experiences, in order to accurately reflect their perspectives, regardless of whether it conformed with my underlying values or not. Through my legal experience, I am accustomed to understanding and considering different perspectives, which together build a complete picture.

IV. Methods

The data for this study drew upon a diverse sample of health professionals from medicine, surgery and dentistry, based in private practice, hospital, school, and community settings, in four metropolitan areas in New Zealand. In total, I interviewed 59 individuals. This section first describes the recruitment of the participants, ethics approval, participants’ demographics and interviews, moving then to detail the analysis methods.

A. Sample Recruitment and Ethics

Three categories of participants were recruited to take part in this study – health professionals; families; and stakeholders. The only specific inclusion/exclusion criteria related to parents and children. Parents/guardians were required to have attended at least two appointments with a health professional relating to their child’s health condition; and children were required to:

(a) be aged between five and 15 years at the time of diagnosis; and

(b) have, or have had, a medical or dental condition requiring treatment over a period of at least six months within the last two years.

Children, who were vulnerable, in the opinion of their parent/guardian or health professional, were to be excluded, but none of the families I approached declined on this basis. Causing no harm to the participants was an important principle of research. At the very least the researcher seeks to do no harm, so the participants are unaffected by the
process, and at best derive benefit. This was particularly relevant to the parents and children in this research, as it involved them discussing personal issues of health. A balance needed to be achieved in recruiting children and parents, whereby the treatment was sufficiently recent for them to have good recall, but not currently being administered, which would make children vulnerable. Further, I took care to arrange interviews at a time and place convenient to them, and conducted them at their pace.

A wide age range of children was selected in anticipation of including younger children, firstly, to respect their views and experiences, and secondly, to explore the extent of their participation and competence. Unfortunately, children younger than 10-years-old were not represented in this study.

The principles of informed consent, confidentiality and the right to withdraw at any stage were also of vital importance, particularly as sensitive and confidential medical information was being discussed. By fully informing participants prior to interviews, in writing and orally, and being committed to protecting their anonymity, it would likely provide them with a sense of control and security to be frank during discussions. Further, it was recognised that participants may seek to contact me post-interview, and were advised that they were welcome to do so. Three parents did subsequently contact me to advise of their positive experiences of participating, such as, giving their children an opportunity to talk about their health conditions, or enabling them to reflect on their relationship with their child.

As part of the ethics application, I consulted with Ngāi Tahu Research Consultation Committee ("Committee), as it was of potential interest to Māori. The Committee considered the research to be of importance to Māori Health and strongly encouraged that ethnicity data be collected as part of the research project. I purposely recruited three stakeholders from a support organisation who supported children and their whānau with a long-term health condition. Unfortunately, however, amongst the health professionals and families no Māori were represented.

The University of Otago Human Ethics Committee ("the Ethics Committee) approved the research on 23rd December 2013, reference 13/279. During the course of the research, I extended the range of participants twice to include private dentists and dental therapists. The Ethics Committee approved the amendments on 9th May 2014 and 18 March 2015 respectively. These extensions enabled me to more fully consider dental health practices in three different settings, to provide deeper understanding of the factors that promote and hinder children’s competence, and to compare consent processes.

830 Following interviews with parents and children, three parents contacted me to advise of the benefit they and their children had derived from being able to talk, and reflect upon, the medical treatment and informed consent processes.
831 See Appendix B for Information Sheet and Appendix C for Consent Form sent to all adult participants; Appendix H for Children/Young People’s Information Sheet; and Appendix I for Children/Young People’s Consent Form.
832 Not simply ethical issues, but also factors that increase the credibility of the research.
Additionally, prior to commencing the research in the hospitals, approval was obtained from the relevant medical officers.

The recruitment aim was to seek diversity, both in terms of healthcare environments, and also health specialties. I sought to achieve these aims not only for health professionals, but also for children and parents. The justifications for such diversity were:

1. To be able to compare and contrast health professionals’ practices, and children and parents’ experiences, across health disciplines and environments; and
2. To fill gaps in research, particularly in the private health sectors and in all dentistry environments.

Table 2 provides an overview of the categories of participants and the numbers of each. It can be seen from this table that in terms of health professionals, I recruited from those practicing medicine, surgery and dentistry, and from within healthcare environments of private practice, hospital and school/community youth service.
<table>
<thead>
<tr>
<th>Category of Participants</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children</td>
<td>7</td>
</tr>
<tr>
<td>Parents</td>
<td>6</td>
</tr>
<tr>
<td>Hospital Doctors</td>
<td>7</td>
</tr>
<tr>
<td>GPs-private/school/community youth service</td>
<td>6</td>
</tr>
<tr>
<td>Hospital Dentists</td>
<td>3</td>
</tr>
<tr>
<td>Private Dentists</td>
<td>3</td>
</tr>
<tr>
<td>Hospital Nurses</td>
<td>3</td>
</tr>
<tr>
<td>Nurses- school/community youth service</td>
<td>3</td>
</tr>
<tr>
<td>Public Health Nurses</td>
<td>2</td>
</tr>
<tr>
<td>School Dental Therapists</td>
<td>2</td>
</tr>
<tr>
<td>Stakeholders: Non-Government Organisations (NGO) supporting long-term health conditions</td>
<td>5</td>
</tr>
<tr>
<td>Stakeholders: Lawyers-private/public/government/child advocate</td>
<td>4</td>
</tr>
<tr>
<td>Stakeholders: Miscellaneous including policy; training, advising, regulation of health professionals; and child advocacy.</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>59</td>
</tr>
</tbody>
</table>

1. **Health Professionals**

I aimed to recruit 12 doctors from hospital and private practice; eight nurses from hospitals and schools; five dentists from hospitals; three private dentists; and two school dental therapists. Within that sample, I sought diversity of specialty and experience. In recruiting health professionals, I began with my personal network, and then used the snowball effect, being referred to their friends and/or colleagues. This strategy proved effective.

Table 3 details the categories of health professionals; their gender; age at the time of interview; length of their experience in their present health specialty; and overall professional experience.
Table 3: Health Professionals by Gender, Age, Professional Experience in Present Specialty and Overall Professional Experience

<table>
<thead>
<tr>
<th>Health Professional</th>
<th>Gender</th>
<th>Age</th>
<th>Professional Experience in Present Health Specialty</th>
<th>Overall Professional Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Doctor</td>
<td>4 Female 3 Male</td>
<td>37-67 years</td>
<td>3-36 years</td>
<td>10 – 42 years</td>
</tr>
<tr>
<td>GP</td>
<td>4 Female 2 Male</td>
<td>35-51 years</td>
<td>4 - 23 years</td>
<td>10 - 28 years</td>
</tr>
<tr>
<td>Hospital Dentist</td>
<td>3 Female 2 Male</td>
<td>40-41 years</td>
<td>7- 18 years</td>
<td>16-19 years</td>
</tr>
<tr>
<td>Private Dentist</td>
<td>1 Female 2 Male</td>
<td>41-47 years</td>
<td>15-18 years</td>
<td>16½ – 20 years</td>
</tr>
<tr>
<td>School Dental Therapist</td>
<td>2 Female 2 Male</td>
<td>23 and 45 years</td>
<td>5 months and 21 years</td>
<td>5 months and 21 years</td>
</tr>
<tr>
<td>Hospital Nurse</td>
<td>3 Female</td>
<td>48-55 years</td>
<td>6 - 8 years</td>
<td>25 – 34 years</td>
</tr>
<tr>
<td>School Nurse/Community nurse</td>
<td>3 Female 2 Male</td>
<td>43-55 years</td>
<td>2 - 11 years</td>
<td>22 – 30 years</td>
</tr>
<tr>
<td>Public Nurse</td>
<td>2 Female</td>
<td>47 and 54 years</td>
<td>8 and 13 years</td>
<td>25 and 37 years</td>
</tr>
</tbody>
</table>

(a) Doctors

I recruited surgeons and hospital doctors from different medical specialties. I identified health specialties that were likely to involve oral and written consent: pediatrics, paediatric and plastic surgery, anaesthesia, obstetrics and gynecology. The hospital doctors comprised of two paediatric surgeons; one plastic surgeon; two paediatricians; one obstetrician and gynecologist; and one anaesthetist. These doctors practiced within three different hospitals, had wide ranges of experience in their present area of practice, as well as their overall experience, and were of both genders. I was very fortunate to meet very helpful hospital doctors, and a stakeholder, who referred me on to potentially interested colleagues.

Secondly, amongst the GPs, diversity was achieved through recruiting from four different practices, males and females, with varying lengths of experience. Additionally, I purposefully recruited one GP who also practiced in a school and community youth service.
(b) Dentists

Whilst all hospital dentists, and both dental therapists, practiced in the same hospital and clinic respectively, they all varied in experience. The hospital dentists had hospital experience of between seven and 18 years, and one dental therapist had practiced for 21 years, with the other only five months.

The three private dentists were from different private practices, and two were male and one female, although were of similar experience.

(c) Nurses

The eight nurses had experience in four healthcare environments – hospital, public health, school and community youth service. They had further diversity: three school nurses were employed at different schools, with one also practising at a community youth service; the three hospital nurses had different employers, with varying specialties – diabetes, oncology, paediatric critical care, and medical services; and the two public health nurses had differing experience, although the same employer.

(d) Information Documentation and Arranging Interviews

Upon receiving confirmation of their interest in the study, I emailed a personalised letter, an information sheet and consent form. Interviews were either arranged over the telephone or by email. The consent forms were signed, and either returned to me, prior to interview, or at the start of the interview.

I had anticipated that it may be difficult to secure the time and interest from a range of health professionals, given the demands of their work, but this could not have been further from the truth. They all graciously gave me their time, showing interest in this area, by explaining their practices, and recalling examples that highlighted some issues they had encountered.

2. Parents and Children/Young People

It had been my intention to recruit parents and families through non-government organisations that supported children and parents in managing lifelong/chronic health conditions, such as cancer, diabetes and asthma. I had hoped, in particular, to reach Māori whānau through this method, as one NGO provided education and advocacy services to them. My rationale was that the NGOs would have relationships with families who had experience of healthcare systems/processes, and be able to approach them to enquire of their interest in participating in this study. This proved an effective strategy for one lifelong/chronic health condition, but not for others. One in particular was initially very reticent about even taking part at an organisational level. Their initial response to my approach was defensive, viewing that their children did not have treatment choices.
parents and 10 children. I recruited two parents and two children/young people from one support organisation (SH9). This Stakeholder, having participated in an interview with me first, met with potential families to explain the study to them and confirmed their willingness to participate, before I contacted them. The other five children/young people and four parents, I knew, or was referred to them by mutual friends/colleagues. The only parent I did not approach was of a young person aged 19 years at the time of interview, was living independently, and had initiated contact with me independently of her parents.

My aim was to recruit diverse health conditions and healthcare environments, of both genders and of different ages. Table 4 outlines the children/young people’s health conditions, and ages, at time of diagnosis, treatment and interview.

sometimes having to be physically forced to have it administered. The agency explained that their “children do not have a choice over treatment” and that “some of our parents have to pin down their children” [in order to administer medication] otherwise they will end up in hospital.” Speaking for parents, she believed they would be very concerned about me asking children questions. However, with a change in personnel, this organisation willingly participated, but not to the extent of recruiting parents and children.

836 The names are fictitious and some of their genders have been changed to help protect anonymity. However, the ratio of girls to boys, the health conditions and ages have been retained to preserve as much authentic personal detail as possible.
Table 4: Children/Young People by Health Condition and Age

<table>
<thead>
<tr>
<th>Child</th>
<th>Health Condition</th>
<th>Age at diagnosis</th>
<th>Age at time of treatment</th>
<th>Age at interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Samantha</td>
<td>Osteosarcoma</td>
<td>10 years</td>
<td>10-14 years</td>
<td>14 years</td>
</tr>
<tr>
<td>Amanda</td>
<td>Osteosarcoma</td>
<td>13 years</td>
<td>13-14 years</td>
<td>16 years</td>
</tr>
<tr>
<td>Oliver</td>
<td>Leukemia</td>
<td>14 years</td>
<td>14-17 years</td>
<td>18 years</td>
</tr>
<tr>
<td>Alistair</td>
<td>ADHD</td>
<td>9 years</td>
<td>10 years</td>
<td>10 years</td>
</tr>
<tr>
<td>Poppy</td>
<td>Vaccinations; Achilles condition; Tooth extraction and Braces</td>
<td>N/a; At birth; 15 years</td>
<td>11-12 years; 14 years; 15 years</td>
<td>14 years; 14 years; 16 years</td>
</tr>
<tr>
<td>Brenda</td>
<td>Endometriosis</td>
<td>15 years</td>
<td>15-17 years</td>
<td>19 years</td>
</tr>
<tr>
<td>Donald</td>
<td>Tooth extraction</td>
<td>10 years</td>
<td>11 years</td>
<td>11 years</td>
</tr>
</tbody>
</table>

The parents interviewed were all mothers, and they and their children lived in three different geographical areas. Their ages ranged from 37 to 54 years and they all had professional backgrounds, with two having nursing experience. In two-parent families, of which there were three, they were able to choose whether one, or both, parents participated in the interviews. In all three cases, the mothers chose to solely participate, as they had been more involved in attending consultations with health professionals regarding their child.

The children had been treated in hospital, at private GP or dentists’ practices, or in school, for surgery, medicine or dentistry. They comprised of three children/young person receiving cancer treatment and surgery in hospital; one receiving medication at the GP for Attention Deficit Hyperactivity Disorder (ADHD); one undergoing surgery in hospital for endometriosis; one had a tooth removed at his dentist; and one had an operation for an achilles condition in hospital, routine teenage vaccinations in school, and dental surgery and braces fitted at a private dentist. The children/young people were aged between 10 and 19 years at the date of their interview. There were three boys and four girls.

(a) Information Documentation and Arranging Interviews

Prior to meeting with the families, I contacted the parents by telephone, explaining the purpose of the research and the process of interview. I informed the parents that I would be focusing on their child’s participation in the engagement with health professionals, specifically, the information given by the health professionals, involvement in discussions, the decision-making and consent giving processes. All parents indicated their and their children’s willingness to participate, confirming also that they had consulted with, and
informed, their child of the study. The parents received a personalised letter,\textsuperscript{837} the same information sheet as the other adult participants,\textsuperscript{838} with children/young people receiving a shorter and simpler one.\textsuperscript{839} Similarly, parents signed a generic consent form,\textsuperscript{840} signing also one to consent to their children participating,\textsuperscript{841} while children signed their own consent form.\textsuperscript{842}

(b) Recruitment Strategies

Having secured seven children/young people and six parents, I undertook the following strategies to attempt to increase my sample size:

1. I followed up a telephone call from a parent of a six-year-old diabetic child, who had become aware of my study. However, arranging an interview proved difficult, and the parent ultimately did not follow through.

2. One of the parent participants was aware of a work colleague whose child had a long-term health condition. Although the other parent initially expressed an interest to this participant, she did not give her consent to forward her contact details to me, nor did she initiate contact with me.

3. I emailed a nurse working at a community youth health organisation to enquire if they could be of assistance, but did not receive a response.

4. I enquired with another youth community health organisation as to whether they would be interested in taking part in the study in their own right, and also as a means to recruiting families. After showing initial interest, they did not respond further.

5. I considered the possibility of speaking with groups of children and young people, in order to provide a different context to gathering data. The avenues that I explored were through camps, organised by support organisations for lifelong/chronic health conditions. However, this was not viable for one camp, as it is designed to give relief to children/young people, from the pressures of their illness, and therefore understandably they did not wish a researcher to affect that respite. For another, there was a sense of them protecting their members from a researcher speaking with children. They expressed concern over discussions I may have with children, fearing that I may suggest to them that they had a choice over taking their essential medication. Despite being reassured that the children would be the ones educating me over their health condition and medication, they were unwilling to contact their members.

\textsuperscript{837} Appendix F.
\textsuperscript{838} Appendix C.
\textsuperscript{839} Appendix H.
\textsuperscript{840} Appendix C.
\textsuperscript{841} Appendix G.
\textsuperscript{842} Appendix I.
3. **Key Stakeholders**

In recruiting stakeholders, I was aiming again for diversity. I purposefully recruited stakeholders with different backgrounds and roles. The backgrounds sought were health and/or law. I recruited from three government and non-government agencies responsible for healthcare and advocating for children’s wellbeing and interests; three health support organisations for children suffering with long-term illnesses; two health professional regulatory bodies; four lawyers; a medical ethics educator; and a play therapist. One avenue that I explored, which was unsuccessful, was seeking judicial approval to interview two judges. This application was denied on the grounds that it was considered to be inappropriate to ask judges to comment on the existing law. Although their perspectives would have been very insightful, I secured the participation of four solicitors, all with different roles. One advised and represented clients on consent issues in private practice; another was an in-house DHb solicitor; the third advised on legal and policy issues for a Government agency; and the fourth was a leading child advocate.

B. **Interviews**

The sequence of interviews began with health professionals, followed by NGOs, parents, children, and stakeholders. This gave me a general sense of the processes and perspectives from the health professionals, and issues that had arisen for children and parents, from both health professionals and the NGOs, before interviewing the parents and children. A few of the participants were out of sequence depending upon their availability.

The interview locations were a consideration in the research design, as I sought to make it as convenient and comfortable as possible for the participants, to promote a relaxed dialogue. The participants chose where to be interviewed. I was conscious that for most, time would be a factor, and so I gave them as much control as possible. I interviewed

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843 One agency supporting children with a lifelong/chronic health condition declined to participate in an organisation capacity to comment on their work with their members and any consent related issues that have arisen, as it did not consider the consent process to be of relevance to their organisation. Further, it declined to assist me in recruiting families for the study because i) the health professionals who treat this health condition are not based in the same geographical area as the children who would be participating and therefore they would not be involved in the study; and ii) consent for treatment can remain in place for up to three years and is not given for individual “administrations.” The agency considered that the health condition they deal with is “very different to other diseases, conditions or dental procedures.” They concluded that “whilst a good study not for our families.”

844 Of five regulatory professional bodies approached two agreed to participate. A third was initially interested but with a change of personnel questioned the relevance of the study to their organisation. The Chief Executive of another advised that during her seven years in post no issues of informed consent regarding children had come to her attention, and referred me to an experienced health professional who was willing to participate in that capacity. After much persistence with the fifth they simply did not follow through with participating.

845 One of which was from a government agency and has been included under “lawyer” rather than Government agency.

846 See Table 2, page 129.

847 I interviewed the two of the three NGOs supporting families with lifelong/chronic health conditions following the health professionals, as I had hoped that they would refer me to parents and children. However only one referred me to any families.
most health professionals and stakeholders at their places of work, except for three health professionals, and one stakeholder, who were interviewed in their homes; three health professionals, and one stakeholder, met me in my office; and one health professional and two stakeholders were interviewed by telephone. All the parents and their children were interviewed in their homes, except one parent, who was interviewed in her office; one young person was interviewed at her college; and another at her mother’s office. When planning the interviews with the children/young people, I was mindful of addressing the power imbalance that they may feel when I was seeking their views and feelings, as “the relations and contexts within which communication takes place fundamentally shape the nature and outcome of the research.” Thus, it was crucial to recruit children who had experience of, and opinions on, engaging with health professionals and informed consent. I was confident from the information I had received from parents, and also of what I knew of the children/young people I had already met, that these children had relevant experiences and opinions that they wanted to share. Further, they were likely to feel validation and confidence from being in a familiar environment, aware that their parents had participated and supported their participation.

All interviews were audiotaped and the consent forms specifically included their permission for this. I checked with those participants who had sent me their consent forms in advance of the interview that they agreed to be recorded. This was of significant benefit to the interview, as I was able to concentrate on the participants and their responses, which enhanced rapport, rather than breaking eye contact and having a more stilted approach through note taking. It also ensured greater accuracy.

I conducted in-depth semi-structured interviews with the participants. These occurred over 20 months, between March 2014 and November 2015. The interviews are best described as conversations and discussions that developed naturally. Whilst semi-structured, there was flexibility to adapt the flow of questions, and add some new ones, depending upon the substance and direction of interviews. Most participants only required a few key questions to explain their experiences, whilst a few needed more direction on specifically the information being sought. Sensitive issues, particularly those discussed by parents relating to their children’s health, treatment and relationships with health professionals, were addressed through active listening and empathy, giving them time to describe events. Also, parents were aware in advance, through the information provided to them, of the focus of the interview, which provided them with parameters and structure.

Having worked in the fields of child and family law, which sometimes involved children who were in need of care and protection, I was aware of child protection policies, and the exception to confidentiality, if children make disclosures, or are at risk of significant harm. In the unlikely event of a child disclosing abuse or neglect during interview, I would have

848 Pia Christensen and Allison James, “Researching children and childhood: cultures of communication” in Pia Christensen and Allison James (eds), Research with Children Perspectives and Practices (2nd ed, Routledge, Abingdon, 2008) at 7.

849 See Appendices J - M.
agreed on a course of action in collaboration with my supervisors, and understood that a referral to Oranga Tamariki – Ministry for Children may have been required.

As the interviews progressed, it was possible to share some of the views of earlier participants, obviously preserving confidentiality. For example, it had surprised me that the practice of one health professional was to involve children in more complicated matters than simple ones, as that had run counter to what I had imagined would be the situation, and I wondered what the views of some other participants were.

I felt very comfortable interviewing the participants in this study, as with over 20 years experience as a solicitor specialising in child and family law, I am accustomed to interviewing people from all walks of life, in usually emotive situations. Further, as a Safeguarder in the Scottish Children Hearing System, representing children’s welfare and best interests, and reporting also to Sheriff Courts on child care and child protection matters, I was familiar with speaking to parents and children in their homes, learning about their circumstances, and discussing these with involved professionals. It has always felt natural to me speaking with children, as I am curious about their perspectives. This is enhanced by my experience of having two children and over 12 years experience of teaching children to swim. When interviewing professional participants, I felt confident in discussing medical consent matters, as I was secure in my legal knowledge.

1. **Health Professionals**

The interviews with health professionals considered the stages of informed consent processes: discussions; informing; giving options and advising; assessing children’s competence; and obtaining consent. Their interviews ranged in duration from 21 minutes to one hour and 14 minutes. The topics discussed in the interviews included:

- Personal details, such as their length of experience and specialty.
- Processes for consulting with children and parents, including strategies for involving children, and explanations given about health conditions, treatment and options.
- Processes for assessing children’s competence, including the factors considered.
- Factors that influence children’s competence.
- Consent processes.
- Challenging consent situations.
- Understanding of the law on consent.
- Views on children giving/refusing consent.
- Views on whether changes to the law would assist practice, and if so, how.

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Appendix J.
2. **Parents**

The general structure of the interviews with parents followed the history of their children’s health condition, from initial consultation, to investigations, diagnosis and treatment. This assisted me in understanding the chronology of events, and provided the participants with a logical unfolding timeline. I sought to understand, in particular, the extent to which children were involved in discussions in consultations with health professionals; the ways in which children learned about their health conditions and treatment; how treatment decisions were made; and consent provided.

The duration of these interviews ranged from 35 minutes to 2 hours and 22 minutes. The latter was of exceptional length, as it spanned four years of treatment and procedures, involving chemotherapy and three operations. The others were within the range of 39 minutes to 55 minutes. The interviews with parents were in private, their children being unaware of discussions.

3. **Children/Young People**

I interviewed the children/young people following the interviews with parents, in the same visit. Prior to interview, I had considered whether to interview them alone or with their parents present. I decided this after interviewing each parent, depending upon whether they offered that I speak with their children alone, or I suggested this, if I sensed that the parents and children would be comfortable. I was graciously given complete privacy with three children/young people, their parent being in a separate room. I knew two of these parents and children, which was likely to have been a factor in them feeling comfortable with me being alone. The third was a confident/strong-minded young person, who was capable of, and comfortable with, participating alone. Naturally, I interviewed the young person, whose parents were not approached, alone, in a private room at her college.

I interviewed the other three children in the presence of their parents. However, for two interviews we were in an open-plan lounge, with their parent in the kitchen area. Both parents were unobtrusive, and took no part in the interview, to the extent that for most of the interviews, I was unaware of their presence. The children were not distracted, nor appeared influenced by their parents’ presence, as they were fully engaged and focused on the interview. I had not previously met these parents or children before the interviews.

Of exception was one young person with Asperger’s Syndrome, whose mother and grandmother asked to be present, and actively assisted with the interview to keep him focused on answering the questions. Asperger’s Syndrome causes communication and social difficulties, and it was extremely helpful to have them present. It appeared that this was a role to which the family were clearly accustomed.

851 Appendix K.
Before engaging in each interview, I checked with the children/young people at the start, that they understood its purpose. They confirmed they had read the information sheet, discussed it with their parents, and had all signed the consent form. I also explained that I would be recording the interview, as it helps me to listen to them without taking notes, and they all agreed. I reinforced to them that this was voluntary and that at any point they could ask to stop or take a break.

The interviews ranged from seven minutes to fifty-four minutes. The interview of seven minutes was with the young person with Asperger’s Syndrome. He was straight to the point with his views. The interview of 54 minutes was with a very capable young person, who had insights and views on many aspects of her health experience. I met her for the first time at the interview, and the length was therefore not attributable to any pre-existing relationship. The other interviews ranged from 14 minutes to 28 minutes.

I had anticipated that I might need to visit the children/young people on two occasions, the first being to build rapport, and the second to interview. However, I did not require the rapport building visit, as they were all very engaging. I was able to position myself as the non-expert, and they as the expert. They appeared to show a genuine interest in the topic, also appreciating my interest in them. After a few initial icebreaker questions about their day, school and what they liked doing, I asked them general questions about what decisions they are allowed to make at home. We then spoke specifically about their health condition and its treatment. The topics covered were: how involved they were and felt in consultations with health professionals; the roles they and their parent played before, during and after consultations; how they learned about their health condition and its treatment; to what extent health professionals explained these matters; how treatment decisions were made; the consent processes; and their views on children having rights to consent. I took the lead from the children, asking them to further explain or give examples on what they were describing. They all recalled events freely, and were easily able to articulate their views and feelings.

Exceptionally, I visited one child twice, in a two-stage process, before and after her surgery. In the second interview, she was able to describe events immediately preceding, and subsequent to, her operation. Additionally, in the month between interviews she had also had dental surgery and braces fitted. She described the reasons for requiring these, her consultations with the dentists, both before and subsequent to the procedures, and how decisions were made.

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852 Appendix H.
853 Except for the young person whose parent was not approached to participate.
854 Appendix I.
855 Christensen and James, above n 848 at 9; Helen Roberts, “Listening to children” in Pia Christensen and Allison James (eds), Research with Children Perspectives and Practices (3rd ed, Routledge, Abingdon, 2017) at 153.
856 See Appendix L.
4. **Key Stakeholders**

The majority of stakeholders were interviewed upon concluding the interviews with the health professionals, parents and children. They were identified as having a role, and/or interest in, the consent processes. Prior to interview, I contacted the organisations by email and telephone, confirming their willingness to participate, and to identify the relevant person(s) who would be interviewed. I sent those people a personalised letter, the information sheet and consent form. The interviewees were key people within organisations who had knowledge of practice, policy or legal issues. Their backgrounds were in health, law, ethics, youth work and policy.

Discussions centred on their, and their organisations’, roles and experience in medical informed consent processes. The topics covered were their roles in advising, promoting knowledge of, and regulating on, children consenting; any issues that had arisen for them or their members in this area; their views on the regulation of children consenting; and their opinions on whether changes to the law could be beneficial.

The interviews ranged from 13 minutes to 72 minutes. The factors that most influenced the length of the interview, in my view, were the relevance of the topic to the agency or participant, the participant’s experience, and their available time. The shortest interview was with an agency in which the lawyer interviewed had efficiently prepared, by gathering together fact sheets and print outs of case summaries, with which the agency had been involved. The lawyer had only two years experience and did not have extensive personal knowledge, so there was little to discuss. Conversely, eight interviews were 50 minutes or more, with the participants having extensive experience in their professional fields, and knowledge of consent issues.

Finally, one stakeholder taught an ethics seminar to fifth year medical students, which I attended. During this seminar, which lasted 90 minutes, the students reinforced their understanding of *Gillick*, were taught that competence is a legal test that is task specific, were given case studies to practise applying the law to practical situations, discussed effective communication, and practical means of resolving difficult situations.

C. **Administrative Procedures**

Following each interview, I allocated the participants codes, and when transcribing did not use their names, localities or other identifying details, such as the names of schools or health professionals. The transcriptions were kept in folders on my computer, which were secured by a password. The audiotapes were transcribed, and then deleted from the dictaphone, with the downloads also kept in a password protected folder. The consent forms were kept in a folder and the participant master-list was kept separate from the

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857 Except for the two NGOs who were interviewed following health professionals. See f/n 847.
858 See Appendix E.
859 See Appendix C.
860 See Appendix M.
coding profile, both of which were kept in a locked drawer at my home. Email correspondence was either deleted or, if needed for later reference, kept in the folder with the consent forms.

D. Data Analysis

Upon completing the data collection, the challenge for the researcher is to “transform data into findings.” 861 The researcher has a large quantity of experiences, reflections and opinions, and the task is to make them coherent. There is no one process or formula for achieving this. 862 The researcher needs to be committed to the process of moving from an inductive to a deductive process, firstly analysing participants’ transcripts, comparing and contrasting them, to identify categories, patterns and themes. 863 This system enables the researcher to make sense of the participants’ experiences, looking for consistencies, inconsistencies and gaps. 864

Thus, in an inductive process the researcher allows the data to speak for itself, directing the researcher to the issues and themes, whereas deductive processes involve the researcher identifying themes from previous research and theories, for example, and considering whether the existing data supports them, or whether further data collection is needed.

I began analysing the interviews during the data collection phase, by highlighting key words, practices, process, perspectives and opinions in the transcripts. Although I was already familiar with their interviews, I read the transcripts several times, finding that the more I read them, the more I understood their experiences, and spotted further nuances. This assisted me when undertaking the first stages of analysis, of immersing myself in the data, in order to code it. Coding the data involves “categorizing, classifying, and labeling the primary patterns in the data,” 865 giving it structure. I began coding the data based on the sequence of the interview schedules and the issues that emerged from the interviews. These naturally followed the logical timeline of consent processes:

- Relationships and communication between children, parents and health professionals;
- Information given to children on their health conditions and treatment;
- Opportunities for children to participate in discussions;
- How children’s understanding is promoted and the importance placed upon it;
- How treatment decisions are taken;
- How or whether children’s competence is assessed by health professionals;
- The importance health professionals place on trust with parents and children;
- The roles parents play in children’s participation;

861 Patton, above n 797 521.
862 At 521-522.
863 Creswell and Creswell, above n 793 at 181.
864 At 181.
865 Patton, above n 797 at 553.
• How consent is given;
• The factors health professionals consider in the consent processes, in particular, the significance of children’s age;
• Whether there are different considerations and processes when children or parents disagree with treatment;
• Views on children having the right to consent to, and refuse, treatment;
• Health professionals’ understanding of the law on children consenting.

I systematically worked through the categories of participants beginning with each health professional group – GPs; hospital doctors; dentists/dental therapist; and nurses, before moving to children, parents and stakeholders. I worked through each transcript and organised the data into the themes by cutting, pasting and colour coding. If one section of the transcript applied to more than one category, I would include it in all relevant categories. Upon completion, I had a colour coded word document for each participant category that assisted me to identify sub-themes within categories. Describing the issues, and supporting them by all the relevant quotes within each category, also assisted with identifying sub-themes. From this analysis, I was able to identify commonalities and differences across the health professional groups. However, in order to fully understand how children’s competence is promoted, demonstrated and assessed, I needed to analyse more deeply, beyond the descriptive. This involved firstly inductive, and then deductive coding, by specifically considering factors that supports and hinders the development of children’s competence (Chapter 9).

Having coded the data and carved it into themes, I reflected upon how best to present it. My intention for this thesis was for children and parents to be at its core. In order for the reader to fully understand their experiences, I considered it essential to provide a coherent picture through their own words. Thus, with the themes having been identified, and following the informed consent process for structure, I described each child and parent’s personal accounts in stand alone case studies. These provided compelling accounts of their journeys, from diagnosis, through consultations with health professionals, their processes of understanding and deciding upon treatment, to consenting. Once presented in this way further themes, similarities and differences could be identified. Similarly, with the data from the other participants, I found that the more I described and compared the data, the deeper my understanding developed, with more themes emerging. I wrote sections or chapters for all the themes, and found that when focusing the chapters on competence and the consent processes, I was able to draw upon my earlier work.

This was a very labour intensive, time consuming and on-going process, throughout the writing of the thesis. It required in-depth consideration and understanding of the data. I chose to code the data manually, as I preferred to have control over the process, and felt more comfortable with that, rather than relying upon a computer system, such as, NVivo.

866 These are contained in Chapter 8.
In this way I developed a thorough understanding of the data. The quotes used throughout Chapters 8 to 11 were selected to best reflect the richness of the participants’ experiences and highlight the themes.

E. Strengths and Limitations of the Research

The originality and richness of the data are the main strengths of this study. This is the first study of its kind in New Zealand to consider children’s competence, its assessment, and the consent processes in healthcare. Even worldwide these issues have received little attention.867 There is no single study that has considered the breadth of healthcare - medical, surgical and dental treatment, in different healthcare environments. In doing so, it provides insights and understanding of the factors that promote and constrain children’s competence, provides clarity on the factors that health professionals consider when assessing competence, and the consent processes in different healthcare environments. The richness of the data, particularly from parents and children, gives participants’ voices, and rarely heard personal accounts. Further, the spectrum of treatment, ranging from the routine, such as vaccinations, medication at the GP and extraction of a tooth, to the more complex surgical procedures, enables comparisons to be made in how children’s competence develops and is demonstrated, and also on the consent processes.

One limitation of the study is that the participants are relying upon their memory of events. However, these events were reasonably fresh in their minds and were mostly exceptional and emotive circumstances, likely to improve their recollection from the mundane. The ideal combination of methods would be to include observations of children participating in consultations, health professionals assessing competence and taking consent. However, this would have additional ethical and privacy issues, and be time consuming, beyond the scope of this study, but could be considered for further research.

A further limitation is the small sample. My aim was to recruit 10 children and young people and their parents. I had anticipated that it could be problematic to recruit families, as an access point is needed that does not compromise the patient’s confidentiality, and results also in children who meet the criteria. It was my hope that I could recruit families through the NGOs, and it was disappointing, although understandable, that only one agreed to assist in this way. Recruiting mainly through my personal network meant that families with higher socio-economic status, such as parents in professional roles, with children aged 10 years and over, were recruited. Unfortunately, no Māori whānau were represented. The mothers were all well-educated with high health literacy. Nonetheless, prior to their recruitment I was unaware of their views and experiences of their children’s participation in the informed consent processes. Further research in this field would benefit from a more expansive sample, including fathers, children under 10 years of age, lower socio-economic backgrounds, Māori whānau and other ethnicities (particularly

867 See Chapter 5.
Pacific and Asian in the New Zealand context). Also, within the sample of children only two experienced dental treatment at private dentists, and only one was prescribed medication at the GP. The access points for such cases are limited. In the case of dental treatment, hospitals deal with serious dental health conditions, but unfortunately the one I approached did not give me ethical approval to recruit children. The low sample of children means the study has only scratched the surface in eliciting children’s views and experiences of decision-making in healthcare. Nevertheless, this is mitigated by the richness of the data that was obtained from parents and children and the spectrum of treatment.

Finally, children’s cases were not triangulated with their health professionals, which would have given further clarity and perspective on their respective experiences. However, this would have been difficult to secure, without compromising confidentiality, and protecting anonymity. Participants were more likely to be open in expressing their true feelings and views, due to this confidentiality and anonymity.

V. Chapter Summary

This chapter has explored the nature of qualitative research, the rationale for using that approach and described the sample in this study. Central to this thesis is eliciting participants’ experiences, perspectives, feelings and understandings of the issues, which become central to the development of a theory or hypothesis. The issues of competence and consent processes are aptly suited for a qualitative approach, due to the little attention they have received in research and their personal/emotive nature. Diversity was key amongst all the participants, recruiting those with a range of specialty or experience within medicine, dentistry and surgery, in four different healthcare environments – hospital, private practice, school and community youth service. This enhanced the richness of the data, enabling consideration of how children’s competence was promoted and assessed within each, together with whether and how the informed consent processes vary. The combined contributions from participants provide a vivid picture of the multitude of personal, ethical, professional and legal issues they face, when children receive, or refuse, medical treatment. This qualitative research method provided, in particular, the parents and children with the opportunity to describe, reflect upon and give their views on significant, life changing events, explaining how the consent processes either empowered, or disempowered, them. Their voices draw the researcher and readers into their worlds, allowing some insight and understanding of their experiences.

The following four chapters narrate the experiences of children and their parents in consultations, decisions and providing consent (Chapter 8), consider health professionals’ practices and experiences on promoting and assessing competence (Chapter 9) and obtaining consent (Chapter 10), and finally exploring health professionals’ knowledge, understanding and views on the law, together with all the participants’ views on children consenting (Chapter 11).
Chapter 8

Experiences of Children and their Parents in the Consent Processes

Fundamental to understanding the development and promotion of children’s competence and the consent processes is revealing the interactions between children, parents and health professionals. By doing so, insight is gained into their perceptions, feelings and views. The following seven case studies trace the experiences of each parent/child dyad, depicting the nuances of their worlds, as the children’s health condition and treatment unfold.

This chapter highlights the experiences of six parents and their children868 – Wilma/Samantha, Jenny/Amanda, Tania/Oliver, Laura/Alistair, Diane/Donald, and Anna/Poppy, together with one young person, Brenda. The health conditions for which they were treated were cancer (three), ADHD (one), dental treatment (two), teenage vaccinations (one), and surgery (four). Their experiences are diverse, both between and within these different healthcare environments, but they do share some commonalities that will be developed in the following three chapters, and discussed in detail in Chapter 12.

I. Samantha (aged 14 years)

It was an interesting day. They didn’t say much. When we got to the hospital early in the morning the oncologist or surgeon, I don’t know who he was, put us both in a room and then went to privately talk to Mum and didn’t tell me anything. I did not have a clue what was going on, and even after that, he didn’t say that I was diagnosed with cancer. (Samantha, aged 14)

She (Samantha) looked me straight in the eyes and said ‘what is going on?’ I didn’t really know how to answer and I was saying, ‘well, we haven’t had the tests yet’, and she just said, ‘no, tell me what is going on.’ And she said to me, and I can still remember it as clear as day, and will never forget these words, she said ‘whatever it is Mum, there are only two things I want to know, promise me no lies and promise me you are going to be with me.’ (Wilma)

This was Samantha’s first experience of being diagnosed with osteosarcoma, bone cancer, just above the knee. Following this diagnosis, Samantha was admitted to hospital for treatment. The health professionals were anxious to commence chemotherapy as soon as possible, but as they did, Samantha was without the vital support of her mother:

Samantha got quite frightened and was quite fragile. I was her only support person, and so, she was very emotionally attached to me. When you are going through something

868 Their names have all been changed, and the genders of the children may or may not have been switched to protect their identities, but their ages and health conditions are authentic.
that is the worst thing in your life you have a right to have a support person with you, and that I think was very wrong that day, when they took her up to clinic. ‘We are just going to start pre-hydrating’ [said the nurse]. They said they wouldn’t put the chemo on, but they did, and I was getting these terrifying calls from Samantha saying ‘they are switching medicine on. I don’t know if they are putting on the right things. I need you back here.’ As a patient she should have had the right to say you are not doing this until my mother is here. She was 10 and shouldn’t have forced it on her. (Wilma)

Samantha had little or no understanding of what was happening to her and what cancer was:

Int: Did anyone explain to you what cancer is?
Samantha: No. My Mum knew what it was so she explained it. She has done health science and stuff like that, double masters.

Int: Did anyone explain to you what chemo is and what it does?
Samantha: No, again it was left to my Mum to explain that. They gave us a book and told us we had two hours to read this before we switch the chemo on.

None of it was explained, like what are the survival odds, what does a poor responder mean? … I explained to her in the best way I could what cancer was. No-one really sat down with Samantha and explained it. … Even with normal tests. … They would say to Samantha ‘we’re off for a renal scan.’ Well, what does that mean? They’ve got these things on the wards … generally for six and under. There is a dolly to show what an injection is, and they have wards for teens, but they have nothing for that age around 10 [years]. I asked them why this was and they said, ‘you are not supposed to get cancer between 10 and 14 [years]!’ (Wilma)

Although Wilma had given her consent for chemotherapy, she did not feel that she had done so in an informed way. She was given “a thick file” (Wilma) and essentially told ‘we need to get the chemo on, you need to sign it…. you have a choice but you don’t really’ (Wilma). Whilst Wilma understood the urgency of treatment starting, she felt health professionals lacked empathy in relating to their situation. To Wilma their focus was on fixing the problem, rather than treating the person. She described feeling like a “commodity” (Wilma) and likened it to taking your car into the garage to have it repaired, commenting, “sometimes the fact that they are dealing with people gets lost” (Wilma).

This was highlighted to Wilma by the manner in which she was told of Samantha suffering from a rare genetic disease called Fanconi anaemia that affects the bone marrow and the production of all types of blood cells. Wilma had been previously unaware of Samantha suffering from this condition and so knew nothing about it, or of its implications for Samantha’s cancer treatment:

I was told that Samantha had Fanconi anaemia as I was walking down a corridor. ‘By the way, the test results are back. She’s got Fanconi anaemia.’ ‘What does that mean? What are you going to do? Stop treatment?’ ‘No, we think we are just going to carry on.’
Rather than ‘come into my office and let’s sit down and have a conversation’. I just think they need to have a little bit more respect. (Wilma)

As a consequence of such lack of information and involvement in treatment, both Wilma and Samantha felt unimportant. Wilma observed that “somewhere along the road we had lost her. It was like a light had gone out. Everything was being done to her.” Samantha believed too that she had been “dealt with reasonably poorly. They don’t speak directly to me. … ‘Sorry, could you talk to me and not at me, and tell me actually what is going on?’”

Wilma was aware that there was a lot that she was not being told, but even when she began to ask questions she received “ambiguous answers” (Wilma), although that did vary with health professional and area of medicine:

I have to say, and it depends on the personality [of health professionals], but there does tend to be this kind of thing, especially with oncology, ‘well, you don’t really have a choice, so we’ve just got to do this.’ (Wilma)

On one occasion, for example, when Samantha needed to be fed through a nasogastric tube, the insertion of the tube was a very upsetting process for both Samantha and Wilma, as six nurses held her down, forcibly inserted it. As a result, Samantha “shut down after that, psychologically she was crushed - ‘leave me alone, don’t touch me,’ you couldn’t go near her. (Wilma).”

Personalising Samantha to the health professionals became very important to Wilma. She did this, for example, by placing Samantha’s photograph on the door of her isolation room. Wilma recalled health professionals commenting on this photograph, reflecting to her that this was the first time they had seen Samantha as a person, as they are in the habit of treating health conditions.

Over the course of four years, from diagnosis, Samantha had three operations on her leg. The first operation occurred when she was 10-years-old and involved removing a bone and inserting a rod:

It was a bit confusing at first. He [the surgeon] told me that the people upstairs are going to try and save you, and then maybe if you survive, then we might put together whatever is left of you. (Samantha)

We were never given a choice whether the rod got put in or not. (Wilma)

For two years, Samantha lived with the rod in her leg, before having a second operation. This involved transplanting bones into the leg to support it, called an allograft:

869 Wilma further commented “Samantha has Fanconi anaemia, and I have learned more about that now, after four years from the Internet, than I ever did when I was there. Nobody really explained it to me.”

870 Another nurse only informed Wilma afterwards that there were many options for the fitting of a nasogastric tube, such as giving a mild tranquillizer.
They put the titanium rod in my leg, and by that stage, 2012, the bone was not really growing around it like it was supposed to do. So they were going to do a rotationplasty or amputate the leg then, but the oncologist sort of talked the surgeon out of that and into doing allografts instead. Yet again, I did not know any of this. I was in hospital, wondering once again why I was there. … I only sort of figured it out after what they had done. They told me after the surgery, so I got no say and could not do anything about it then. (Samantha)

At no time did somebody sit down and say ‘look, we are not quite sure what to do with Samantha, but here are the options.’ … Now to me that is the critical part, because it would have significantly different outcomes. … At no stage were we given choices or had the options explained to us, or the pro and cons. Not me and not her. (Wilma)

Samantha understood that this operation was not a long-term solution, and so three years after diagnosis, Samantha needed a third operation. Wilma felt pressure from the doctors to proceed with this operation, but she created time, to enable her and Samantha to consider the options – “They said ‘well, it has to be done’ and I said ‘no, not this time. … We need to work through this.’” (Wilma)

Samantha and Wilma took their time to consider the options and began to process the reality that Samantha might need her leg amputated. Samantha’s way of dealing with that was to withdraw into her bedroom, where she made her decision:

She takes a while to think about things. She basically went to her room for two weeks. … She took control of it. … That was very empowering for Samantha. I said to her ‘it is your decision, but you have to know what you are signing off for.’ (Wilma)

All I wanted was not to be in pain and be able to walk. … I had been in pain for four years. You want anyway to stop that. (Samantha)

Wilma considered that it was particularly important for Samantha be involved in this decision, not only due to its significance and irreversibility, but also to ensure that health professionals became aware of what was important to Samantha’s quality of life, which they had omitted to do previously:

It is interesting, at no point did any of the staff ask Samantha about her home life and interests. … You know, when it is something that affects quality of life, like cutting off someone’s leg, I think the people involved, both the family and the child, should be involved on the basis that we know the personal stuff. They know the medical stuff, but they don’t know if Samantha is a footballer and if she lives for her sport or doesn’t. Those are things that they cannot answer. (Wilma)

The decision Samantha reached was an amputation and rotationplasty, which involves amputating part of the leg and rotating the lower part, so the ankle joint acts as a knee. Samantha was 13 (nearly 14) years old when she made this decision. Wilma understood
that it was clearly important for the doctor and Samantha to be able to discuss this decision:

I learned with experience of where to position Samantha when speaking with the doctors so Samantha would be included. I said to Samantha, ‘you sit here. There’s the doctor, you tell him the issues.’ I think where you place the patient is important. With this I said, ‘Samantha has made a decision, you need to ask her about it.’ He did ask Samantha about it, and asked if she had any other questions, ‘is there anything else you need to understand about it?’ There is a deep respect there for Samantha. (Wilma)

At the time of this operation Samantha was 14-years-old. She believed that she had “signed off” on it, as she understood that it could not be done legally, unless she gave her consent:

… he [the surgeon] needed consent from the parent and also the child. It is the type of surgery that was to benefit the kid. If the kid doesn’t sign off you can’t get the surgery legally done. (Samantha)

This operation proceeded, and Samantha felt empowered from having been included in the decision-making:

She knows it was her decision and she is very proud of it. …I think there is a real power in that. ‘It is my body, my decision and I have got this much control back in my life.’ … It is a psychological power. (Wilma)

It is easier on kids. You get concerned and stressed when you don’t know what is going on. (Samantha)

Wilma sensed that this involvement and control contributed to Samantha’s recovery:

… it was very empowering to Samantha who took ownership of it and amazing the difference in the healing. Samantha was a bit older, but even the doctors on the ward and surgeons said ‘she has just healed so well, she’s really taken on the challenge.’ You know, this is the third time we have had to teach her to walk and before it was such an issue getting it done, but this time she has taken control of it. (Wilma)

Samantha has enjoyed the normality returning to her life:

I have a knee joint and I can get a normal gait. … I’ve got no pain. … [I can] walk and swim. … I’ll be able to get back involved in some sport. … I’m eating better because it is easier when you are not in pain. (Samantha)
II. Amanda (aged 16 years)

Amanda was 13-years-old when she was diagnosed with osteosarcoma in her leg. Throughout the course of her treatment, from the initial investigation and diagnosis, through chemotherapy and a laparoscopy, to surgery, Amanda was actively involved in her healthcare.

During consultations, it was important to both Amanda and her mother, Jenny, that Amanda was present at every meeting, so she could listen and understand what was being discussed. It appeared to Amanda, however, that this was perhaps not the norm, or at least not the expectation of her oncologist, as he had seemed surprised:

My mum told him I had been to every meeting and knew what was going on and I was so confused about why he would talk about me behind my back. … My mum would not go to a meeting and then come back and tell me the information. I want to hear it for myself. (Amanda)

So every time we see an oncologist or orthopedic surgeon she is always present. There has never been a time we have excluded her. She was basically like a co-pilot through this. When you’ve got a 13½ year old they are not like a child you can say wait outside. (Jenny)

Jenny intentionally positioned Amanda nearest to the doctor so that Amanda knew it was important that she contribute – “She knew she was always the number one participant.” (Jenny). Jenny encouraged and supported Amanda in explaining her symptoms to the doctor:

Mum would make me sit next to the doctor and usually I tell the doctor what is wrong and then Mum will say more. I will say what I think, like I have a sore leg. So she will let me describe what I think first and then she will come in. (Amanda)

Amanda was also able to answer the doctor’s questions and follow/understand discussions, but did not ever ask any questions, as her Mum and Aunt, who accompanied her to appointments, had covered those. Amanda had confidence in them having matters under control, and so there was no need for Amanda to think of further questions:

Jenny: The problem is that she has never engaged at all with any medical professionals. They ask her every time if she has questions and she always says ‘none.’ I do not think that she has asked a question ever.

Int: Why do you think that is?

Jenny: I think that she thinks that the experts have it under control. It may be that once she has heard the questions from my sister and I, that there were none left. She is an introvert not an extrovert. … My view is that she would think ‘I don’t have to worry here because the adults are doing the advocacy so I can leave it to Mum.’
Jenny found too that having her sister present at appointments supported her, allowing her to absorb the information:

My sister asked 20 questions. I asked some, but I’m more an absorber of information and processing it. She can be like a rattling gun with questions. … You need at times of stress a second brain to hear what is being said because you don’t absorb it. (Jenny)

Prior to the commencement of Amanda’s chemotherapy treatment, Jenny and her sister raised the issue of Amanda’s future fertility with the doctors. A gynecologist spoke with Amanda about this, and whether she wanted to undergo a laparoscopy. Amanda checked with her Mum and Aunt, who both considered that she should proceed, and so Amanda gave her consent:

Well, my Mum could have easily signed it, but I don’t think she [gynecologist] even thought of giving it to my Mum. She gave it straight to me, ‘it is for you. You are the one who is having the operation.’ (Amanda)

… they contacted a gynecologist. She engaged with Amanda and spoke to her about it. Amanda just said to my sister and I, ‘what do you think’, and whatever we said was fine with her. … Amanda signed that consent. … I think that is just her practice, she wanted her to sign it. We both did. (Jenny)

Jenny felt that at 13-years-old Amanda was slightly young to take this decision on her own.

The laparoscopy was carried out at the same time as the port-a-cath, and two days later Amanda started chemotherapy treatment. Amanda felt unprepared for this:

I was straight into treatment. No-one explained to us what the treatment was [or] how long it would take. … I was like what is happening. (Amanda)

… none of us had any real understanding of what chemo was like. We just learned slowly but surely. (Jenny)

Whilst Amanda and her Mum had been given information, Amanda thought that it was difficult to understand:

I can’t remember if this was before or after my first treatment, but they did give us a guideline, but we did not really understand it until I started having it. He explained that I had this path to go through and once I get here I have an operation and then do the path again and every three weeks you have a different treatment and then change it again for a week. So he was explaining it but we were like what does that mean? (Amanda)

Once treatment had begun, communication/information about it from medical staff was lacking, or limited:
I had so many nurses. ... They don’t really know what type of treatment or how long. They just know that you are having chemo and your blood count is good. (Amanda)

The oncologist had very poor inter-personal skills. … There was no communication. We found it difficult to communicate with him and he did not get on her (Amanda’s) wavelength. (Jenny)

However, with her Mum’s support, and with experience, Amanda understood the treatment:

Mum was going through the guide, saying ‘okay you have had this one so we go onto this one.’ After about two months we knew how I was going to react to it and how it went. (Amanda)

This brought Jenny and Amanda very close, spending intimate time together, under traumatic circumstances:

It was quite a bonding time. We spent more time together than the average 13-year-old would spend with their mother. She would be asleep or having treatment and I would be there and you have this space together. (Jenny)

Amanda found that she became highly knowledgeable and competent in the management of her treatment, knowing, for example, the dose and timing of her medication, the level of pain relief and gastric feeding:

I knew my medication and when to take it. Sometimes with chemo I would want to take it as early as possible. … I knew I had to have one and half tablets and the nurse gave me one tablet. I told her, but she did not believe me. So I asked her to check and she comes back confirming I was right. … I had the control of how high the morphine would be. There was an extra pump if I needed it. My feeding stuff I could choose how fast I wanted it and if I was eating I would choose it lower. (Amanda)

She would check that the nurses had the correct doses and would correct them saying ‘I have this then and I don’t have that then.’ (Jenny)

Also, at times, Amanda assisted with procedures, such as the insertion of her nasogastric tube and the insertion of lines into her veins:

I also knew what veins would work and what would not. … They tried to get it in a vein in my hand and I told them it can’t be done. They said that they would try anyway, but it did not work. I told him at this point that I wanted another doctor. He said ‘no.’ The nurse went to get another doctor and she put the line through a vein in my arm. They were not listening to me. … They told me I needed a nasal tube. … They asked me if I wanted them to do it and I said ‘no, I’ll do it.’ (Amanda)
... if we needed a gastric tube fitted she (Amanda) ... was very good at assisting with procedures because she is so practical ... athletic and nimble. (Jenny)

However, sometimes Amanda was not permitted to assist:

Int: In general, do you think that the medical staff considered how competent and capable you were?
Amanda: Some of them asked me if I wanted to do things and were happy that I did. Others insisted that they did it or did it straight away.

After two cycles of chemotherapy, Amanda underwent surgery to remove part of a bone in her leg. She understood the process, as the surgeon had related well to her and explained the procedure:

My surgeon who was really nice, complete opposite to my oncologist, I can’t even explain him. The surgeon explained what he was going to do. He said that the tumour was about 10cm but to get the whole tumour he had to go one cm out on each side and take the whole bone and not replacing it because it is not a bone you need. (Amanda)

She absolutely loved, as did we, the orthopedic surgeon. She knew that there something eating away at the bone and the surgeon cut out 12cms. She knew that had to be cut out and I presume she picked up from our conversations that enough of the bone had to be taken so that it would encompass the tumour so it was not pricked or penetrated. (Jenny)

Jenny gave written consent for this operation, but Amanda strongly believed that she should have given written consent, as she understood the procedure, and was the one undergoing it:

I think I should have signed because it is my leg. Mum signing off for me to get a bone removed, ‘all good Mum, you are not getting bone removed.’ ... My Mum signing off for an operation I am having is weird. I am having an operation I accept it. I was in their presence when they were talking about it. I understood what they were saying and what was going to happen. I should be signing off. Even although I was 13 [years old] I still understood what was happening. ... I would have been happy to sign everything, but sometimes they did not come to me; they went straight to Mum. (Amanda)

Amanda signed that (laparoscopy) consent. All other consents I signed. (Jenny)

III. Oliver (aged 18 years)

I felt that because Oliver had Asperger’s, she [Consultant Oncologist] was questioning what he was feeling was real or was it in his head? I said ‘for goodness sake, it is a social disorder.’ She just lacked the understanding. (Tania)

This was not an unfamiliar experience to Oliver, who has Asperger’s Syndrome, and his mother, Tania. At the age of 14 years, Oliver was diagnosed with leukemia. Tania
experienced some difficulties with some health professionals, due to them being unable to understand Oliver’s different style of communication:

… they were not sure and thrown by the Asperger’s. I had a few issues about [conveying the] symptoms he was feeling to some of the consultants because they did not know whether he was exaggerating or telling tales. I told them ‘my son does not lie and if this is how he says he feels that is how he feels.’ … [H]e said he felt like he had fire ants in his central nervous system, very poignant description, but it was taken that he was lying. (Tania)

On one occasion, the Consultant Oncologist had even made inquiries about Oliver with professionals, such as teachers, social workers and nurses, rather than with Tania:

This one particular Consultant Oncologist, very stoic, thought she knew boys as she had boys, quite bitey. She would stand at the doorway and be quite dismissive. I took her into the hallway to have a discussion as I was so angry because Oliver would talk to her and it was just like she wasn’t listening and then come and talk to me and she would take the attitude that I did not know what I was talking about either. … She rang the teachers, social workers, nurse and they all said ‘if you want to know about Oliver ask his mother,’ so she very coyly had to come back and ask me. (Tania)

This was frustrating for Tania, as Oliver is high functioning, being intellectually at an age appropriate level, and having good comprehension and understanding of issues. Thus, it was important to Tania that she understood the information provided by health professionals, so that she could explain and discuss it with Oliver. She sourced the necessary information from nursing staff:

I found a couple of the more senior nurses who had longer shifts, and they were fantastic with their information and knowledge, which is what I needed because I had that medical mind and I needed to sort it out in my head like a nurse. That also helps me explain things to Oliver, as we had lots of volleying discussions between him feeling revolting. (Tania)

On occasions when Oliver was sick and in pain he was unconcerned about being involved, but at other times, he felt a “bit more refreshed and settled” by being involved. (Oliver).

Throughout Oliver’s treatment, Tania, in effect, acted as an interpreter between the health professionals and Oliver to ensure he understood. This role came very naturally to her, as she was not only accustomed to fulfilling this role, having performed it throughout his life, but was also comfortable with the environment and medical terms, having a nursing background. Whilst health professionals spoke directly to Oliver, giving him opportunities to ask questions, he did not always understand their explanations, so Tania would explain them in terms she knew he would understand. This not only enabled him to participate in discussions, but also reduced his level of anxiety:
The doctors would come in and go ‘blah, blah, blah’ and then I would relay to him a little more simply. … He was there when they talked about it and the doctors, nurses, anesthetists would often say ‘so Oliver do you understand?’ And if he didn’t they could reiterate and I would reiterate over the top of it as I knew how to relay it to him so he could understand it and we had discussions volleying backwards and forwards. Anxiety is a huge thing for Asperger’s and that was the thing to contain. I was the go-between. If I had not been there they would probably have struggled. … I knew how to communicate with health professionals. … I had to make sure everything was being included. (Tania)

Until Oliver was 16-years-old, Tania signed the consent forms, after which Oliver signed them, or gave his oral consent, without Tania being present. However, health professionals would still call her by telephone to also secure her verbal consent:

They just give it to me and I read it and sign it. It is normally for IT, or painkillers or antibiotics. It is normally a checklist. (Oliver)

When I wasn’t there they would ring me on the phone to get parental consent, which I would give, and Oliver would sign the form. He was over 16 [years]. (Tania)

IV. Alistair (aged 10 years)

Alistair was nine years old when he realised he was struggling to learn in school. He asked his parents (Laura and Douglas) for a tutor, and while initially they doubted he needed one, as his teacher had not raised any concerns, they agreed. The tutor recommended they obtain a “full educational, cognitive and psychological assessment” (Laura) of Alistair, so she could tailor her support to his needs. Alistair and his parents followed the assessment process, the outcome of which concluded Alistair had Attention Deficit Hyperactively Disorder (ADHD). Laura followed this up with her GP, who confirmed the diagnosis, and advised that Alistair should be treated with medication. Laura was surprised by the GP’s approach, as she had expected alternatives to be discussed:

I thought she would give me options. I did not expect her to be so directive, ‘you should definitely think about this, because if you don’t you are being unfair.’ So I did feel a little pressure from the doctor to take it seriously. … My first reaction was ‘[Alistair] doesn’t need this because I think other strategies might be more effective, and let’s wait and see.’ (Laura)

Laura began to educate herself on ADHD, even though the GP had told her ‘you don’t want to read too much about this’ (Laura). She sourced educational material through a work colleague and also through the psychological service that had assessed Alistair. Laura found that the literature reinforced her own knowledge:

871 The assessment involved Alistair’s parents having consultations with an educational assessor, clinical psychologist and their GP, together with Alistair undergoing a hearing test and being observed at school.
Laura: I watched some educational DVDs and tried to understand it a bit more. … A public health nurse at work gave me it. Her daughter has ADHD and she was a really good source of information as well.

Int: Did any health professional you consulted give you any leaflets or refer you to any websites?

Laura: The child psychologist service did. They’ve prepared, along with the PHOs [Public Health Officers], a really good handbook for parents in quite simple language. But by the time I had that I had pretty much understood all of the information before, so that just reaffirmed what I had read or understood.

However, there was “no patient material targeted at kids though, in their language, for their needs as a consumer of services. All the literature is targeted at adults” (Laura). Therefore, the role of explaining ADHD, and its treatment, rested on Laura, who not only needed sound understanding, but also awareness of the complexity of her language:

When I first started to talk to Alistair about it I realised that I was using the same language, which was very clinical. I was talking to him in a way that he would never have understood it, so then I had to think really carefully about the words I used. We watched a video together and I thought ‘this is so hard to actually help him because I don’t really understand it.’ It takes me a long time to figure out what this condition is in order for me to interpret that, change my language and talk to him about it. It was really tricky. I didn’t know how he would understand why he was taking tablets. (Laura)

Alistair’s parents then discussed his health condition and its treatment with him, and supported him in making the treatment decision:

Both me and Alistair’s Dad said to him ‘it is completely your decision. If you want to start it and try it we will support you to do that and if you don’t want to start it that’s fine too.’ … He said he wanted to take the medication because he wanted to learn, and I think that made it quite clear for me. (Laura)

They [Mum and Dad] talked to me about it, but they said it was all up to me to make the decision. (Alistair)

Alistair, aged 10 years, made the decision in the context of his family, rather than during a consultation with a health professional. He only met with his GP afterwards. At this GP appointment, Laura alerted the GP to the fact that Alistair had taken the decision, and her impression was that the GP was surprised, but pleased with this:

I think when we went back for that visit she assumed that Alistair was pretty on-board with how it would work. … I remember telling the doctor that we’ll let Alistair make the decision on it, and she looked quite pleasantly surprised. I got the feeling that she thought that was novel, that it was good, and there was going to be no issues. It was going to be an easy consultation, pretty much ready to try it out and see how it worked. (Laura)

At first [the GP] asked my Mum if I wanted to [take the medication]. Then she asked me. (Alistair)
The GP examined Alistair, explained the medication and check ups and confirmed Alistair's understanding of the treatment:

Laura: It was pretty much a given what we were doing. So the GP had assumed that Alistair was on-board with it and there wasn’t so much of an opportunity for the doctor to talk to Alistair about what the options were, but she did check in with him if he understood what was happening here and that he was okay with it.

Int: At that consultation how much of the dialogue was with you and how much with Alistair?
Laura: I would say 80% directed to me.

She asked my Mum questions and then she also asked me some questions. … Well, she wasn’t exactly asking questions, but she was doing stuff like looking in my ears and shining a light. (Alistair)

Despite most of the conversation being with Laura, Alistair still felt included in the consultation, rating the degree of inclusion eight and a half out of ten. Although Laura did not detect the GP assessing Alistair’s competence, the GP did comment that Alistair was interested and smart, and had checked his understanding.

For Alistair the decision was a simple one - he wanted to try the medication to test whether it would improve his concentration, and was not surprised that his parents had allowed him to make this decision:

Alistair: I wasn’t really surprised because I think I should have chosen whether to take them, and I wanted to take them.

Int: Why did you decide to take them?
Alistair: I decided to take them for the first week to test them out to see if they made a difference. So I tried them out and they did make a difference. … When I first took them I finished my [school] work first and I don’t usually do that. … My marks are going up slowly.

Although Laura initially questioned whether the decision to take medication was the correct course of action, she recognised, when reflecting upon the journey they had taken, that Alistair had a sense of his own wellbeing. Her thinking had shifted and broadened, from initially believing that a decision, such as this one, was a parental decision, to listening to and valuing Alistair’s judgement:

I still felt as a parent I am the one who makes decisions about that, but actually this situation has shown me that he was right to make that decision. [T]he GP … basically said ‘a good parent would make this choice,’ and then the influence of your study and thinking more about those issues, I thought, ‘well, it is probably not my decision.’ And I did not want to make a decision that could potentially hold him back when he (Alistair) had identified that there was a problem and wanted to take action. (Laura)

It was basically only my choice, the choice was not made for me. (Alistair)
Thus, Alistair’s involvement in the decision-making led not only to growth for Alistair and Laura, but also resulted in a development of trust between them:

After it happened I realised I should trust him because he seemed to know better than anybody what he needed. … I think children do need to feel trusted by those who involve them in decisions because medication of any kind is a major decision that they have to be on board with. … I think it worked really well for Alistair. I think he needs to feel trusted and because it is working well for him at school. … It is a great feeling when you do actually trust your kids to make a decision. (Laura)

V. **Donald (aged 11 years)**

Donald was 10-years-old when he and his mother Diane were advised by their dentist to consult with an orthodontist, due to concern about the growth of an adult tooth. At the orthodontic appointment, x-rays showed that a tooth was growing in the roof of Donald’s mouth, and was unlikely to push out the deciduous tooth. The orthodontist recommended that this deciduous tooth be extracted, advice which Donald was less than impressed with:

We went to see the orthodontist and had various x-rays and worked out Donald had a tooth at a silly angle in the roof of his mouth. His solution was to take out one of his baby teeth to allow this other tooth to move to try and let other teeth naturally fall into place. Even at that appointment [Donald] wasn’t happy. As soon as the orthodontist said that his recommendation was that you go back to the dentist and have this tooth removed, he ran then actually out of that room and into the waiting room trying to get out. … He was quite, quite annoyed. (Diane)

Diane was unsure what Donald’s objection was, but she wondered whether it might have been as a result of Donald witnessing his older sister having an upsetting experience at the dentist three or four months earlier.

A couple of months later, Donald returned to his dentist for his tooth to be extracted. Donald made it very clear that he did not want this to happen. He refused to follow the dentist into his surgery, and when the dentist took Diane into his room, Donald seized the opportunity, and bolted outside. He was coaxed into returning by a dental nurse, but strongly stated to the dentist that he did not consent to the tooth being extracted:

… he (the dentist) said ‘could you have your tooth out?’ And I said ‘no, I don’t really want my tooth out.’ Then he said ‘could you please do it for your Mum and your Dad.’ And I said ‘I don’t give you permission to touch my mouth or my teeth.’ I just didn’t want to get it out. (Donald)

… he [Donald] said ‘it’s my mouth, my tooth and I don’t give you permission to take my tooth out.’ (Diane)
Donald knew that he could not be forced to open his mouth by the dentist and wanted to make it clear to him that he did not give consent to have his tooth extracted:

I thought that if I said that they would have to agree that they couldn’t take it out, and if I wasn’t going to open my mouth they can’t do it. I just think that if they are going to try and get my mouth open they can’t really do that without me co-operating and trying to open it. (Donald)

The dentist, turning to Diane, confirmed that it would not be feasible for him to proceed in light of Donald’s refusal:

That’s when the dentist looked at me and went ‘what am I supposed to do with that? He told me he doesn’t want me to take the tooth out and I am not going to take the tooth out because this is not going to work.’ (Diane)

Diane recalled that the interactions with the dentist had been mainly with her, rather than Donald:

Int: What were the interactions between Donald and the dentist?

Diane: Not too many because it was more between me and the dentist because he [Donald] was not co-operating. So the dentist spoke to one of the dental nurses who was trying to persuade him to come back into the surgery and when he came back in the dentist spoke to him again and said ‘are you going to come through?’ And that’s the only time really when he spoke to him directly, and that’s when [Donald] told the dentist he did not want him to take the tooth out.

Diane thought that perhaps the dentist could have engaged more with Donald, but acknowledged that Donald’s opposition was strong:

He could have possibly come down a little bit to Donald’s level. The dental nurse, when she tried, sat next to him on the step outside. The dentist was standing above Donald and if he’d crouched down, got on his level, and he could have maybe tried a little bit harder to explain about the actual injection and what it does and ask him what his fear was. Because [Donald] was being so stubborn and physical about it, he was adamant that the tooth was not going to come out. (Diane)

At the next routine check-up, the dentist found that Donald needed a tooth filled due to decay. The dentist advised Diane that this tooth was next to the one that needed extracting and both could be treated at the same time. Diane thought that perhaps Donald was not in the surgery at the time of this conversation:

He did say that the tooth that needed filled was the tooth next to the one that needed extracting and he said to me, because then [Donald] disappeared, ‘we could see how it goes and if we can persuade him to have a filling we could maybe do it at the same time.’ So he did mention the extraction, but I can’t remember if Donald was in the room. (Diane)
Donald was not advised of this plan in advance of the following appointment, thinking it was for the filling only:

I didn’t really talk to him about the extraction other than sowing the seeds, by saying it is the tooth next to the one that needs extracting. I think we did mention that there was a possibility of the tooth coming out, but certainly that is not why we were going to the dentist. It was almost that me and the dentist, we did have a little secret agenda, so we hadn’t hidden anything from him, but we hadn’t really talked about it. (Diane)

Nevertheless, before Donald returned to the dentist Diane spoke to him about injections, how they worked and of the noises to expect in the dental surgery. She also explained that when she has something unpleasant to deal with she copes by thinking about how it will be over in a short period of time:

In the prep work I did with him I tried to talk to him about the injection … about what it does and how it anaesthetises your face and a little about how it works, that the brain stops sending the pain messages. And I talked about the sounds in the dentists and how they can be worse sometimes than what you are having done. … I also talked to him about what it was like when I don’t like having things done to me and if the appointment is at 4.30pm I know the appointment will be over by 5pm. So I think this is going to be a horrible half an hour, but it will be over in half an hour and usually it is not as bad as I think it is going to be. (Diane)

Donald understood why it was advisable for the tooth to be extracted sooner than later:

I understood that if I didn’t get it out I would have to go through a lot more pain in my life, and if I didn’t have it out I would have to have my mouth cut open and it pulled out. (Donald)

After the dentist filled Donald’s tooth, the dentist asked Donald if he agreed to have his other tooth extracted, although Donald was distracted at the time:

The dentist did a really canny thing and distracted him with a movie, which was playing on the ceiling of the surgery, and he was lying back with headphones. … He did the filling and then said to me ‘should I do the tooth now?’ He lifted Donald’s headphones and said ‘I’m going to take the tooth out’ and Donald nodded and let him do it. (Diane)

I kinda changed my mind, because in the meantime I was watching ‘The Simpsons’. … He [the dentist] kind of whispered in my ear ‘I’m going to take your tooth out now’, and … I just shook my head, and I didn’t even feel a thing. (Donald)

Although Donald had not been included in discussions about the tooth being extracted, he understood the necessity for it being done, and it was a relief to him:

I knew that if I got it out there wouldn’t be much to worry about again for a while because it was always on my mind that if I didn’t get it out it won’t be perfect, so I thought I might as well get it out and get it off my mind, so I did. (Donald)
Donald felt more confident about being able to handle dental procedures in the future, having experienced the injections and tooth extraction. Diane reflected also that Donald needed to understand and be engaged in the process, as he is not the type of child who will simply comply with what adults want him to do:

… some children are very compliant and just go along because the adult has said so. I’ve got one who doesn’t want to go along because the adults have said so, that is not a good enough reason. He’s got to be engaged. (Diane)

VI. Poppy (aged 16 years)

Poppy experienced three different types of healthcare procedures between the ages of 11 and 15 years. Firstly, she was vaccinated against diphtheria, tetanus and whooping cough at the age of 11 years and against the Human papillomavirus (HPV) at 12 years old. Secondly, at 14 years, she had an operation on her achilles tendon, for a condition with which she was born, and thirdly, she had dental surgery and braces fitted at the age of 15 years.

A. Vaccinations

When Poppy was 11-years-old she was given information at school, through the vaccination programme, about the booster vaccination against diphtheria, tetanus and whooping cough. She took the information home to her parents who helped her to understand the importance of vaccinations, such as showing Poppy her Plunket book. Anna, Poppy’s Mum, thought this had helped Poppy to cope with being vaccinated, as previously she had been quite fearful.

Poppy trusted her parents to make the right decision for her, and her mother consented to the immunisation:

We got a booklet and it had all the information in it. We had to get parents to sign it and then hand it back in. I did not read it. I got Mum to sign it because I trust her in what she decided, and I never bothered to read it. (Poppy)

A year later Poppy was due to receive the HPV vaccination, that helps prevent cervical cancer. Poppy attended a presentation about it at school – “We had a massive talk about that one” (Poppy). She was also given a significant amount of information to take home, which Anna and Poppy considered together. Anna had recently been for a smear test and was able to share the information she had received from the nurse about the HPV vaccination:

Huge amounts of information. … It was almost like a booklet. … I had a chat to her. … I had a smear maybe about a month or two before and I remember the nurse
mentioning it. … I said to [Poppy] ‘I’ve been for a check up and they said how they are seeing results now, the incidence is coming down now.’ I read the information. She did not read it all. I explained where the cervical area is, because at 12 I think she had some idea. (Anna)

Poppy was happy to agree to the vaccination, but did not consider this was a major decision, again trusting her parents’ judgement:

*Int:* When you brought the information home do you remember having discussions with your Mum about whether you should have it?

*Poppy:* Yes. I am pretty sure she asked me, and said ‘you’re all good getting it?’ ‘Yes.’

*Int:* Do you feel that you contributed to the decision of whether you had it?

*Poppy:* Yes. I feel like I did, but I feel like it was not that big of a decision. Like I trusted Mum to make the right decision. I saw her read the forms.

*Int:* Why do you think that you agreed with her decision?

*Poppy:* I trusted that she would do the right thing, like if it was sensible she would do it; if it wasn’t, she wouldn’t. I trusted her. If I didn’t want to get it she would be okay. She talked about why.

I think for Poppy we read it and understood it and were happy with it. … I said to her too that they would not produce something in New Zealand that was not safe. I told her that I would do it if I were her age. … It was like ‘I trust you, in which case I will do it’. (Anna)

Anna gave written consent for the vaccination, and Poppy thought that she had also signed. It was significant in Poppy’s decisions to agree to these vaccinations that most of her peers were receiving them - “everyone was doing it”, a fact that Anna also understood as significant - “the fact that everyone was having it made her feel safe.” (Anna)

**B. Achilles Surgery**

Poppy was born with an achilles tendon condition that was monitored annually at the hospital by the same orthopaedic surgeon. At every appointment, before about the age of 12 years, Poppy felt that the surgeon discussed her achilles mostly with her parents, with which Anna agreed:

*Int:* Before 12-years-old how involved did you feel?

*Poppy:* A three or four [out of ten]. Mum and Dad did the talking, and I think it was because we did not have to make major decisions, like it was not an operation or anything. They were talking to Mum and Dad, which I kind of get because I was younger. So I kind of understand that because if they told me stuff I wouldn’t remember it, but I do remember that they would talk to Mum and Dad.

Not from a young age, but from intermediate age, about 11 [years]. (Anna)
From about the age of 12 years, Poppy grew in confidence, feeling more able to engage with her orthopaedic surgeon:

I would say around 12 [years], because before that I was shyer, and Mum knew better what to say. (Poppy)

At the appointments they were very good at talking to her, and particularly now, they make less eye contact with me and more directly to her. (Anna)

Though the degree to which Poppy felt included had increased, she thought that she was still not really involved in discussions:

Before the last one I would say about a five or a six [out of ten]. Involved to a point. Like I was involved because it was my achilles, but I was not really involved much in the discussions. I was always there and I was always listening and if I had questions I could ask, but I didn’t really. (Poppy)

At each annual review, until Poppy was 14 years of age, the surgeon had advised that an operation was not required. However, around the age of 14 years, Poppy began experiencing difficulties with her achilles. She was unable to stretch it, and so the orthopaedic surgeon recommended surgery:

It had been giving her a bit of grief because she could not stretch it or get relief from it. They graded it a four out of five and said it will just get worse. (Anna)

It was getting tight, tighter, and impacting on my sports, so we checked it out to see if everything was okay or there was anything more I could do. And this is when they recommended to get the operation. (Poppy)

This came as a surprise to Anna and Poppy, as they anticipated the surgeon’s advice would be similar to that of the previous 13 years:

We weren’t mentally prepared and hadn’t prepared questions. (Anna)

It was a little bit like ‘okay, not expecting that!’ (Poppy)

Nevertheless, at this appointment Poppy was more involved in discussions. She and Anna had talked about how they would approach the consultation, discussing what information was required, and agreeing that Anna would begin the conversation, with Poppy following on:

Usually we go in and sit down and they will ask ‘what is going on?’ In the last one Mum said it was getting tight and I was having some problems with my hip. And then the doctor said to me ‘what is going on?’ So Mum would outline it because sometimes I forget stuff. So I will talk to Mum before we go to the doctor and she makes sure I have told them everything. (Poppy)
She always asks me to start. So I say ‘this is Poppy, she’s been having trouble with her foot lately, but she will explain it to you in her words.’ She doesn’t like starting off. (Anna)

Then during the consultation, Anna assisted Poppy to be further involved in discussions by redirecting the conversation at times. For example, Poppy recalled how during the examination of her achilles the surgeon spoke to her mother rather than to her, but Anna steered the conversation towards Poppy:

Probably about a seven [out of 10]. I felt at some parts they were looking at my achilles and talking to Mum and then Mum would talk to me. So Mum kept me involved, more than they did I felt. Yes, Mum knows. Mum gets it more than the doctors. They were talking to her a lot more. (Poppy)

They spoke to her. They spoke to me as well, but they spoke to her more, and gave her more eye contact. To me that is the indicator. (Anna)

The surgeon explained the operation. He used a number of techniques, such as a drawing, looking to Anna to assist in explaining it to Poppy, and recommending some Internet sites:

When it gets technical I can see them looking at me to try and explain it to her in a way that she’ll understand and then drew a picture. They showed her that there were several ways in which they could do it. I thought that this was really great because they really related to her. They said ‘don’t google it because you will see some ghastly things. If you are going to google it then go on these sites.’ Of course she did, because that is what they do! I thought that was really nice because they related to her. I had no interest in googling it. She and her friends have. (Anna)

Poppy felt less anxious from being involved in the discussions:

It felt a lot better. This one was the first one that I felt involved in discussions because it was an operation. It makes me less nervous because I have a say and that made me feel good. (Poppy)

Anna gave consent for the surgery at this appointment and completed the necessary forms:

[The surgeon] asked if we agreed to the surgery and we had to fill out a questionnaire and … papers. (Anna)

However, Poppy was still thinking about whether she wished to proceed with the operation or not. It was important for her to talk things over with her parents to help her make the decision:

Int: Have you had discussions with your Mum and Dad after that consultation?
Poppy: Yes, quite a few. I went through a phase where I did not want to get it done. It was just because of the recovery, like it seems like a pain, quite a few months off school … but in the longer term it will be better.

**Int:** Did you have any questions for your Mum and Dad about what is being suggested?

Poppy: Yes, I asked them what they think I should do, if I should get it or not? And they said ‘yes, get it. If you don’t get it you will regret it later in life’, which is true. … Like Mum and Dad said ‘it is okay if you do not want to have it done, if you completely don’t want to, but we think that you will regret it.’ … Mum and Dad helped me look long-term.

At one stage she threatened not to go and I think she understood that, at the end of the day, it was her body and she could say ‘no’, but she also understood that it needed to be done. (Anna)

Anna thought it had helped Poppy to proceed with the operation because she had known and trusted the surgeon since birth.

Following this appointment with the orthopaedic surgeon, Anna and Poppy had a telephone call with a pre-operative nurse. This was important, as there were details about the operation they were still unsure of, such as whether Poppy would need an anaesthetic, and what would happen on the day of surgery.

Poppy’s parents received a letter advising them of the time of the call. There was no written communication directly with Poppy. Before the call with the pre-operative nurse, Poppy and her mother discussed how this call would be organised, so that Poppy could participate. Poppy decided that she wanted the support of Anna, and agreed they would each use a telephone line. When the nurse rang, she asked to speak with Anna, who advised her that Poppy was on the other line, as she wanted to listen. The three-way conversation worked well, as Anna could support Poppy to cope with the uncertainty, and then shock, of requiring an anaesthetic for the operation:

Poppy was listening in, but not answering, so I said ‘what do you think about that sweetheart?’ Because we learned on the phone that she would need a general anaesthetic, which shocked her a bit, so she went quiet. I was asking more and more questions and then sort of bringing Poppy in. (Anna)

I was on one phone and Mum was on the other, so it was the three of us, and it was a bit easier. … We talked about getting the anaesthetic. … That was the first time we were told I would be going under. (Poppy)

The nurse explained to them that the anaesthetic had risks, and that although Anna would be signing for it, Poppy should understand them. She suggested that she send Poppy two booklets, one designed for adults and the other for children:
… she thought that she would send Poppy both because the adult one might be a bit too technical and the other one a bit too childish, and maybe Poppy could find a happy medium. (Anna)

Following the call, Poppy was anxious to understand the process, and immediately read the booklets when they arrived:

I asked her how she felt about that and she said it was a bit scary. I said ‘let’s see what the booklets say,’ and as soon as they came she opened them straight away and took them upstairs and read them. She agreed that the kids’ one was a bit babyish and the adults’ one a bit much. We talked about when me, her Dad and a friend had anaesthetics. (Anna)

On the day of the operation, Poppy and Anna met with a nurse at the hospital, who completed the forms by directing questions about Poppy’s health to Anna:

Then I was taken through to a little room with the nurse who went over the form and was asking me and Mum questions about me, which was a bit weird. She would ask Mum ‘has she got ….?’ And I am sitting right there. … I am like ‘I am right here.’ It was questions like ‘has she had an anaesthetic before and any allergies?’ She asked me my age and height, things I could not get wrong. (Poppy)

Poppy and Anna then met with the anaesthetist and the surgeon:

Then we went through to theatre. I had met the surgeon before, but not the anaesthetist. The anaesthetist talked to me. The surgeon talked a bit to me, but more to Mum because it got a bit technical. The anaesthetist did talk to Mum too. He would explain it to me and then to Mum, which I understand completely as I am under her care. (Poppy)

The anaesthetist was very good and spoke straight to her. (Anna)

When it came to signing the consent form, the anaesthetist turned his attention to Anna, explained the form and asked her to sign it because Poppy was under 16 years of age:

He explained to her ‘because you are under 16 [years] your Mum has to sign for you’. (Anna)

Poppy: It is interesting because I observed, because I knew I would be talking to you [researcher] again, and so I was watching who was talking to me and who was talking to Mum. The consent form with the risks, they talked more to Mum, which is kind of sensible. They did not really tell me about the risks, which is understandable. Int: Did they explain to you why your Mum was signing the form? Poppy: No, they didn’t, but I know it is because I am under 16 [years]. The only form I filled in and signed was the information, not the risks.
Anna signed another consent form on the morning of the surgery for the operation. Poppy accepted this process, but felt she should have taken joint responsibility for the risks, and signed that form along with her Mum:

I did [sign the form] with Poppy there. We asked all our questions and both of the doctors explained because she was under 16 [years]. I remember them reading out to Poppy and explaining what we were signing and then they said that ‘Mum has got to sign for you’, and she understood. (Anna)

I was happy for Mum to sign it because I trust her and the doctors, but I would probably have liked to sign that risk one, along with Mum. If I did I would probably be more worried, but it felt right that I should because I am taking the risk. But that is just how it is and kids probably wouldn’t care. (Poppy)

Poppy acknowledged that while she had not given written consent, she had given verbal consent - If I was saying ‘no’ they would not have gone ahead with it. (Poppy)

C. Dental Treatment

At 15 years of age, Poppy needed dental surgery that involved cutting incisions into her gum to expose her two canine teeth, and then fitting fast braces to pull them down. The dentist explained the procedure to both Poppy and Anna, and Poppy’s parents supported her to make the decision of whether to proceed with the surgery and braces:

*Int*: When you were getting information about the advantages and disadvantages of going ahead with the surgery or not how did you feel the split of attention was between you and your Mum?

Poppy: Pretty even. They talked to Mum more about the financial stuff and me about the pain stuff, about what it would feel like, and to Mum about how long it would take and cost. Pretty even, eye contact back and forward.

*Int*: Do you feel like you made the decision?

Poppy: Yes 100%. I think that is got to do with the dentist and Mum and Dad. Like we got the consult and then they said we can think about it because there is the option of getting the bottom row as well. … They were really nice about it. They said you don’t have to but you can if you like.

Poppy understood that essentially this procedure was cosmetic, as her teeth would have eventually come through the gum, but they would have likely been crooked. Poppy realised also that the process would be easier and less expensive if she had it done before the teeth emerged. Poppy’s parents and the dentist advised her to have the lower and upper braces fitted, as she had a semi-cross bite:

They wanted to initially fit braces top and bottom, so that was interesting because Euan [Poppy’s Dad] and I suggested to her it would be good to do both. It makes sense, but she did not want to. She was adamant, so she just stuck to the top one. She had a semi-cross bite, but it wasn’t bad enough and she said she was happy with it. We explained to her that it might be harder when older and more expensive if you have to redo it again,
whereas if you do them together they start lining up. But, no, she did not want to. (Anna)

Poppy was strongly of this view because the issue was not sufficiently serious to warrant fitting bottom braces too, as the cross-bite was slight, and her teeth were straight:

… they said we can think about it because there is the option of getting the bottom row as well. … I felt quite strongly because my bottom teeth are straight and I think there was a little issue with a slight under or over bite, but it was really small and it seems to have fixed itself. And it was about $2,000 more to get the bottom row done and for me it was not worth it. If they were skew I would have, but it was not worth the extra pain and an extra two hours. (Poppy)

Her teeth are completely straight, it is just the cross bite. She said she would rather live with the cross bite, and it wasn’t terrible, just a cosmetic thing. (Anna)

Also, Poppy was aware from her friends, who had both sets of braces fitted, that they are more painful.

Although Poppy appeared very clear about the decision, Anna thought it best to further discuss the options with her, and to check with the dentist about the advantages of fitting bottom braces at this stage:

We … talked about it and kept encouraging her to do the lower layer. She said ‘no, no’. Then I emailed the dentist, told him she wasn’t keen and so could he give me a price to just do one and ‘could you just explain to me again the advantage of doing the cross-bite, sorting it now?’ Because sometimes you meet and there is a lot of information, so we followed it up by email and I made Poppy read the email. (Anna)

Poppy’s parents continued to be of the view that it was better to have both braces fitted now, to avoid potential future difficulties with her lower teeth and as it was more cost effective. However, in retrospect, Poppy’s decision was the right one, as the cross-bite corrected itself:

We were not that happy about it, but it has turned out that it was the right decision because the cross-bite has corrected itself. … You can see the economics in doing both at the same time. (Anna)

During the surgery to expose Poppy’s canine teeth, the dentist communicated directly with Poppy. Anna used her own experience of dental treatment to suggest to Poppy to signal to the dentist during the procedure, so she was in control:

Anna: She was definitely in control of it. I was just a sidepiece. I literally just sat in the room and did nothing. They talked to her the whole time. We agreed if you put your hand up they will stop because it is hard to communicate.

Int: Who suggested that?
Anna: Us, because I had had a root canal in the past and it is really hard to communicate with the dentist.

When I got the teeth exposed [the dentist] told me ‘I’m going to do this and is that okay?’ And I said ‘yes that’s fine’, and she was nice about it because I could put my hand up if I wanted her to stop. (Poppy)

After Poppy’s braces were fitted, she had dental appointments to tighten and check them. From 15 years of age, Poppy took responsibility for making these appointments and attended most by herself. Poppy found that the dentist focused on her, even when Anna accompanied her:

Going back every three or four weeks I do that myself, just after school. Mum sometimes comes with me, every second or third time, but that is just to pay. ... The dentist that does my braces, whenever I see him I usually go alone and if Mum is there he is used to talking to me. (Poppy)

However, Anna is aware of the appointment dates, in case Poppy needs to be reminded of them, but this has not been necessary:

_Int: When Poppy goes to the dentist does she make the appointments and go on her own?_
Anna: Yes. When she’s there she makes the next appointment and they text her and me. I spoke to the receptionist and said ‘she is a teenager so it is probably good that you flick it to me too so I can put it in the diary and remind her the day before’, but she has been good.

Anna believed that the familiarity of the dentist, and trust the whole family has in him, helped Poppy’s confidence to attend by herself.

**VII. Brenda (aged 19 years)**

At 14 years of age, Brenda began to suffer from constant pain in her lower abdomen and felt fatigued. She attended numerous appointments with her GP, gynecologists, dieticians and nutritionists, who each tried to diagnose the cause of her symptoms. When she attended these appointments, her Mum, who helped her recall all the important information she needed to give to the health professionals, accompanied her:

The relationship was that I would answer everything that I could and because we were really close, if I forgot anything, because my mind was a bit fogged up, she would be like ‘and there is also ...’, not in a harsh way, but as a gentle reminder. It was very well done. (Brenda)

Anna also commented that the family has had the same GP for years, but recently Poppy had changed her GP within the practice, and found that they “connected” better.
Brenda felt important during consultations, as the focus was on her and she was given privacy and opportunities to ask questions:

Brenda: My doctor would always talk to me, well both of us, but they would ask me about how I felt. They would ask my Mum to leave the room if there were more personal questions. I was very well taken care of.

Int: Was that by all the different professionals?

Brenda: Yes, I cannot think of anyone who made me feel like I was not important.

Int: Did you have opportunities to ask questions?

Brenda: Yes. There was pretty much, one of my doctors in particular at the hospital, ‘do you have anything you want to ask or are not sure about? Don’t try and google it, and if you have any questions you can always ask as it is not that well known about.’

A year later, when Brenda was 15-years-old, it was suggested that she have a laparoscopy to further investigate the cause of her pain. The doctor gave Brenda the choice of whether to proceed, which she did, as the pain was causing her to miss school, and she was wanted it resolved:

They said this is our recommendation, ‘are you okay with this … or would you rather try other methods of treatment?’… I had had a year of suffering and was over it. (Brenda)

Brenda was unsure whether her Mum had signed a consent form for the laparoscopy, but she could not recall doing so herself. After surgery, Brenda discovered that she had endometriosis, which the surgeon operated upon:

After I woke up they explained ‘you do have this [endometriosis] and we have taken it out and once you have recovered from the surgery you should be better.’ When he [gynecologist] came to talk to me it was much more general, it was talking to me, but also to my parents as well. I don’t know if it was because you are this age. (Brenda)

Unfortunately, the condition was unresolved and Brenda had multiple hospital admissions and meetings with her gynecologist, before proceeding to a second surgery at the age of 16-years-old, followed by a third one at 17-years-old. She made the decisions to proceed with both operations and signed each consent form - “I felt very involved and treated very well in both of them. … I am pretty sure I signed at least two forms” (Brenda).

**VIII. Chapter Summary**

Whilst each child’s/young person’s experience is unique, some common features emerge, such as: the importance of parents’ roles in assisting their children to participate; the evolving nature of children’s competence; and generally the reliance upon parental consent in the consent processes.
A. Roles of Parents

Occurring both inside and outside of consultations, parents’ roles took several forms: emotional support; promoting communication and relationships with health professionals; enhancing children’s understanding of their health condition and treatment; and supporting their decision-making.

1. Emotional Support

Emotional support was needed by all children, but was clearly seen and provided by Wilma, for example, prior to Samantha receiving chemotherapy, and also by Anna and Diane when they enhanced children’s understanding of vaccinations and dental treatment respectively. As a result Samantha, Poppy and Donald were better able to cope with treatment.

2. Promoting Communication and Relationships

Both prior to and during consultations, parents promoted their children’s abilities to communicate and to develop relationships with health professionals. For example, they prepared them for how and what may be discussed, and once in the consultation sat them strategically, signaling to health professionals the importance of involving their children.

3. Enhancing Children's Understanding and Decision-making

Parents commonly carried out research following consultations, and discussed it with their children, to promote their understanding of their health and its treatment. At times, this compensated for the lack of explanations given by health professionals and resources available to families, as Wilma and Laura experienced.

Once children’s understanding was developed, most were then able to make health decisions, with the support of their parents, who gave them space, time and permission, such as: Samantha (rotationplasty); Amanda (laparoscopy); Alistair (medication); Brenda (surgery); and Poppy (surgery and braces). Whilst their parents were unaware of any deliberate process health professionals undertook to assess their children’s competence, health professionals engaged with their children during consultations when consent was provided.

B. Evolving Competence

Competence evolves over time, rather than being determined by age. The time period will vary, depending upon, for example, the nature of the health condition and its treatment. For example, Alistair’s competence evolved over a focused period, from when
he identified an issue with his concentration, through diagnosis, to providing informed consent for treatment; whereas Poppy’s competence of her achilles condition developed throughout her lifetime.

C. Reliance on Parental Consent

Commonly, the consent processes involved children giving their verbal consent and parents providing written consent, when required, until children reached 16 years. For example, Poppy was unable to provide written consent as she was under 16 years, and Brenda and Oliver began providing written consent after they reached 16 years. The exception was Amanda, who gave written consent for the laparoscopy.
Chapter 9

Promoting and Assessing Children’s Competence

I. Introduction

Having stepped inside the lives of the families, I move across to the healthcare environments to consider the perspective of the healthcare professionals, looking firstly at what supports and constrains children’s competence. Emerging as significant, were several external factors, common across the healthcare environments: time; privacy; the parents’ roles; building of relationships; and educating on health conditions and treatment. This chapter examines these factors, before then turning to how health professionals assess competence, specifically identifying the criteria they consider.

II. Promoting Competence

A. Time

1. School Medical Service and Community Youth Service

During the interview process, the issue of time emerged as being significant for a number of health professionals, specifically in building relationships and trust, promoting children’s competence and responsibilities, protecting their safety, and assessing their competence. This was most apparent in the School Medical Service (SMS) and Community Youth Service (CYS).

In the SMS and CYS, time was a great asset that enabled children to discuss their situation, enhancing not only their understanding, but also having all their needs addressed. At times, such needs extended beyond simply the initial physical concern, snowballing into much more complex, emotional and social issues:

> Sometimes what can be a relatively simple issue or problem can then turn into something huge. So what you think may be a five minute consultation, an hour and a half later you are still going. … A good example is that the girls will come in and say ‘I need a plaster.’ I say ‘okay what for?’ So we start off with the physical and then they will be doing this, and I’ll say ‘okay show me your arms’ and I know they have been cutting. … So we start with that, treat the physical, tick all the boxes, check that there is no infection, then you need to go into what’s going on here, moving onto the social issues.
> (Nur2)

873 They raised this in conversation, rather than it being an identified theme that was questioned on. Thus, time could be of significance to other health professionals.
874 The school nurses (Nur1 and 2) were based in their respective schools and the GP (GP6) visited one of those for three hours each week.
875 See also Chapter 10 for further consideration of the SMS, page 212-215.
Some of our appointments go for 45 minutes. The way we run it here, we look at the severity of the condition. We are dealing with huge abuse issues and huge social issues. Terminating pregnancy would be one. (Private/School/Youth Service, GP6)

For example, one nurse in a CYS recalled a child attending with her aunt. Although the child was seeking contraception, she divulged that she did not wish to have sex. It transpired that the aunt’s intention was to prostitute her.

Through intimate conversations between children and health professionals, trust, mutual respect and competence develop, as the health professionals listen, discuss and support children’s understanding and decision-making abilities:

I think young people need to be respected and to understand. (Private/School/Youth Service, GP6)

I think it is about respect for them, and giving them the opportunity to express, in a way that they can, and to make good decisions about their health. That is about their voice and about time to listen to them. (School, Nur1)

The kids coming here, sometimes, it is the first time that they have been shown dignity, respect and understanding, and just love. (School, Nur2)

This can be particularly valuable for those from challenging backgrounds, where they may not receive such support and encouragement at home:

The kids out here are used to being told what to do, when to do it and their decision-making capabilities are sometimes limited because they are not being supported at home to make decisions. There is sometimes fear and intimidation that goes with that, so if they can have more of a voice, a stronger voice, about their own decisions that’s perfect. (School, Nur2)

2. School Dental Service

In contrast, time was scarce in the School Dental Service (SDS), and as a consequence, did not lend itself to developing relationships with children and their parents. Rather, it was functional in nature:

Everything we do is timed. We get x amount of time to do this, right down to the filling. We have lost the human element that they are children. … Now that we have come into the hub it is very production line. (Dental therapist, DT1)

One feature exacerbating the development of relationships was the disjointed contact school dental therapists had with families. Usually they examined children at school first, and if further treatment was required, they may again see the child alone, or with a parent. Time constraints not only limited dental therapists’ opportunities to establish
relationships with children and their parents, but also their opportunities to promote children’s competence, for example, through education on dental health.

3. Hospital

In other healthcare environments, such as hospitals, children can be encouraged to participate in consultations, when given time and space:

With younger kids we have toys. ... Often you can see the child listening intently in the corner to the conversations and then you can engage with them in play. It is giving them the time, opportunity and time to talk. With adolescents it is the same thing, time, but also privacy. ... When we’ve got teenagers and adolescents it is important that they are given the opportunity to talk about things by themselves. (Paediatrician, HD6)

Usually my first appointments are just talking. Most of the patients are quite complex so it usually takes about 30 minutes to get through, taking a history and why they have been referred. (Hospital dentist, Den3)

Sit down and talk to the child absolutely. We don’t as healthcare professionals listen to children enough. … It is about sitting down next to them, not necessarily above them, sitting on the ground with them. (Hospital nurse, Nur3)

With teenagers we are trying to see them without the parents. (Obstetrician/Gynecologist, HD7)

When children need continuing hospital care, either as an outpatient over an extended period, or when admitted as an inpatient, it gives them greater opportunities to develop trusting relationships with health professionals. For example, hospital dental treatment may extend over many years for a cleft palate, where “there is a set schedule … from birth to 25” (Hospital dentist, Den3). Through trusting relationships, children’s understanding and confidence develop, enabling them to ask questions. Sometimes these questions can be very direct, for example, relating to their mortality:

As a nurse you are there 24 hours with the child either on day or night shift. They don’t sleep at night. So there is lots of time for them. … They will ask you, because you have developed a relationship with them, so you know them quite well, and it is a very intimate time, and they would ask me ‘am I going to die?’ (Hospital nurse, Nur3)

Yet, within other hospital contexts, time is very limited, such as in paediatric surgery. For example see Chapter 8, page 146 where Wilma described how no time or space was given to her and Samantha to explain Samantha’s health. Wilma reflected “Hospitals are a bit manic at times. I wonder if they need, when they have important information, they call you back or do it in some other way and not in the middle of a clinic with five other people standing around and lots of other things going on.” (Wilma). Similarly, in the context of the GP, no time was given to Laura and Alistair to explain and consider the

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876 Chapter 10 considers the SDS system further at page 220-223.
877 For example see Chapter 8, page 146 where Wilma described how no time or space was given to her and Samantha to explain Samantha’s health. Wilma reflected “Hospitals are a bit manic at times. I wonder if they need, when they have important information, they call you back or do it in some other way and not in the middle of a clinic with five other people standing around and lots of other things going on.” (Wilma). Similarly, in the context of the GP, no time was given to Laura and Alistair to explain and consider the
“on average over two clinics … 45-50 children” (Paediatric surgeon, HD1), and spoke of usually having “10 minute slots” with patients to take a medical history, “examine the person and decide the likely diagnosis and whether they need an operation or not. If it needs an operation then I go through the consent process” (HD1). Then on the day of surgery, it can be “a bit like a railway station” (HD1) due to its busyness. As a result, there is little time for children to be supported in discussions, or enhancing their understanding and decision-making. Similarly, when children need a general anaesthetic (GA), appointments are ‘about 10 or 15 minutes at the most, [but] it obviously depends on their medical history. If it is a bit more complex, then it will be more time” (Anesthetist, HD5). Yet, despite anaesthetists and paediatric surgeons being under similar time constraints, the degree to which they assess children’s competence, and obtain their consent, are very different.878

4. Dentistry – Hospital and Private

Having the ability to develop trusting relationships with children and their parents was a striking feature of dentists.879 They fostered trust by using a number of strategies - encouraging parents’ interest in their children’s dental health;880 involving parents and children in explanations and discussions; breaking down processes and procedures; using simplified language to pitch information at the right level; and preparing children for what is to come, for example, through a process which is known as “show, tell and do.”881 These strategies enabled dentists to work with both parents and children, securing children’s co-operation for an examination or treatment, whilst parents provide consent.882 Dentists recognised that “when you deal with a child you are in a triangle of you, the child and the parent” (Hospital, Den3).

Over the course of what could be many years, children become accustomed to attending the dentist, becoming familiar with the routine/process, during which time, parents and children develop trust to follow the dentist’s advice. Through developing experience and trust, children are able to attend without their parents, when they reach their teenage years. Yet, parents continue to be involved, despite their physical absence, as dentists keep them informed, and obtain their consent when required.883

diagnosis and treatment for ADHD, page 156. In contrast, Poppy and Brenda were given time for explanations and questions, pages 164 and 170 respectively.
878 See Chapter 10, at pages 199-200.
879 This was a theme that emerged through the data given by private and hospital dentists, rather than being specifically questioned upon.
880 A range of methods are used, such as having information on the practice’s website, giving explanations before and during treatment and drawing diagrams.
881 This is a process where dentists firstly show children the equipment, such as suction and air, and then tell them in language they will understand, what will happen, what the equipment is for and what noises they will make. This can be of particular importance to children on the autistic spectrum, for example, who are very sensory to noise. Lastly, the examination/treatment is carried out.
882 See Chapter 10, page 209 where the consent process is in dentistry is considered.
883 See Chapter 10, pages 210-211 where private dentists sometimes telephone parents to also obtain their consent.
B. Privacy

Privacy can be of immense importance to teenagers when they consult with health professionals, particularly for contraception or sexual health treatment/advice, as health professionals in all healthcare environments experienced. For instance, teenagers may be reluctant to consult with their family GP in some close communities, where large numbers of family members live, as they may not trust that their confidentiality will be respected. The implication to them of such a breach could be that many family members become aware of their health issues:

They have an innate distrust of health professionals telling their stuff. They don’t go to GPs because they don’t trust them. They don’t trust that the receptionist, who might be an aunty or related, won’t tell their stuff. … I think the children here are right to be nervous because people do talk about their stuff, and I know that, because I hear it, but I also know because they tell me that. They ask, ‘You are not going to tell Mum?’ Because before you know it, Grandma and Granddad will know, and then Uncle and Aunt, and before you know it there are 10 people there. That whole lack of regard for privacy is a real issue. (School nurse, Nur1)

Thus, some children may access contraception or sexual health advice at school or a CYS, which they perceive may better protect their privacy, but consult their GP for less sensitive matters:

Sometimes they have appointments that they are happy to share. They might come here for contraception, but go to their family doctor for an ingrown toenail and that is often to do with family. They don’t want to be seen at the doctor. (CYS/School nurse, Nur5)

Int: Are they worried about their parents finding out?
Nur1: Always. Usually the first thing they ask is ‘you are not going to tell my Mum are you?’ That’s when you know it will be sexual health.

Nevertheless, health professionals are mindful of balancing children’s privacy with potential supports. Most of the participating GPs and nurses, who prescribed contraception, spoke of encouraging children to be open with the significant adults in their lives.

C. Parents’ Roles

1. Introduction

Parents play a vital part in the development of children’s competence, for instance: they can prepare their children for appointments; promote their engagement with, and trust of, health professionals; provide emotional support; and enhance their understanding and decisional capacities. On some occasions, however, parents’ can act as the antithesis of these, creating barriers for children in their engagement with healthcare systems. This
section explores the importance of parents’ roles, and their impact on children’s participation from health professionals’ perspectives.

2. Parental Support in Engaging with Health Professionals

Within all healthcare environments, health professionals experienced parents preparing and supporting their children, both practically and emotionally, for consultations and treatment. Sometimes these supports began prior to consultations, for example, by parents preparing their children for what to expect:

A lot of parents are good at getting the doctor book out, or whatever, so the child is not coming in not knowing what is going to happen (Private, GP5).

Preparation was particularly important when children were expected to undergo a procedure, such as surgery or a blood test, or an intimate examination. Health professionals found that the most helpful strategy was for parents to be honest and upfront, as then children understood what was going to happen and why:

Most parents have explained it [the operation]. Some parents bury their heads in the sand and just go ‘I’m not going to tell them as they might get too scared,’ but that is actually not a very helpful strategy. The best thing to do is just be honest about it…. They do actually need to know what is going to happen. …You can’t operate on a child who does not have some understanding of what you are doing. It is not fair to the child. Some people try to completely ignore it and pretend it is not happening and I say you can’t actually do that. (Paediatric surgeon, HD1)

In most situations I probably rely on the parent to inform the child about what it is all about before they come, but I check out whether that has happened. …. Parents should tell their child why they are going to the doctor and if they don’t understand what is going to happen they need to find out what is going to happen so they can explain it. I have had children arrive and they have had no idea they are going to have a genital examination and that has been a reason for refusal. I think that is perfectly reasonable. I think being straight up if there is going to be a procedure, like a blood test or expose a bit of their body to a doctor that they would not normally expose. (Paediatrician, HD2)

At times, Mum or Dad, usually the Mum, has brought them in not wanting to have that conversation in front of the child and the child is not ready to have surgery from my point of view if they have not had that conversation before they arrive here. (Plastic surgeon, HD4)

Occasionally, children took the initiative of seeking medical attention, which parents supported:

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884 See for example Anna preparing Poppy for consultations with her surgeon and the telephone call with the pre-operative nurse prior to her achillies operation at page 165, Laura preparing Alistair for what his GP may discuss with him at page 156 and Diane preparing Donald for dental treatment at page 160.
Sometimes you find that parents bring in kids because it is the child who has the primary concern, and it is the parent who is helping support the child’s self determination, or the child has said they feel unwell, but the parent was happy to wait a bit longer. (Private, GP3)

Once in consultations, commonly parents and children provide a medical history together. Hearing directly from children was important to most health professionals, as children’s experiences of the symptoms may be different from their parents’ observations:

The general principle is that you should always engage the child and the family into the consultation so you can get the history from both the patient and the family. … It is always important, and wherever possible, to put the questions towards the child if you are asking around symptoms. ‘Does it hurt, where does it hurt?’ It is important that the child is giving this history, as much as possible, rather than the parent interpreting the child’s symptoms. (Paediatrician, HD6)

Parent for outside things, child for inside. (Private, GP4)

Broadly speaking, as children mature, their capacities to engage increase, and parental involvement decreases. Commonly, health professionals found that children were able to provide them with a medical history, around the age of 10 years, and began consulting alone, as teenagers, with their dentist and GP. All GPs had experienced some parents showing sensitivity to their children’s desire to consult with them alone, for example, by offering to step out of consultations:

Sometimes the parent will volunteer. They will say ‘I’m here and just want to make sure that this and this is known about it and I’ll leave you to it.’ Obviously that is a chance for the kids to say things that they are not happy to say in front of the parent. … It is normally with the teenagers with issues with mood or anxiety, or poor sleep. (Private, GP5)

Often we make that decision together. Often the parent will offer, ‘I feel like it is a good idea, shall I go’, and often the child will say ‘yes’, but sometimes they say ‘no.’ (Private, GP2)

Mostly GPs found that this arrangement worked well, but on occasions some children had struggled, when unprepared:

I had one situation where the Mum had told me beforehand that her child was self-harming. That put me in a difficult position as I felt that we had gone behind the child’s back, which we had, and then when they came to see me it felt a bit staged with the

885 Children’s abilities to do so are influenced by many factors that are discussed in Chapter 12, pages 242-256.

886 This appeared to be more common with private dentists than private GPs.
Mum when she said that she was going to leave so the child could talk to me on her own. The consultation with the child was awkward (Private, GP1).

Following diagnosis, health professionals generally explained to both parents and children health conditions, and advised upon treatment. The relational nature between some health professionals, parents and children was exemplified in this process, such as one paediatrician giving families handouts on medication, enabling parents to discuss it later with their children, and others experiencing parents encouraging their children to ask questions.

In all healthcare environments, parents and children commonly made decisions together. However, participation in decision-making was not necessarily equal, and the extent of children’s participation was dependent upon a number of factors, such as: parents’ roles and attitudes towards promoting children’s participation; the state of children’s health, as they may be too acutely ill; and whether children have formed views. One common factor across all healthcare environments affecting children’s participation in decision-making was the parent-child dynamic. Most health professionals recalled examples of contrasting parental behaviour, where parents either promoted or constrained their children’s participation and competence. Parents constraining their children’s participation are considered in more detail below, but two examples in the dental context highlight this contrast.

Firstly, in the hospital dental setting, where the most severe or complex work is undertaken, children may be involved in the decision of how treatment is to be carried out – either in the dental chair, which may be under the sedation of nitrous oxide, or under a GA. Commonly, parents and children work this out together with the dentist:

I had a nine year old who needed three big teeth out. Between us all he agreed that we should do this while he was asleep… I asked him and his parent what they thought? They could try it in the chair or do it while he’s asleep. The parent and the child decided to do it while he’s asleep. It is very rare to have a parent saying ‘no’ to a GA and a child saying ‘yes.’ Parents will go off their children or the children off their parents. (Hospital Dentist, Den3)

In contrast, at the SDS, where routine examinations and treatment occur, some children may be unable to participate. For example, a dental therapist recalled asking a child, aged

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887 Chapter 10 explores the consent processes in each healthcare environment in detail.
888 This also ensured that parents were aware of potential side effects of medication.
889 Except for the SMS, where children consult independently.
890 See pages 184-185: when children suffer from cancer they commonly regress through the emotional and physical effects of their illness.
891 See page 205, for example, where some GPs experienced children lacking views on some treatment, such as antibiotics, but having strong views on how warts were removed. Likewise, at pages 201-202 for cosmetic/elective surgery children’s views were decisive for surgeons in whether to proceed.
892 Although children attend the SMS alone, parents could still constrain children’s competence and participation. For example see Chapter 10, page 215 where a school nurse recalled a situation where a father refused to allow his child to be prescribed antibiotics.
around 12/13 years of age, if he would like her to take his loose tooth out, to which he responded 'yes’. The dental therapist felt that the boy should be given a choice, and that it was a simple decision, which he was able to make. She issued a care plan for the boy to take home to his parents to sign. When they returned, the parent was “very annoyed” that the dental therapist had asked the boy his opinion, and said it was the parent’s decision. The boy did not challenge his mother’s stance. The dental therapist felt that the boy was accustomed to this family dynamic.

These two examples highlight the relational nature of competence, which is dependent upon the successful triadic dynamic:

... keeping that triangle happy and complete. Not one person over there is part of overall management, and end up with less complaints and stress for the parent - 'What are you doing to my child? Why didn't you tell me?' (Hospital Dentist, Den3)

Within this triadic dynamic, health professionals agreed that the levels of children’s engagement and competence varied with children’s internal characteristics, such as their personality, intelligence, experience, health and gender:

There are huge variations on the level of engagement and understanding. It is not really age related. It is more on the experience of their health, particularly if they have an on-going condition. (Private, GP2)

... but it depends on the kid. ... I always talk to the child directly, even if the parents go, 'she will not understand you.' ... I don’t have a specific age. You get to know the child, but around about 11/12 they are pretty onto it. ... 14-year-old boys are wonderful, they just do as they are told, but 14-year-old girls want to know everything. (Hospital dentist, Den3)

If they are older I will talk to them and find out their view. It is quite interesting, there are two broad groups of kids. Some of the older ones ... I ask them a question and they will turn to their mother, and I'll say 'I asked you the question it is your body', and there are others who you can’t shut up. (Paediatric surgeon, HD3)

Further, there was consensus amongst health professionals that age was a misleading indicator of children’s competence, with several hospital practitioners recounting young children having capacities beyond their developmental years. For example, two-year-olds taking interest in their dental treatment, a nurse being “outsmarted by a three-year-old” (Nur3) and a four-year-old coping with the removal of a mole under local anaesthetic:

I, last year, removed a mole from a four-year-old’s foot under local anaesthetic. You can’t do that for most four-year-olds, so I think there are some children who are mature beyond their years and others are not. ... There are some 20-year-olds who couldn’t do that. It depends on the individual. (Plastic surgeon, HD4)
3. **Parents Creating Barriers**

Occasionally, across all healthcare environments, parents’ behaviour may have the effect of creating barriers for their children being able to consult directly with health professionals, or from receiving the healthcare they require. This may occur due to parents being accustomed to talking for their children, the parent-child relationship, or from their own beliefs. When parents block their children’s engagement, health professionals can assist by focusing on the child and redirecting the conversation. For example:

Sometimes parents try to talk for the child and I will often try to talk to the child because they are the ones who have the complaint. … If a parent tries to control too much I’ll try and take it back and direct it towards the child because I think the child needs to have a sense of control. But I’m the one who makes that decision based on how I feel the interaction is going. If I felt the parent was trying to answer on behalf of the child I would direct my questions directly to the child and I would turn towards the child and blank the parent. (Private Dentist, Den6)

There are some parents who don’t want you to talk to their child, but I think it is also a learning process for them, so if you role model it hopefully they can see that their young person has a voice too. (Private/School/Youth Service, GP6)

Some health professionals in private practice and CYS adopted another strategy by asking parents to step out of the consultation, into the waiting room. This allowed nurses, GPs and dentists space to develop relationships with children, whilst also enabling some children to focus better on engaging with their health professional. In dentistry, for example, some children could cope better with the treatment, “rising to the occasion a bit better” (Private, Den6). However, some health professionals perceived that this strategy was not available to them, due to both their apprehension of parents complaining, and a sense of it being parents’ right to remain:

*Int:* Have you asked a parent to step out?
*DT1:* No, I have never done it. Have my colleagues? I think they have suggested ‘would you like to go to the waiting room’, but it is their right to be there. You could allude to it, but as far as saying you would like them to leave you with their child, you couldn’t do that.
*Int:* Why do you think you could not do that?
*DT1:* Because they would complain very quickly.

Despite having strategies available to them, health professionals may be unable to redress the balance, particularly when the parent-child dynamic is well established. The strength of parents’ beliefs, together with health professionals’ concern for intruding upon the parent-child relationship, can result in children’s voices being unheard, and denied treatment at times, even when they are competent to consent. For example, a paediatric surgeon felt unable to take the consent of a competent 14½-year-old girl, when her mother withdrew her consent for her daughter’s operation, as the hospital could not
guarantee that there would be no male medical staff involved in her care. Despite the girl’s competence, the surgeon was reluctant to seek her consent, when the girls’ mother held such strong beliefs, due to the conflicting position this could create for the girl:

I have had a difficult situation where I had a Maori lady who had five kids, but became a radical feminist lesbian activist. The girl had an area of lung that had bronchitis, so it had infection in it, so she needed a bronchoscopy to see if there wasn’t a foreign body or something, and then she needed to have that bit of lung taken out because it kept making her sick and getting infections and the rest of her lungs were absolutely fine. Mum insisted that she wouldn’t have any discussions with men. The daughter was 14½ when I first met her. She was bright. I got consent for the operation from Mum. … Then at the anaesthetic pre-assessment she saw a female. She didn’t know who would be giving the anaesthetic on the day of surgery because the lists only come out the week before. When the anaesthetist told her this she got really aggressive and was going to punch her and insisted that she be told who would do it. The anaesthetist genuinely didn’t know. … Then we had this big discussion about the child being 14½, theoretically she could give her own consent and we went over that, but the problem is that for her to do that she had to be going against her mother’s wishes, and therefore we did not feel we could ask her that because she has to live with her mother and obviously her mother has some fundamental problems and beliefs that we’re not going to fix or alter. But that basically meant that her daughter could not get appropriate care. … In situations like that you sometimes think, ‘should we just be getting consent from her’, because she is of an age, she understood what we were talking about completely, but to ask a child to consent against the wishes of her family is too hard. (Paediatric surgeon, HD1)

Further, the surgeon believed that it would be futile to ask the girl her views, as she would have been unlikely to be able to express them:

It wasn’t fair to ask the child to do that in my view because she had to go against her mother’s wishes, and trying to work out what her wishes were in that situation is really difficult, because she is never going to say in front of her mother that she’s okay having a man involved in her care because she knows her mother does not want that. (Paediatric surgeon, HD1)

Similarly, most GPs gave extreme, albeit rare, examples of situations where parents dominated consultations, hindering their children’s ability to communicate directly with them, and in the wider context, preventing the development of their children’s responsibility and independence for their health. For example:

GP1: I had a 15-year-old morbidly obese girl with terrible eczema. The mother was dominant and angry. She deferred responsibility for her daughter’s health on her daughter. She blamed her daughter for the way she was, saying she sneaks sweets and fizzy drinks into her room, buys chocolate and crisps with her pocket money. The daughter was very immature, although bright and intelligent enough, but really dominated by her mother. Her mother spoke to her like a six-year-old. I spent a lot of time trying to support the mother, telling her she is not to blame, but also trying to make her realise that her daughter is nearly old enough to get married and be independent and
she can make these choices for herself. The mother said to her daughter, ‘you tell her’, and then stormed out.

Int: It sounds like the mother was the barrier to you accessing your patient.

GP1: She was a barrier, but there was no way through. I was not able to consult with her on her own and she was very immature emotionally.

Some parents think that they know best and their behaviour holds that young person back and dependent upon them, which is a good thing for them [the parents], and they are not willing to let them grow up. That can be a challenge and also in this particular case the young person was quite happy to have her Mum in the whole consultation, because she knows everything, but I actually thought it was important to remove the parent to give the young person her own voice. (Private/School/Youth Service, GP6)

4. **Lifelong/Chronic Health Conditions**

Moving into the fields of three lifelong/chronic health conditions - cancer, diabetes and asthma, parental support is vital, on emotional and educational levels. When diagnosed, families may feel grief and become overwhelmed, not only from the diagnosis, but also from entering a very unfamiliar world of hospitals, health professionals and treatment. This section considers the importance of the roles parents provide in emotionally supporting their children when diagnosed with cancer, with the following sections exploring the comprehensive education systems, and parents’ involvement within them, for diabetes and asthma.

(a) **Cancer - emotional support**

Once diagnosed with cancer, children commonly regress emotionally, needing their parents to take control of the situation, and provide them with emotional support to cope with the realities of their illness and its treatment:

They regress, not just physically due to symptoms. It dents their confidence, so there is a psychological regression, and it can be emotionally as well, wanting more from their Mum or Dad, which to me is a very natural and normal behaviour. (NGO, SH9)\textsuperscript{893}

Social workers will move heaven and earth to get a family member to hospital … to do the emotional support and help with the distress that happens with chemo. (Play therapist, SH8)

At the point of treatment, children may have little involvement or understanding of it, possibly as a consequence of this regression, the extent of their illness, and a tendency for the system to be parent-led. Discussions relating to treatment may be only between parents and health professionals, or with children as a bystander in the room:

\textsuperscript{893} The NGO supports young people and adults between the ages of 13-24 years. Its role is more psychosocial support, for example, providing them with someone to talk to about how they are feeling, coping with their treatment, and organising peer support/activities. They may also at times provide advocacy type support to assist them in having their voices heard.
It is part of the maturity and also I imagine comes along with the medical model that they would be consulting directly to the parents with the child in the room with them. (NGO, SH9)

In such situations, children rely upon their parents to be open and honest about their situation for them to understand it.°894° The degree of openness has a knock-on effect to health professionals’ and children’s relationships. For example, one hospital nurse who had cared for children with cancer, described that at times her ability to be open and honest with them was restricted, or “directed by parents in what they want you to do” (Hospital nurse, Nur3). She found that this would place her in a difficult situation, at times, when children asked questions about their health, as she may not be able to be honest with them. She explained that the starting point is:

… working with [the parents] in terms of what they want their child to know [and] if you begin those questions with parents early on you can understand what it is the parent is trying to do. Sometimes parents initially did not wish their children to know anything, and then it would be a matter of allowing the parents [time] to get over the initial shock, and then working with them in terms of what they want their child to know. (Hospital nurse, Nur3)

From there she could help parents to understand the reality of their children’s experiences, and negotiate with them, as “we are doing all kinds of stuff - they might lose their hair or have surgery. They know something is going on.” She found that when she was permitted by parents to explain the treatment to children, they were capable of understanding it, in particular, remembering the terminology, as they are continually exposed to it. She believed that:

… the more honest you are with them [children] the easier the process is for them. What I learned from children is if you are lying to them they figure that out very quickly. They are a lot smarter than we are. (Nur3)

Through their illness, children could mature beyond their years,°895° developing an understanding and an acceptance of their health condition, which sometimes could be beyond that of their parents, who had different emotions to handle:

These are children who have lived with an illness for a very long time. They have a maturity about them that another child of the same age may not have. … They have been around death, been around very sick people, and they know, and they do have an understanding, and sometimes it is more mature than a parent’s understanding. The child is living with it and the parent is distraught that they may lose their child. (Hospital nurse, Nur3)

°894° See Chapter 8 page 171.
°895° See Chapter 11, page 238, where Wilma experienced this with Samantha: “I can speak from our experience of oncology, from 10 [years], they grow up pretty fast. Within months they have literally grown years” (Wilma).
On occasions, as a result of such grief, it was difficult for parents to recognise the extent of their children’s experience and understanding. For example, when treatment had failed, parents may wish their children to undergo further treatment or procedures in the hope that, on this occasion, it would be successful. The above nurse recalled such a situation in which a 13/14-year-old had relapsed with cancer several times. Following an unsuccessful bone marrow transplant she made it known to the nurses that she did not wish to undergo any further treatment and wanted to die at home with her cat. However, her parents “had a whole different understanding of that. They wanted her to have a chance, one more chance” (Nur3). Although initially the girl did not want her views to be known, it reached a point where her parents had to be told, and after many multidisciplinary meetings, including considering legal advice, her parents agreed with her view and took her home.

In the experience of the above nurse, like that of the paediatric surgeon below, children intuitively know when they are going to die, and can ask in a direct way – ‘Am I going to die?’ This can be a very difficult question for nurses to handle when parents have instructed them not to disclose this to their child – “It was very difficult to handle that question from a young child, ‘well, we will wait and see’, but they know” (Nur3).

Parents and children might try to protect one another from the reality, but sometimes children are more able to face it:

Children always know that they are dying. Everyone is too scared to tell them. It is not for the children’s sake you don’t tell them, it is to protect everyone else. Parents say ‘you can’t tell them’, and I say, ‘but they know anyway’, and actually they have a right to know. … I have some children who have malignancies and they say, ‘How is my father going to cope with this? Are you sure we need to tell my father?’ ‘Yes we do actually!’ The child is saying ‘I think I need to tell him.’ (Paediatric surgeon, HD1)

On the other hand, some children need their parents to protect them from the reality of the situation, until they are ready to deal with it. For example, an NGO staff member recalled parents supporting their 15-year-old son’s decision not to be informed of his prognosis. Whilst he was aware of meetings between the health professionals and his parents, and was continually given the opportunity by his parents to be informed about those, he was not prepared for the details. They believed that he was making the choice to live each day as it comes. 896

Cancer is a stressful and emotional journey for families, which parents and children navigate together. Children rely on their parents to help them cope with the rigors of treatment, and also to understand it. However, even within such a harsh health area, where treatment options are limited, and the illness is sometimes terminal, children’s

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896 In the opinion of this stakeholder the child had regressed to around 10-11 years, and prognosis was one month to a year.
competence can flourish, as their understanding, decision-making abilities and maturity develop beyond their years.

(b) Diabetes - education and evolving capacities\(^{897}\)

The striking feature of diabetes was the educational structure provided to families, aimed at promoting parents’ and children’s understanding and management of diabetes. A comprehensive education and monitoring system exists, comprising an initial three-day programme in hospital upon diagnosis, on-going hospital reviews, and educational sessions and camps in the community, from both hospital diabetes nurse specialists and an NGO. Before considering this educational structure, I consider the importance of parents’ roles to children’s growing autonomy.

(i) Parental responsibility and children’s growing autonomy

Parents play vital roles in supporting their children’s learning, understanding and management of their diabetes. The roles parents provide largely depend upon the age at which children are diagnosed, the parent-child dynamic and the degree of responsibility parents are prepared to relinquish, and children are prepared to take. Children should progressively take more responsibility for their diabetes, often starting around the age of eight years, although sometimes younger:

Nur4: Usually around eight they start to take an interest in helping, some younger.

Int: What aspects of managing their health will children 12 and under take?

Nur4: Testing, drawing insulin into syringes and checking doses with parents. Most would be doing injections or helping. Some on pumps they are really savy with the buttons and just get on with it, but we say to the parents they have to be checking. Quite a lot of kids text Mum or Dad at lunchtime and say ‘my blood sugar is this and I’m going to eat that,’ so they are calculating in their heads how much to give. Other kids don’t want to do that at school, so they do it at afternoon tea. They are definitely taking responsibility.

From 13 years of age, teenagers should be taking more ownership for testing and taking their insulin, but parents still need to be involved. However, this may result in some conflict:

The conflict is usually around not testing, not remembering to take insulin on time, alcohol, forgetting to take their kit or insulin if they are going away on holiday or for the weekend. … We say to the parents to stay involved to whatever degree you negotiate with your teen and the teen has to agree. (Nur4)

Hospital diabetes nurses can assist in the transition of responsibility from parent to teen:

\(^{897}\) The emotional support provided in the cancer context applies equally to diabetic children, as diabetes is life changing, necessitating daily management. Children may “have to test their [blood sugars] four, five, six times a day, take insulin two, three, four, five times a day, eat healthily, and do it for life. That is a huge thing” (Hospital nurse, Nur4).
... it is the exceptional family that can manage negotiated hand over of those tasks and responsibility to the teenager. That is part of my job to help that happen, but some families are really resistant to it happening. (Nur4)

This transition is challenging for most families, as either parents are reluctant to relinquish control, or conversely, teenagers are unwilling to assume responsibility, particularly if they have been accustomed to their parents taking care of it for a number of years. It is important that the transition occurs over a period of time, so that teenagers become accustomed to the responsibility before they become fully independent. In extreme situations where this has not been achieved, it could result in young adults at university continuing to be reliant upon their parents for the management of their diabetes:

Some families are really resistant to it [the transition] happening. I have had students at uni who are still ringing Mum, and that really worries me because they should be living independently, but are not managing to do that. (Nur4)

(ii) Three-day initial programme for diabetes (the programme)

The programme begins in hospital, after diagnosis. The focus of the programme is on educating parents and children together, so parents can support their children. The volume of information given by diabetes specialist nurses can be overwhelming, so they provide it in chunks. The programme covers matters, such as, the nature of diabetes; its causes and symptoms; testing for blood sugars; injecting insulin; and advice on a healthy diet. The aim is for children and their parents to learn these over the course of two or three days, but there is no time pressure, as “no-one pushes them home” (Hospital nurse, Nur4). Teaching methods are tailored to each family’s learning style, with flexible methods available, such as, using pictures and DVD, giving explanations, and when English is not the families’ first language, an interpreter is provided. Supplementary information can also be supplied to families through an NGO, including “a child orientated information pack” (NGO, SH11). It is crucial for the successful management of diabetes that children are supported in their learning by their parents.

(iii) Reviews

Within the first two or three months following discharge from hospital, children have two follow up reviews, the first taking place within the first month, and then every three months. Children and parents meet in hospital with a panel of health professionals, comprising a doctor, nurse and dietician. As children grow, mature and become more experienced, they typically take more responsibility for these reviews, with their parents being present for less time. Initially, these can be quite daunting for some children, but their confidence and abilities increase, as they become familiar with the professionals and process. Sometimes the panel needs to encourage parents to allow their children to
develop this independence, but they are mindful also of the importance of parental involvement:

**Int:** Do you find there is a general need to educate parents on children taking responsibility and speaking for themselves?

Nur4: Some parents need that. … Sometimes one of the doctors will say to the parent ‘okay, be quiet, that’s enough.’ Occasionally they will be asked to step out for a moment, but we really try not to separate because we don’t want to get into that. The person with diabetes has to engage with the health system for the rest of their life and we don’t want to be the ones that put them off that.

(iv) Transitional day

Upon reaching Year Eight at school, children attend ‘a transitional day’ hosted by two diabetes nurses - their current one, and the one to whom they will be transitioned. Also, two Year Nine students, who transitioned the previous year, also provide information on the ways in which diabetes is managed in their college/high school. Separately, parents are given the opportunity to attend a session held by a psychologist to learn about supporting teenagers with diabetes.

(v) Camps

Two camps are organised by an NGO each year to further support children/young people’s education and independence. One is for children of eight to 12 years of age and the other for 13-17-year-olds. The camp environment is an ideal setting for developing their learning and independence through educational sessions and from observing their peers:

It is a huge step forward for them because they see other children doing the same thing as them, and often that’s when they step up to wanting to do their own injections or draw up their own insulin, because everyone else is doing it. (Nur4)

Camps are invaluable for the child in seeing how other people do it and cope. (NGO, SH11)

(c) Asthma

In asthma management, supporting children’s knowledge, independence and responsibility of their health condition are also of importance. In common with cancer and diabetes, children and parents can be supported by an NGO, which plays a crucial role in providing both emotional and practical support. The importance of their role increases, for families who are unable to access GP services, for example, due to cost or a breakdown in relationships:

… they are not going to go to the GP because they owe some money, they don’t like the receptionist’s attitude, or for whatever reason, we are the first call to help. I can ask the
doctor if he can do a prescription even although that person has not been every six months for a follow up about their asthma, which they are supposed to do otherwise they don't get a script. We can ring up and they will do it, but we are still trying to empower them to get a better relationship with their GP. (NGO, SH10)

This NGO has the advantage of being familiar to, and trusted by, the families, who have known them for many years. Nurses initially meet with children, and then their whānau, in their home, before again meeting children at their school or sports club. These external environments for educating children can encourage them to assume more responsibility, as outside of the home they may be less reliant on their parents, and in a better frame of mind to learn:

Usually I would see the child first at home and deal with them, then expand to the whānau. … The environment in which you speak to them changes everything. In the home they are not so independent and don’t take responsibility for their health as much, but at school they actually absorb the information more because they are independent, there by themselves. Around their parents they are more babyish, but at school they are more grown up. (NGO, SH10)

During these discussions some children may come to realise that they are capable of managing their asthma:

Sometimes when I am educating them the switch turns on and they realise that they can take control of it. … We give them that permission by informing them and they take charge of their health. … Teach them good habits when they are young, make them health literate. (NGO, SH10)

D. Summary of Promoting Competence

Consistent with the existing literature, a number of factors emerged from the data demonstrating that children’s competence is influenced by several factors, such as time, privacy, support from parents, and trusting relationships with health professionals and parents. 898 It is the presence and interplay of these elements and factors that promote, and enable children to demonstrate, their competence. Through children, parents and health professionals working together in partnership, both trusting relationships and children’s competence develop. Nevertheless, if some factors within these elements are absent, others can compensate. 899 For example, children consult alone in the SMS, with some having unsupportive parents, but through time, privacy, and respectful relationships with health professionals, who effectively communicate and provide appropriate information, children have the opportunity to discuss all of their health concerns, understand treatment, consider their options and give consent. Yet, when some factors are absent or restricted, and the existing ones are unable to sufficiently

898 These factors are represented within the elements of my Competence Model – Space, Voice, Support and Influence. See Chapter 12, page 255.
899 For example, see Chapter 8, pages 146 and 156 where Wilma and Laura respectively compensated for the lack of information provided.
compensate, children can be somewhat bypassed. This was seen for example in the SDS and paediatric clinics, where time was limited and the processes functional, with health professionals’ focused more on the result, or outcome, of treatment, rather than on the process by which informed consent is given. The result is that children’s competence is constrained in such environments.

When systems are focused on supporting children and parents’ understanding of health conditions, children are able to progressively take more responsibility for their health, and become more experienced and independent. This was particularly highlighted in the structured educational supports for children with diabetes, and also for those with asthma. Although the same frameworks appear not to exist for cancer, children still develop knowledge and experience of living with, and managing their condition, through their parents, health professionals and peers. As a result, some children mature beyond their biological years. However, with the emotional and physical demands of cancer, children also regress, needing their parents’ protection.

Health professionals need to carefully navigate the parent-child dynamic to ensure that positive relationships continue with both parents and children, as parents play crucial roles in supporting their children’s competence, and in the practical management of their health.

III. Competence Assessment

This section turns to the factors that health professionals consider when assessing children’s competence to consent. Whilst there is no prescribed process for such assessments, common techniques are used by them.

A. Process and Factors

All health professionals agreed that they used their clinical judgements during consultations to assess children’s competence. This was more an instinctive process, rather than following any formal process:

I don’t think I am doing it consciously to be honest. You have a conversation with them and make that decision. (Private, GP4)

I don’t do a formal process; it is a gut feeling. (Paediatric surgeon, HD3)

I think we all gauge that [competency] from how they interact. (Anesthetist, HD5)

Although not a conscious/formal process, health professional did have regard to a number of interlinking factors distilled as: children’s level of interest/independence in their health; their ability to engage with them and explain details about their health;
children’s intelligence and understanding; ability to ask and answer questions; and their development and maturity. All agreed that age is an unreliable indicator of competence.

**B. Child’s Engagement, Independence, Articulation and Knowledge of Health**

Health professionals were influenced by children’s ability to engage with them in consultations, shown through, for example, the degree of eye contact, the level of interest in their health and knowledge of it:

I don’t think I have criteria that I am ticking off, age, appearance, questions, … [but … looking for cues: good eye contact; body language; the way they answer, are they confident, are they not? (Private, GP4)

If they are competent speakers and … are engaged in that process. Some older children are, and are able and forthcoming about details about their medical history and surgeries they have had and allergies. (Anesthetist, HD5)

*Int:* What is your ‘gut feeling’ about competency based on?
HD3: … it comes down to how much eye contact you are having with the kid. … If they are maintaining eye contact, I talk to them as much as I talk to the parent. … It is based on the interaction of the child. Interaction is not quite the word I am looking for.

*Int:* Responsiveness?
HD3: Yes, and attentiveness. Are they paying attention or are they playing on the iPad? … If a child is keen to be involved I am happy to involve them. Most of the time it is communication through the parent. …[but … I try to involve them as much as they want to be involved. … [I]t is sometimes quite difficult to be certain as to how much of that looking at the i-pad is a defence from having to be involved.

**C. Intelligence and Understanding**

During clinical interactions, all health professionals were looking for children’s understanding of the information they had imparted. For those who had established relationships, such as private doctors and dentists, they may already have a sense of this over a period of time:

I guess you know from talking to the child what their understanding is, and you often know the children anyway, in a general experience. (Private, GP5)

Others were observing whether children appeared to have age appropriate intelligence and understanding, as these two hospital doctors identified:

If they come across at least average or above average intelligence …[and] are understanding, when I have a discussion about what is going to happen with the anaesthetic, including risks, I’ll get them to sign the consent form. (Anaesthetist, HD5)
I suppose you usually have an understanding of where they are intellectually from the conversation. … You have asked them how they are doing at school. Are they age appropriate in reading and writing? … So if they are performing averagely at school, you think intellectually they are according to their peers. (Paediatrician, HD6)

However, health professionals recognised, particularly those in the school setting and dental professionals, that there was a need to adapt their language to explain it in a way in which they could understand:

There are difficulties because of the vocabulary of students here. Contraception names are on the wall. I ask do you know what that means, and often it is ‘no’, so it is putting it in simple terms and checking that they have understood, and getting that voice. (Private/School/Youth Service, GP6)

I do try to make sure they understand what I’m talking about. I think that’s less jargon and more straightforward language. (Private, Den5)

This could be challenging if matters were complex, as one paediatrican raised, and questioned how their understanding could be tested:

… it depends on the age of the child and the complexity of the information. Can you reduce the information to a point where they can understand it? It is difficult. How do you test with a parent whether they understand and give consent? (HD6)

D. Questions

Two ways in which health professionals could gain a sense of children’s understanding were from how children answered questions and what questions children asked. At the outset of the consultation, health professionals might check children’s understanding of the reasons for consulting, and then during discussions, ensured they understood the explanations given:

I usually start by asking them whether they have any questions. It depends on the situation, but usually I would ask them to ‘tell me what you understand we are going to do today? Tell me what you understand of the procedure?’ So it is what they are saying to start with. It is probably the same as adults. Then I give my spiel and ask if they have any questions. I guess with adults as well if I am not happy that they do understand I will ask them to tell me what they understand I’m going to do and then give them the chance again to ask questions. (Obstetrician/Gynecologist, HD7)

The quality of the questions children asked were also relevant for health professionals when they were assessing children’s competence:

I think too, part of that consent process is asking if they have any questions and if they ask any sorts of questions about the process, especially ones that are obviously well thought about. That is another ‘tick box’, and I think you are probably able to make these judgements. (Anesthetist, HD5)
However, as one hospital nurse identified, children’s willingness to ask such questions might only develop once they had established a trusting relationship with their health professionals:

I need to gain their trust and so I would have a very high level of engagement. … The first point of contact they don’t ask you very much. It comes after some trust. (Nur3)

E. Age

All health professionals agreed that age was an unreliable indicator of children’s competence, and instead their abilities, experience and maturity were of more relevance:

No set age as children have different developmental abilities and inabilities. (Paediatrician, HD2)

The difficulty is that there are such variations. You could get some 12-year-olds that could be Gillick competent and some 18-year-olds who probably aren’t. (Paediatric Surgeon, HD1)

Some recognised that young children could be competent to different degrees, and at different stages of the informed consent process, such as being able to give a medical history, or consent to an examination or treatment:

Kids at a young age can give the history. (Paediatrician, HD6)

Int: Do you tend to find there is an age at which the child appears to be capable of giving consent?  
GP5: I see it more as a continuum. In some ways a three-year-old gives consent, if you are going to do liquid nitrogen. Even a four/five-year-old, if you say to them ‘can I look in your ears’ they are giving consent.

…there are different competency levels in children. … It is not that they are not competent, it is a growing level of competence. … There are even some children in my experience, I believe, can make that choice at eight, nine or 10 because of their experience. (Hospital nurse, Nur3)

Conversely, children regressed after diagnosis, as they coped emotionally and physically with their health, but then developed experience, and mature beyond their biological years, as they lived with their illnesses.900

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900 See Chapter 8 where Samantha at pages 147-149, Amanda at pages 150-153 and Oliver at page 155 all developed competence, as they became more knowledgeable and experienced of managing cancer.
IV  Chapter Summary

Many factors intertwine together to promote children’s competence: a conducive physical environment within which to consult with health professionals; being listened to; having opportunities to learn, practise and be responsible for managing their health; and receiving support from parents and health professionals, who value working in partnership with them. These factors should be in place to enable children to develop and demonstrate their competence at the optimal level.\footnote{See Chapter 12, page 255 where these factors are represented in my Competence Model.} However, if any factors are constrained or absent, others can compensate, to still effectively promote children’s competence.

Whilst health professionals have no prescribed criteria or formal process for assessing children’s competence, they all agreed that children’s level of engagement/interest in the process and their understanding are necessary for them to be competent to give consent. The degree of children’s understanding can be assessed from their responses to questions, the quality of questions asked and the accuracy of their recall of explanations provided to them. On the other hand age is an unhelpful measure.

Therefore, the relational nature of competence is demonstrated, not only through the relationships children have with their parents and health professionals, but also from the obligations/responsibilities health professionals and parents’ have towards children in providing the necessary factors.
Chapter 10
The Consent Processes

I. Introduction

Consent provides health professionals with the legal authority to examine and treat patients. Without consent, health professionals not only disrespect patients’ bodily integrity and dignity, but also risk breaching the law and their professional guidelines.\(^{902}\)

This chapter explores the practices and attitudes of health professionals in obtaining consent in each healthcare environment. Firstly, the practice in hospital is considered, where mostly parents provide written or verbal consent, with children also consenting verbally, or at least co-operating with treatment. However, exceptions to this general rule were found. The second section considers general medical and dental private practice, where commonly parents and children provide verbal consent jointly. In the final section, the consent processes of the SMS, the vaccination programme and the SDS are explored. Although all occur within the school environment, there are varying consent processes. Commonly within the SMS, children provide oral consent for treatment, such as contraception and antibiotics, which I discuss. Finally, the chapter turns to the vaccination programme and the SDS, where reliance upon parents’ consent, and the impact of this upon children’s abilities to access treatment, are considered.

II. Hospital

A. Surgery, Medicine and Dentistry

1. Overview

In hospital, verbal consent is given for most investigations, examinations, tests and treatment;\(^{903}\) and in writing, by way of a prescribed form,\(^{904}\) for procedures, such as surgery, dentistry when receiving treatment under GA, and for anaesthetics. The effect of both verbal and written consent is the same, providing agreement for the medical intervention – “Just because it is written does not mean that it is any better than verbal” (Paediatrician, HD6).

Although it may appear that consent is a one-off act, it is in fact an ongoing process. Prior to providing consent, patients should have time to understand and consider the information and advice, before giving consent:

\(^{902}\) For example, Crimes Act s 2(1) (assault), s 129 (sexually violation and assault) and s 135 (indecent assault), and s 196 (common assault).

\(^{903}\) At the time of interview a Paediatrician (HD6) explained that there was a move to formalise blood tests by seeking written consent, with stickers having been developed stating ‘test signed consented.’

\(^{904}\) See Appendix K for an example of a written consent form.
Consent is really a gradual process that doesn’t necessarily occur during that one consultation. (Plastic surgeon, HD4).

The College says we should do our [written] consents in a timely manner, not the day of surgery, so people have got time to think about it. Not everyone does that. Some people do it the day of surgery, and some don’t do the consents themselves, they get their registrars to do them, but medico-legally it is safer to do your own consents, to see people, talk to them and confirm on the day of surgery, and I always see them afterwards too. (Paediatric Surgeon, HD1)

Before considering hospital doctors’, dentists’ and nurses’ processes, Table 5 summarises the consent processes, classified in areas of health. It draws attention to the differences/inconsistencies in practice. Although most parents give written consent, and children consent verbally, there are exceptions. In anaesthetics and obstetrics, competent children may give their sole written consent, with parents consenting verbally. Also in gynecology, both parents and children may give their written consent. In other areas, such as paediatrics and nursing, where written consent is not required, parents and children usually give their verbal consent together. Commonly, in nursing practice, nurses will be instructed by doctors and parents to carry out the treatment, with parents having first given their consent to doctors. If doctors have not also secured children’s consent or co-operation, nurses will to do so before administering the treatment.

Table 5: Practice of Hospital Practitioners Taking Consent

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Written Consent</th>
<th>Verbal Assent/Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paediatric Surgery</td>
<td>Parents</td>
<td>Children</td>
</tr>
<tr>
<td></td>
<td>Rarely by children</td>
<td></td>
</tr>
<tr>
<td>Plastic Surgeon</td>
<td>Parents</td>
<td>Children</td>
</tr>
<tr>
<td></td>
<td>Rarely by children</td>
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<tr>
<td>Anaesthetic</td>
<td>Children</td>
<td>Parents</td>
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<tr>
<td>Obstetrics</td>
<td>Children</td>
<td>Parents</td>
</tr>
<tr>
<td>Gynecology</td>
<td>Joint consent by parents and children</td>
<td>N/A</td>
</tr>
<tr>
<td>Paediatrics</td>
<td>N/A for most treatment/procedures</td>
<td>Joint by parents and children.</td>
</tr>
<tr>
<td>Forensic/Genital examinations</td>
<td>Parents</td>
<td>Children</td>
</tr>
<tr>
<td></td>
<td>Rarely children</td>
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<td>Nursing</td>
<td>Parents when required</td>
<td>Joint consent by parents and children.</td>
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<td>Dentistry</td>
<td>Parents</td>
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2. **Written consent**

Forms are used for parents/guardians/patients to consent to procedures, such as, surgery, anaesthetics, dental treatment under GA and on occasions, genital examinations. The form contains complex language at an adult level, as this paediatric surgeon explained: “You are getting into the technical language that is on the consent form because the consent form is quite a complicated document” (HD1).

Although the form indicates that patients can sign, most participating hospital doctors (4 of 6) who used such a form, usually asked parents to sign it, rather than children. For example:

> My understanding is that if you are happy that the child understands and has the appropriate level of competence to understand what you are talking about then potentially a child can do their own consent form. In practice we don’t do that a lot, I guess because usually there is a parent there. … We don’t commonly get 14/15-year-olds to do their own consent. (Paediatric surgeon, HD1)

Consequently, discussions and explanations on consent were aimed towards parents, although children would be present:

> I do my level best to keep the language in terms most parents would understand. (Paediatric surgeon, HD3)

> All the discussion about consent is done in front of the child. (Paediatric surgeon, HD1)

Whilst most children would not usually be required to sign the form, they may need to act as interpreters, on occasions, where their parents were unable to understand it, due to having poor English:

> We have some people [parents] whose English is not that great and usually in that circumstance the child’s English is great. So sometimes the children will read the consent form to their parents and tell them what it says. (Paediatric surgeon, HD1)

Likewise, written consent for dental treatment under GA was usually taken from parents, although one hospital dentist indicated that she arranges for both parents and children to sign when they are 14-years-old. This form is “a general consent for full dental treatment” (Hospital Dentist, Den1) to provide for an unexpected, but necessary, procedure, partway through treatment, so that dentists “can do the right thing for the child at the time” (Den1).

The usual practice was for parents to sign the consent form until their children are 16-years-old. This process seemed to arise from hospital doctors’ and dentists’ understanding of the law, or established practice within hospitals. For example:

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905 See Appendix N for an example of a written hospital consent form.
Of course, you can’t sign your consent form until you are 16 years anyway. (Plastic Surgeon, HD4)

Technically it is 16 years to sign your own consent…. because that is the age of consent. … I know that someone that is in a position to be able to make a reasonable informed choice can do so, but it is the generally accepted thing that the age of consent is 16 years of age. … I must admit I don't routinely offer the opportunity, unless they are getting into teenage years. … I am happy to put pressure on a 10-year-old about compliance, but I am not going to necessarily say, ‘hey, you can sign your consent form.’ (Paediatric surgeon, HD3)

For one doctor who practiced in two specialist areas, obstetrics and gynecology, this resulted in a somewhat contrived practice. When practicing in obstetrics, only children signed their consent forms, whereas for gynecological procedures, both parents and children signed. The difference stemmed from the doctor’s understanding of the law, that “under 16s can access contraception without their parents’ consent,” which relates to her field of obstetrics, but for gynecological procedures, “legally I have to get the parents to sign” (HD7). It appeared that an earlier professional experience had influenced this doctor’s understanding and practice, when a 15-year-old, who had signed her own consent form, was refused surgery, due to the absence of her parent’s written consent:

I remember once as a paediatric house surgeon getting a 15-year-old to sign a consent form for an orthopedic procedure and getting told off for not getting the parent’s signature and they wouldn't perform the procedure. (Obstetrician/gynecologist, HD7)

Nevertheless, there were specialties within hospitals where it was acceptable for competent children to routinely sign consent forms, such as in anaesthesia, and as shown above, obstetrics. Upon assessing children’s competence, the anaesthetist had a logical process for taking consent, where she took consent from either: (i) competent children; (ii) both children and parents, where children appeared competent, but she was not absolutely confident; or (iii) parents, when children were incompetent. She described her system as follows:

If I have decided that they are competent to make their own decisions, and I frame it as, 'there is no minimum age of consent and it seems to me that you understand what is involved here’ and the parent is there, [the child signs]. … If I am really not sure about a child but they have engaged, perhaps if they are young, then I will get Mum, or whoever is with them, to sign as well, so I don’t feel uncomfortable with it. (Anaesthetist, HD5)

In doing so, these health professionals not only respected children competence, but also recognised the importance for children’s self-esteem and growing independence:

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906 See Chapter 8 at page 166 where Anna signed Poppy’s consent form when, at the age of 14 years, she received an anaesthetic, as they were told Poppy required to be 16 years before she signed it. Thus, Anaesthetists may have differing practices and understandings of the law.
It would be easy for me, wouldn’t it, just to say ‘you are under 16, I’ll get Mum to sign.’ I guess it is about giving them a sense of empowerment I think for me. (Anaesthetist, HD5)

… if I have a 15-year-old who I think is competent it seems slightly insulting to her that I have to get her parent to sign the consent and that is why I get the 15-year-old to sign as well as the parent. … They are the one having the procedure. (Obstetrician and Gynecologist, HD7)

On occasions, some hospital doctors, who did not routinely obtain children’s written consent, did so when parents were not present, or had poor English; when the outcome of the procedure was uncertain; and when children of 14 or 15-years of age requested to do so:

I have done it before. 14/15-year-old with the parents in the room, ‘well, if you want to do your own consent form you can do the form.’ … The more common time when we would ask someone to give consent who was of that age would be if the parent did not have good English but the child did, or if there was not anyone immediately there but we knew the parents knew as we had talked to them on the phone or whatever, and we knew that was okay. I guess the other times are where you cannot get in touch with the parents at all. (Paediatric surgeon, HD1)

I’ve had one child who was a frequent flier getting a [procedure] on his oesophagus every month or so. His Dad was in the clink [prison], his Mum didn’t come, and so from 14 [years of age] we got him to sign. … I have had the occasional child who has wanted to sign their own consent form. … I tend to make a point of getting them to sign their own consent form, or at least countersign their own consent form, if I’m not sure I am necessarily going to make them better. This may or may not work. (Paediatric surgeon, HD3)

The above surgeon recalled a situation when he involved, and sought the consent of a 13-year-old, for a novel procedure, the success of which was uncertain:

There is enough uncertainty about it that if she decided that she didn’t want the procedure I would be happy not to do it. But if she wants it I am not going to make her any promises. (Paediatric surgeon, HD3)

3. **Verbal consent**

Verbal consent was given for most examinations and treatment in hospital, but when written consent was required, the party who did not sign the form gave verbal consent/agreement. Children and parents jointly consenting/agreeing was important for all hospital doctors and dentists, and was usually taken jointly, rather than on an individual basis:
Unless there is a specific reason I don’t think there is a need to ask the individuals separately. (Paediatrician, HD6)

Commonly, parents and children accepted health professionals’ advice, or “children go along with what their parents go along with” (Paediatrician, HD2). However, there were contrasting perceptions of the significance, or weighting, of each person’s consent, with some health professionals proceeding on the basis of parents’ consent, as the first hospital nurse below described, whilst others relied upon children’s consent, as the second obstetrician/gynecologist outlined:

Children are very much with the parents and so it is about the family-centred philosophy, children and families together, and so the consent is always from the child as well as the parent, with acknowledgment that the parent has the overriding guardianship and acknowledgment that the parent gives signed consent. (Hospital nurse, Nur8)

I do not need their parents’ consent, but I encourage them to involve their parents. I am struggling to think of a pregnancy where parents have not been aware and ditto with contraception. So while they sign their consents I go through it with them and usually their parents are there as well. (Obstetrician and Gynecologist, HD7)

On rare occasions when children attended hospital without a parent, health professionals might seek the consent of both parents, as one hospital dentist recalled doing when she treated a 10-year-old girl who attended hospital with her mother’s friends. In this situation, the dentist ensured that she had the consent of both parents, together with the child, who was “very competent” (Den3). Her rationale was to promote ongoing relationships with the parents, whilst also ensuring that the child had the security and reassurance to give her consent, safe in the knowledge that both her parents were involved and in agreement with the treatment plan.

Additionally, in hospital health professionals placed greater importance on children’s verbal consent for cosmetic/elective surgery, such as chest-walling abnormalities, circumcision and correction of bat ears, or when the success of surgery was uncertain. Children’s consent was either given explicitly or sensed through children’s level of cooperation and non-verbal cues:

At the stage I speak with the child. It is implicit. I can tell from their body language, and I will ask them ‘do you want this done?’ I don’t think I have operated on anyone where there has not been at least that sort of agreement. … The child has got to agree to it. (Plastic surgeon, HD4)

If the child said to me ‘I do not want this’ or is signaling that, I would be a lot more wary about going ahead. … Although you are not formally involving them in a consent process you are still saying ‘well, is it what they want?’ Explaining to the parent that it is about the child and what they want. (Paediatric surgeon, HD1)

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The above surgeons were clear that if children refused to consent to such surgery they would not proceed, regardless of parental consent:

... it is their body, their decision, especially if it is a cosmetic-related thing (Plastic surgeon, HD4).

‘I am not actually going to go against his wishes, as I understand them, because you signed the consent.’ (Paediatric surgeon, HD1)

When the procedure was necessary, but non-urgent, hospital doctors used several strategies to assist children to cope better, such as being matter of fact and honest with them, as the first paediatrician below described, or by giving them time, as the second paediatrician and plastic surgeon both explained:

The most common thing is kids don’t want to have a blood test. They don’t want to have anything that is going to hurt, so you explain that they will go to the ward and there are things that we can do not to make it as unpleasant. But then I will say, ‘I know it is something that you are not going to like, but it is something that is important that we have to do to find out what is happening’. (Paediatrician, HD6)

HD2: I have had the child not wanting a blood test those sorts of things. …

Int: How is that resolved?

HD2: ‘We won’t do it today because you weren’t prepared for it. We’ll do it another day when we’ve got time to have the numbing device’, or do we really need it?… I don’t want to be holding children down to do anything. (Paediatrician, HD2)

I would rather not operate. For most things we do you can always come back and do it on another day when they want to have it done. (Plastic Surgeon, HD4)

However, where treatment was urgent, or these strategies were ineffective, children could be offered a sedative to reduce their anxiety, which assisted them in coping with the anaesthetic. However, the question arose whether they were giving consent to the sedative and to the treatment, or were in effect no longer able to refuse, as this anaesthetist recognised:

Int: Have you had challenging situations, like that where the parent has consented, but the child is clearly not co-operating?

HD5: Yes and we give them a pre-med.

Int: So is that like a sedative?

HD5: Yes

Int: And how do you feel about that?

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908 This situation related a mother requesting that her eight or nine-year-old son be circumcised. In the surgeon’s opinion it was not an unreasonable procedure for his condition, but there were other options. The surgeon knew the child well and was aware of his experience and understanding of the hospital system, as he had previously received treatment for cancer over three or four years. The boy expressed his unwillingness to be circumcised, and the surgeon informed his mother that she would not proceed with the operation unless the child agreed. She encouraged him and his parents to discuss the situation, which they did, and the circumcision went ahead.
HD5: Well now, thinking about it, it is a bit fraught, isn’t it. But I guess they still have the right to refuse to take the pre-med, and then it is a matter of thinking about getting a psychological assessment. … I give them a good pre-med to make them less anxious and if they are really not compliant then I send them off to a psychologist.

Int: What is your process for going through the pre-med with them?

HD5: I would say to a kid ‘I will give you something to make you feel a bit more chilled out, make this a little bit more pleasant for you.’

In such situations, hospital doctors and dentists weighed up the medical need of proceeding, contrary to children’s refusal, against whether “you are going to miss some sort of window of opportunity” (Plastic surgeon, HD4). The impact on the child, and the strength of their views and feelings, of proceeding against their wishes were weighed up. Whilst younger children could be held down, older children’s refusal was more likely to be respected, as they could not be physically forced, and were more aware of the situation:

Most are pretty good, but every once in a while one is held down, and at a young age, especially if they have had a pre-med, they won’t remember it, and I think the dental need outweighs that. I think the kids are fine if they don’t remember it. … Sometimes a parent says ‘yes’ to a GA and the child says ‘no’, and at about nine you can’t hold them down. They are just too big and they know what they want. I have refused to do a GA when the child has said ‘no.’ … She was kicking, screaming, refused to take the pre-anaesthetic, and we just couldn’t hold her down. The weight of the dental need was not as great as the mental need. The anaesthetist and I decided that she can come back if she wants, but right now no. We can’t fake her out. You can hold a child down and you can give them a shot in the leg to make them do it, but she is old enough to make her own decisions to say ‘I’m not doing this.’ (Hospital Dentist, Den3)

If, after I have explained to a 14-year-old who needs dental treatment, and is an otherwise normal 14-year-old, but she decides she does not want the pre-med and to not undergo the anaesthetic then we don’t proceed. (Anaesthetist, HD5)

4. Nursing consent

In hospital, there is a dual process of consent, where upon parents giving their consent to doctors, doctors and parents direct nurses to administer the treatment to children:

The notion of nursing consent isn’t the same as the consent you sign on a piece of paper. It is ‘I am going to do this, is it okay because you already have the consent?’ And because we spend so much time with patients, and we are hopefully talking to them, we know exactly what they are thinking, what they want and why. (Nur3)

On occasions, there can be difficulties where children form different opinions from parents and doctors, especially when challenging decisions need to be taken, such as, whether to end treatment when its success is unlikely. The above nurse expressed her frustration about the age of consent being regarded as 16 years in hospitals. This could have the effect of precluding younger children from making these decisions, without an
internal process, such as multi-disciplinary meetings, or court action. In most cases, parents’ consent prevailed, as the processes were time consuming and involved, and the nurse’s role was to manage children’s expectations and emotions around that. Often children simply acquiesced to their parent’s consent:

If a teenager said ‘no, I have come to the end, I don’t want any more’ and the parents are not ready to accept that, if the child is 13 or 14 and not legally able to give consent, unless we go through a major process, then it is still a matter of ‘your parents have consented you still have to do it.’ So it is negotiating with that child around how we are going to handle this. You are kind of in a no-man’s land, especially for the ones who get closer and closer to the age of consent. … [T]here is pressure put on the child to say ‘the parents are giving consent, you have to do this’ and often through that pressure children will acquiesce. (Nur3)

Conversely, when children consented and parents refused, internal/external steps were more likely to be taken, so that children could receive treatment, such as for cancer. This could be frustrating for nurses, who were unable to administer the necessary treatment without parental consent or a court order, as one nurse recalled when caring for a nine/10-year-old child:

If a parent doesn’t give you consent you can’t do anything, unless somebody says so. As a nurse my hands are really tied in terms of consent. … I can remember a child who had a form of cancer. … The parents chose a very alternative route and left the country to do so. The child did not want that. She wanted to stay here and do what we were saying. She was a bit younger, about nine or ten. … That was getting close to court, as no court in New Zealand would have let them go to South America to treat the child with snake venom. (Nur3)

Therefore, it would appear that mostly there is a lack of reliance on children’s consent, where parents have not also consented, exemplified by the strong view of this hospital nurse:

… we would never rely on a 12-year-old to give consent of course, never, ever. There is no way we would do that. We do have a legal requirement about the guardian consenting. Even if the child was here on their own and the parent was in Australia we would gain consent from their parent. … [A]lthough consent of the child is acknowledged, and that is documented, we would never ever solely rely on that under the age of 16. Think of the mess you could get yourself into. (Hospital Nurse, Nur8)

5. Summary of Hospital Surgery, Medicine and Dentistry

Within and across disciplines in hospital there are inconsistencies in practice. Mostly parents’ written consent is relied upon, with some health professionals only recognising children’s competence to consent as a matter of default, when parents are unavailable or for serious and uncertain procedures. Ironically, sometimes children’s consent is not sought, but they act as interpreter to facilitate their parents’ consent. Conversely, other
health professionals routinely assess children’s competence and take children’s consent. Nevertheless, regardless of who signs the form (parent or child), the other usually gives their verbal consent.

Likewise, when only verbal consent is required, both parents and children confirm their agreement. In this sense, the family gives consent. Difficulties can arise, however, when parents and children disagree on treatment. When parents refuse, children’s consent may not be relied upon without an internal process, and possibly a court order. Conversely, when children refuse treatment, they are encouraged, and may also be pressurised or sedated into consenting/co-operating. However, generally children’s refusal is respected when they insist, unless outweighed by their health need. In particular, in elective surgery, or where the outcome is uncertain, surgeons ensure children are consenting, by being attuned to children’s reluctance. In these situations, parental written or verbal consent will not override children’s refusal, and thus agreement needs to be reached.

III. Private Practice

A. General Medicine

1. Joint consent of children and parents

GPs most often experienced children being accompanied by their parents/caregivers, when they consult with them, and so give their consent together. For some treatments, children do not have much of an opinion, such as for antibiotics, but for others, like the removal of warts/verrucae, children have stronger feelings and views. One GP explained that he provides parents and children with three treatment options for removal of warts, and even younger children have an opinion:

If the child comes in with a wart I would give the child and the parent three options. There is a wart. They always go away. It may take a year or two. We can try freezing it with liquid nitrogen. That might take three or four sessions. It has a 70-80% chance of working. You can try wart paint. That takes four-six weeks and has a 70% or 80% chance. There is no right or wrong answer, it is what you are comfortable with. … Even the younger children will have quite strong views about liquid nitrogen. I describe what is involved and some kids will say ’I’m not having the liquid nitrogen.’ … [T]hey know the liquid nitrogen might hurt. You do need their co-operation, so they are making the choice. (GP5)

Generally, most GPs only proceeded with treatment against children’s refusal if safety was an issue. Where the treatment was non-essential/non-urgent, time could be given for children to develop the necessary maturity and understanding, as described by one GP who waits until children have reached the level of maturity to decide that the pain of having a verruca frozen is worth the result:

909 Four of the six GPs interviewed confirmed they take consent from both parents and children.
GP4: I think medical treatment goes better if you’ve got the child on board. … I look on it as parents bring in children for a verruca to be frozen. I won’t do it unless the child is old enough actually to make that leap between ‘I know it is going to be sore now but I hate this thing, it is a complete pain in the neck, it is inconvenient and I know that pain now equals pain later.’ There are different ages that that happens. If … a seven/eight year old or eight/nine year old is going ‘no Mum please don’t, I won’t do it’, it is not necessary, it is purely a cosmetic thing, that verruca will never hurt the child, but the treatment might.

Int: Would that be the same for a wart?

GP4: Yes any of those cosmetic things, the mother maybe doesn’t like it, but the child would rather have the verruca than the pain now, and deal with it later. I don’t think it is really a decision the parents should be making.

Likewise, another confirmed that she would not prescribe for acne cream when teenagers were unconcerned - “where the mother wants the teenage boy to have treatment for his acne and he doesn’t care. In that situation there is no prescribing against his wishes” (GP2).

As children develop and grow, they may become prone to other common conditions, such as, ingrown toenails, which are more prevalent in children of 12 years and over. Similar to that of warts, there are options for treatment, which commonly children decide on, and give their consent, together with their parent:

GP5: The older kids, something like an ingrown toenail that is infected, the options are antibiotics for a few weeks, which might help, or remove the toenail. ‘What would you rather do?’ Again there is not right or wrong answer. Some people don’t like taking medicine and other don’t like procedures. The ingrown toenails are with children of 12 and over so it is more the child giving consent.

Int: Do you find generally that the child is giving their opinion and consent?

GP: Most do, very rarely would they say ‘I don’t know.’

Int: Then does the parent tend to follow the child’s view?

GP5: Yes. Sometimes they will have a chat and come to an agreement.

Similarly, teenagers may be capable of reaching a collective decision with their parents for more complex procedures, such as, breast reduction surgery, as one GP recalled. In contrast, however, a collective decision was not made when one mother, who sought a referral for circumcision surgery, for her 10-year-old son. Although the GP, who consulted with them, did not consider there was a medical reason for the procedure, she made the referral, without confirming the boy’s view, as she perceived her role to be to “make a referral to the hospital, and it is for the surgeon to consider consent” (GP1). The GP sensed that the boy was being heavily influenced by his mother, as he was very withdrawn. In that situation, she doubted he would be able to freely express his views.

Consistent with the findings amongst hospital doctors, GPs also held differing perceptions of who principally gives consent. For some, it was usually parents, and as
such, they were not mindful of assessing children’s competence to consent, although children needed to co-operate and agree:

*Int:* When you consult with a child is it in your mind whether this child is competent or could be competent to consent?
*GP2:* Yes it is interesting. I probably don’t except unless they are on their own, and there is no-one else to consent. …

*Int:* Why do you think that is?
*GP2:* I think that it is because the parent is there for the good of the child.

*Int:* And following on from that who are you expecting to consent?
*GP2:* The parent. We have a discussion about the treatment and options if there are options and I discuss that with the parent and the child if older. We talk about it and it depends on the child whether they are also consenting.

*Int:* When you have an under 16, do you have a process for gauging whether they may be competent to consent?
*GP4:* Not if they are with their parents I’m afraid I don’t think of it. Apart from in a way that if you are seeing somebody and you are treating them as a human being, ‘I’m about to stick a needle in you is that okay?’ ‘I’m about to feel your tummy, is that okay? ‘I’m about to put my hands on you.’ You don’t do that without consent.

*Int:* Why do you think that is that you are not going through that process of assessing competency?
*GP4:* I don’t know because I’m not that self-aware at the time. I wonder in retrospect if a) it doesn’t seem necessary and time is short: ‘The parents are there why would I bother?’ I wonder how much of an impact that whole 16 is the age of consent at the back of my head, and so I don’t need to do it.

The predominance of parental authority was highlighted by one GP who described having “implied consent” from parents to consult with children when they attend alone, viewing them “as an agent of their parents, delivering themselves to the doctor.”  (GP3)

Conversely, some GPs were more mindful of the evolving nature of children’s competence, and the importance of taking their consent, even although parents commonly agreed too:

*Int:* As the child gets older and they could possibly have the competency to give consent, does your procedure differ from younger children?
*GP5:* Generally, I’ll give more explanation, but generally even from a five-year-old you’d still want their consent to do a procedure.

*Int:* When you carry out these types of procedures (wart removal/ingrown toenail) who are you taking the oral consent from?
*GP5:* Primarily the child when they are older, but it is always good to have the parent on board. It is hard to think of a situation where the child has consented and the parent has said ‘no’. That has never been a big issue.

Of exception was one GP, who distinguished between “treatment” and “procedure”, considering that consent was not required for the former, as the health conditions were treated with medication, and no harm could be done, but for the latter consent was required.
2. **Children consulting alone**

Teenagers have more independence and ability to consult alone with their GP, seeking treatment/advice on common illnesses, such as infections, where the treatment options are easy to understand; seeking repeat prescriptions for long-term condition, such as asthma; or on sexual health/contraception matters, in which they seek privacy. In consultations, GPs’ attention may be more focused on their competence, when they are alone:

I would have a few between 13 and 15 who have come in without their parent, and that is always really interesting, because there is no parent there and they are really competent. They know what is going on, there is a good dialogue, and obviously they are actively consenting. (GP2)

Young people presenting for stuff that they have got to consent for where it is on you to establish whether they are competent to consent. (GP3)

However, for one it raised some concern of whether their parents were aware of their attendance:

It makes me quite uncomfortable I must say. Again, in retrospect, at the time you just get on, but I am conscious that 15-year-olds come in on their own and I must say one of the questions I ask is ‘do your Mum and Dad know you are here?’ ‘Oh, yes, they have sent me and they have given me the money.’ And I always check before I leave, let your Mum know that this is what I have given you so if you are sick on it she’ll know what to do. (GP4)

3. **Summary of general medicine**

When children and parents consult with GPs together, they usually give joint consent. It was important to most GPs that children understood and agreed to treatment. Yet, sometimes GPs could experience difficulty in ascertaining some children’s views, depending upon the parent-child dynamic/relationship, highlighting the relational nature of competence, and how it can impact on children being able to participate in the informed consent process. When children refused treatment, the GPs confirmed that their refusal would be respected, unless safety was an issue. All GPs had experienced children refusing treatment. Despite this respect for children’s autonomy, only a minority (two of six) perceived that they principally relied upon children’s consent, with most focusing more on parental consent, unless children consulted alone. The issue of whose consent is relied upon is particularly important when children and parents disagree about whether treatment should be prescribed. Although the GPs had not experienced children consenting and parents refusing, this could occur, as one school nurse had experienced
when the child consented to antibiotics against her father’s refusal.\textsuperscript{910} Children could be left untreated unless health professionals are secure in their authority to prescribe on the strength of competent children’s consent.

B. Dentistry

1. Children’s consent equates to co-operation

Consent for private dentists means that children understand the advised treatment and co-operate with it:

For me I think informed consent is, I’m talking about teens/adolescents, that they understand what I’m telling them needs to be done and they are agreeing to it being done. (Den5)

All I’d be doing is explaining the procedure as we go. It is not so much an informed consent thing, as I just want the kids to understand what is going on so they know what is going to happen … and we can get the procedure done. (Den4)

There is implied consent by allowing the treatment to carry on. I don’t bully people into having treatment, I will discuss it with them but, I suppose, I assume the consent has been given by allowing it. (Den6)

At times, children’s cooperation is promoted, not so much through their understanding, but by distracting them:

We explain everything at the same time. We have a DVD on the roof. When they are having treatment they will invariably watch that and so we don’t give them information as we are trying to distract them as much as possible. Treating kids is one of the most challenging things I find to do. You really want to try and get them to switch off. (Den4)

One factor in the extent to which children give informed consent is the nature or complexity of the treatment. For example, one private dentist explained that she takes the consent of children for basic matters, such as examinations and usually for x-rays, but always obtains parental consent for procedures such as tooth extractions:

Even kids 13, I will ask if it is okay to take x-rays and get them to consent to things like that, and talk to them about the appearance of the teeth and what they would change. … I would never talk about crowns or things like that, it would be just basic procedures. … I would never take out a child’s tooth without the consent of the parent, even if they were 13, I would always get the parents’ consent. (Den6)

Similarly, for fillings dentists advise parents on the best option, either an amalgam (silver/metal) or white filling, based on factors, such as, children’s co-operation and the

\textsuperscript{910} See page 215 where a school nurse (Nur2) relied upon the girl’s competence and consent to prescribe them.
easiest and least painful filling to insert. Parents usually accept that advice, but children are not really involved in these discussions and decisions, although they need to cooperate:

It is quite interesting because I probably don’t involve the child that much about whether they have a white or silver filling for kids six to eight or nine [years of age]. … Parents of those children definitely have ideas of what they want their children to have and children tend to allow their parents to control the process. … Even a 13-year-old, I will put a white filling in, but only charge for a silver one, because I imagine that kids or people want a white filling, they don’t want people to see them. … But with a child that is older, with greater understanding, I am more likely, if I was going to discuss anything with them, then I might discuss certain options like whether I was going to fill or leave it, if there was an option of not filling it. But I have to say I wouldn’t say, ‘would you like a silver or a white filling?’ So you are making me think how I practice. … I would never have said I was a patriarchal or matriarchal person, but yes I suppose I do make decisions for them and I just maybe make assumptions about them that I maybe shouldn’t make. (Den6)

Int: Have you ever had a child, who is of sufficient age and maturity, being part of that discussion?
Den4: No never. Kids just sit back and let the parents and us make the decisions. I have never had a child question anything, other than, ‘no, I don’t want an injection.’

Den5: I think the child is guided and led towards the method or option that is recommended by the parent and by me.

Int: Is there an age at which you see that changing where the child is more autonomous from the parent?
Den5: Most are led by the parent until about 16 and some until they are 19/20 [years old]. It is a bit of a transition at that age where they have a bit more understanding and are a bit more confident.

2. Children Consulting Alone

It is not uncommon for teenage years to consult with dentists on their own, as they and their parents have established a trusting relationship with them. Dentists guide children in the necessary treatment, and parents trust that the right decisions will be made:

The parents are confident that they don’t need to be here to make the decisions for the child. They are more confident that the child can come on their own or after school and trust my judgment and that I have their best interests at heart. (Den5)

However, when the treatment involves options, or is complex, dentists will confirm parents’ consent before proceeding.\footnote{Some hospital dentists also experienced some children consulting with them alone, but this was exceptional. It appears to be more common for teenagers to consult the dentist alone than the GP, as it was not unusual to the dentists that they did so, whilst for GPs it was rare.}

\footnote{As will be seen below in Section C page 220, dental therapists contact parents to obtain their consent over the telephone when the treatment plan changes from that to which they have consented.}
Usually [when there are options] nothing is done immediately. It’s a matter of me ringing the parents, after talking to the teen or adolescent, and explaining that these are the things we need to work out and the options for treatment. Mostly I’ll speak to the parents on the phone, occasionally the parents will come in, so I can talk them through the process of what to choose and what to do. (Den5)

The issue of contacting parents for consent may relate more to cost than to children’s competence, as private dentists need to be assured of payment for the treatment:

… it [consent] is not just for the procedure, it is for the payment. That is always tied into it. Very few things we would ask a child for consent without consulting the parents because the parent always has to pay for it. (Den4)

3. **Summary of private dentistry**

In private dentistry, parents and children commonly agree with the dentists’ advice, with children taking a relatively passive approach to consent, allowing the dentist to guide and direct them. In that process, however, dentists will explain the treatment in order that children understand, and provide an environment in which children’s independence and competence can develop, as shown by teenagers consulting alone. Children and parents will provide joint consent, even if parents are not physically present, as dentists require to be assured that parents agree, and will accept the cost.

III. **Schools**

Commonly, children receive medical and dental treatment in schools in three contexts. Firstly, secondary schools may have a SMS on site for children to seek general medical advice and treatment from a nurse, and possibly, a GP. Secondly, children may be enrolled in a SDS from the age of two years until 12/13-years-old (Year Eight). Dental therapists examine and treat children’s teeth, either in a van that visits their school, or in a dental hub (clinic) located in the school grounds. They carry out preventative procedures like examinations, x-rays, and Fischer seals, as well as restorative procedures, such as fillings. Thirdly, public health nurses immunise intermediate school age children around the age of 11 years with a tetanus/diphtheria/pertussis booster vaccination, and girls around 12 years, with the human papillomavirus (HPV) vaccination, to protect against HPV infections and cervical cancer. The following sections consider how consent is given in each of these health contexts.

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913 Chapter 9 page 176: dentists used a variety of strategies to develop children and parents’ confidence and trust that promotes children’s co-operation.

914 At the time of interviewing it was only girls who received the HPV vaccine. This has now been extended to boys who can access it at their GP.
A. School Medical Service

1. Introduction

Children always consult on their own with the school nurse/GP by the very nature of it being within the school. This environment promotes their responsibility and competence to manage their health by providing a service in which they can openly discuss matters; freely ask questions; and take time to understand information, make decisions, and give their consent. This can be of particular importance in sensitive matters, such as sexual health/contraception, and when children are otherwise unable to access treatment. This section explores the consent processes for contraception and antibiotics, being two common reasons for children accessing the SMS.

2. Consent Process for Contraception

A striking feature of children seeking contraception/sexual health advice was the extent to which school nurses and doctors follow the stages of the informed consent process. They fully discuss children’s situations; educate them on contraception; explore options; support their understanding of how contraception works and is administered; advise on the risks and benefits; support them in making choices; assess their competence; and take their consent:

Here (school) I generally always see the young person on their own and I allow more time because of the importance of their understanding. … I ask about whether they are sexually active. We talk through what their options are for contraception, what contraception would work for them, do they want to get pregnant, do they talk to their parents, how would their parents react? In discussions I am assessing their ability to consent, kind of from a Gillick point of view. Do they understand why, do they understand how and what they have to do? So you can imagine it takes a long time. Here we just take the time it needs because we recognise it is really important, because if they don’t understand they are not going to follow through. (Private/School/Youth Service, GP6)

When providing explanations, health professionals recognise that they need to adapt their language by using terms children will understand:

We get them to voice their understanding. However it can be challenging if they are shy or not confident. Using I guess their terms. They have nicknames for all these that they have heard, for example, the jab. (GP6)

Nevertheless, in some situations, determining children’s level of understanding and competence can be complicated, for instance, when children/young people may be developmentally delayed, or have had challenging childhood experiences that

\[915\] Community/youth services were found to have the same characteristics. GP6 practiced in a school, community youth service and a private GP’s practice, and a nurse (Nur5) practiced in schools and a community youth service.
compromise their understanding. If available, a specialised opinion or a team approach may assist in gaining a better sense of children’s competence before prescribing contraception:

Some young people are developmentally delayed, particularly if they are becoming involved in risky sexual behaviours, relationships, and so we will have a conversation about what approach as a team we are going to take here and whether to involve other people… to see what is the developmental level, what are we working with, to gauge their functional level and get a bit more feedback and then we have to make a decision as a team what we are going to do and whether to involve family if there are developmental issues. (Nur5)

At other times, GPs may need to use their judgment on the degree of children’s competence, including whether it is in children’s best interests to prescribe contraception, despite children having limited understanding:

There are times when, yes, understanding is not there, but safety. I can think of a number occasions. For example, a young person in the early years of high school, had had a pretty rough life and been in foster care, having sex, and doesn’t really know who they all are, and putting herself at risk and wouldn’t remember to take tablets, but doesn’t want an injection, because doesn’t want a needle and doesn’t understand that concept of what it means to be pregnant. I think that’s a very difficult situation to deal with and also getting parental consent breaks that confidentiality. They are putting themselves at risk but talking to their parents could put them at greater risk, so that is a really grey area for consent, but in this case she did agree to get the depo. In terms of her degree of understanding of what that means was limited but I think enough to agree. I think it was the right thing to do and we continued to work around the other issues. (GP6)

Although children are autonomous in accessing this service, health professionals encourage them to use their family supports, if available:

For contraception we don’t need to tell their parents, but we talk about involving parents as much as possible. And when I say parents I am actually saying that quite loosely as a lot of these young people are not with their parents, they are with aunts and other sorts of homes. (Private/School/Youth Service, GP6)

If they have talked to Mum and she said ‘go to the nurse’ then that’s fantastic. The ideal situation is that they have spoken to an adult and have consent from that adult to come and see me. (Nur2)

Once children are prescribed contraception, their on-going independence and responsibility in managing it are supported through the use of a computer reminder/recall system. Follow up appointments can be programmed into girls’ mobile telephones and details of alternative agencies given to them:
The girls who have the depo go onto a recall system on the Medtec 32 system, standard practice software system. So I put their injection onto the notes and it goes onto screening and recall, and it comes up straight away. While the student is with me I'll get her to date into her phone for the next 12 weeks and I book them for the next appointment. So they are booked even if they forget, and I can go and get them. If it falls in the school holidays I give them a family planning number and a list of option of where they can go. (Nur2)

Thus, when children seek contraception from the SMS, nurses and GPs provide an environment for them to comprehensively discuss, understand, make decisions and give their consent. They engage alone in this process, and co-consent from parents is not required, although children are encouraged to involve them.

3. Antibiotics

An anomaly exists in the consent process for antibiotics in schools. Although children give their consent, health professionals also attempt to contact their parents/caregivers before prescribing antibiotics, and send them a letter when they are unable to speak with them:

We have made a blanket rule for under 16s that we would always try and contact the parent to let them know we are prescribing this medication before we gave it to them. … We are just taking steps to inform the parent. … Most young people are competent to understand why they are taking antibiotics and what the risks of not taking it. What they are not so good at is taking it on time and taking the whole course, so there is a degree of understanding. (GP6)

The purpose of the letter appears to be to inform parents, rather than to seek their consent, but this may not be always apparent. Also, there are differing practices of when parents require to be informed: under 14 years; under 16 years; or on a case-by-case basis. For example:

Nur2: Amoxyl is a really good example, which I prescribe all the time, for suspected strep throat, upper respiratory infections, ear infections. We talk about that and if they are under 14 [years] then if I can’t get hold of Mum, Dad, Aunty, caregiver, a letter is given to the student stating that this is what has been prescribed, the treatment, dose, duration of treatment and possible side effects.

Int: Is the purpose of that letter to inform rather than to get consent?
Nur2: Well it is to obtain consent.
Int: But you have already prescribed it so when and how are you getting consent?
Nur2: I’m getting consent from the student, and I suppose, yes this is an interesting one. … The student presents, if they meet the criteria for treatment then we obtain full consent from the student, but a letter needs to go home to the parent if we can’t talk to them. … It is not asking for their consent it is informing them.

Int: You said that you send a letter home for under 14s, so I assume not for over 14s. Why is that?
Nur2: I actually don’t know. Those are the guidelines here. I know that at 14 they can be left at home alone so there is something about that age.
Nevertheless, despite parents being informed, health professionals can rely upon children’s competence even when parents disagree with their child’s decision to take antibiotics, as one school nurse had once experienced:

It has only happened once and it was a young woman who has had numerous strep throat results. She wanted the treatment and the father is opposed to antibiotics. He wanted to treat her with a more traditional healing process. They are Māori. She wanted antibiotics. She was very clear about that so what we did was I initially sent a letter home to her Dad. I couldn’t get him on the phone because he works at nights and sleeps during the day. I said ‘this is the situation I have antibiotics here.’ He said ‘no’ and the student said ‘just give them to me and I won’t tell him.’ So she was 14 and so had a long conversation about that and in the end I gave her the antibiotics. She had full understanding. It was not the first time she felt miserable with strep throat so I gave her the course and it is easy with amoxyl because you can give three tablets at once. I think in fact what happened she came here in the morning and took her tablets. I’m not sure if Dad found out but I did say to her if there are any issues it is really important he rings me and I was prepared for that and just explaining that she does have a right to this treatment. (Nur2)

4. Summary of school medical service

Overall, the SMS provides an environment in which children competence is promoted and respected, through the time health professionals spend with children, building relationships and supporting them in the stages of the informed consent process. However, the prescription of antibiotics, a common and relatively simple treatment, has raised questions over the consent process, in particular, whether children are sufficiently competent to consent, and if so, the purpose of the telephone call and letter to parents. When children are assessed as competent there should be no need for these, although children may prefer that a letter be sent to their parent/caregiver to support them in their compliance. At times, they may forget to take their antibiotics, despite understanding the importance of completing the course at the time of prescription. Nevertheless, if children were not competent, for example, by not understanding the importance of completing the course, then parental consent would be required.

This process contrasts with that of contraception, where there is no process or option for parents to receive a telephone call or letter. Although privacy is likely to be the issue, both require adherence to the prescription, raising the question as to why their processes differ.

B. School Vaccination Programme

Children of around the ages of 11/12 years receive vaccinations at school. In order for children to be vaccinated, parents require to provide written consent, while children consent verbally. Public health nurses rely upon parents and children both consenting, as children will not be vaccinated when either refuse. This section explains how children are
informed about vaccinations, how consent is taken, and the barriers to relying on children’s consent, when parents refuse.

1. Information

At the outset of the vaccination process, nurses show children a video at school and provide them with written material to take home. During the presentations children have the opportunity to ask questions, either during or after these. However, children rarely seek out further information, as the nurses try to anticipate their questions, and children may feel self-conscious:

We show the video and it is a good opportunity for children to ask questions. And what we try to do is try and answer these questions before they think about them and we go over it again and say ‘if anyone wants to stay and talk, please talk to us.’ On the back of the consent form there is also a phone number. I think we have had the occasional child ring, but really it is part of being proud. (Public Health, Nur6)

During the presentations, nurses adapt their language by simplifying their explanations, as they are aware of children’s varying educational abilities:

We have to change our language a lot because developmentally they can be very different. When we are doing the three doses of hpv/gardol I talk to them about how their phone batteries drop down and how it needs charged up and it lasts a bit longer next time if you charge it up fully. You use tools like that. (Nur7)

The students are then given information and the consent form to take home to their parents. The expectation is that parents will use “the consent form in the way that it is designed - which is information for you to read to your child or to talk with your child about”. (Nur6)

Nevertheless, the rationale for providing children with information is more to enhance their understanding to a level that will secure their co-operation, rather than to give their informed consent. This is highlighted when children have English as a second language, as interpreters will be provided for parents over the telephone, but not for children, either during the presentation, or at the point of vaccination. In such situations, nurses rely upon parents to have adequately explained the vaccinations, and reasons for them, to their children, but are unable to check children’s understanding. Thus, children may be blindly following their peers:

Nur7: … you may have children who have English as a second language and you can’t really explain to them, but you are hoping that that work has been done. There are forms in different languages.
Int: So how do you know that they are understanding and consenting?
Nur7: We do get an interpreting service to translate the forms. If they haven’t come and English is a second language, or not a language at all, we will get an interpreter on the
phone to explain it to the parent. We would hope that the parent has explained it to the child.

Int: You couldn’t rely on that.

Nur7: No, you couldn’t. It is only an observational thing for them to see what’s happening for the other children, so it is a bit of a grey area.

2. **Consent Process**

On the day of vaccination, children are usually vaccinated in their school hall; an environment that lacks privacy, although screens can be arranged, if required:

They are generally in a hall. We like a big space where you have exits, one way for children to come in and another to exit so they don’t get mixed up. … They (screens) went out the window. It could have been because the programme was so big in 2009 that it was easier to do away with the screens because everyone was getting done at the same time. (Nur6)

We see them in a hall, but can see them in private if something is really going on. (Nur7)

Before nurses vaccinate each child, they “sit down [with the child] and have the one-to-one” to understand “how they really feel about it, and whether they are happy to get it or not” (Nur6). This process enables children to either give their consent or refuse:

So the child is actually approving at that time the vaccination. Children at that time can refuse. (Nur7)

I actually think that we get the true consent from the child more so when we sit down with the child when they are vaccinated. That engagement between the child and the public health nurse when we are talking about what to expect and what it is going to feel like. That’s when I think we get the real ‘okay, I am happy for you to give it to me.’ (Nur6)

Nurses value these opportunities to discuss any issues or concerns with children, as it is important for them to understand any challenges children may be experiencing. For example, one nurse recalled a child refusing the vaccination, as she was in turmoil, due to not being in the care of her parents, and this was one aspect of her life that she could control:

I did have a child who was stressed. She wasn’t needle phobic, but she had so much going on in her personal life that she chose not to be vaccinated because she wanted to control something. … I had communications with her caregiver or parent as to what was going on and there had been a family break up and this was the only thing that the child could control and she was in the care of somebody else at the time. I explained to them that this is not the time to vaccinate. She needed time, help raising her self-esteem and some control over her life. (Nur7)
This child was not forcibly vaccinated, as “[t]here would be another time. It wasn’t something that was going to kill her” (Nur7). Whilst children’s refusal is respected, their consent may not be relied on, where parents have refused/failed to provide written or verbal consent. The consequence is that children may be denied the opportunity to be vaccinated at school, despite their competence, and willingness, to verbally consent:

Nur7: We do get children who don’t return their forms and won’t have given it to the parent.
Int: What happens in that situation?
Nur7: They come with their class, but their form has not come, so we will not be vaccinating, but we may be ringing up.

However, there are variations amongst the DHBs, as some will accept children’s consent without parents’ consent:

We still have problems with things like immunisations. The HPV vaccine, for example, where if they are under 16 they still need parental consent, as well as their own consent, so it gives you a double hoop to go through. That is not uniformly applied, and some will accept the consent of 14/15-year-olds, but it depends. Even for immunisations, which is a fairly benign procedure, there is still a mixed view from different DHBs. (PSD, SH4)

Both participating public health nurses did not consider that there was need or value in children co-signing the consent form, as “parents will always have that final say” (Nur6), and they did not “want to make it more complicated” (Nur7).

3. Barriers to children consenting

The barriers to the public health nurses trusting children’s competence to consent arose from their concerns of exposing themselves to professional risk. Although clearly aware of “Gillick competence”, and capable of assessing it, they felt unable to rely upon that assessment at times. As a consequence, they may refuse to vaccinate competent children, preferring that children attend their GP to receive the vaccines. For example, one nurse recalled such a situation involving a 14/15-year-old girl, in the care of Child Youth and Family (now known as Oranga Tamariki - Ministry for Children), who wanted the HPV vaccination. Her parent had refused to consent, and although the nurses assessed her as competent, they felt unable to proceed, instead advising her to consult with her GP. Their concerns were that they might miss important information about the girl, due to their lack of relationship with her, and also felt professionally exposed by the law’s ambiguity:

Int: What was it that made you feel you did not have the right to immunise that child?
Nur7: It is interesting because we use the ‘Gillick competency’ to make that professional decision and we could see that she had the capacity to do decision-making and understood what it is all about, but we didn’t feel we were in a position to be the ones to take the responsibility for that. Someone who knew her better and longer and because
she had this on-going relationship with her GP service was a better setting and a safer setting for her. …. We are protecting ourselves. Yes, it does appear she is competent, but do we want to risk that and maybe she has had it somewhere else before or there are other things that could come into play that might make it not safe for her to have.

Nur6: I would not feel confident to say I am going to base my decision on the Gillick competence. I would rather refer her to a service that knew her better than I did to carry it out, as there is the potential to bounce back or backfire.

Int: *Why is that?*

Nur6: I feel it is not tight enough via the law. I don’t know the law that well, but I am not convinced that we are covered safely.

Although in theory children can visit their GPs to be vaccinated, they may encounter barriers, such as, cost, and possibly insistence of parental consent:

… the young girl could go to the GP by herself. She might be refused, as they do not want to do it without parents’ consent, and someone would have to pay the bill. (PSD, SH4)

A further barrier to following children’s consent, when parents refuse, is avoiding difficulties with schools, as vaccination programmes need their goodwill, agreement and support:

… immunisers are only in the school by grace and favour to some extent, so if they were to kick up a bit, the school committee could say these kids can go to the GP and get it done and we wouldn’t get the coverage. … They have a big enough job immunising those who want immunised without fighting with the ones who don’t. (PSD, SH4)

4. **Summary of school vaccination programme**

The mass vaccination programme contrasts in environment from the individual, private approach of the SMS. Educating and immunising children in a group setting does not lend itself to developing knowledge of, and relationships with, children, or cater for children’s individual needs, such as providing an interpreter for those with poor English. For some children, the public nature of the education session and treatment environment will not support their competence, as they may feel inhibited in asking questions, and only proceed with the vaccination as their parents have consented, and through peer pressure. Nevertheless, with information sent home, parents have the opportunity to support their children’s understanding through discussions.

Although time is restricted, vaccinations are relatively simple for children to understand and decide upon, and nurses appear to have sufficient time to assess children’s competence and confirm their consent or refusal. However, nurses’ abilities to assess and rely upon children’s competence are compromised by a number of factors. Firstly, the system places more significance upon parental authority and consent, than to children’s
status and their competence consent.\textsuperscript{916} As a consequence, competent children who have consented may be denied treatment when parents refuse consent. The barriers inhibiting nurses are their concerns of exposing themselves to professional risk, emanating from both their lack of relationship with children and feeling exposed by the law.

C. School Dental Service

1. Introduction

In the SDS, parents provide what is known as “enduring consent plus x-ray” (Dental therapist, DT1) at the time of enrolment in the service for their children’s teeth to be examined, cleaned, x-rayed and have fluoride and Fischer seals applied. This consent “endures” until the child leaves the service, usually in Year Eight (12/13-years-old). Parents give further written, or verbal, consent for additional treatment. Naturally, children give their verbal consent/agreement during the examination/treatment, but the consent process is particularly parent-led, resulting in dental therapists having limited ability to promote children’s competence. Children receive little information about their health and treatment, and their consent will not be relied on, when parents have failed to provide their consent.

2. Information

School aged children have dental examinations at school by dental therapists, either in a dental van that visits their school, or in a dental hub (clinic) located in the grounds of their school. When children need further treatment there are two systems. For children seen in the van, they receive a brief form to take home to their parents, who then make an appointment at a hub, and usually accompany their children for this treatment. Children who had their initial examination in a hub are given a “care plan, which briefly outlines the treatment required, the type of filling, … anesthetic, and anything else, and that is issued to the child to take home to the parent”, and on the reverse it has space for “a medical history update and consent box” (DT1). Children are instructed to give this to their parents to sign, and they return to the hub alone for this treatment.

At the examination, the dental therapists’ aim is to provide children with enough information so that they understand the treatment, and will pass the consent form onto their parents to sign:

\begin{quote}
\ldots you would say to them this is what we need to do and this is how it is going to be happen, so you are alleviating their fears, because that’s how you get the form taken home. You have got the child at least understanding what you are going to be doing so they are more than likely to take the form home and know that it is for their own good and request that the parents sign it and bring it back. (DT1)
\end{quote}

\textsuperscript{916} A feature that is common also to the SDS.
They keep the information brief and basic, as time is short:

DT1: You say to a child, ‘you need to come back and we need to’, rather than [use] the word “fillings.” ‘We need to fix up a couple of things,’ or if it is just preventative work you outline to them, ‘it is just this little thing we need to do,’ and you say ‘you need to take this home tonight and put it in your book bag and ask Mum and Dad to sign it.’ You don’t go into too much detail. They are welcome to read the care plan, but it is really quite a basic form: tick this box for a filling and put three fillings silver, tick the local anaesthetic box.

Int: What is the reason behind not going through it with the child?

DT1: I suppose it is a time factor if I am completely honest. I keep it quite basic so they can understand. If they needed a filling I will tell them they have a hole in their teeth and they will need to come in to get it fixed. (DT2)

Although including more information on the form could allow parents the opportunity to discuss it with their children, some may not have the necessary understanding to do so, or may pass on their own fears:

I think things could be a bit more informative to the families, giving them a bit more information, but more so that the parent can talk to the child. … Some will try and discuss the options or plan but not have a lot of idea themselves. Some put their fears onto their children and sometimes they are both uptight in the waiting room before you have them in the door. (DT1)

When further treatment is needed, such as fillings, parents usually attend with their children, unless their child attends a school where the hub is within its grounds. The dental therapists explain the treatment, and discuss the options, mostly with parents. Although children are present, they are not really involved:

Int: To what degree is the child involved in those discussions?

DT2: With the filling it is mostly the parents as I feel they are the deciding factor. Discussions are directed at the parent.

Int: Why is that?

DT2: In a lot of cases the child does not really know. If the parent is there they make the decision. Other times when we speak to the children and ask them questions they turn to their parents and look at them.

Int: With the 12 and 13 year olds would you do the same, that you direct the discussion and decision-making to the parent?

917 See page 174: “Everything we do is timed. We get x amount of time to do this, right down to the filling. We have lost the human element that they are children. … Now that we have come into the hub it is very production line” (Dental Therapist, DT1).
DT2: Usually when they’re older, like 12 [years], I would mention it to the child, but I think I would still, with the parent there, direct it to the parent.

3. Consent

Dental therapists rely on parents signing and returning the consent form, when children attend alone for treatment, as without it they cannot be treated. Children do not sign/co-sign consent forms, although they do verbally consent/agree at the point of treatment. However, dental therapists will not rely upon children’s consent, in the absence of parental consent, including when additional/alternative treatment is necessary mid-way through treatment:

DT1: If that treatment was to change part way through, you were going to fill that cavity with a white filling and suddenly it changes, you really need to contact the parent or guardian and update the consent [or] … you could be fixing a tooth and once you have cut your cavity you have noticed that the size of the tooth needs filled, so you would need to contact the parent and get consent. If you couldn’t you’ve got the local anaesthetic working but you just cannot do it unless you get consent.

Int: So if it was a competent child, would you take the child’s consent if the parent couldn’t be reached?

DT1: I would want to if they had the age of understanding but I would be restrained by the policies that we have here that say only consent from a parent. I probably would not call up my team leader or service manager because they would say to me ‘no’, which is unfortunate.

Int: In a situation where you cannot get hold of the parent but the child is competent and consents would you go ahead with it?

DT2: I think it would depend on the type of treatment it is. If it is something invasive like a filling then I would wait until I get consent.

The dental therapists’ understanding of the “policy” is that they need the consent of parents, or if unavailable, another relative or caregiver, and are unable to rely upon competent children’s consent:

DT1: If I started taking consent from a child I would probably get myself into trouble. It is written or verbal consent from a parent or a caregiver. Well, actually not even a caregiver. If the child was with a Grandmother or Aunty, you would have to say ‘I’m sorry, off you go’. But when you are in a low decile area, and there have been four failed appointments, and they have turned up with Aunty, you don’t bend the rules, but you try and phone Mum or Mum is happy and knows you are here.

Int: So in that situation if the child was of “an age of understanding” would you take the child’s consent or the Aunty/Grandmother’s consent?

DT1: I would take the Aunty/Grandmother’s consent. I could not put in my documentation that I had taken the child’s consent. We are working in this area under consent from the parent.

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918 Sometimes dental therapists will obtain parents’ consent by telephone prior to treatment.
We contact the parent to make sure we get their consent before we do anything. … Even if they [children] do understand and consent, in my shoes I feel I still need to contact the parent to cover myself. (DT2)

As a consequence, children’s competence may not be assessed or relied upon – “I think with the parent’s consent I do not assess” (DT2). The reason for such reliance on parents’ consent is fear of reprisals from parents. For example, one dental therapist expressed concerns over whether parents would understand and accept their competence assessment, and leading on from that, whether they could rely upon children’s recount of their medical history.

4. Refusal

Although children’s consent will not be relied upon, their refusal is respected, regardless of parents’ consent, and at times, pressure, to proceed:

Some parents can get very stressed and uptight and I have had a parent say to me that they were not going to leave until it is done and we have to say we do not work like that. We have some parents who offer to hold their children down. (DT1)

5. Summary of school dental service

In the SDS, there is little opportunity for the promotion of children’s competence to participate in their dental treatment. Although children commonly attend alone, and receive treatment within a learning environment of school, there is little time or opportunity for children to learn about their dental health and treatment. The system depends on the written and verbal consent of parents, and does not take account of children’s growing understanding and independence, as parental consent is given at the age of two years and endures until children reach 12 or 13 years. Naturally, children’s cooperation is required, but even when they are competent, their consent will not be relied on. This could result in them failing to receive necessary treatment. This system is much more akin to the vaccination programme than to the SMS, as it is dealing with high numbers of children, and supports parental authority in preference to children’s competence.

IV. Chapter Summary

Overall, across healthcare environments, children and parents provide joint consent. Children’s consent is mostly verbal, indicated through their agreement and co-operation, with parents providing either written or verbal consent. However, the significance of each differs, with there being inconsistencies in practice, within and across healthcare environments. In hospital, generally more reliance is placed upon parents’ consent/refusal, highlighted when either parents and children disagree, or when parents are not present to consent. There are exceptions, however, where some health
professionals (anaesthetist and obstetrician/gynecologist), confident in their assessment of children’s competence, routinely rely on children’s consent. Whilst the hospital environments are similar between specialties, the differences seem to relate to accustomed practice and respect for children’s competence and independence, rather than an inability to assess competence or ignorance of the law. For example, although the paediatric surgeons did not routinely rely upon children’s written consent, they were prepared to do so in exceptional situations, such as, when parents were unavailable. Significant to them was their pre-existing relationship with the children and an awareness of children’s experience.

In schools, health professionals (public health nurses and school dental therapists) may feel exposed to professional risk by relying on children’s consent when they do not have pre-existing relationships with children, lack time, and operate within systems where greater respect is given to parental authority than to children’s competence. They perceive that their policies and/or the law leave them unprotected. In contrast, the SMS best promotes and respects children’s competence and takes their sole consent. Health professionals have time to develop relationships, discuss and listen to children’s situations, provide explanations, support their decision-making and take their consent. Although an anomaly arose with antibiotics, this process could be resolved by clarifying to health professionals that prescriptions are given on competent children’s consent, and a call or letter to parents is not required, unless children make that request.

When children consult alone, some health professionals may give greater attention to children’s competence, in order to take their consent and rely upon it, such as some GPs. This contrasts with private and hospital dentistry, SDS and public health nurses, where health professionals will also confirm parents’ verbal consent. In private and hospital dentistry, the reasons are to ensure parents continue to be involved, and to develop relationships with them. In private dentistry, cost is also a factor.

In all healthcare environments, generally, health professionals will respect children’s refusal, despite parents’ consent, unless safety is an issue. Thus, health professionals appear more secure in their practice of respecting children’s refusal, than relying upon their consent, when parents and children disagree.

The rationale behind health professionals relying upon parental consent are: misunderstanding of the law, that children require to be 16 years of age; established practices within hospitals; lacking confidence in the law protecting them; cost (private dentistry); concerns relating to children being unable to accurately recount their medical history; and fear of reprisals from parents. In the next chapter, health professionals’ understanding and perspectives of the law are considered further, together with all participants’ views and experiences of the current legal framework.
Chapter 11

Knowledge, Understanding and Reform of the Law on Children Consenting

I. Introduction

As a consequence of the law in New Zealand being fragmented and uncertain, it is important to ascertain how the participants in my study understood the law and implemented it in practice. The first two sections of this chapter begin by examining health professionals’ understanding of the current legal framework and their suggestions on changes, if any. Included also are the views of stakeholders, who have experience of advising and training health professionals on consent laws. The final section explores the perspectives of parents and children on the law who, of course, experience its effects most keenly.

II. Health Professionals’ Knowledge of the Law

As part of the interview process, health professionals were either asked about their knowledge on the law, or it arose naturally in discussions. Their knowledge and understanding was variable, with around half having some understanding that competent children have the right to consent:

Anyone can give consent as long as they have full understanding, explored all the avenues, regurgitation of information, so I know they understand. As far as I am aware anyone of any age can give informed consent. (School nurse, Nur2)

I am aware that there is no legal minimum of age of consent (Anesthetist, HD5)

My understanding is that informed consent can come from the young person under the age of 16 if you consider that they understand what’s going on, why, taking into consideration their age, intelligence, education so you can get informed consent. (Private/School/Youth Service, GP6)

However, within their general awareness there were confusions, such as that it only applied to sexual health, or that parental consent is also required until children are 16 years:

I did think that they had to be 16, except for sexual health and abortion. (School nurse, Nur1)

My understanding is that at 16 children can consent for everything and anything. I’m talking medically. It is irrelevant what the parents think, but before that, at any age you

See Chapter 3.
think the child can comprehend what you are talking about you need them to consent as well as the parent, but at 16 it becomes the child. (Hospital dentist, Den3)

Int: What teaching did you get during your degree on informed consent for under 16s?
Informed consent was quite a big thing. We were taught for under 16s the guardian was definitely most important but unless the child was understood and was well informed then you could get consent from them, but usually for any sort of treatment I do at school I definitely get the caregivers’ consent. (Dental therapist, DT2)

Misconceptions and inconsistencies amongst medical professionals have also been experienced by three legally qualified stakeholders, when advising and/or training them:

Completely mixed up. … There are very different levels of understanding of what they can and can’t do. (Lawyer, SH12)

I feel there is a lack of understanding amongst health professionals and parents about this area. (Lawyer, SH6)

The most common misunderstanding of the law amongst health professionals participating in my study was that children were required to be 16 years old before they could lawfully consent. Generally, this confusion appeared to stem from either their experience of hospital practice, where commonly parents sign consent forms, or from their understanding of *Gillick*. Although many were aware of *Gillick*, there was confusion about its interpretation and applicability in practice. For example, some considered that it only applied to sexual health, whilst for another, although she interpreted it as enabling her to consult with competent children under the age of 16 years, “if anything it hammered home that, without specific criteria, you shouldn’t take consent from an under 16-year-old” (Private, GP4). Thus, *Gillick* confirmed to her that the age of consent was 16 years. She recalled feeling relief at time of this decision, because in her experience, prior to it, there was concern amongst the profession over whether “we would be taken to court, not too sure if we’d be sued.”

Compounding inconsistencies in practice was caution or reluctance amongst some practitioners to follow *Gillick*, despite their awareness of its applicability. For example, in hospital there seemed to be a sense that children’s consent was optional, the preference being to defer to parents for consent, until children were 16-years-old:

I know that you have this *Gillick* competence concept. … In practice we don’t do that a lot, I guess because usually there is a parent there. … I don’t know how widespread it is, *Gillick* competence. I suspect it is not widespread at all. (Paediatric Surgeon, HD1)

Also, there may be some uncertainty over the implication of *Gillick*, as experienced by one hospital doctor during her employment as a registrar. She received specific

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920 All practiced in different contexts of private practice, DHB, and a non-governmental agency.
instructions from her boss not to use the term “Gillick competent”, but instead to state, “competent to make decisions” (Obstetrician and Gynecologist, HD7). This suggests caution around using the term “Gillick competent”, and may imply a lack of understanding of what it means.

Similarly, other health professionals were reticent in following Gillick, such as public health nurses and dental therapists, who tend to practice defensively, due to concerns of complaints from parents, or feeling exposed by the law.921

These issues of uncertainties/misunderstandings on the law, and inconsistencies in practice, may be a wider phenomenon than the participants taking part in this study. For instance, one stakeholder recalled a survey that had been undertaken involving 20 DHBs in New Zealand. The responses to the questionnaire that was circulated showed inconsistencies in practice and an over-reliance upon written consent:

The analysis of it showed that there was a great disparity across the country, and a very poor understanding of the principles involved, for example, The Health and Disability Consumers Act. People making noises, token efforts. … There was too much emphasis on the outcome rather than the process, with the outcome being a signature on a piece of paper. (NGO, SH1)

A number of factors are likely to contribute to such inconsistencies. Firstly, there may be a lack of uniformity in the curriculum for medical students across the medical schools in New Zealand on the issues of consent as “there are 25 teaching hospitals, [and] it is impossible to know whether there is a consistency and uniform standard of the teaching of consent” (NGO, SH2). It may be that recently graduating health professionals are more aware of competence and consent issues, as two stakeholders involved in the education of medical students both teach that competent children under the age of 16 years have the right to consent, whilst in the experience of a third stakeholder “the newer graduates are much more aware of these sorts of non-clinical aspects of care” (NGO, SH1).

Secondly, in some health specialties more experienced practitioners may not have received recent training, or be set in their ways:

… unfortunately the way the system works as far as [area of health] is concerned, they come under the influence of an older and more mature group who are burdened with tradition, ‘this is the way we have always done it.’ It is very unbalanced. It is either one end or the other, not much in the middle. There is a top there too. It is cultural and that is what has to be changed. (NGO, SH1)

Most health professionals reported deriving a sense of security from established professional practice and peer or collegial support in the consent processes:

921 See Chapter 10.
In a DHB we have a board lawyer if we have concerns and can draw upon the expertise of other health professionals, like paediatrics and liaison teams to talk with the families. (Hospital nurse, Nur8)

What I would do if I had a situation that I was not sure about I would ring the Medical Protection Society to get their advice on the rules around it. (Private, GP5)

I suppose I could google ‘Gillick’ and talk to other doctors to get peer support. (Private, GP1)

Thirdly, as the law lacks clarity it is likely to be interpreted in different ways. Two stakeholders, employed by the same DHB, who both educate or advise health professionals on the law and its application in practice, but who have differing views on children’s right to refuse treatment, highlighted this:

If they are competent to make the decision then they can consent or refuse. It is a matter of practice and figuring out what is the best, healthiest way to proceed, but at the end of the day like an adult if they are competent then they can refuse. (Lecturer, SH5)

I would take the view that although competent a child does not have the right to refuse consent. (Lawyer, SH13)

Further confusion and uncertainty in the law was exemplified during an interview with one stakeholder, who recounted an advice call from a health professional, checking whether parental consent was required for a 20-year-old patient. The advice provided was that as the person was over 16 years of age the patient could give his own consent.

Finally, for some health professionals there may be a lack of relevance of the law, or disconnect between the law and practice:

It is remarkable when you talk amongst practitioners about the Code or Medical Council standards, they see it as ‘guidelines’. ‘No, if you cross that line you are probably going to get into trouble.’ (NGO, SH7)

Of more importance to them may be a general sense of being skilled in their profession and building relationships with parents and children, to promote children’s autonomy:

I suppose my view is that the most powerful tool we have is educating clinicians about consent in childhood, irrespective of what the law says. In fact, a well-informed and skilled child health workforce is our best defence for practice and particularly either parent or child feeling that they didn’t have the proper opportunity to exercise autonomy. … I am much less worried about the law and much more concerned that we have a well-educated and skilled workforce who understands the Gillick principle and how to apply them in practical everyday settings. (NGO, SH2)

Thus, there is considerable confusion amongst health professionals around the law on consent and refusal by children under 16 years. Whilst some were aware of Gillick, there
was uncertainty and caution around its applicability in practice and misunderstanding of its interpretation. Health professionals derive more security from their peers and professional frameworks, with there being detachment between the law and professional practice.

III. Reservations on Changing the Law

Health professionals and stakeholders expressed a number of reservations about the law changing: (a) the lack of need or value to health professionals; (b) how change could be formulated/expressed; (c) the implications for the professionals and families; and (d) reliance on competence assessments.

A. Lack of Need or Value to Health Professionals

The law’s lack of relevance and impact on practice were considered to be reasons for not changing it. The attitude appeared to be: “if it ain’t broke, don’t fix it.” Most health professionals were either satisfied with, or unconcerned about, the current position, having not encountered consent difficulties in practice. Some attributed this to good communication with families and the obtaining of parental consent. For example:

I have never run into any trouble. We have issues with special needs adults, but I have never had a situation where they [children] have not had a consenting adult with them. (Hospital Dentist, Den1)

I think my practice works because I communicate with parents and children and I am not sure that it mega mega matters where the law stands, as long as we communicate, and we both agree, and it is in the best interests of the child. I certainly wouldn’t want to do anything that was against the law but at the same time I don’t think that laws really matter that much for the majority of the treatment I do. I don’t think we really do need to change any laws. (Private Dentist, Den6)

Taking a pragmatic view, some stakeholders and health professionals questioned whether a change would assist health professionals in practice, as the issue is more the law’s application in individual situations:

I actually don’t think that it will solve that many problems. I think the problems are often very problem specific, with this particular child and this particular procedure, and the law can’t help that. That’s professional judgment of competency and understanding. (Lawyer, SH12)

The question that we need to ask ourselves is the fact that section 36 [COCA] is vague for under 16s and leaving it open, is that actually harming children? It is hard to prove that it is. I think that doctors don’t worry too much. If a kid comes along with a minor

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illness they are not going to say ‘we are not going to give you anything for your cold, or stitch up your wound without consent.’ I think they exercise a lot of common sense. (Lawyer, SH14)

I don’t think a change in the law is necessary. It is a bit like court, you have got law and then you have practice. I guess over a period of time we may get to the point where it is a more common thing to do consents for 14 or 15 year olds, but whether there is anything you could do in the law that would make that happen is hard to know. It is more a practice thing. (Paediatric surgeon, HD1)

Having both skilled health professionals and flexibility in the law’s application were considered by some to be of more importance to protecting children’s right to be heard, and protecting health professionals against complaints, than changing the law:

While I feel very strongly about children’s rights and particularly the child’s right to be heard and the Convention rights of the child, practically children’s best defence for their voice to be heard is a well-trained workforce. … I think if practice is at a high standard that is your best defence against complaints. Particularly what we know about complaints is that communication skills are the prime defence against complaints (NGO, SH2)

I am happy with the ambiguity and flexibility. (Paediatric surgeon, HD3)

The concern of one health professional related to the law balancing children’s growing autonomy, whilst continuing to protect them, and was satisfied that the present law enables parental involvement:

I am presuming that if an under 16 [year old] needs treatment and they are competent and we have asked them at least or tried to convince them to tell their mothers that we can actually give it. If that’s how it stands then that covers it. I still think we have to remember that they are still children. They may look very grown up, they may have got themselves into a very grown up situation but actually underneath it all they are still children, and I wouldn’t want to take away children’s protection. The problem with that is that some children do not have protective parents. (Private, GP4)

**B. Application of the Law and its Expression**

Whilst most stakeholders were open-minded about the possibility of changes in the law, some expressed reservations about how the law could be expressed:

The problem with changing an Act is that it is hard to get nuances into law and that is presumably why they did not go there. It is a fairly nuanced sort of thing to do. (PSD, SH4)

You can’t put a rule around it. It has to be case-by-case. (NGO, SH1)

This linked to some health professionals’ concerns of preserving flexibility in the law, particularly around children’s variable and changing competence:
There are so many grey areas, emotional, intellectual, maturity, it is such a variable feast. (Plastic surgeon, HD4)

Whether changing the law would result in a better understanding of that [Gillick competence] I don’t know, unless the only thing you could do is change the age to 14 [years] and say that between 14-16 [years] it depends on the competence of the child. … The difficulty is that there are such variations. You could get some 12-year-olds that could be Gillick competent and some 18-year-olds who probably aren’t. (Paediatric surgeon, HD1)

Of more relevance and practical application to some health professionals were professional practice, guidelines and policies. For some hospital practitioners, for example, directions like DHB policies provide greater guidance for their practice:

That’s our practice and how we are told to practice, so that’s through guidelines and things. (Paediatrician, HD6)

Int: If the law were to be changed, clarifying it for under 16s, do you think that would aid nursing practice or aid your practice at all?
Nur8: Not particularly, because I guess you have that legislation but sitting under that is the DHB policy as well and we are employees so we follow our employer policy, which of course needs to be aligned with the legislation, so it is relatively straightforward. DHBs have got it relatively well sewn up as regards to that.

Whilst such documents should be drafted in accordance with the law, this is not always the case, as they may not clearly reflect the current interpretation of the law.923

Thus, for most health practitioners the law has little significance on their practice, with their professional/peer practice and guidance being of more influence.

C. Potential Impact on Families and Professionals

A few health professionals and stakeholders raised concerns about potentially negative consequences for families, if the law was changed, making it clear that children under the age of 16 years have the right to consent. These concerns related to: (i) potential pressure on children; (ii) adverse reaction from parents; (iii) how health professionals would assess competence, and have security to rely upon it;924 and (iv) whether it may open up the potential for some unethical health professionals to exploit families.

923 See Chapter 3 page 43-44.
924 See also page 182 and 223 where DT1 described her experiences of parents’ asserting their rights.
1. **Pressure on children**

The pressure envisaged by one paediatric surgeon related to children being required to give their consent, when they were not capable, or emotionally ready to do so:

*Int: Do you think there is a need to change the law?*

HD3: The trouble is if you change the law significantly it becomes much more of a fudge factor. The 14-year-old who is not ready to make those decisions is then expected to make those decisions, if they can’t really adequately emotionally, intellectually, whatever, come to a decent informed decision then to actually demand that of them is unfair.

*Int: But then is it not the case that what you are doing with every patient is assessing the competency and ability of that patient to give consent, so you remove any age barrier then what you are doing is dealing with the individual?*

HD3: Yes. The thing is I’ve got the horrible feeling, I can see people willing to say to their five-year-old, I’ve seen this sort of thing happen, here’s Mum and Dad say to their five-year-old ‘will you make the decision?’

Similarly, a stakeholder from a lifelong/chronic health support organisation anticipated a different form of pressure, where children who are in denial of the nature of their health condition are asked to consent:

For [our NGO] it would be useful for there to be clarification, but how that will portray on an individual basis, especially if a teenager is in the middle of that denial.  (NGO, SH11)

However, in situations such as these, it is likely that children would not be assessed as competent, and therefore not have the right to consent. 925

Two stakeholders raised a different form of concern, relating to health professionals potentially taking advantage of children’s naivety or trust, if they were treated in the absence of parental presence or consent, for example, by starting treatment early or prolonging it. As a counter-balance, they believed that parents might be more enquiring and confirm options.

2. **Adverse parental reaction**

Some health professionals participating in my study had experienced complaints from parents, who found it “very disturbing” (School nurse, Nur1) that their children were permitted to consent. As a result, one school nurse described having experienced “many a barrage of unpleasantries down the phone” (Nur1), and has had to explain the law to them. Similarly, a hospital doctor recounted the following interaction with a parent:

925 For example, see page 36 An NHS Trust and another v Mr and Mrs A and others, above n 206 in which the child was in denial about suffering from HIV.
HD5: I said to this 15-year-old, who was obviously articulate and quite intelligent, ‘there is no minimum age for consent so you can sign this consent form’ and his Mum said ‘I am a lawyer and that is not acceptable!’

Int: What did you do after that?
HD5: I said there is no minimum age of consent and I think he is competent.

Additionally, the following two stakeholders predicted adverse public reaction to the law clearly providing for children’s right to consent:

I can tell you that the right wing groups that are so vociferous and carry such weight would scream their heads off and say ‘nanny state.’ (Lawyer, SH9)

I think there would be a fairly strong negative response, similar to the anti-smacking, probably from the same people. A lot of people would see the value in it, but my guess is that without a lot of preparation the majority of New Zealanders would not be happy with it. (PSD, SH4)

Nonetheless, despite this concern, stakeholder SH4 considered that such a reaction could be managed, particularly if done over time and with the support of key agencies, provided there was clear professional guidance on how to apply the law:

It could be noisy, but it can be managed and the fact that there was not too much noise from the public around the smacking stuff. I think it was because we spent quite a few years talking about not smacking kids, the public discourse was you shouldn’t do it and discussion about how to manage bad behaviour. … If brought in with really good information and really clear guidance from Ministry of Health, DHBs or Health and Disability Commissioner, or someone who is charged with the issues of consent, or a range of bodies and practitioners to give formal guidance. (PSD, SH4)

Further support for first educating parents and children was found amongst some health professionals, particularly those who commonly consult with children alone, such as in the SMS. Some believed that the potential benefits to children would be to increase their ability and confidence to access health services, and it may also free health professionals to respect children’s competence by taking their consent, without fear of retribution from parents:

I think it is important for the parents to understand that their children have a right and are entitled to this service. … I think it would be beneficial particularly when they [children] go to their own GP or another service, like dental service or sexual health. … [T]hey are not used to being told that they have options and rights. (School nurse, Nur2)

I think rather than it being clear to us it is whether the parents know. … I think making it clear when they enroll the child in the service that the child can give consent. (Dental therapist, DT2)

A consequence of parents having greater understanding of children’s growing competence, may be that they talk more to their children about health matters:
Parents who demand this, this and this for their child, it is not necessarily helping them to develop their own independence. So just talk, which doesn’t happen a lot. (Private/School/Youth Service, GP6)

Break down some of the communication barriers in families. (School nurse, Nur2)

D. Reliance on Competence Assessments

Finally, some health professionals were reticent over children’s right to consent being more clearly stated in law, due to their concern of relying on their assessment of children’s competence.926

Int: If hypothetically the statute was changed to say that under 16s had the right to give their own consent to medical, surgical or dental treatment, if they are deemed to be competent, do you think that would aid or change practice at all?

Nur8: Absolutely not. I think that it would completely muddy the waters. I still don’t know how you deem they were competent. What you or I may deem competent another person may not.

IV. Support for Changing the Law

A. Clarity and Consistency on Children’s Right to Consent

Most stakeholders and a minority of health professionals were supportive of a law change, the most common reason being to give clarity. For example, one stakeholder, who also practiced as GP, supported greater clarity in the law, as at times she and her colleagues had sought clarification from the Medical Protection Society, but remained apprehensive over the advice:

As a GP it is incredibly difficult to make the call and I and my colleagues have called the Medical Protection Society to help clarify. And even then it is not clear, so clarification would be useful from a GP perspective. (NGO, SH11)

Of the health professional groups, nurses viewed either a change in the law or clearer guidance on the assessment of competence most positively. Most considered that these would provide them with more security:

I think we all feel we are in a vulnerable place and we are trying to act wisely and you try to do it safely within the legislation, but you actually know there has been a case that you defer to but it is not a New Zealand law case, and probably having some guidance to have more clarity. (CYS/school nurse, Nur5)

926 See pages 218-219 where Nur 6 and Nur 7 expressed their concerns of relying upon competence assessments in the vaccination programme.
I think a change in the law would assist that. Nurses are very afraid of the law and the consequences if you don’t do what the law says so I think a change in the law would very much help that. (Hospital nurse, Nur3)

Nevertheless, changing professional practices may prove difficult, as the above nurse ruminated: “I think it might be a hard sell. There would have to be a tremendous amount of education” (Nur3).

Some of the research participants who were supportive of change, also preferred to maintain flexibility in the law, like those who did not support change. For example, two health professionals weighed up pre-determining an age at which competence is presumed, against flexibility to adapt with children’s differing competence:

It would be good to have it a bit more black and white, and the only reason I say that is if things go wrong, because it is really difficult to go back and say why you did something. It is much easier if you have it black and white, in this case you do x. … But I can see the difficulty in doing that because then you would have to have a set age. The patient is mature enough and intelligent enough to do it is quite good. (Private Dentist, Den4)

I think it would be good to be clearer, but I guess it is, because it is subjective of whether they are competent, you can’t just make it from 13 year olds, there is such a variation, but I think having it tighter somehow. (Private, GP2)

The solution for two stakeholders was to incorporate a competence test into statute:

The simplest thing would be to amend section 36 to say that under sixteens can consent to their treatment and put in the Gillick formula. In other words, put the common law position into statute. (Lawyer, SH14)

Well, you could say that you do a test of competence and if they are competent they agree, a bit like the PPPR Act. That is what you do in that situation so you could do the same for children. (PSD, SH4)

Health professionals and stakeholders identified two potential benefits of the law being clearer. Firstly, giving health professionals greater assurance to rely upon their competence assessments, and therefore providing treatment on the strength of children’s consent, particularly when parents refuse:

_int: Do you think if it is clearer in the law, that would give you more confidence to only take the consent of children if competent?_

HD7: Yes, because I am accustomed to taking their consent for pregnancy related procedures.

_int: Do you think you could benefit from more widely available training?_

HD7: Sometimes I think it would be useful as I am a very rules based person and that would give me confidence to know what the rule is. Telling me the rule would give me confidence to say ‘she is under 16 [years], I assess her as competent, therefore I do not
actually need to involve the parents’ is reassuring and provides a back-up and I guess that training has been more ad hoc.

\textit{Int: If the law and policies were clear, that if in your opinion the child had the necessary level of understanding to give the consent themselves, do you think that would aid your practice?}

\textbf{DT1:} Yes it would, very much so, especially in the lower decile areas where it is very difficult to get consent from the parent. It would be in the child’s best interests and you are able to get that understanding across to a child.

I don’t think that a child’s consent to something that is considered to be in their best interests should be able to be overridden by a parental refusal to consent. I find that very concerning, and if there is one thing that could be changed in the law I think it would be helpful to have that clarified. (Lawyer, SH13)

Secondly, clarity should lead to greater consistency in practice. For example, if the law was clearly stated in one statute, such as in the COCA, or perhaps a new Act, this would simplify the advising and teaching of practitioners/students, which in turn, could enhance consistency in health professionals’ practices:

You would not have to have the discussion we always have to have about ‘the COCA says this, the Code says this, Courts have said this.’ (Lawyer, SH13)

I think it would help if there was one provision in one Act, such as in the Care of Children Act, that we could refer the students to, as the statutory provisions are patchwork at the moment, and that is reasonably specific, because I think that otherwise it leads to different practices. (Lecturer, SH5)

\textbf{B. Clarity on Competence Assessment}

A small number of health professionals, together with two stakeholders, considered that a practical and specific competence test would be useful, such as “a recognised national toolkit” (Lawyer, SH13) that is “well validated and widely accepted” (PSD, SH4):

I think it would be good to have more guidelines around that, being more explicit about how professionals go around judging competency. (Paediatrician, HD6)

How you measure competency? If there is some sort of test that has been used in the past, some simple questions you can ask to gauge competency, [that] would definitely help. (Hospital Dentist, Den2)

Currently, as there is a lack of specification over the criteria to follow, some health professionals were uncertain on whether they are following the law’s requirements or accurately judging competence:

Those judgments talk about competency, but then that is a very difficult area. How do you judge competency? None of them say explicitly about how you come to that
judgment that someone is competent. You could say that if you disagree with me then they are incompetent! (Paediatrician, HD6)

I still don’t know how you deem they were competent. What you or I may deem competent another person may not. I am not sure how you assess competence. How would you really assess competence in a 16, 15 or 14 or 13 year old? As I say health professionals have a basic intervention with the child and so how do you assess competence when you take them out of their day-to-day life and this is potentially the first time you have met them for such a short period of time. (Hospital Nurse, Nur8)

For others, they were not so much concerned about their current assessments, but were more anxious about justifying their judgement, if challenged. For example, a dental therapist considered that there would be benefit in a clear process for assessing and documenting competence, which parents could understand, to avoid criticism/repercussions.  

Both public health nurses were of a similar opinion, believing that a tool could help to spread the risk, rather than competence assessments resting on the shoulders of one health professional:

I think a tool would be really good for our service. If a nurse professional does the assessment and writes it down and then it is overseen by some other professional of the same standing, so it is not just sitting on the judgment of the one person, because it takes away the risk of personal leaning. (Nur7)

Thus, there is a lack of drive from health professionals to change the law, as presently they do not encounter many difficulties in practice. Also, this may be as a result of the lack of connection between the law and their practices. However, most stakeholders, and some health professionals, saw merit in there being greater clarity in the law, which could result in health professionals having greater assertion/confidence in proceeding upon children’s consent. Additionally, it may be prudent to have clear guidelines on assessing competence, to protect them against potential challenges.

V. Parents’ Views on Children Consenting

During interviews, parents were asked their views on law that enable children to consent. All parents were supportive of children participating in the process, as they had directly experienced benefits for their children. The benefits they identified included their child feeling more in control and less anxious; being able to better cope with their treatment; and developing greater trust, with either them or their health professionals. For example, Laura, whose son Alistair was prescribed medication for ADHD, emphasised that medical interventions can be significant for children, so they need to be trusted to be

927 See also Den 4, page 235: “… the only reason I say that is if things go wrong, because it is really difficult to go back and say why you did something.”
involved in the process, such as, by being consulted, having the opportunity to understand and to give their consent:

I think that this has been a really good journey for us. I realise that I should have trusted Alistair and will trust him every time in the future, because he knows what he needs, and I think I felt disappointed that I wasn't ready to trust his decision-making. So from this point on I am taking a backseat. … I think children do need to feel trusted by adults who involve them in decisions, because medication of any kind is a major decision that they have to be on board with. So they have to have the information that will help them understand the benefits and disadvantages, and it is about informed consent for kids too. (Laura)

Similarly, Wilma was able to compare the difference to Samantha when she was not involved in her first two operations, compared with the third one, when she was involved in the decision. She described the benefit as “a psychological power”, which is “very important and crucial to the healing process.”

However, most parents expressed some concerns about children making final decisions. These related to matters like the potential responsibility, or pressure, placed on children, and their lack of maturity or life experience. For example, Wilma was mindful of children’s varying circumstances and capabilities, believing that “some flexibility” is required, and to involve them in “an age appropriate way.” She recognised that although children with serious health conditions can grow up quickly, they are also vulnerable. Thus, she questioned whether children would want to make the final decision:

Int: In New Zealand there is no specific statutory provision for under sixteens to give consent to medical or surgical treatment. What is your view on the law being clearer and giving them that right? 
Wilma: I think there are two sides to that. There is a difference between being involved and having that whole decision put on you. Often you are dealing with a very fragile person, who perhaps does not fully understand what is going on. I can speak from our experience of oncology, from 10 [years] they grow up pretty fast. Within months they have literally grown years. However, I don’t think they want to be responsible for the whole decision. I think they want to be involved and included.

Likewise, two other parents expressed their concerns about children’s potential vulnerability and limited life experience, when considering the level of responsibility children should bear. Whilst acknowledging the desirability and benefit of children being involved, they felt this should not be to the exclusion of parents:

I think they should [be involved], but I think it needs co-done with the parents. I don’t think they are in any position to be fully informed. I don’t think they know enough and don’t think they are mature enough. They are as traumatised as anybody. I think they should definitely be part of it and I think it should be like a co-pilot. I don’t think they are equipped to be making major decisions at that age. They should absolutely be part of it and be heard. (Jenny)
It is hard. I agree it is her body and that she should have a right, but I don’t think her perception on life is there. She would not want to do this procedure because it affects where she can go for six weeks. It is hardly a long-term vision. At this age their view is very narrow-minded. … It is classic that she is half an adult half a child, so I think she deserves to be treated as an adult, but at the same time I don’t think she really understands the importance of this. … I’d like to think that she can make the decision, but I don’t think she can. (Anna)

Wilma also raised practical considerations about how such a law would be translated into practice. She wondered whether it would simply become another bureaucratic process, within which children are lost, defeating its intention of treating children as individuals:

I think that there should be something that says they should be included, but then does that just become another paper pushing? Sometimes there is so much politics of people covering their bums that they are not actually seeing the people. (Wilma)

Therefore, whilst parents were supportive of their children being included and heard in consent processes, they were concerned about the responsibility of decisions for children. The importance of inclusion lay in children having more control, being less anxious, coping better and building trust.

VI. Children’s Views

During the interviews, children were asked about the importance to them of being included in decision-making and giving consent. All except one child valued being actively involved in discussions and in decision-making. They felt it gave them greater respect and equality, as well as emotional benefits:

I think it is really important. At the end of the day it is my body. … It makes me less nervous because I have a say and that made me feel good. (Poppy, aged 14)

It is easier on kids. You get concerned and stressed when you don’t know what is going on. (Samantha, aged 14)

It is for them, for their sake. They are going through it, not the parents. The parent is not having some bone cut out, or their leg chopped off. It is the child and their choice. … Maybe I could have chosen not to have treatment (chemotherapy), but obviously I had to. But I still think that everything should go via the patient, no matter what age. (Amanda, aged 16)

It is not just people over the age of 16 [years] who should have their voice heard to do stuff to you and your health. (Donald, aged 11)

I think they definitely should get their input and that should be taken into account. But especially if they are quite a bit under 16 [years], the children will be like ‘no I don’t want
it because it will be scary’, like injections, but definitely they should not be just ignored, and ‘you are the problem we are going to fix it’, without their input. (Brenda, aged 19)

On the other hand, Oliver who suffered from leukemia, recalled he was unconcerned about being involved:

Well, I was so drugged most of the time that I couldn’t care less, so I just went along with it. (Oliver, aged 18)

In order to gain a sense of their views on the level of importance for children to be included in decision-making, they were asked to rate this out of ten, where one is the least and ten the most important. All except one rated it between eight and ten, with Oliver rating it five. Despite this high rating, some appreciated that children’s maturity or capability to make final decisions and give consent will vary:

It depends how mature they are. Girls, I think, are more mature. Even although I was 13 [years old], I understood everything that was going on and I knew what medication I was on and when to take it. … I think 16 [years] is too high and should drop. (Amanda)

Similarly, Poppy recognised that children are not always able to consider longer-term issues. She reflected on her own experience, having been initially concerned to proceed with her operation because of the short-term inconvenience, but that her parents had assisted her in understanding the wider perspective. Poppy reported her understanding of children’s development, and corresponding, their limitations:

I guess it is really important for them [children] to be involved, but I don’t know about the final decision. I guess they are not capable of making really big decisions, like life threatening. I would definitely have issues with that. … There are a lot of laws put around teenagers making decisions and we are not actually capable of making really big decisions. I understand because our brains are not fully developed and so they shouldn’t have to make a really massive decision on their own. They should have parents. … I reckon that they should have a right more to participate. That they should have a say on whether they get an operation or whatever, but then you could not give a two-year-old that right because they would always say ‘no.’ I reckon 12 [years of age]. That is when the doctors started involving me, and it felt like the right time. … But, even for me, why I said ‘no’ was because in the next few months I am going to be in a cast, not able to go into town with my friends. I think teenagers look [to the] short-term, not long-term, and Mum and Dad helped me look long-term. (Poppy)

Finally, Samantha recognised also that there may be situations in which decisions need to be taken on children’s behalf, but she considered that health professionals should at least ask them:

It is hard depending on the situation. Sometimes it does call for, depending on the options, for someone just to take charge. Generally, I’d say just ask people what they want. (Samantha)
VII. Chapter Summary

Overall, most health professionals did not regard the law as having influence on their practice. Around half were unaware of how the law regulated children consenting, and there was a sense of them differentiating between law and practice. Perhaps as a consequence of this lack of relevance and misunderstandings of the law, few health professionals anticipated any benefit in it changing. However, some health professionals expressed caution and unease about the law’s lack of specification on how to assess competence and to prove their assessments, and of relying on children’s consent. For most stakeholders, and a minority of health professionals, clarity and consistency of practice were identified as benefits. Flexibility in the law was important to those resistant to change and those supportive of it. Nevertheless, some were realistic as to how the public in general, and parents in particular, may perceive changes that made children’s rights to consent clearer. The anticipated reaction was that it would be viewed as challenging the authority of parents to make decisions on their children’s behalf. However, as this study has shown, the parents and children were supportive of children participating in the decision-making and them giving consent together. Most children expressed this in terms of their right, and/or to respect the fact that they are the ones undergoing the treatment. Children and parents appreciated, and had experienced, the emotional and psychological benefits that involvement can bring, together with the potential health benefits, such as, being less stressed.
Chapter 12

Discussion, Recommendations and Conclusion

… the common law has never treated [parental] rights as sovereign or beyond review or control. Nor has our law ever treated the child as other than a person with capacities and rights recognised by law.\textsuperscript{928}

I. Introduction

The focus of this thesis was children’s competence and right to consent, examining the reality of the informed consent processes for children, parents and health professionals. My research has shown that the key to children developing and demonstrating competence is in the success of the relationships that surround them, in particular, with their parents and health professionals. Each participant brings to the relationship their experiences, knowledge, preferences, values, attitudes and personalities that impact on their interactions. Intertwining with, and influencing, these relationships are laws, policies, practices and healthcare environments, which together can either promote or constrain children’s competence. The multitude of influencing factors highlights the complexity of children’s competence, yet, for health professionals there is little guidance on the factors they should consider when assessing competence, and how assessments should be conducted. Further, compounding the complexities are the inconsistencies and lack of clarity in New Zealand’s law. My findings have shown differences in health professionals’ practices in obtaining consent and uncertainty in their understandings of the law. This is perhaps unsurprising given that the COCA is silent on children consenting to general medical treatment, and has left the gap to be filled by other laws.

In this chapter, I firstly discuss the participants’ experiences, considering the importance of parents’ and health professionals’ roles to children’s competence. I depict the relational nature of competence, with its intertwining factors, in a conceptual model that I have developed, and called, “The Competence Model.” The Competence Model has evolved from my research, encapsulating my empirical findings, together with the international research and theory evidence base. My intention is that the Competence Model is used to assist medical students/professionals and parents in understanding the complex and relational nature of children’s competence, and how best to promote it, and may also assist health professionals when assessing children’s competence. I then discuss the implications of health professionals’ practices on obtaining consent, before examining how the law has defined competence and provided for children’s right to give consent. Finally, I make practical and legal recommendations for better consistency, clarity and respect for children’s competence and rights. I argue that given the interpersonal nature of children’s competence, parents and health professionals need to

\textsuperscript{928} Gillick, above n 4 at 184A per Lord Scarman.
be inclusive of children when consent is required, and that children’s right to consent needs to be clearly stated in the law.

II. Competence

This research has found competence to be relational, consistent with previous studies, which have considered the factors influencing children’s competence.\textsuperscript{929} The roles, knowledge, skills, and attitudes of parents and health professionals are pivotal to the development of children’s competence and their agency. In particular, the themes emerging from my study were parents’ roles in providing emotional support and promoting communication and relationship building; health professionals’ and parents’ roles in enhancing children’s understanding and supporting their decision-making; the importance of parents and health professionals taking account of children’s evolving capacities; and finally, the general practice of health professionals in relying upon parental consent, despite children’s competence.

A. Parents’ Roles

1. Emotional support

All the parents in my study promoted their children’s competence by providing them with emotional support prior to, during, and after consultations. For example, it was present when parents exhibited care, empathy and understanding for their children’s situation; and took steps to provide them with the security, support and knowledge to better participate in, and cope with, their treatment. In the context of cancer, earlier studies found that children appreciate honesty and inclusion, seeking to work in partnership with their parents and health professionals.\textsuperscript{930} This was consistent with Amanda and Samantha’s views, and also with how their parents responded to meet those desires and needs. For instance, Jenny ensured that Amanda was present at every consultation, describing her as a “co-pilot.”\textsuperscript{931} Likewise, there was openness and inclusion between Samantha and Wilma, with Samantha making it clear, when diagnosed with cancer, that she wanted Wilma to support her and to be honest. Whilst Oliver expressed ambivalence about his inclusion, it was clear from the steps Tania took, supporting his communication and understanding, that his participation was supported emotionally and practically.

Unlike previous studies involving cancer, there was no indication from these three families that parents were gatekeeping information.\textsuperscript{932} They all described openness in their communication, although the lack of information flowing from health professionals

\textsuperscript{929} For example Coyne and others n 20 at 42; Alderson, \textit{Children’s Consent to Surgery}, above n 20 at 155; Miller and Jawad, above n 611 at 187; Kilkeary and Donnelly, above n 21 at 40-1; Garth, Murphy and Reddihough, above n 71 at 50; Wangmo and others, above n 18 at 17.

\textsuperscript{930} For example, Ellis and Leventhal, above n 18 at 283; Wangmo and others, above n 18 at 17.

\textsuperscript{931} See Chapter 8, page 150.

\textsuperscript{932} For example, Young and others, above n 19 at 306; Wangmo and others, above n 18 at 16.
to Wilma and Samantha was a source of frustration and stress to them. In Amanda’s situation, layers of scaffolding were evident from the support of Jenny and her extended family. Jenny described having family members present at appointments, and researching information, allowing both her and Amanda to manage the rate at which they processed and absorbed the information. This helped to protect them from feeling overwhelmed in times of stress.

Parental emotional support also came in the form of assisting their children to cope with their treatment. For example, Diane and Anna prepared Donald and Poppy respectively for consultations and treatment, by extending their knowledge and understanding of their health conditions and its treatment, resulting in them becoming more resilient to cope with it. Preparatory steps such as these are invaluable to health professionals and children, as it reduces the prospect of children refusing treatment through fear, and either failing to be treated, or being forced to undertake it against their wishes.

In providing emotional support, parents demonstrated the importance to them and their children of being in a partnership with health professionals. This support created the foundations from which their children could develop the skills to participate in discussions, decisions and treatment.

B. Parents’ and Health Professionals’ Roles

1. Promoting Communication and Relationship Building

(a) Parents

All parents participating in this research valued health professionals taking the time to talk and listen to their children. For instance, Anna spoke of the doctor connecting with Poppy, Jenny described him getting on Amanda’s “wavelength”, and Wilma recognised the doctor’s “deep respect” for Samantha. Nevertheless, at other times, parents found health professionals to have “very poor inter-personal skills” (Jenny), “could have maybe tried a little bit harder” (Diane) to communicate and relate to their child, and were dismissive, by not listening (Tania). Yet, simply engaging with children is insufficient. It is the purpose of the engagement that is important. Existing research found that health professionals predominately engage with children to help establish a rapport, and to hear how children feel. Similarly, my study also found that, at times, health professionals’ interactions were tokenistic, such as, when they mostly

933 Chapter 8 page 169 and f/n 872.
934 At page 152.
935 At page 149.
936 At page 152.
937 At page 159.
938 At page 153.
939 For example, Garth, Murphy and Reddihough, above n 71 at 49-50; van Dulmen, above n 462 at 565.
communicated with parents, or used sophisticated language, which children found difficult to understand, by “talking at an adult level” (Wilma). At other times, health systems treated children more as objects of concern, rather than as active participants. For example, Wilma vividly described the depersonalised care Samantha experienced during her cancer treatment, being excluded from discussions and decision-making, receiving no explanations of medical terms, and no interest being taken of her as a person. Similarly, Alistair was observed and assessed, but no health professional explained the results to him, or the meaning and implications of ADHD and the treatment options. The only time that Alistair met with a health professional to discuss his condition and treatment was at the consultation with the GP when medication was prescribed.

Nonetheless, parents used a number of strategies to connect their children with health professionals during consultations, such as preparing them in advance, seating them strategically, and assisting with communication. In preparing their children for consultations, parents conferred with them beforehand, on what might be discussed, and how to approach these discussions. For example, Laura alerted Alistair to the types of matters his GP might raise, as she knew it was likely he would be prescribed medication for ADHD; and Anna and Poppy agreed how each of them would contribute to discussions with the surgeon.

Once in consultations, some parents (Wilma and Jenny) sat their children strategically, signaling the importance of their children’s inclusion, to both the health professionals and their children. Parents then prompted, or reminded, their children of important details to advise health professionals during discussions. This gave children the opportunity to describe how they felt, in their own words, and encouraged them to speak directly to health professionals. In turn, this directed health professionals’ attention and conversations to the children, such as Poppy during an examination with her surgeon.

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940 See Chapter 8 for example at page 154: “Oliver would talk to her and it was just like she [Consultant Oncologist] wasn’t listening” and at 163: “Involved to a point. Like I was involved because it was my achilles, but I was not really involved much in the discussions” (Poppy) and at page 164 “I felt at some parts they were looking at my achilles and talking to Mum and then Mum would talk to me. So Mum kept me involved, more than they did I felt. Yes, Mum knows. Mum gets it more than the doctors. They were talking to her a lot more” (Poppy). Also Samantha describes how she was excluded at pages 145, 146, 147-148; Alistair and Donald were involved to marginal degree in consultations at pages 156-157 and 159 respectively.

941 At page 1.

942 See Chapter 8 pages 145-148.

943 At pages 155-157.

944 At page 157.

945 At page 156.

946 At page 163.

947 At page 150: “Mum would make me sit next to the doctor” (Amanda); and at page 149 “I learned with experience of where to position Samantha when speaking with the doctors so Samantha would be included” (Wilma).

948 At pages 149 (Samantha), 150 (Amanda) and 163 (Poppy).

949 At page 164.
Further aiding communication between children and health professionals was parents’ role as interpreter. Most evident in this role was Tania, who was accustomed to this role already, due to Oliver’s Asperger’s Syndrome. Tania could assist health professionals to better understand him, whilst also supporting Oliver’s understanding of their explanations. When this occurred during consultations doctors could check that she had covered matters correctly.

Thus, children are able to participate more in discussions with health professionals when parents support their communication. Parents take deliberate steps to prepare their children, seat them strategically, support their recollections of their symptoms and act as interpreters.

(b) Health professionals

Some healthcare environments lend themselves more than others to the development of either a partnership with parents and children, or fostering relationships and communication with children, when they consult alone. There were many factors influencing the degree to which health professionals were able to achieve this, such as: the attitudes of health professionals towards a partnership; time; the numbers of children being treated; privacy; parents roles; and children’s preferences, personality and health.

(i) Partnership, time and numbers of children

A striking feature of hospital and private dentistry were the strategies dentists used for developing a trusting relationship with both children and parents.\(^950\) It was important to them that there was consensus and co-operation for treatment to proceed. Children’s competence was supported through these trusting relationships, such as, participating in discussions in hospital,\(^951\) and understanding about the treatment in private dentistry.\(^952\) In private dentistry, children’s autonomy evolved, with them taking responsibility when consulting alone.\(^953\) These dental environments contrasted starkly with the SDS, where dental therapists’ abilities to develop relationships and involve children in discussions were limited.\(^954\) The focus on individual children was lost,\(^955\) and dental therapists had limited opportunities to educate children and parents about children’s dental health.\(^956\) This stemmed from the disjointed nature of treatment, where children were initially seen alone; the lack of time; and the emphasis on parental consent.\(^957\) As a consequence, children’s competence could become further constrained, when parents were not mindful of supporting their participation, as dental therapists were unable to mitigate the.

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\(^950\) See Chapter 9 page 176.
\(^951\) See Chapter 9 page 180 and Chapter 10 page 201
\(^952\) Chapter 10 page 209.
\(^953\) At page 210.
\(^954\) At page 220.
\(^955\) See Chapter 10 at page 174.
\(^956\) See Chapter 10 page 220. Dental Therapists usually see children alone for an examination and consult with both parents and children when carrying out further treatment.
\(^957\) At page 222.
impact. This finding is consistent with existing research, showing children can become socially conditioned to be passive, when health professionals and parents are complicit.958

Similarly, in the vaccination programme and hospital paediatric surgery clinics, health professionals were limited in their abilities to develop relationships with children and support their competence. They examine and treat high numbers of children in a short space of time, and as a consequence the environment resembles a production line, more functional in nature, rather than relational.

Contrastingly, in the SMS and CYS, the promotion of children’s competence is evident through trusting and respectful relationships.959 Health professionals give children the time necessary to fully discuss their situations, and support them in their understanding of their health and treatment options, enabling children to make decisions and give consent.

(ii) Privacy

Consistent with earlier studies, my research has confirmed that privacy is important to teenagers.960 Health professionals in the SMS, CYS, and some private GPs, experienced teenagers seeking privacy, especially when they consulted about sexual health matters.961 Also, a paediatrician and obstetrician/gynecologist routinely provided teenagers with the opportunity for privacy in consultations.962 Naturally, children have privacy when they consult alone at the SMS, but in other healthcare environments, the ease to which privacy can be accommodated depended upon factors, such as, the relationships health professionals have with children and parents; the receptiveness of parents; whether parents have prepared children for consulting alone;963 and in the vaccination programme, when children experience issues.964 As a consequence, children may be able to demonstrate their competence more easily, and may be more apparent to some health professionals, when given privacy.965

(iii) Balancing the Triadic Dynamic

Whilst most parents are supportive of their children when consulting with health professionals, parents could at times inhibit their children’s competence.966 Existing research suggests that health professionals may experience difficulty in managing the

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958 See Coyne and others, above n 20 at 40; See Chapter 9 pages 181 where DT1 spoke of a mother who was annoyed that the Dental Therapist had asked her son’s opinion; and HD1 at page 183 who did not take the views or consent of a competent 14-year-old whose mother refused consent; and Chapter 10 at page 206 GP1 who did not wish to interfere with the parent-child dynamic.

959 See Chapter 9 page 174.

960 Beresford and Sloper, above n 19 at 176.

961 See Chapter 9 page 177.

962 At page 175.

963 At page 179.

964 Chapter 10 page 217.

965 At page 208.

966 Chapter 9 page 182.
dynamic between children and parents, and may be complicit in supporting parental authority, rather than promoting children’s participation. This is consistent with the experiences of some health professionals in my study who chose not to interfere in the parent-child dynamic when parents dominated discussions and/or expected to make decisions for their children. Advancing research one step further, my findings revealed the strategies that health professionals adopted to redress the balance of participation in consultations, such as, redirecting conversations, role modelling, asking parents to leave consultations, asserting the importance of children driving the treatment, and confirming their right in law to take children’s consent when challenged by parents. These strategies can compensate for situations where parents do not adequately prepare children for consultations, or support their interest in their health, by allowing them, for example, to play on their iPads during consultations. These strategies may also have the effect of empowering children, and enhancing their competence, by enabling them to participate in discussions, make decisions, consent and cope with treatment.

2. Enhancing Understanding

Confirming the findings from earlier research, the health professionals and parents in my study enhanced children’s understanding of their health conditions and treatment in partnership. However, at times, some parents experienced having to compensate for the lack of information health professionals provided.

(a) Parents

Consistent with earlier studies, and revealing further insights, my research demonstrated strategies of how parents promoted their children’s understanding through researching, explaining, sourcing further information and setting their treatment in a wider context. In order for parents to do this successfully, they needed to be certain about their own understanding. Some parents (Wilma, Jenny, Laura and Tania) used a number of strategies to extend their knowledge, such as, using family support and sourcing information from nursing staff and educational materials. Jenny found, for example, that having family members present at appointments, and researching information, allowed both her and Amanda to process and absorb information, at a level and rate that they could manage. Once parents were sufficiently informed, they could support their

967 Van Staa, above n 525 at 459.
968 For example Runeson, and others, above n 476 at 73.
969 For example see Chapter 9 pages 181 and 183 and Chapter 10 page 206.
970 See for example Den6 Chapter 9 page 182.
971 See for example GP6 Chapter 9 page 182.
972 See for example Den6 Chapter 9 page 182.
973 See for example HD1 and HD4 Chapter 10 page 201.
974 See for example the experience of HD5, Chapter 11 page 233.
975 See the experience of HD3 Chapter 10 page 192.
976 For example, Ellis and Leventhal, above n 18 at 281. Kilkelly and Donnelly, above n 21 at 40-1; Garth, Murphy and Reddihough, above n 71 at 50; Wangmo and others, above n 18 at 17.
977 See Chapter 8 pages 146 and 156 where Samantha and Alistair respectively relied upon their mothers to explain their health conditions and treatment.
children’s understanding, such as, Laura in explaining ADHD, and Jenny, the cycles of chemotherapy, to their respective children. Nevertheless, when doing so, parents needed to be conscious of the language they used in their explanations, as Laura realised. Having the opportunity to give these in the presence of health professionals may be reassuring to parents, as Tania found when giving Oliver explanations.

Further, my findings revealed that sometimes parents needed to compensate for the lack of information provided by health professionals, confirming that of previous studies. For example, Wilma was not provided with information on Samantha’s cancer treatment or Fanconi anaemia, and Laura needed to research ADHD, so that they could explain these to Samantha and Alistair respectively. When children do not fully understand, and/or are frightened, they may refuse treatment, resulting in it being forced upon them. In my study two children refused treatment – Samantha (nasogastric tube) and Donald (tooth extraction). Samantha’s experience highlights how at times the system can exclude parents and children, making it very difficult for parents to prepare their children, as they have no control or voice. In Donald’s situation, the dentist appreciated it was not viable for Donald’s tooth to be extracted against his will, and upon Diane realising the strength of Donald’s reaction, she was able to enhance his understanding and support him in coping with the treatment at a later date.

(b) Health Professionals

Similarly confirming and extending upon the findings of earlier research, the health professionals in my study described using a variety of strategies to enhance children’s understanding, for example, by simplifying their language in explanations; avoiding jargon; using common terminology; breaking down processes and procedures; drawing; playing a DVD/video; directing them to websites; giving handouts to parents; and by dentists, a process of “show, tell and do.”

A salient finding in my study, between and within health environments, was the purpose for which health professionals secured children’s understanding. Whilst it was important to all health professionals that children understood, in order to co-operate or agree with treatment, they were more focused on securing children’s understanding when their consent was being relied on, such as in the SMS, or when children were required to manage long-term conditions, such as diabetes and asthma. For diabetes in particular, an impressive structured educational programme exists in hospital and in the community. Nonetheless, in other environments, much less emphasis was placed upon children’s understanding, such as in the SDS, vaccination programme, and paediatric surgery clinics,

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978 Young and others, above n 19 at 307
979 Chapter 8 page 146.
980 At page 155.
981 Chapter 8 pages 147 and 158 respectively.
982 For example, Garth, Murphy and Reddihough, above n 71 at 48.
983 For example, Chapter 9, page 177, 182 and 189.
984 Chapter 9 page 173.
985 See Chapter 9 pages 187-189.
where time was short and parents’ consent was relied upon. In the SDS and the vaccination programme, children were given sufficient information to secure their co-operation, but the processes were not conducive to promoting children’s competence to make decisions or consent. Whilst public health nurses encouraged, and were open to questions, children were inhibited from asking any, due to being in a class setting. However, a mitigating factor in the vaccination programme, which seemed limited in the SDS, was the information sent home with children, which their parents could discuss with them.

3. Decision-making

(a) Parents

Advancing understanding on how decisions are made, my research found that parents and children make decisions on two levels, and in two contexts, at times. The first is with health professionals during consultations, and the second is a continuing process at home. Three parents (Wilma, Anna and Laura) experienced their child making decisions within the context of the family/home, which was then communicated at a later appointment to health professionals. In the minds of the parents and children there were treatment choices that they wished to consider.

Exploring each of these situations, Wilma took control before Samantha’s third operation, creating the time and space Samantha needed. Yet, had it not been for Wilma making this assertion, and reinforcing the importance of Samantha being involved, the decision was likely to have been made for her, as she had experienced with the earlier two surgeries. Until the consultation when Samantha advised the doctor of her decision, there was no sense of Samantha and Wilma being included in a partnership with health professionals.

Secondly, Poppy made her decision on the fitting of braces at home, after considering her dentist’s and parents’ advice, together with using her friends’ knowledge and experience. Both the dentist and Poppy’s parents supported her in reaching her own decision, by providing her with the required information, and the time and space to weigh up her options.

Thirdly, Alistair made his decision to take medication in the context of his family, rather than at an appointment with the GP. His parents educated him on his condition and

986 See Chapter 10, page 216: “… what we try to do is try and answer these questions before they think about them … but really it is part of being proud” (Public Health, Nur6).
987 See Chapter 10 page 221.
988 See Chapter 8 page 161: Poppy’s parents supported her understanding of vaccinations.
989 See Chapter 8: Samantha decided upon surgery following cancer treatment (page 148); Poppy upon dental surgery and braces (page 168); and Alistair upon ADHD medication (page 156).
990 See Chapter 8 page 148.
991 See Chapter 8, page 168.
992 See Chapter 8, page 156.
treatment, before giving him permission to make this decision, which they supported. This decision was then communicated to the GP. It appeared to Laura, however, that the GP had assumed that she and Laura had made the treatment decision earlier, without Alistair being present, when they discussed the outcome of the assessments. Thus, Alistair’s parents’ support was crucial for him being included in the decision.

In other situations, whilst parents and children may appear to make decisions during consultations with the health professionals, children may be contemplating matters further. For example, in Anna’s mind the decision to proceed with Poppy’s achilles surgery was agreed to by both of them at the hospital appointment with the surgeon. However, for Poppy, there were on-going considerations, further discussion with her parents, research on the Internet, and weighing up whether she was prepared to endure the short-term inconvenience for the long-term benefit. This highlights the continuous nature of decision-making, and the importance of ongoing parental support in giving children the time and information to prepare themselves for the treatment and its aftermath.

Thus, all of these situations demonstrated not only the importance of parents’ roles in giving their children information, time, space and approval to make their decision, but also the competence of children to make decisions.

For the remaining three parents and children there was a lack of treatment choice, so they followed the recommended treatment. Although Donald was not involved in the decision to proceed with the extraction of his tooth, due to his reaction when the procedure was first attempted, he was sufficiently aware of its need, and ultimately did agree, albeit somewhat distractedly.

Consistent with previous research, having considered the effects of children being either excluded or included in decision-making, the children in my study reacted negatively when excluded from decision-making and experienced positive benefits when included. For example, Samantha felt stressed, frustrated, confused and depersonalised when excluded, and conversely, felt less stressed, positive and committed to her recovery when included. Samantha’s situation contrasts starkly with Amanda’s, who throughout most of her cancer treatment was able to demonstrate high degrees of autonomy and competence, when permitted to assist with the administration of treatment. This allowed her some control within a health context in which that is generally lacking, and

993 Chapter 8 Jenny/Amanda (page 151) and Tania/Oliver (page 153) followed the cancer treatment protocol. Jenny commented: “It is like a train. There is not a lot of decision-making.”
994 See Chapter 8, pages 160. Brenda was sufficiently experienced in suffering with the pain and competent, to make her decisions during consultations with health professionals.
995 For example, Ellis and Leventhal, above n 18 at 282; and Coyne and Gallagher, above n 524 at 2337. See also Alderson, *Children’s Consent to Surgery*, above n 20 at 15-22.; Lambert, Glacken and McCarron, above n 20 at 3097; Garth, Murphy and Reddihough, above n 71 at 48; Miller and Jawad, above n 611 at 187; Coyne and others, above n 472 at 278.
996 Chapter 8 pages 147 and 148. Samantha’s experience is consistent with earlier research: De Vries and others, above n 601 at 5-7.
997 See Chapter 8 page 152.
as a result she appeared to be focused and determined to become healthy. Further research into the correlations between involvement and recovery may be valuable to health professionals.

(b) Health Professionals

Existing research has found inconsistencies in whether children participate in decision-making. In the experience of the participating health professionals in my study, children and parents commonly make decisions together. For example, in hospital dentistry, dentists strived to work with children and parents together to decide on how treatment was administered, either in the chair or by GA, and also on what treatment. This gave children some degree of control and responsibility. Likewise, most GPs and one paediatrician spoke of ascertaining from both parents and children their feelings and views, and deciding upon treatment together. Despite public health nurses in the vaccination programme only having contact with children, joint decisions could be made between parents and children at home, after considering the information provided.

A number of factors influenced the degree to which children were involved in decision-making, confirming findings from earlier research: parents’ roles and attitudes towards promoting children’s participation; whether options were given; the attitudes of health professionals; whether their protests are respected, which depends on their age; the state of children’s health, as they may be too acutely ill; and whether children have formed views. For some simple treatment, children are not involved in discussions and decisions, such as antibiotics, as they may not have formed opinions, and dental fillings, as private dentists may assume that children do not have an opinion, that they will follow the dentists’ advice, or agree with their parents. In contrast, for life-changing procedures, such as cosmetic/elective surgery, children’s views were

998 For example Runeson, and others, above n 476 at 73; and Alderson, Children’s Consent to Surgery, above n 20 at 23.
999 Chapter 9 page 180.
1000 See Chapter 10 page 201.
1001 See Chapter 9 for example pages 179 and 206.
1002 See page 216: The expectation is that parents will use “the consent form in the way that it is designed - which is information for you to read to your child or to talk with your child about”. (Nur6)
1003 For example Runeson, and others, above n 476 at 73.
1004 See Chapter 9, pages 180-181 where parents can either work in partnership with health professionals and children in making decisions or create barriers, where for example, they consider it is their right to make decisions on behalf of their children.
1005 For example, see Chapter 10 page 205 where GP5 described the options given for wart removal. This contrasts with the lack of choices given by private dentists for fillings at page 210.
1006 For example, see Chapters 9 and 10 pages 178 and 201-202 where health professionals indicate their respect for children’s bodily integrity.
1007 See pages 203 for example, where Den3 spoke of younger children being forced to undergo dental treatment, but older children’s protests being respected.
1008 See Chapter 9 page 184 for example, when children suffer from cancer they commonly regress and are at times very ill.
1009 See for example page 205 where children may not have opinions about antibiotics but have strong views about wart removal.
1010 Chapter 10 page 210.
decisive. These situations highlight how children’s competence may not necessarily be related to the complexity of the treatment, but rather to the seriousness of the treatment or the consequences of its outcome.

In the SDS, children’s competence to make decisions was not promoted, restricted by time, minimal information provided to children and parents, and adherence to parental consent. Although the separate engagement with children and parents is similar in the vaccination programme to that of the SDS, it does provide information, which may stimulate discussions between parents and children.

Naturally, as children consulted alone in the SMS, they make the decisions. Health professionals give children time to discuss, and consider, information and options, enhancing children’s competence and self-determination.

C. Evolving Competence

Children’s competencies evolve through participation and scaffolding, as supported by Childhood Studies, Sociocultural Theory and the Capability Approach. These theories, individually, and in combination, support the philosophy that children learn through participation, and with support, can further develop their skills and independence. All the children in my research demonstrated evolving competence to participate in their health treatment, for example, by discussing and learning about their health conditions and its treatment, making decisions, consenting and coping with treatment.

The evolving nature of children’s competence was seen most clearly in Poppy’s situation, having lived with her achilles condition from birth, until her operation at 14 years of age. As Poppy grew in confidence, matured and developed experience, she participated more in consultations, had a greater need and desire to understand her health and its treatment, until finally, she contributed to the decision on her operation. Likewise, Poppy’s growing competence can be traced from when she was vaccinated to when she underwent dental surgery and had braces fitted. At the age of 11/12 years, she had little interest or concern in simple, and common, vaccinations. However, by 15 years, the balance of involvement and responsibility swung more to Poppy, when she considered, discussed and understood the information and choices for her braces, and then made the decision based on what was important to her.

Similarly, Samantha’s competence developed over four years whilst she lived with cancer, being treated in hospital and undergoing three surgeries. By the time she made her decision on the third surgery, her maturity, independence and experience had all evolved.

Although over a more focused period, Alistair and Amanda’s competence evolved too, as they learned about their health conditions and treatment. Alistair demonstrated between

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1011 See Chapter 10 page 201.
1012 See Chapter 6 pages 114-115 and 116-118.
the ages of nine and 10 years, his competence to make a treatment decision, and Amanda’s competence was demonstrated in practical ways of managing her treatment. For Oliver, he developed experience and skills to engage with health professionals and provide consent without a parent present, whilst Donald’s ability to cope with dental surgery evolved through his experience and advice from his mother. Finally, for Brenda the transition was not so apparent, as she began with a high degree of agency, but once she crossed the threshold of 16 years, she also provided consent without a parent.

D. Competence Assessments

My study extends research on how health professionals assess children’s competence. Whilst Alderson’s study into children’s consent in surgery found that competence is assessed through interpersonal relationships, and that parents’ and health professionals’ attitudes are of importance, together with children’s inner qualities, my research has distilled the criteria which medical, surgical and dental health professionals, in four healthcare environments, considered. It is significant that they have regard to common criteria, assessed within clinical interactions, despite the criteria and process not being prescribed or formal. The criteria they rely on are: the importance of children’s abilities to communicate with health professionals about their health; their level of independence/interest in their health; their understanding and intelligence; their development and maturity; and their ability to ask and answer questions. These findings further demonstrate the relational nature of competence, highlighting health professionals’ and parents’ responsibilities to support children’s participation.

E. The Competence Model

The relational nature of competence, together with its intertwining elements, can be represented in my conceptual model, “The Competence Model”, as shown in Figure 2. The findings of this study, in conjunction with the international research and theoretical base, have shown that competence is not simply an individual ability, developed or demonstrated by children, but is a relational one between health professionals, parents, children and the healthcare environment. For example, each participant’s experiences, knowledge, preferences, values, attitudes and personalities impact on the ways in which they interact, and in turn, influence children’s opportunities to participate, develop and demonstrate competence. Further, intersecting with this triadic dynamic are environmental factors, such as the state of children’s health, the urgency of treatment, privacy and the time available. The interplay of all these factors results in children’s competence either being promoted or constrained. The Competence Model depicts this interplay and dynamic.

1013 Alderson, Children’s Consent to Surgery, above n 20 at 152-155.
1014 See Chapter 9, page 191.
1015 See Chapter 9, page 191-195.
The Competence Model has been adapted from the ‘Lundy Model’, which represented the dynamic nature of, and the inter-related factors required for, upholding children’s article 12 rights under the UNCRC.\textsuperscript{1016} Whilst Lundy’s quadrants are Space, Voice, Audience and Influence, I have replaced Audience with Support, to reflect the relational nature of competence.\textsuperscript{1017}

In the Competence Model, Space relates to the physical environment within which health professionals consult. Voice denotes the internal factors influencing children’s abilities to express themselves, such as their personality, experience, age and preferences. Equally, it relates to the attitudes, practices and abilities of health professionals to actively listen to their voices. Support represents the ways in which adults, particularly parents and health professionals, assist children in participating in informed consent processes, for example, by supporting children to provide their medical history, understand about their health condition/treatment, discuss and decide on treatment options and give consent.

\textsuperscript{1016} Lundy, above n 61 at 932.
\textsuperscript{1017} In Lundy’s Model ‘audience’ depicts that children’s voice must be heard and interlinks with ‘influence’, which is that their views must be acted upon: Lundy, above n 61 at 933.
Influence relates to the professionals, laws, policies and guidelines that can give effect to competent children participating, and giving, or refusing, consent. The quadrants or elements (elements) have been placed deliberately in this order, as they provide a logical sequence to informed consent processes, in the sense that children need a conducive environment (Space), for their voices to be heard (Voice), through the promotion and support of their competence (Support) to participate in giving/refusing consent (Influence). Children’s competence is best promoted and demonstrated at the centre point, where all the factors are present, but exists in lesser degrees, in the singularly overlapping areas.

F. Summary of Competence

The research participants’ experiences highlight the multitude of factors influencing competence, confirming that it is not age related. Of more importance are the relationships and support between children, parents and health professionals. My Competence Model summarises and highlights the relational nature of competence, also exemplifying the theoretical underpinnings of Childhood Studies, Sociocultural Theory and the Capability Approach, that all view children as social actors, whose agency and capabilities develop through the scaffolding of those more experienced.

The Competence Model is of further significance, in light of my research discovering the importance health professionals place upon children’s interactions during consultations, when assessing their competence. Given the relational nature of competence, health professionals and parents need to be aware of these factors, such as, the purpose of health professionals’ communication needs to be more than a social chat, or simply children answering questions, as has been found in earlier research. Unless health professionals and parents adequately support children’s participation and relationships, children are unlikely to be able to develop and demonstrate their competence.

It may be understandably challenging for some children to demonstrate their competence in an unfamiliar and predominately adult-based system, such as in hospital; and correspondingly demanding for some health professionals to promote and assess it, given their time constraints. However, as the children I interviewed have shown, with support, they can demonstrate high degrees of competence, which may not be initially apparent from their interactions during consultations. Thus, competence needs to be reviewed at different stages of treatment, as children’s health, their relationships, understanding, maturity and experience all develop.

1018 See for example van Dulmen, above 462 at 565.
1019 See Chapter 9 page 150 for example: Amanda was quiet in consultations but highly competent in understanding and managing her cancer treatment.
III. Consent Processes

A. Reliance upon Parental Consent and Reasons

Commonly, children and parents consult together with health professionals and consent is given collectively. This is a practical and natural approach during clinical interactions, and is not an issue when children have an opportunity to contribute to discussions and decision-making, and parents and children agree.

Nevertheless, a striking finding of my study is that in most healthcare environments parental consent is relied upon. This was highlighted when written consent was required, and/or when parents and children disagreed. For example, the consent form in hospital is designed for adults, and despite age being an unreliable indicator of competence, it was the practice and understanding of many health professionals that parents were required to provide written consent until children reached 16 years of age. This was the experience also of the parents who provided written consent for their children when under the age of 16 years. As a consequence, some health professionals focused more on parents’ understanding and/or on their parental authority, when taking consent.

Likewise, the consent processes in the vaccination programme and SDS were designed for parents to consent, resulting in limited respect being given to children’s competence. Whilst public health nurses educated children on the vaccinations to gain their understanding and co-operation, the focus was more on parents’ understanding and consent, as highlighted by the anomaly of interpreters being provided for parents to sign the consent form, but not for children. Therefore, there was no way of knowing the extent to which those children understood and gave consent. Additionally, although nurses gave children opportunities to express how they felt, and give their verbal consent

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[1021] On the proviso that health professionals do involve children in discussions and do not marginalise them. See chapter 9 pages 175 and 176 where some health professionals in this study spoke of the strategies they use for involving children. However, see Chapter 8 where some children in this study experienced exclusion, for example, Poppy felt little involvement until about 12 years (pages 163-164), Samantha struggled to be included (145-148), and no health professional explained to Alistair his condition and treatment until the consultation with his GP at which medication was prescribed, where 80% of the conversation was directed to Laura (page 157).
[1022] See Chapter 10. For example, the paediatric surgeons, plastic surgeon, one paediatrician HD2, all hospital dentists, both public health nurses and both school dental therapists all usually take the written consent of parents.
[1023] For example, see Chapter 10 page 199 and Chapter 11 pages 225-226.
[1024] See Chapter 8 Anna/Poppy (page 166), Tania/Oliver (page 155) and Brenda (page 170). Of exception was Amanda for her laparoscopy (page 151) and also Samantha, who recalled, “signing off” for her third operation (149).
[1025] For example Chapter 10 page 198 in hospital “All the discussion about consent is done in front of the child” (Paediatric Surgeon, HD1) and “I do my level best to keep the language in terms most parents would understand” (Paediatric Surgeon, HD3); and at page 201 “… with acknowledgment that the parent has the overriding guardianship and acknowledgment that the parent gives signed consent” (Hospital Nurse, Nur8).
[1026] See Chapter 10, page 216. This issue also arose in paediatric surgery where children may be given the responsibility to interpret the consent forms for their parents, in order that parents can give consent, but are not required themselves to consent (page 198).
at the point of vaccination, the environment and system created pressures on them to co-operate, as usually prior written consent from parents was given, and the public setting created peer pressure and lacked privacy. Conversely, when parents had either not returned the forms or refused consent, children could fail to be vaccinated, due to the reliance upon parental consent. This was despite the nurses knowing the law and being able to assess children’s competence.

There is no reason from a legal standpoint preventing competent children signing their consent forms or giving verbal consent. Whilst it may not be considered expedient or practical, there were health professionals, in time-pressured environments, assessing children’s competence, taking their consent and relying on it.1027

Similarly, in the SDS, dental therapists relied on parental consent, with limited opportunity to promote and respect children’s competence. Thus, competent children were unlikely to receive dental treatment where parents had not consented.1028

Comparable difficulties, with more serious consequences, could arise also in hospital, when parents and children disagreed on treatment, such as where parents refused chemotherapy. This could result in children not receiving treatment, unless there was an internal process, and possibly a court order.1029

Conversely, when parents consented but children refused, most health professionals agreed that they would not forcibly treat them, unless the medical need predominated.1030 Nevertheless, children could be pressurised, held down or sedated in order for treatment to proceed.1031 This finding is consistent with earlier research, which found health professionals could be complicit with parents in treatment proceeding, despite children’s strongly expressed refusal.1032 However, as we saw with Donald, when health professionals respect children’s refusal, and parents work with their children to assist them to cope, treatment can proceed calmly.1033

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1027 See Chapter 10 page 199.
1028 Denial of treatment can occur in other healthcare environments. See Chapter 9 page 183 where HD1 recounted a competent 14 year old who was left untreated due to her mother’s refusal and disruptive behaviour.
1029 See Chapter 9 page 186. Additionally, children are likely to be affect negatively when they are insufficiently included in the consent process and their competence is undermined. The positive effects of inclusion and negative effects of exclusion are examined in Chapter 5 pages 95-96. For example, Ellis and Leventhal, above n 18 at 282; and Coyne and Gallagher, above n 524 at 2337; Alderson, *Children’s Consent to Surgery*, above n 20 at 15-22; Lambert, Glacken and McCarron, above n 20 at 3097; Garth, Murphy and Reddihough, above n 71 at 48; Miller and Jawad, above n 611 at 187; Coyne and others, above n 472 at 278. Also see Chapter 10 page 203-204: exclusion in the consent process can create issues for nurses when they are required to administer treatment to children.
1030 See Chapter 10, page 202 where some spoke of strategies that they use to encourage children, such as being honest and giving them time.
1031 See Chapter 10 pages 202, 203 and 204.
1032 See Chapter 5 page 81: Runeson, and others, above n 476 at 73.
1033 See Chapter 8 page 159.
There were several reasons for health professionals relying upon parental consent: convenience; cost of treatment; parental authority/rights; misunderstanding of the law; the law’s lack of relevance to practice. The simple answers were convenience and cost. Some health professionals considered it unnecessary to independently assess children’s competence and take their consent, as parents and children commonly consulted together and agreed to treatment. However, issues arose when parents and health professionals did not provide environments conducive for children to express their views and give their consent, or when parents and children disagreed. Therefore, it is necessary for health professionals to be mindful of the factors in the Competence Model to ensure children participate. Nonetheless, a mitigating factor was how attuned some health professionals in my study were to children’s feelings and views, through children’s non-verbal cues.

In private dentistry, some dentists regarded consent for treatment to also include consenting to meet the cost. Whilst dentists could in theory take the sole consent of competent children, practically the two are inter-related, as parents could block treatment by refusing to pay. While cost was not an issue about which I specifically questioned health professionals, it is interesting that it was raised by dentists in private practice, but not by GPs, who had experienced parents giving their children the money to meet the consultation cost, when they attended alone.

However, for other health professionals the rationale for relying upon parental consent was deeper, lying in the historical view of children, believing that parents’ authority was greater than children’s status. As a consequence, parental decisions/consent prevailed over competent children, for example, “the parent has overriding guardianship” (Nur8), and “[w]e were taught for under 16s the guardian was definitely most important” (DT2). Following on from this belief, some health professionals feared reprisals/complaints from parents if they relied upon children’s consent, as some predicted, or had already experienced, parents criticising them for seeking children’s opinions on treatment, or taking their consent. Most health professionals were mindful of the need to foster and maintain relationships, with both children and parents, so that they could work together in partnership. This dynamic needed to be delicately balanced to ensure that both parents and children could participate, which was better facilitated in some healthcare environments than in others. For example, dentists developed strategies to promote partnerships and trust, whereas in the SDS and vaccination programme, there were limited opportunities, due to limited time and the

1034 For example see Chapter 10: GP2 (page 207), GP4 (207) and HD6 (200).
1035 See Chapter 10, page 201 for example: HD1 who sensed a boy was reluctant to undergo a circumcision and HD4 who will not operate unless parents have discussed it with their children and the procedure is being driven by the children.
1036 See Chapter 10 page 208: GP4.
1037 Chapter 10 page 201.
1038 Chapter 11 page 226.
1039 For example Chapter 9 page 181: DT1.
1040 For example Chapter 10 page 219: Nur 6 and Nur7.
1041 For example Chapter 10 pages 180 and 181: Den3
disjointed nature of contact with families.⁷⁰⁴² In the vaccination programme, diplomacy beyond the parent-child dynamic was needed, as permission of both schools and parents was required to enter schools to immunise. As the aim is to immunise as many children as possible, in a convenient location, the programme does not wish to cause upset or issues for schools and parents. Where parents promote children’s understanding about their health, and support them in contributing to decisions and giving consent, children’s competence can still develop, and respect can be given to their consent.⁷⁰⁴³ However, where parental support is absent, and/or parents and children disagree on consenting to treatment, children’s competence and right to consent are disrespected. Whilst in most situations children and parents will reach consensus, there needs to be clear law, guidelines and practices to resolve disagreements.

Children are no longer regarded as vulnerable, incapable, or the property of their parents. Understandings of children’s capabilities have progressed through theories, such as Childhood Studies, Sociocultural and the Capability Approach, and children are viewed now as social actors, with agency and voices. Together with the laws of Gillick, UNCRC and the COCA, these theories give respect to children’s evolving capacities, with parental authority correspondingly diminishing and yielding to children’s competence. Moreover, Gillick and the Capability Approach have advanced thinking on children’s autonomy by supporting children’s right and freedom to make their own decisions once competent.

Despite this progression in the understanding of the development of children’s competence, my research found that most consent processes remained rooted in the belief of children becoming competent at a certain age, that being 16 years old. Many health professionals lacked an awareness of the law for children consenting, with some understanding that children could only do so at 16 years, or only for sexual health matters. It is unsurprising that health professionals are uncertain of the law for children consenting to health treatment, as it is not clearly stated. However, even amongst those who were aware of the law, it lacked influence.⁷⁰⁴⁴ There was a sense amongst some health professionals that assessing children’s competence and taking their consent was optional, as they could proceed with treatment on the strength of parents’ consent. Further, there appeared to be detachment between law and practice, their practice having formed over many years and become habitual.⁷⁰⁴⁵ Some health professionals derived security from the practices of their peers, and regarded their policies of more relevance than the law.⁷⁰⁴⁶

Amongst those health professionals who were aware of the law, some felt that it did not sufficiently protect them against professional risk, were they to rely upon their

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⁷⁰⁴² See Chapter 9 page 174.
⁷⁰⁴³ See Chapter 8 pages 161-162 where Anna supported Poppy’s understanding on the vaccinations.
⁷⁰⁴⁴ For example, see Chapter 10 page 198: In practice we don’t do that a lot (HD1); and page 199 “I know that someone that is in a position to be able to make a reasonable informed choice can do so, but it is the generally accepted thing that the age of consent is 16” (HD3).
⁷⁰⁴⁵ See for example Chapter 11 page 227: SH1
⁷⁰⁴⁶ See Chapter 11 pages 227-228.
assessment of children’s competence and their consent. They expressed frustration by the constraints of policy, or felt exposed by the process and law, resulting in defensive practice. Clearly, the law and professional training are failing these health professionals and children.

B. Reliance on Children’s Consent and Reasons

Nevertheless, there were health conditions and environments where children’s competence and consent were routinely respected. For example, children’s competence was assessed, and their written consent obtained, for anaesthetics and obstetrics/gynecology procedures, and their verbal consent relied on in the SMS and by GPs, when children consult alone.

The healthcare environment was a contributing factor, as in the SMS, children attended alone, and had time and privacy. However, this does not fully explain the situation, as in hospital there was much less time available, and children usually attended with their parents, but some doctors still relied on their consent. It appeared that the common factor amongst those who routinely obtained consent from children was respect for them and their growing autonomy and competence, highlighted by the attitudes of these health professionals:

… giving them a sense of empowerment (HD5)

… seems slightly insulting to her that I have to get her parent to sign.” (HD7)

… it is their body, their decision.” (HD4)

Int: Do you tend to find there is an age at which the child appears to be capable of giving consent?

GP5: I see it more as a continuum. In some ways a three-year-old gives consent, if you are going to do liquid nitrogen. Even a four/five year old, if you say to them ‘can I look in your ears’ they are giving consent.

Additionally, although some health professionals may not have routinely obtained children’s consent, there was some degree of flexibility in their practices, by taking, and relying upon it, for example, when parents were unavailable or unable to consent, due to language difficulties, or if children expressed their wish to consent.

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1047 See Chapter 10 page 219: Nur6 and Nur7; page 222 DT1.
1048 See Chapter 10 page 222: “I would want to if they had the age of understanding but I would be restrained by the policies” (DT1).
1049 See Chapter 10 page 219: We didn’t feel we were in a position to be the ones to take the responsibility. … We are protecting ourselves. Yes, it does appear she is competent, but do we want to risk that” (Public Health, Nur7); and “I feel it is not tight enough via the law” (Nur6).
1050 See Chapter 10 page 198 for example “[i]n practice we don’t do that a lot, I guess because usually there is a parent there” (HD1) and page 207 “[n]ot if they are with their parents, I’m afraid I don’t think of it” (GP4).
1051 See Chapter 10 page 200.
Nevertheless, these situations appeared to be default positions, rather than as a deliberate means of promoting and respecting their competence and right to consent.

C. Children’s Views

Confirming the findings of earlier studies, the children in my study were strongly in favour of children being included in decision-making and giving consent.\(^{1052}\) For example, when reflecting upon their cancer treatment, both Samantha and Amanda believed in their rights to be involved and to give consent, supporting the findings of Coyne and others, whilst challenging that of Wangmo and others, who found children viewing it as a need, rather than a right.\(^{1053}\) Nevertheless, the two are not mutually exclusive, as some children may view it in terms of both, depending upon their personalities, values and self-esteem. Whilst neither Samantha nor Amanda was specifically asked their opinion on whether they differentiated between minor and major decisions, it was clear from their responses that they did not do so.\(^{1054}\) This is also consistent with the literature, indicating teenagers prefer to be informed and involved in both major and minor decisions.\(^{1055}\)

D. Summary of Consent Processes

Whilst parents and children commonly gave joint consent, health professionals mostly relied upon parents’ consent, regardless of children’s competence. This was most notable when written consent was required, such as in hospital, the vaccination programme and the SDS. The forms were designed for parents, and despite children’s competence, children would not usually be required to sign them. Nevertheless, some health professionals were mindful and respectful of children’s competence, having a practice for assessing competence and taking their written consent. These health professionals gave priority to children’s competence over other factors, such as established practice, their perception of parental authority, or fear of exposure to professional risk from parents’ challenges. When priority was given to such extraneous factors, children’s health could be compromised, by being denied treatment when their parents refused consent. Health professionals need to feel empowered and confident to assess and follow children’s competence to avoid such situations, and parents need to understand the development of competence and children’s rights.

\(^{1052}\) See Chapter 11, page 239.

\(^{1053}\) For example Coyne and others, above n 20 at 35; and Wangmo and others, above n 18 at 17.

\(^{1054}\) See Chapter 8 page 149 where Samantha felt less stressed by being involved. Also at page 147 Wilma described the negative effects to Samantha of the nasogastric tube being forced against Samantha’s will; and conversely at page 149 described the positive effect to Samantha of contributing to a major decision. See also Chapter 11 page 239 where Amanda clearly regarded inclusion as her right: “It is for them, for their sake. They are going through it, not the parents. The parent is not having some bone cut out, or their leg chopped off. It is the child and their choice. … Maybe I could have chosen not to have treatment (chemotherapy), but obviously I had to. But I still think that everything should go via the patient, no matter what age” (Amanda, aged 16).

\(^{1055}\) For example, Coyne and others, above n 472 at 278. Also, Chapter 10 page 200 where HD3 recalled a 13-year-old girl whom he would consult with on her view on proceeding with a novel procedure where the outcome was uncertain.
Conversely, where children refused treatment, counter to their parents’ consent, their refusal would be respected, where safety was not at issue. Therefore, despite the law being less clear on children’s right to refuse, more respect may be given to it, which appears to relate to both respect for children’s bodily integrity and their evolving competence.1056

**IV. Law**

**A. Competence**

New Zealand law has had a limited role in defining competence, on occasions, following broad criteria, such as sufficient intelligence and maturity, understanding, and the ability to foresee the consequences of treatment,1057 and at other times, failing to consider the issues of children’s competence to consent entirely.1058 Rather, it rests upon health professionals to apply these broad criteria in assessing whether children are sufficiently competent to consent. This research has shown that whilst health professionals’ processes are organic/informal, rather than prescriptive, they are agreed on the relevant criteria.1059 This finding is significant, due to the lack of existing research into how health professionals assess competence, and particularly given that my study is trans-disciplinary.

This consensus amongst health professionals, together with the findings that competence is relational, involving many interlinking factors, supports the argument that competence assessments are best left to health professionals, rather than the courts. Australia’s experience highlights the procedural complexity and difficulties that can be encountered when courts become over-involved. By categorising health conditions in terms of “therapeutic” and “non-therapeutic”,1060 and requiring courts to assess and determine whether children are competent in the latter category, has resulted in courts acting as gatekeepers to treatment, and intrudes upon child-parent-health professionals relationships. In my view, courts’ involvement in assessing children’s competence lacks proportionality, as the emotional and financial cost to families of applying to court outweighs any benefit, such as, acting as a check and balance for protecting children.1061 Further, as shown by the experiences in gender dysphoria cases, there usually was no dispute over children’s competence, and courts relied upon the evidence and opinions of health professionals, in effect rubber-stamping their assessments. This process moved

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1056 See Chapter 10 page 206: GP4 describing waiting for children to understand the pain involved in removing a wart; Chapter 9 page 178 and Chapter 10 202 where HD4 respects children’s views and the need for children to understand and desire surgery; and Chapter 10 pages 201 and 202 where HD1 also expressed respect for children's views and desire for surgery.

1057 See Chapters 2 and 3 where Gillick, the Code, PPPR Act s 5 and Professional Guidance are examined.

1058 See Chapter 2 pages 31-36.

1059 See Chapter 9 pages 191-192.

1060 Re Marion, above n 264.

1061 For example, Re Alex, above n 278; Re Jamie, above n 266; Re Julian, above n 322; Re Mason, above n 322 where families required to undergo litigation, including a court hearing and involving medical experts, possibly professionals involved in children’s care and education, parents, relatives or other carers, and the children.
away from the essence and context of Gillick – children demonstrating, in a natural interaction with health professionals, their level of understanding, maturity and intelligence, relative to the decision that requires to be made.

English law also developed complexity, retreating from Gillick, by differentiating between competence to consent and competence to refuse treatment. However, competence is not simply possessing sufficient understanding, maturity and intelligence to agree with health professionals’ advice, but is to make the decision, to either consent to, or refuse it. Whilst Gillick did not specifically deal with the refusal of treatment, it supported children’s autonomy to make decisions independently from their parents.

The focus of competence assessments needs to be on the process of the decision-making, and not on the outcome. To differentiate between consent and refusal undermines children’s competence. By simply dismissing children as incompetent when they refuse treatment, and overruling their decisions without further enquiry, lacks respect for their competence, bodily integrity, values, priorities and goals. Protectionists will argue that it is the role of adults to safeguard children against making mistakes, but mistakes in whose eyes? In the eyes of an adult who possesses a different set of values, attitudes, experiences and goals?

This debate returns to the one of whether children and childhood are valued in their own right, or are preparations for adults and adulthood. An example of this was Patrick, who featured in Alderson’s study, when he underwent surgery to straighten his back, resulting in him looking “normal”, but was unable to play football, which he loved. By focusing only on fixing the problem sight is lost of children as people. In my research, Samantha experienced this attitude from health professionals until her third operation, such as when she was forcibly fitted with a nasogastric tube. Samantha and her mother were not given information or options to assist Samantha in coping with its fitting. Whilst there may not have been options about whether it was fitted, there were options as to how it was fitted. Samantha’s experience is consistent with earlier cancer studies that have shown children are not involved in decisions when it may affect the efficacy of treatment, including for nasogastric tubes. Contrastingly, other studies have found that some health professionals do give children choices for minor procedures in curative situations, for example, whether to insert a porth-a-cath, provided these did not affect the overall efficacy of the treatment. Yet, in these studies the health professionals’ decisions appeared to be based upon the outcome rather than children’s competence. Health professionals may be assuming that children will refuse treatment if given the choice, and are incompetent when they so refuse. Accordingly the decision is made for them.

At times courts also focus on the outcome of decisions when children refuse treatment, rather than on the process by which they make them. When courts decide on children’s

1062 See Re R, above n 291; Re E, above n 393; Re S, above n 395; Re L, above n 397.
1063 Gillick, above n 4 at 172 per Lord Fraser; at 184 per Lord Scarman; and at 201 per Lord Templeman.
1065 See Chapter 8, page 147.
1066 De Vries and others, above n 601 at 6.
1067 Coyne and others, above n 472 at 278; Ruhe and others, above n 469 at 1149-1153.
competence, and determine them as incompetent, there needs to be more transparency and clarity on the reasons for them not being competent. It is insufficient to simply say that they do not fully understand the consequences or the gravity of the decision, such as, in Re E, where the Court considered the child was unable to understand the full implications of the process of dying, the manner of death and the extent of family suffering.\textsuperscript{1068} Before deciding that children are incompetent, courts need to specify what factors children are lacking and what more is expected from them. Asking probing questions brings to the surface the courts’ underlying concerns. To dismiss children as ever being competent to make certain decisions focuses too heavily on their age and status, and pre-judges the situation.\textsuperscript{1069}

Whilst greater competence is required for more complex and serious decisions, it is undermining and belittling of children, and their competence, to say that they will never be in a position to understand a medical procedure or treatment, or that they are unable make a decision until adulthood. When courts consider applications relating to medical treatment, children’s competence needs to be the first consideration, in my view, for if competent, children should have the right to make the decision to either consent to, or refuse, treatment.

\textbf{B. Consent}

New Zealand law is fragmented. With a gap in COCA, it is necessary to look to the common law, other statutes, and regulations to piece together the extent of children’s rights to consent to, or refuse, medical treatment.\textsuperscript{1070} However, this can lead to differences in interpretations and uncertainty, as the data in this study has shown.\textsuperscript{1071} Understandably, most health professionals were uncertain of the law, and some stakeholders held different views on whether the law provides for children to refuse treatment.\textsuperscript{1072} For some, the law’s lack of clarity inhibited their willingness to rely on competent children’s consent.\textsuperscript{1073}

In Scotland the position is clearer, with a statutory right for children under the age of 16 years to consent,\textsuperscript{1074} and most likely refuse treatment,\textsuperscript{1075} when they understand the nature and possible consequences of the treatment. Certainty and clarity are likely to be

\textsuperscript{1068} Re E, above n 384. Likewise in \textit{Re S}, above n 384 and \textit{Re L}, above n 386, where the children were not informed of the process of dying due to its distressing nature. The children cannot be deemed incompetent without the necessary information and in any event how can anyone understand the full implications of dying?

\textsuperscript{1069} For example \textit{Re Alex}, above at 278.

\textsuperscript{1070} See Chapter 3 where New Zealand legal context is considered.

\textsuperscript{1071} See Chapter 11 pages 225-228.

\textsuperscript{1072} See Chapter 11 page 228 where two stakeholders employed by the same DHB had different understandings of whether children have the right to refuse treatment.

\textsuperscript{1073} See Chapter 10 page 219.

\textsuperscript{1074} ALCSA s 2(4).

\textsuperscript{1075} Whilst the ALCSA does not specify refusal, and there is an absence of case law to clarify the issue, it is likely that it would be interpreted to include refusal: Norrie, above n 14 at 436; Wilkinson and Norrie, above n 14 at 480; SLC, above n 14 at [3.77]; \textit{John Houston}, above n 14 at 945 per Sheriff J McGowan.
contributing factors to the absence of case law in Scotland, but without further research, it cannot be fully explained.

V. Recommendations

This research has found inconsistencies in the approaches of courts when deciding medical consent issues, and in the practices of health professionals, when taking consent. Some health professionals were uncertain of the law, whilst for others, there was the sense that following it was optional, with established practice or policy being of more relevance. Some expressed apprehension that the law was too uncertain to provide them with protection and security, if they relied upon children’s consent. Therefore, the following recommendations are aimed at providing greater clarity, certainty, confidence and consistency in both the law and practice.

A. Review of Health Professional Guidelines

Health professional guidelines, standards and policies, and universities’ seminars/courses on competence and consent, should be reviewed, and where necessary updated. It is essential that these are consistent and align with the law, particularly as my research found that professional guidance, policies and peers guide some health professionals more than the law.

1076 See Chapter 10 page 198 for example- “My understanding is that if you are happy that the child understands and has the appropriate level of competence to understand what you are talking about then potentially a child can do their own consent form. In practice we don’t do that a lot, I guess because usually there is a parent there. … We don’t commonly get 14/15 year olds to do their own consent.” (Paediatric surgeon, HD1)
1077 See Chapter 10, pages 219 for example “We are protecting ourselves. Yes, it does appear she is competent, but do we want to risk that” (Nur7) and “I feel it is not tight enough via the law. I don’t know the law that well, but I am not convinced that we are covered safely” (Nur6).
1078 For example, between 2017 and 2018, the Dental Council undertook a process to review its informed consent practice standards, and produced its final document in May 2018. The document clearly defines competence and the rights of children under the age of 16 years by giving direction on the criteria for competence, the informed consent process, and children’s rights to consent to, or refuse, dental treatment: Chapter 3 pages 43. See Chapter 3 pages 43-44: where inconsistencies amongst DHB Informed Consent Policies are highlighted. For example, Canterbury DHB’s Policy on Informed Consent dated June 2015 at pages 16-17 refers to the Guardianship Act, and despite stating that there is no age for giving informed consent, goes on to direct that parental consent is required with the child being involved as much as possible and agreement sought where possible. This policy indicated that it would be reviewed in June 2016, and so may have been superseded, but if so, has not been made public. On the other hand Waikato DHB’s policy dated 1 June 2017 at 5.1 states that competence is not linked to age and that children under 16 years can give consent if fully competent and Capital and Coast DHB considers the provisions under the COCA.
B. Education Opportunities for Health Professionals and the Public

Professional development opportunities on competence and consent through seminars, workshops and courses would provide health professionals with opportunities to clarify their understanding and processes, and apply the law to complex practical situations. My research has given an indication of health professionals’ lack of knowledge and misunderstanding of the law, together with some of the barriers to them accepting competent children's consent. By having collegial opportunities to undertake professional development/training, health professionals may derive support and confidence, by reinforcing best practice, and discussing issues they have encountered, or are of concern, to them. My Competence Model may be of use in such training events to help explain and summarise the multitude of factors influencing children’s competence, and reinforcing health professionals’ and parents’ responsibilities in supporting children’s competence.

Of equal importance is the need to raise public awareness of children’s competence and right to consent. This would result in a greater understanding of how children’s competence develops and can be supported, and people will know better what to expect when consulting with health professionals. This could be done through leaflets, websites, and schools, if supported by agencies such the Ministry of Health, Ministry of Education, Office of Children’s Commissioner, and school principals/boards.

C. Competence Toolkit and Revision of Consent Forms

Further supporting the education and practice of health professionals, a collection of health and legal agencies/personnel could consult, draft and produce guidance on the law, together with a universal process or ‘toolkit’ for assessing competence. It has been 20 years since the Ministry of Health produced its “Consent in Child and Youth Health: Information for Practitioners”, and whilst it remains a valuable and practical resource, it could be updated.

Also through this process, a universally applicable toolkit for assessing competence could be developed. Some health professionals in my study expressed concern over assessing, or relying on, their competence assessments. This may provide health professionals with reassurance about the universally recognised criteria amongst health professionals, and the expected or advised process. It would need to be easy and quick to use to make it practical, and could be based upon either the BMA’s toolkit, or the criteria and process in Appendix A.

1079 See Chapter 11, pages 225-227.
1080 See Chapter 10 page 218-219 nurses feeling exposed by the law in the vaccination programme; page 222-223 dental therapists bound by “policy” and parental authority; page 226 established practice of hospital doctors; and page 199 from the belief that children need to be 16 years.
1081 Ministry of Health, above n 93.
1082 British Medical Association, above n 414.
Additionally, this group of experts could review the written consent forms used in hospital, SDS and the vaccination programme, to consider whether they need to be in more child-friendly language, and whether children should provide co-consent.

D. **Amend the Care of Children Act 2004**

Amending the COCA to give competent children the right to consent to, or refuse, medical treatment could be achieved by inserting a new sub-section (2) into section 36. This sub-section would provide for children under the age of 16 years to consent to, or refuse, medical treatment, where they demonstrate sufficient understanding of the nature and possible consequences of that treatment, and are able to communicate and make the treatment decision. It would not affect section 36(1), which presumes young people are competent, or section 38 that presumes children/young people of any age are competent to consent to, or refuse, an abortion. Preserving these sections would continue to protect children/young people’s competence and autonomy, whilst also retaining the clarity of the current law in respect of these two groups of children/young people.

Alternatively, section 36(1) could be amended by removing the age threshold, and the words “as if the child were of full age”, and inserting the same competence criteria as outlined above. In this proposal section 38 would be repealed, it being subsumed within the general provision of section 36. However, this option is less promising, as discussed below, when I weigh up the advantages/disadvantages of the proposals.

In addition, section 16(1)(c) should also be amended to clearly state that parental rights, responsibilities and duties should be exercised in a manner consistent with children’s evolving competence, on a sliding scale from direction to guidance. This aligns with article 5 of the UNCRC, and is consistent with the proposed amendments, as parents have more involvement when children’s competence is developing, than when children attain the competence to make decisions and give consent.

The primary advantage of these amendments is that they provide greater clarity of children’s legal position. My research has shown that clarity is needed, as the law is fragmented amongst statutes, regulations and case law; courts have taken inconsistent approaches to children’s competence and their rights to consent; and most health professionals in my study were uncertain, and understandable confused, about the law. Nonetheless, it should be acknowledged that the majority of health professionals were unsupportive of a law change. They had not encountered problems in practice, the law lacked influence in their practice, and they sought to preserve the flexibility of the current law. However, a minority of health professionals and most stakeholders supported a law change to provide greater clarity. Both those resistant to, and in favour of, change expressed the desire for the law to be flexible. Clarity and flexibility would be possible

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1083 See Chapter 3, New Zealand Legal Context.
1085 See Chapter 11 pages 230 and 235.
with the proposed amendment, as the competence criteria are sufficiently broad. It is essential that the law retains flexibility, due to the varied and complex situations health professionals encounter, and also has criteria that can be easily applied and assessed by health professionals. Whilst competence must be assessed on a case-by-case basis, the application of objective criteria would assist in reducing inconsistencies and aid children’s and parents’ understanding of the assessments. This is likely to be of particular importance when there are disagreements between parents and children, and is also consistent with the my recommendations of education opportunities and the use of a toolkit for competence assessments. My Competence Model may also be of assistance in supporting health professionals’ and parents’ to understand the factors that influence children’s competence.

In addition, most of the children strongly supported their rights to participate and consent being respected,1086 such as Donald - “It is not just people over the age of 16 [years] who should have their voice heard to do stuff to you and your health” (Donald, aged 11).1087 The children had experienced the benefits of inclusion,1088 and for some, the detriments of exclusion.1089 Parents too were supportive of children’s inclusion, desiring to work in partnership with them.1090 Effectively codifying Gillick in a new section 36(2) of the COCA would not detract from the importance of guardianship rights, duties and responsibilities. Health policies and professional guidelines, sitting beneath the legislation, should promote triadic relationships with children and parents, and where appropriate, encourage children to involve their parents, when they consult alone. My Competence Model may be a useful tool to support health professionals in their assessments of children’s competence, as it encapsulates the intersecting elements influencing children’s competence. For example, in order for children to voice their understanding to health professionals, they need support and space. Further, the Competence Model could be used as a training/educational tool for medical students, health professionals and parents, to show the complex nature of competence, and how they can best promote children’s competence. This is important given the findings of this, and existing studies, showing children’s competence to be relational,1091 and commonly parents and children giving joint consent.1092 In New Zealand, these findings are of particular significance for Māori culture, which traditionally is less individualistic. Whilst no Māori whānau participated in this study to share their perspectives and experiences, three Māori stakeholders, supporting Māori tamariki and whānau with a longterm health condition, acknowledged not only the importance of involving families, but also promoting children’s

1086 See Chapter 11 pages 239-240.
1087 See Chapter 11, Knowledge, Understanding and Reform of the Law on Children Consenting, page 239.
1088 For example see Chapter 8 page 149: Samantha was more committed to her recovery; page 157 trust developed between Laura and Alistair; page 160 Donald felt better able to cope with dental treatment; and page 164 Poppy was less anxious.
1089 This was most significantly experienced by Samantha. See Chapter 8 pages 145-147.
1090 Chapter 11, Knowledge, Understanding and Reform of the Law on Children Consenting, page 237-239.
1091 See Chapter 5, Literature Review; Chapter 8, The Experiences of Children and Parents in the Consent Processes; and Chapter 9, Promoting and Assessing Children’s Competence, Part II.
1092 See Chapter 10, The Consent Processes; Wiering and others, above n 600 at 64; Alderson, Children’s Consent to Surgery above 20 at 148-149; Kilkelly and Donnelly, above n 21 at 67.
independence and responsibility. They found that the environment in which they spoke to children was important. When children are at school, they absorb “the information more, because they are independent” and “are more grown up”, but that “around their parents they are more babyish … and don’t take responsibility for their health as much” (NGO, SH10). Further research in this area, including Māori whānau, would reveal how they support their tamariki’s competence and make health decisions.

As this study showed, there were inconsistencies in health professionals’ practices of taking children’s consent, with some not assessing children’s competence, and/or relying on parental consent, rather than relying on competent children’s consent. Taking children’s consent not only respects their rights and competence, but also, their participation provides positive benefits. It seems incongruous that the COCA does not provide for children under 16 years giving consent to, or refusing, general medical treatment, given that it recognises: certain rights of children; the rights of children over 16 years to consent to, or refuse, general medical treatment; and also the rights of girls to consent to, or refuse, an abortion.

Secondly, clearly stating children’s rights in one statute simplifies the law. This, in turn, should reinforce to health professionals the importance of assessing children’s competence, and provide them with the confidence to rely on competent children’s decisions. Commonly, such decisions are made collectively with parents and health professionals, but as this research showed, there was uncertainty and insecurity amongst some health professionals in taking children’s consent, when parents had failed to provide their consent. The proposed amendments should give clarity to competent children’s consent being relied on, as guardianship rights would yield to children’s competence. This is consistent with children’s evolving capacity reflected in the COCA, section 16(1)(c); Gillick; and the UNCRC, article 5. Otherwise, overriding competent children’s decisions reduces them to an expression of their views, and undermines children’s competence.

Thirdly, if the age threshold was removed, it would reinforce and support what this, and existing, research has found; that the ability and rights to consent/refuse are not based on age. It is competence that unlocks these rights. Nonetheless, one significant disadvantage to this proposal is that it would remove the presumption of competence for young people, which currently exists. The implication is that health professionals would

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1093 See for example, Chapter 10, pages 198-201, 209, 211-212, 220 and 224-225.
1094 See Chapter 11, Knowledge, Understanding and Reform of the Law on Children Consenting, page 237-239; and for example, Lambert, Glacken and McCarron, above n 20 at 3097; Garth, Murphy and Reddiough, above n 71 at 48; Miller and Jawad, above n 611 at 187; Coyne and others, above n 472 at 278.
1095 COCA s 3.
1096 COCA s 36(1).
1097 COCA s 38.
1098 See Chapter 10 page 219: Nur6 and Nur7; page 222 DT1.
1099 Gillick, f/n 4 at 184 per Lord Scarman; Hawthorne v Cos, f/n 9.
1100 See page 24.
1101 See page 10-11.
1102 See Chapter 5 pages 85-86 and Chapter 9 page 194.
be required to assess young people’s competence, rather than only doing so only if they had some indication of young people’s decision-making capacity being compromised. Further, it is possible that some health professionals may assume that this change requires them to take parental consent, instead of young people’s, as some do presently when treating children.\footnote{1103} Thus, these weaknesses make this proposal less preferable than adding a new section 36(2).

When health professionals are uncertain about the level of children’s competence to make a specific decision, they could either take the joint consent of parents and children,\footnote{1104} if they are in agreement, or otherwise seek an expert opinion on the level of children’s competence. This would be appropriate in exceptional cases, where, for example, children disagreed with their parents and/or health professional, or the decision was a complex one. They should clearly document the basis for their assessments in such cases, and would also seek advice from their legal advisors, ethics committee and professional regulatory bodies. Health professionals should be immune from liability, as they would be when taking adults’ consent, provided they follow the law and professional guidelines, and act reasonably and in good faith.

In the event that children are assessed as being competent, they can lawfully give, or withhold, their consent. Their decisions should not be overruled on the basis of welfare and best interests principles. Competence means having the ability to make a decision, and this should not be undermined by someone else’s subjective judgement based on welfare and best interests. The English case law demonstrated how the courts, when focusing on welfare and best interests, either failed to apply competence criteria, or otherwise raised the threshold of what children were required to meet.\footnote{1105} This subjective approach may make it difficult for health professionals to have confidence in their competence assessments.\footnote{1106}

In theory, amending the COCA, by inserting a new sub-section (2) into section 36, as proposed, should not be an issue, as Gillick is already accepted law in New Zealand. The COCA would simply reflect the common law. Crucially, the provision should be drafted in such a way that it is not reduced to simply an expression of children’s views. Nevertheless, there would need to be a consultation process to consider submissions on such law reforms, including representatives from tangata whenua, to ensure that the Treaty of Waitangi and tikanga Māori are respected and considered. The most controversial aspect of these proposals is likely to be the yielding of guardianship rights to competent children’s rights, and their decisions not being overridden on the basis of

\footnotetext{1103}{See Chapter 11, Knowledge, Understanding and Reform of the Law on Children Consenting, pages 225-226.}
\footnotetext{1104}{This was the practice of HD5. See Chapter 10, page 199.}
\footnotetext{1105}{See Chapter 4, part III section D.}
\footnotetext{1106}{For example, in An NHS Trust v ABC and A Local Authority, above n 206 at [6] an application was made for declaratory relief to avoid professional risk or criticism. It sought either a declaration that it would be in the interests of a 13-year-old girl to terminate her pregnancy if the Court deemed her incompetent to consent, or if deemed competent “a declaration to that effect so that the position is put beyond doubt and that any later criticisms of the Trust, in taking the steps that they did, can be deflected” (emphasis added).}
welfare and best interests principles. Whilst the most obvious drafting would be in terms of *Gillick*, it would be open to Parliament to enact it differently, such as making it a conditional right based on the welfare and best interest principles,\textsuperscript{1107} or exclude the right to refuse treatment.\textsuperscript{1108} However, in my view the most straightforward approach, and the one that gives most respect to children’s competence and rights to self-determination and dignity, is if *Gillick* was enacted into statute, and no distinction was made between competence to consent, and competence to refuse, treatment, as competence relates to *making the decision*. Distinguishing between consent and refusal has the effects of failing to respect children’s competence, raising the competence threshold, or presuming that children are incompetent, as experienced in England.\textsuperscript{1109} My view is supported by the theories of Childhood Studies, Sociocultural Theory and the Capability Approach together, that regard children as having autonomy and agency, as their competence develops. In particular, the Capability Approach supports the view that once people have acquired functionings, they have the right and freedom to make decisions, which accord with their values and goals.

Finally, by incorporating *Gillick* into the COCA I do not anticipate a flood of litigation for a number of reasons. Firstly, this is the current position in the law and there have not been a huge numbers of cases. Secondly, most parents and children agree on treatment, but when there are disagreements, these are generally managed within the healthcare setting. Thirdly, Scotland has a similar provision to the one proposed and there is virtually no case law in this area. Conversely, there are significant lines of authority in Australian and English Law.\textsuperscript{1110} Leaving competence assessments to health professionals, unless there is a challenge to that process or decision, and clearly stating in law children’s rights to consent and refuse, would avoid such complexities as experienced in Australia and England.

### E. The Legal Capacity of Children Act

Alternative legal reform is to enact a new statute, named “The Legal Capacity of Children Act” (LCCA). LCCA would regulate when children can lawfully engage in acts of legal consequence, one of which would be giving consent to, or refusal of, medical, surgical and dental treatment. This provision would be in similar terms to *Gillick*, namely that children under the age of 16 years can consent, or refuse, on their own behalf to any medical, surgical or dental treatment or procedure, where they demonstrate sufficient understanding of the nature and possible consequences of that treatment, and are able to communicate and make the treatment decision. LCCA would be similar to that of the ALCSA. If enacted, sections 36 to 38 of the COCA would be repealed and inserted in the LCCA.

\textsuperscript{1107} COCA ss 4 and 5.
\textsuperscript{1108} This is the position of Australia and England examined in Chapter 4 pages 58-60 (Australian Law) and 63-69 (English Law).
\textsuperscript{1109} See Chapter 4 pages 63-69.
\textsuperscript{1110} See Chapter 4 II B (Australian Law) and III D (English Law).
One merit of a separate statute is that its focus is on children’s competence and agency, rather than in the welfare context of the COCA, where Courts could decide that guardianship rights and/or best interests usurp competent children’s decisions. LCCA would embed competent children’s rights and freedom to make health decisions in law.\footnote{1111} Further, this provision would be consistent with the Code, in the sense that the Code contains rights regulating the informed consent processes, such as, the right to be fully informed,\footnote{1112} and the right to make an informed choice and give informed consent,\footnote{1113} and is also in line with NZBORA, giving everyone the right to refuse consent.\footnote{1114} For clarity and cohesiveness, the COCA would require amending by removing sections 36 to 38 and inserting them into LCCA.

No distinction is made between consenting and refusing in this provision, for the reasons discussed above. Once competent, the right to make the decision rests with the patient. However, as competence is decision specific, there will be differing levels of understanding required in each situation.

Whilst LCCA provides for children’s rights, it does not preclude parents from exercising their crucial roles of promoting children’s competence and supporting their decision-making. Although parents and children mostly agree on treatment, a statutory right for children respects their competence and growing autonomy.

Further, for health practitioners, such a statute and provision would provide clarity in the law, reinforcing that they should be proceeding with treatment on competent children's consent. On the rare occasions where parents and children disagree, a clear legal provision could assist them. In practice, there would be no change for health professionals who routinely assess children’s competence and rely on it, and for those unaccustomed to doing so, they may gain reassurance and assistance from the recommended professional guidance, education or a competence assessment toolkit.

Nevertheless, as with the above law reform proposals, there would need to be a consultation process, particularly from representatives from tangata whenua, to ensure that the Treaty of Waitangi and tikanga Māori are respected and considered. The most controversial aspect of this proposal, which could be seen as being in conflict with Māori culture and values, is the potential autonomy of children when making decisions. The LCCA would need to be clear that the rights of children do not negate parental rights, responsibilities and duties to guide and advise children. The COCA, professional guidance and policies would promote such involvement.

\footnote{1111} Underpinning of this is found in the Capability Approach. See Chapter 6 pages 115-118.  
\footnote{1112} Code Right 6.  
\footnote{1113} Code Right 7(1).  
\footnote{1114} NZBORA, s 11.
Two major barriers to the proposed law reforms are securing political will and parents’ understanding. Whilst the amendments to the COCA and the LCCA reflect Gillick, and therefore the current law in New Zealand, they would be a blatant and public declaration that children can be competent and independent agents, whose rights cannot be overridden by a welfare and best interests test. Despite a change in Government since the COCA was passed, it is likely that this would be a step too far for Parliament. Given the lack of attention and understanding of this area of law, together with the support for guardianship rights when COCA was debated, it is unlikely to receive the backing of politicians and voters. Compounding this, most parents are unlikely to support such a move, as it could be perceived by them as losing control, and handing power over to their children. This perception is likely, in light of New Zealand only having moved from viewing children as objects of concern and ownership, to individuals with rights and capacities, in 2004, with the passing of the COCA, and only removing the legal defence of reasonable force from the Crimes Act 1961 in 2007. It is likely to be some time before such law reforms will receive public support or be passed in Parliament.1115

VI. Conclusion

This thesis centred on competence and consent within different healthcare environments (hospital, private, school and community youth health), and in various health areas (medicine, surgery and dentistry), exploring children’s, parents’, health professionals’ and stakeholders’ experiences and views. Children and parents provided powerful insights, rarely seen in research, illuminating the importance and benefits of children participating and their competence being supported and respected. Equally valuable were the perceptions of health professionals, providing understanding of their practices of assessing children’s competence and obtaining consent. By having greater awareness of the dynamic between children, parents and health professionals, and of the factors promoting and constraining children’s competence, greater attention and respect can be given to children’s competence. The findings of this study confirmed that competence is not age related, but rather relational, dependent on many interlinking factors, both internal and external to children. Emerging also were the inconsistencies within and across health professionals’ practice in obtaining consent. By responding to the need for empirical data on medical consent processes, and applying the theories of Childhood studies, Sociocultural Theory and the Capability Approach, they demonstrated that children’s competence evolves through the scaffolding of those more experienced, and that once children are competent, their right to make health decisions, and to give, or refuse, consent, need to be respected. As such age-based laws, policies and practices, defining consent, are not reflective of how and when children develop competence to consent. The essence of children’s competence was eloquently summarised by one GP, when reflecting on youth health, when she said that informed consent is about:

1115 Crimes (Substituted Section 59) Amendment Act 2007 s 59. The level of discontent is highlighted by the citizens-initiated referendum in 2009 when the public were asked to vote on whether “a smack as part of good parental correction be a criminal offence in New Zealand.”
… talking with the young person and asking opinions and questioning them in a non-judgmental way, and questioning your own judgment … [T]hey are going from child dependent to adult independent, and in order to help in that journey it is always asking questions and opinions and listening, so they learn to feel that their opinion is counted and to take responsibility. (Private/School/Youth Service, GP6)
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## Appendix A

### Dr Appelbaum’s Legally Relevant Criteria for Assessing Decision-making Capacities

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Patient’s Task</th>
<th>Physician’s Assessment Approach</th>
<th>Questions for Clinical Assessment</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication a choice</td>
<td>Clearly indicate preferred treatment option</td>
<td>Ask patients to indicate a treatment choice.</td>
<td>Have you decided whether to follow your doctor’s … recommendation for treatment? Can you tell me what the decision is? [If no decision] what is making it hard for you to decide?</td>
<td>Frequent reversal of choice because of psychiatric or neurological conditions may indicate lack of capacity.</td>
</tr>
<tr>
<td>Understand the relevant information</td>
<td>Grasp the fundamental meaning of information communicated by physician.</td>
<td>Encourage patient to paraphrase disclosed information regarding medical condition and treatment.</td>
<td>Please tell me in your own words what your doctor … told you about: the problem with your health now; the recommended treatment; the possible benefits and risks; the risks and benefits of no treatment.</td>
<td>Information to be understood includes nature of patient’s condition, nature and purpose of … treatment, possible benefits and risks of that treatment and alternative approaches … and benefits and risks.</td>
</tr>
<tr>
<td>Appreciate the situation and its consequences</td>
<td>Acknowledge medical condition and likely consequences of treatment options.</td>
<td>Ask patient to describe views of medical condition, proposed treatment, and likely outcomes.</td>
<td>What … is wrong with your health now? Do you believe that you need some kind of treatment? What is treatment likely to do for you? … What do you believe if you are not treated; why do you think your doctor has … recommended this treatment?</td>
<td>Courts have recognized that patients who do not acknowledge their illness … cannot make valid decisions about treatment. Delusions or pathological levels of distortion or denial are the most common causes of impairment.</td>
</tr>
<tr>
<td>Reason about treatment options</td>
<td>Engage in a rational process of manipulating the relevant information.</td>
<td>Ask patient to compare treatment options and consequences and to offer reasons for selection of option.</td>
<td>How did you decide to accept or reject the recommended treatment? What makes [chosen option] better that [alternative option]?</td>
<td>The criterion focuses on the process by which a decision is reached, not the outcome of the patient’s choice, since patients have the right to make “unreasonable” choices.</td>
</tr>
</tbody>
</table>

1116 Appelbaum, above n 26 at 1836. I have insert lines in the table that are not in the original.
Appendix B

Participants' Information Sheet

INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the Aim of the Project?
Fiona Miller is collecting the information as part of her PhD study on children’s participation in managing, and providing consent to, medical and dental treatment. There are three principal aims of this project:

1. To consider the current practice of health practitioners in assessing the capacity of children under the age of 16 years regarding their consent to, or refusal of, medical, surgical and dental treatment.
2. To consider the experiences and views of child patients and their parents/guardians in this process.
3. To consider whether the law and policy on consent processes with child patients is satisfactory or needs amendment.

What Type of Participants is Being Sought?
1. Health professionals such as General Practitioners, hospital-based doctors, nurses and dentists, and school nurses who treat children under the age of 16, and organisations who support children with health conditions.
2. **Family Members**: Children aged between 5 and 15 years who have, or have had, a medical or dental condition requiring treatment over a period of at least six months within the last two years, and adult parents/guardians who have attended at least two medical/dental appointments with the child.

3. **Key informants**, such as policy makers, professional advisers, judges and lawyers, who have a role in the regulation and support of health professionals, or have a role in the development of the law, policy or practice on children giving informed consent to medical, surgical or dental treatment.

**What will Participants be Asked to Do?**
Should you agree to take part in this project, you will be asked to participate in a taped interview of around 30-45 minutes with Fiona Miller. The interview will be conducted at a time and venue convenient to you.

Organisations who support children with their health conditions are also invited to pass on information about the study to families they consider might be interested in participating in the study. An information sheet for parents and a separate one for children will be provided which can be passed onto families. An advertisement flyer is also available which we would be grateful if you could place in your waiting room or office.

**What are the topics of discussion?**

**Health professionals**
The discussion will follow your procedures from when you meet with the child patient and his/her family and impart information, through to obtaining consent and carrying out/prescribing the treatment. The questions will also explore any issues and concerns relating to this process, and the regulation of it in professional practice guidelines and in law.

**Children and Family Members**
With the consent of a parent/guardian, Fiona would like to speak with *children aged between 5 and 15 years*. She would also like to first speak with one or both of the child's parents/guardians who have attended with the child at two or more appointments with health practitioners. Discussions will focus on children’s and adults’ perspectives of the interactions children have had with health professionals, including the explanations given, consent processes and how decisions are taken on the child’s treatment. Fiona is aiming to speak with 10 children and 10-20 parents/guardians in the Wellington and Hutt Valley areas.

**Key Informants**
Discussion will explore the regulation and policy regarding children under 16 consenting to, or refusing, medical, surgical or dental treatment.
What Data or Information will be Collected and What Use will be Made of it?
The information to be collected will be your responses to the questions about consent processes, together with brief demographic data regarding your gender, ethnicity, age-range, locality, and for professionals, your role and length of professional experience. With your agreement the research interview will be taped so that key themes can be identified, and relevant quotes and examples of practice can be retrieved, for inclusion in the doctoral thesis and journal publications.

Only Fiona and her supervisors will have access to the information you and the other participants provide. The data collected will be securely stored in such a way that only they will be able to gain access to it. Data obtained as a result of the research will be retained for at least 5 years in secure storage. Any personal information held on the participants [such as contact details and audio tapes after they have been transcribed] will be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

An overview of the key themes emerging through all the interviews with participants will be analysed. Anonymous quotes and examples of practice will also be included to illustrate these themes. No individual or their location will be identified without their consent.

The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity.

You will be offered a copy of your interview summary and will have the opportunity to correct or withdraw any information you provide at any time in the period following the interview and prior to conclusion of the thesis or publication of any journal articles.

At the conclusion of the project, Fiona will be pleased to provide you with a copy of a summary of the research findings and any journal articles written. In addition, she is very willing to attend any continuing professional development seminars to discuss the findings with you and your colleagues.

Can Participants Change their Mind and Withdraw from the Project?
You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What Participants Do if They Want to Take Part or Have any Questions? If you would like to take part or if you have any questions about our project, either now or in the future, please feel free to contact either:-
Fiona Miller and/or Associate Professor Nicola Taylor
Work: 04 801 5156 (Mon, Wed, Fri) Children’s Issues Centre, University of Otago
Cell: 021 0297 4568 University Telephone Number: (09) 373 9717
Email: milfi176@student.otago.ac.nz Email: nicola.taylor@otago.ac.nz
This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
Appendix C

Adult’s Consent Form

Reference 13/279
23 December 2013

Children and Health Professionals: Partners in Health Care?

CONSENT FORM FOR PARTICIPANTS

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. My participation in the project is entirely voluntary;

2. I am free to withdraw from the project at any time without any disadvantage;

3. Personal identifying information [e.g. audio-recordings] will be destroyed at the conclusion of the project, but any raw data on which the results of the project depend will be retained in secure storage for at least five years;

4. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my anonymity.

I agree to take part in this project.

.............................................................................  .................................................................
(Signature of participant) (Date)

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
Appendix D

Letter to Health Professionals

Reference 13/279
23 December 2013

Dear Health Practitioner,

Research Project: Consent to Medical and Dental Treatment by Children Under 16 Years of Age

Thank you for showing an interest in the research I am undertaking for my PhD at the University of Otago, Faculty of Law, under the supervision of Associate Professor Nicola Taylor and Professor Mark Henaghan. The research is about the involvement of children under the age of 16 years in consent processes and decision-making regarding medical, surgical and dental treatment. This is with a view to considering whether the current law and policy is adequate or in need of amendment.

I would like to interview a diverse range of health practitioners, such as General Practitioners, hospital doctors, nurses and dentists and school nurses who treat children, and also support organisations who work with children who have health conditions. I have enclosed information about my study and am writing to invite you to take part in a 30-45 minute taped interview with me. I can interview you at a time and place that is most convenient to you. Strict guidelines regarding confidentiality will be observed so that every endeavour will be made to ensure you remain anonymous. This study has been approved by the Human Ethics Committee at the University of Otago.

Please phone or email me if you would like to take part in the study or if you have any questions.

I appreciate your consideration of my request.

Yours sincerely

Fiona Miller
PhD Student
Appendix E
Letter to Key Stakeholders

Reference 13/279
23 December 2013

Dear Stakeholder,

Research Project about Consent to Medical and Dental Treatment by Children Under 16 Years of Age

Thank you for showing an interest in the research I am undertaking for my PhD at the University of Otago, Faculty of Law under the supervision of Associate Professor Nicola Taylor and Professor Mark Henaghan. The research is about the involvement of children under the age of 16 years in consent processes and decision-making regarding medical, surgical and dental treatment. This is with a view to considering whether the current law and policy is adequate or in need of amendment.

I intend to interview a wide range of health professionals, families, children, and professionals who have a role in the development of the law, practice or policy on children giving informed consent. I have enclosed information about the study and am writing to invite you to participate in a taped interview with me at a time and place that is most convenient to you. The interview would take about 30-45 minutes.

Strict guidelines regarding confidentiality will be observed so that every endeavour will be made to ensure you remain anonymous. This study has been approved by the Human Ethics Committee at the University of Otago.

Please phone or email me if you would like to take part or if you have any questions.

I appreciate your consideration of my request.

Yours sincerely,

Fiona Miller and/or Associate Professor Nicola Taylor
Work: 04 801 5156 (Mon, Wed, Fri)

Children’s Issues Centre, University of Otago

Cell: 021 0297 4568 University Telephone Number: (09) 373 9717

Email: milfi176@student.otago.ac.nz Email: nicola.taylor@otago.ac.nz
Dear Parent(s) or Guardian(s),

Research Project about Consent to Medical and Dental Treatment by Children Under 16 Years of Age

Thank you for showing an interest in the research I am undertaking for my PhD at the University of Otago under the supervision of Associate Professor Nicola Taylor and Professor Mark Henaghan. You must have a child between 5 and 15 years who has a health condition, either medical or dental. I am very grateful to you for giving me your time and considering whether just you, or you and your child, would like to take part in this research. It may be that a support organisation that you or your child consults with has sent you details of the research of my behalf, or you have heard about the research and have asked me for more information.

I believe it is really important to hear from families and children about their experiences of consulting with health professionals in the management and decision-making of your child’s health condition. I would like to hear about such things as how involved you feel your child is, or should be, in discussions and consent processes with health professionals, and how decisions on the management of your child’s health are taken. This will be an important part of my research in considering whether the law needs to be changed.

I have enclosed information that gives details of my study and am inviting you to consider taking part in an interview with me of around 30-45 minutes duration. I would also like you to consider whether your child might be able to participate in the study too.

The interviews could take place at your home or at another place suitable for you or your child. Please note that what I am told will be confidential and will not be passed onto your healthcare professionals or any other organisation.

Strict guidelines regarding confidentiality will be observed so that every endeavour will be made to ensure you remain anonymous. If you agree to take part I will ask you to sign a
consent form, and to agree to your child’s participation by signing a separate consent form on their behalf. I will also check before I interview your child that your child is happy to take part – they have a consent form to sign too.

This study has been approved by the Human Ethics Committee at the University of Otago.

Please phone or email me if you would like to take part or if you have any questions.

I appreciate your consideration of my request.

Yours sincerely

Fiona Miller

Fiona Miller, PhD Student and/or Associate Professor Nicola Taylor
Work: 04 801 5156 (Mon, Wed, Fri) Children’s Issues Centre, University of Otago
Mobile: 021 0297 4568 University Telephone Number: (09) 373 9717
Email: milfi176@student.otago.ac.nz Email: nicola.taylor@otago.ac.nz
Appendix G

Parents’ Consent Form

CONSENT FORM FOR PARENTS/GUARDIANS ON BEHALF OF THEIR CHILD

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:
1. My child’s participation in the project is entirely voluntary;
2. I am free to withdraw my child from the project at any time without any disadvantage;
3. Personal identifying information, such as audio-recordings will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for at least five years;
4. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my child’s anonymity.
5. The researchers will contact me prior to my child being interviewed.

I agree for my child to take part in this project.

............................................................................
(Signature of parent/guardian) (Date)

Name:................................................................. Ph: .................................

Address:.............................................................. Email:..............................

Name of Child:..............................................................
Appendix H

Children/Young People’s Information Sheet

Reference 13/279
23 December 2013

Children and Health Professionals: Partners in Health Care?

Thanks for taking the time to read this to learn more about my study and to see whether or not you would like to take part. If you do decide to – that’s great, thank you! But if you would rather not, that is fine. Whether you agree to take part or not is completely up to you.

Why am I doing the study?
I am Fiona Miller and I am studying at the University of Otago. I am studying about children consenting (agreeing) to medical or dental treatment. What this means is, when you go to the hospital, doctor or dentist, are you asked what you think about receiving any treatment?

I think it is really important that children and young people get to have their say. So that’s why I want to talk to you – so I can find out what you think. That way we may be able to help adults, like doctors, nurses and dentists, think how it could be better for children and young people, and help to make things better for other children and young people.

Who is taking part?
I would like to talk to 10 children and young people between the ages of 5 and 15 years. I will also be talking to some adults such as Mums and Dads, doctors, dentists and nurses. I may not be talking to your doctor, dentist or nurse though.

What will you be asked to do?
I will meet you and your family, probably at your home, but I can meet you somewhere else if that is best. I will talk to you about whether your doctor, nurse or dentist tell you what treatment you need and what you think about that. I will talk to you for about 30 minutes. You can say as much or as little as you want to. You can stop at any time and if you feel you don’t want to take part anymore, that’s not a problem. I can talk to you on your own or you can have an adult with you.

What will happen with what we talk about?
I may take some notes of what we talk about and our discussion will also be recorded to make sure I don’t miss anything important. What we talk about will be confidential (private). I won’t tell anyone what you say.
What you and all the other children and young people tell me will be written in a report that others can read, but this will not have anyone’s name in it that could identify you. The results of the study might also be shown at meetings or talks but this won’t show any of the names of the children who took part.

**Can you change your mind if you decide later that you don’t want to take part?**
Yes, if you change your mind you can tell me and we can stop.

**What if you have questions about the study?**

If you have any questions you can contact either:

Fiona Miller
Work: 04 801 5156 (Mon, Wed, Fri)  
Mobile: 021 0297 4568
Email: milfi176@student.otago.ac.nz
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**This study has been approved by the University of Otago Human Ethics Committee.**
Appendix I

Children/Young People’s Consent Form

Reference 13/279
23 December 2013

Children and Health Professionals: Partners in Health Care?

CONSENT FORM FOR CHILDREN AND YOUNG PEOPLE

I have been told about this study and understand what it is about. All my questions have been answered in a way that makes sense.

I know that:
1. Participation in this study is voluntary, which means that I do not have to take part if I don’t want to and nothing will happen to me. I can also stop taking part at any time and don’t have to give a reason.

2. Anytime I want to stop, that’s okay.

3. Fiona will audio-record me so that she can remember what I say, but the recording will be erased after the study has ended.

4. If I don’t want to answer some of the questions, that’s fine.

5. If I have any worries or if I have any other questions, then I can talk about these with Fiona.

6. The paper and computer file with my answers will only be seen by Fiona and the people she is working with. They will keep whatever I say private.

7. Fiona will write up the results from this study for her University course. The results may also be written up in journals and talked about at conferences. My name will not be on anything the researchers write up about this study.

I agree to take part in the study.

..........................................................................................................

Signed

..........................................................................................................

Date
Appendix J

Interview Schedule for Health Professionals

Children and Health Professionals: Partners in Health Care?

Interview schedule for GPs, Hospital Doctors, Nurses and Dentists, and School Nurses:

Note: Discussion relates to children UNDER 16 years of age

BACKGROUND

1. What are the range of procedures you carry out or treatment you prescribe for children.
2. Estimate the number of children in the last year you consulted with as patients?
3. On average how many children do you estimate you consult with as patients each year?
4. What is the age range of children you consult with?

Consultation with children:
Tell me about your process when you consult with children as patients?
Prompt:
5. What type of information do you impart?
6. What ways are used to explain treatment or procedures to children?
7. How do you give children an opportunity to take part in the discussion or ask questions?
8. At what age would you bring children into the discussion?
9. Describe a consultation with a child that sticks in your mind?

Assessing competency:
What are the triggers or cues that signal to you that a child may be competent to consent to treatment?

Prompts:
10. What are the most important factors for you when considering whether to assess a child’s competence?

What is your process when you are alerted that a child may be competent to consent?
11. How much time do you spend assessing competency?
12. What determines for you whether a child is competent to consent?
What is your process when you have assessed a child as being competent to consent?

Prompts:
13. How does it differ from when a child is incompetent?
14. How many children in a year do you estimate you assess as being competent to consent?
15. What is the age range?
16. What is the youngest age some of your patients could make sensible decisions about proposed treatment/procedure?
17. What does informed consent mean for you in your practice?

Obtaining Consent:

What is your process for obtaining consent to carrying out procedures or prescribing treatment for children?

Prompts:
18. How is the consent actually given or the decision actually made?
19. Tell me about a situation that sticks in your mind where the child has given consent or has actively been involved in the process?

Challenging situations where there has been disagreement about treatment/procedure:

Describe a situation where either there has been disagreement between you and the parents or between the adult and child?

Prompts:
20. What was the child’s involvement?
21. How was it resolved?
22. If you have not experienced this what do you think you would do such a situation?

Describe a situation where a child between the ages of 5-15 years of age has refused the treatment or procedure you are attempting to administer?

Prompts:
23. How did you deal with this?
24. What was the child’s involvement in discussions?
25. How was it resolved?
26. After you have prescribed treatment, or carried out the procedure, what follow up discussions do you have with the parent and child about the degree of compliance by the child, for example taking the medication?
27. Describe a situation where the parent has indicated difficulty in this respect? How has it been resolved?
28. Who do you think should have the final decision on the treatment or procedure?
29. Do you think there is a different standard of competency required for a child who is indicating consent to the proposed treatment from a child that is refusing? If so what is the difference?

Your views on the regulation of children consenting

30. What is your understanding of how your professional guidance and the law regulate children under 16 years of age consenting to treatment?
31. Where does that knowledge come from?
32. Do you think that your professional guidance and/or the law are clear on your obligations in respect of children under 16 years of age consenting/refusing treatment?
33. What issues have arisen for you in your practice relating to children under 16 years of age consenting to treatment?
34. Do you have any views on what changes would make the situation better for your practice?
35. Do you think that children should have the right to consent to medical/dental treatment? If so what would be the criteria for doing so?
36. Do you think that children should have the right to refuse medical/dental treatment? If so what would be the criteria for doing so?
37. How do you feel about children consenting or refusing medical/dental treatment/procedure?
38. Is there any professional development that would be helpful in this area of children consenting to treatment?
39. Do you have any advice to give other professionals in New Zealand or internationally?
40. What advice/message would you like to give to parents and/or children?
41. Is there anything else you would like to raise about the consent process or children under 16 giving consent?
42. Please advise your gender, ethnicity, age-range (30-40; 41-50; 51-60; 61-70; 70+), professional title and length of professional experience.
Appendix K

Interview Schedule for Parents

Children and Health Professionals: Partners in Health Care?

Interview Question for Parents

Background

Tell me about what your child is like, in particular their personality.

Prompts:

1. How old is your child now?

2. How are decisions in your household made and what decisions in your household does your child make?

3. How responsible do you consider your child to be on a scale of 1-10 (1 lowest, 10 highest)

Health

Tell me about your child's health.

Prompts:

4. What health condition does your child have?

5. How old was your child when first diagnosed?

6. What sorts of health professionals has your child seen for their health condition?

7. Can you give me a timeline of what treatment/procedures your child had has, with whom and where?

8. How many times has your child been seen by health professional(s) about their condition in the last two years?

9. When was the last time they saw a health professional?

10. How many times has your child been to hospital for their health condition?

Talking with Health Professionals
Tell me about a typical meeting you and your child have when you meet with a health professional.

Prompts:

11. Do the health professionals spend time talking to your child about their health?

12. In what ways has your child’s health condition, treatment options and risks/benefits of treatment been explained to your child, for example verbal explanations, written material, audio/visual?

13. How participative is your child in discussions?

14. How do you think your child feels when he/she is talked to directly by a health professional?

15. How do you feel about health professionals talking directly to your child?

16. What would assist in your child becoming more involved in consultations?

17. Who do you think has contributed the most to your child’s understanding of their health condition?

18. On a scale of 1 to 10, to what extent does your child understand their health condition and how to manage it? (1 no understanding 10 full understanding)

19. What bits does your child appear to understand and what bits do they not understand?

Health care decisions

Who do you think makes the decisions about the management of your child’s health condition?

Prompts:

20. How are those decisions taken?

21. How involved do you think your child is in the decisions?

22. What sorts of decisions do you make and what if any does your child make?

23. Tell me about a time when you feel your child was included in discussions and decision-making?

24. Have you and your child had disagreements about treatment/procedures? Tell me about that?

25. How do you and your child work out disagreements about what treatment he/she should have, or whether he/she should have any treatment?
26. Do you think children under the age of 16 should be able to give their consent for medical treatment if the health professional thinks they understand what is involved?

27. Do you think YOUR child should give consent to medical treatment if the health professional thinks he/she understands what is involved and why? How would you feel about them consenting?

28. Have your views or feelings on the question of your child consenting to treatment changed since your child was diagnosed? If so in what way(s)?

29. At what age do you think children should be able to consent to medical treatment?

30. Do you think children under the age of 16 should be able to refuse medical treatment if the health professional thinks they understand what is involved by doing so and understand the consequences?

31. At what age should children be able to so refuse?

32. If you could give advice to give health professionals what would it be?

33. What are you and your child’s ethnicity, what is your age and employment.
Children and Health Professionals: Partners in Health Care?

Hi, I’m Fiona Miller. I am studying at the University of Otago in Dunedin. I am talking with children aged between 5 and 15 years, and their families, about children consenting (agreeing) to medical or dental treatment. What this means is when you go to the hospital or doctor are you asked what you think about the treatment you are having?

Your Mum/Dad/other adult has said that it is okay for me to ask you if you would like to help me with my study. I’ll also be talking to your Mum/Dad/other adult but I think it is really important that children and young people get to have their say about it all too. So that’s why I want to talk to you – so I can find out what you think. That way we may be able to help adults like doctors, nurses and dentists think how it could be better for children and young people, and help to make things better for other children and young people.

Everything you say to me will be private, just between you and me, and I won’t tell Mum, Dad, or anyone else in your family what you tell me. Also, I will not tell your doctor, dentists or any nurses that you see. I will be talking to the people I work with about what we talk about but they won’t know your real name, because you can choose a fake name. What I want to know is what you think so there are no right or wrong answers, and if there are any questions that you don’t want to answer just tell me. Sometimes children/young people have a lot to say about some things and nothing to say about other things so you can say as much or as little as you want to and it’s okay if you don’t have answers – just say you don’t know. You don’t have to talk to me if you don’t want to and you can tell me if you want to stop at any time and we will.

What you and everyone else tell me will be written in a report that others can read. This will not have anyone’s names, and nobody will know it was you who said anything in the report because I’ll use your fake name. It is okay if you change your mind after you talk with me. If that happens before the report is written I will not use anything you have said.

[Ask child/young person if they are happy to talk to you. Ask child/young person what fake name they would like. Show child/young person the consent form and ask them to sign it. Explain that we are going through a consent process. This is
them agreeing to taking part in my study. Explain that the doctor, nurse or dentist has to get consent either from a parent/guardian and/or from them. This is one of the things we will be talking about. Explain audio recorder and give child the option of turning it off if they want to.

Warm up questions-
1. How old are you; where were you born; what school do you go to; what do you like to do after school and at weekends; who lives with you in your home.
2. What choices are you allowed to make in your home, for example, what you have for lunch/dinner, what television shows you watch or what activities you do?
3. What jobs or responsibilities do you have at home?
4. What jobs or responsibilities do you have at school?

Health
I'd like to talk to you about going to see the doctor (or dentist or nurse) or when you go to hospital for (cancer/diabetes/asthma/other). Tell me about what happens when you go to see the doctor or dentist or when you go to hospital.

Prompts:
5. Who do you go with?
6. Do you usually see the same doctor/nurse/dentist? Can you remember who you’ve seen? Who do you like seeing the best? What is good about her/him?
7. Mum/Dad tells me that you have seen Doctor/Nurse/Dentist X. Tell me about that?
8. Does he/she talk to you or just to who you go with? How does that make you feel?
9. Mum/Dad tells me that you have also seen….Tell me about that?
10. Who has explained what treatment/procedure you need? How did they explain it to you? For example pictures, a leaflet or show a video?
11. Did you understand it all?
12. Did you get a chance to ask questions?
13. What bits did you understand? Were there any bits that you didn’t understand?
14. Who has helped you understand the treatment/procedure the most?
15. Have you ever seen a doctor/nurse/dentist on your own? If so how old were you and what was it for?
16. Do you think children should be allowed to see a doctor/nurse/dentist on their own?
17. What do you think would be good about seeing the doctor/nurse/dentist on your own, and what would be bad?

Consent to treatment:

Tell me about how it is decided what treatment you are to have.
18. Mum/Dad tells me that you have had treatment x/procedure y. Were you asked what you thought about having that treatment?
19. Who agreed that you were to have that treatment?
20. Were you asked if you agreed? Who asked you?
21. Do you feel you were included in agreeing to the treatment?
22. Mum/Dad tells me that you have also had…Tell me about who agreed to that? Were you asked? Did you feel included in agreeing to have it?
23. Who do you think should agree to what treatment/procedures children have?
24. How old do you think children should be to get a say in what happens to them at hospital, or when they go to the doctor or see the dentist?

25. What would be good about that? What would be bad?

26. Can you think of any situations/ reasons children go to see a doctor or dentist and they can say they don’t want the treatment?

27. Is there an age when children should be able to say to the doctor or dentist that they don’t want the treatment?

28. If you could give advice to doctors, nurses or dentists what would it be?

29. If you could give advice to other children about seeing the doctor, nurse or dentists what would it be?
Appendix M

Interview Schedule for Key Stakeholders

Children and Health Professionals: Partners in Health Care?

Interview Questions for Key Stakeholders

Note: Discussion relates to children UNDER 16 years of age

BACKGROUND

What issues have arisen for your organisation on the question of children consenting to medical or dental treatment?

Prompts:
1. How were those issues resolved?
2. How often in your experience has an issue been raised by one of your members about an issue of children participating in, or consenting to, medical or dental treatment?
3. What is your role in this area? Any other issues in this area for your organisation?

Regulation of children Consenting: Medical, Dental, Nursing Councils and Paediatric Society

Do you think your members will be aware of their professional practice guidance and the law on the issue of children under 16 consenting to medical or dental treatment?

Prompts:
4. What do you base this on?
5. How satisfied do you think your members are with the current situation of the law and guidance on children consenting or refusing medical/dental treatment? How do you gauge this?
6. How does your organisation facilitate discussion with your members on this issue?
7. What is your organisation’s role in raising awareness of this issue with parents and children?
8. Do you think there is a need to raise awareness of this issue? Why?

Views on the regulation of children consenting to treatment
What is your view of the current regulation of children under 16 consenting/refusing treatment?

Prompts:

9. What is your organisation’s view on whether children should have the right in law to consent (and refuse) to medical or dental treatment?
10. What do you think the law should be for children consenting to medical or dental treatment?
11. Is there any professional development, training or supports that would be helpful to you or your members in this area of children consenting to medical or dental treatment?
12. Do you have any advice to give health professionals, parent or children regarding this area?
13. Is there anything else you would like to raise about the consent process or children under 16 giving consent?
14. What are your ethnicity, age-range (30-40; 41-50; 51-60; 61-70; 70+), professional title and length of professional experience?
Appendix N

Example of Hospital Consent Form

Request for Treatment/Procedure(s)

I, [ ] (patient, parent, guardian, person care and welfare attorney) request that the following procedure/treatment be performed on me/my child/personal lacking capacity to give consent.

[ ] (name of patient if different from the above name)

[ ] Description of treatment/procedure(s)

I understand the nature, benefits and risks of the above treatment and/or procedure(s). I have had explained to me the alternatives treatment and/or procedure(s) available, including not having any treatment. I have had the opportunity to ask my questions about the above treatment and/or procedure(s). I am aware that I may ask for more information at any time and that my health information may be used for quality auditing purposes.

I agree that if during the treatment/procedure(s) there is an unexpected finding or event additional procedures deemed to be essential might be carried out.

I agree to my blood being taken for testing in the event of a staff member being exposed to my blood or body fluid.

I understand the nature, benefits and risks of receiving blood components/blood products and agree to receiving these if clinically necessary and in my own best interests.

I understand and agree that written, electronic, radiographic, video, sound and photographic records may be made and stored, and may be referred to at a later date for teaching purposes and/or for Ethics committee approved research.

I understand that this treatment is being carried out in a teaching hospital and agree to observation of and participation in my treatment and/or procedure(s) by students under appropriate supervision.

I understand that following this treatment/procedure(s), I may be sedated and should not drive a motor vehicle, operate machinery or potentially dangerous appliances, drink alcohol or make important legal or financial decisions for at least 18 hours afterwards.
I understand that tissue removed during the treatment/procedure(s) may be submitted for pathological examination, kept and referred to at a later date for clinical purposes, audit, teaching and for Ethics Committee approved research. I understand that the tissue may be returned to me if I wish (a Tissue Return Form (X DHB) or a Body Part Chain of Custody Form (X DHB) is required.. YES NO N/A

Signature of patient/parent/guardian/Date
personal care and welfare attorney

Name of health professional [ ] Date
Signature Designation

The treatment/procedure I intend to perform on [ ] is correctly described above.

Name of person performing treatment/procedure(s) [ ] Designation
Signature Date

Please turn over to add supporting relevant information.