

CHILD-FRIENDLY HEALTHCARE: DELIVERING ON THE RIGHT TO BE HEARD

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I. INTRODUCTION

Under the United Nations Convention on the Rights of the Child (CRC),¹ children capable of forming views have the right to express those views and have them taken into account in all decisions that affect them. The last two decades have witnessed the increased participation of children in decision-making in areas such as education,² family law,³ and on matters of public policy.⁴ However, attention has only more recently focussed on the child's right to be heard in the context of healthcare decision-making. In 2009, the United Nations Committee on the Rights of the Child, the body with responsibility for monitoring implementation of the CRC, stated in the context of healthcare that:

Children, including young children, should be included in decision-making processes, in a manner consistent with their evolving capacities.⁵

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¹ General Assembly Resolution 44/25, November 20 1989, art 12.

² L Lundy, "Voice" Is not Enough: the Implications of Article 12 of the United Nations Convention on the Rights of the Child for Education' (2007) 33 Br Educ Res J 927.

³ See, for example, C Smart and B Neale, 'It's My Life Too – Children's Perspectives on Post-divorce Parenting' (2000) Fam L 63; M Gollop, A Smith and N Taylor, 'Children's Involvement in Custody and Access Arrangements after Parental Separation' (2000) 12 Child Fam LQ 383; K Röbbäck and I Höjer, 'Constructing Children's Views in the Enforcement of Contact Orders' (2009) 17 Intl J Children's Rights 663.

⁴ G Lansdown, *Promoting Children's Participation in Democratic Decision-Making* (UNICEF Innocenti Research Centre, Florence 2001); R Sinclair, 'Participation in Practice, Making it Meaningful, Effective and Sustainable' (2004) 18 Children and Society 106; N Thomas, 'Towards a Theory of Children's Participation' (2007) 15 Intl J Children's Rights 199.

⁵ Committee on the Rights of the Child, General Comment No 12 *The Right of the Child to be Heard* (2009) UN Doc CRC/C/GC/12, para 100.

At a national level, in the UK, much of the increased recognition of the importance of children's participation may be traced to the Report of the Bristol Royal Infirmary Inquiry which set out a new framework for communication between healthcare professionals, children, and their parents or carers.⁶ The Inquiry recommended that:

Healthcare professionals who care for children must be able to listen to children, to respect their needs for information and to be prepared and able to give such information in the right amount and in a way which is suitable for the child's age.⁷

This approach is now reflected in ethical guidance for healthcare professionals working with children and young people. The guidance issued by the Royal College of Paediatrics is indicative of this new approach, requiring that '[p]aediatrians must listen to children and young people and respect their views'.⁸

Acceptance of the principle that children and young people should participate in decision-making about their healthcare is, of course, only a first step. As Priscilla Alderson and Jonathan Montgomery point out '[p]articipation can be worse than useless when used as a pretence of consultation, or to disguise the fact that no real choice is being given'.⁹ Therefore, it is essential to ensure that the development of appropriate participative practices is informed by children's real-life experiences and that practical barriers to participation are identified. This article explores children's participation in healthcare decision-making, with a particular focus on younger children.¹⁰ This focus reflects a concern to explore participation rights in a context which is broader than the mature child's right to decision-making autonomy.

⁶ *Learning from Bristol: The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984–1995* Command Paper CM 5207 (Bristol Royal Infirmary Inquiry, Bristol 2001).

⁷ *Ibid.*, pp 431–2.

⁸ See *Good Medical Practice in Paediatrics and Child Health: Duties and Responsibilities of Paediatricians* (Royal College of Paediatrics and Child Health, London 2002), para 21. In Ireland, see *Guide to Professional Conduct and Ethics for Registered Medical Practitioners* (7th edn Medical Council, Dublin 2009), para 43.1. Note also the policy shift to participation in service planning: see J Lightfoot and P Sloper, *Having a Say in Health: Guidelines for Involving Young Patients in Health Services Development* (University of York, Social Policy Research Unit, York 2002); A Franklin and P Sloper 'Listening and Responding? Children's Participation in Health Care within England' (2005) 13 *Intl J Children's Rights* 11, 12–4.

⁹ *Health Care Choices: Making Decisions with Children* (Institute for Public Policy Research, London 1996) 27.

¹⁰ The focus of the article is on children aged less than 14 years. For this reason, the term 'child' (rather than 'young person') is used throughout, except when discussing issues of competence.

The article begins by considering what participation means and by differentiating between autonomous decision-making by children and children's participation in decision-making. It then evaluates the current state of participation in practice, drawing especially on a study conducted by the authors into the realities of children's participation in healthcare decision-making in Ireland.¹¹ This study helps identify a number of barriers to the delivery of participative practices. In particular, it identifies the potentially inhibiting role of parents, a finding which is replicated by studies in other jurisdictions. The article then investigates the legal status of parental objections to children's participation and argues that both the CRC and the European Convention on Human Rights (ECHR) provide legal support for a requirement that the child's right to participate in healthcare decision-making must be protected, even in the face of parental objections. The article also argues that focussed legislation and codes of practice have a valuable contribution to make to the delivery of children's participation rights in practice and that the introduction of such measures should be a priority.

II. PARTICIPATION: WHAT DOES IT MEAN AND WHY DOES IT MATTER?

As Alderson and Montgomery note, the concept of participation is open to a range of interpretations, ranging from 'having minimal information to having quite a full share in decision-making'.¹² Because of the amorphous nature of participation, it is essential to interrogate not just how the concept is applied but also how it is conceived.

A. Understanding Participation

In understanding what 'participation' means, it is important to differentiate between participation in decision-making and autonomous decision-making. In the latter instance, decision-making power is located wholly with the decision-maker. While he or she may choose to consult with others, ultimately, the freedom to make the decision, as well as the responsibility for the decision and its consequences, rests entirely with the decision-maker. In respect of children and

¹¹ U Kilkelly and M Donnelly, *The Child's Right to be Heard in the Healthcare Setting: Perspectives of Children, Parents and Health Professionals* (Office of the Minister for Children and Youth Affairs, Dublin 2006) <www.omcya.gov.ie> accessed 18 January 2011.

¹² *Health Care Choices*, above n 9, p 27.

young people, the accrual of the legal right to make healthcare decisions depends on the nature of the decision made.¹³ Children aged more than 16 years have a statutory right to consent to treatment¹⁴ and, for children aged less than 16 years, the right accrues to those children who meet the standard for competence as set out in *Gillick v West Norfolk and Wisbech Area Health Authority*.¹⁵ In respect of treatment refusal, the right accrues only when a young person reaches the age of 18 years. Prior to the attainment of this age, in England and Wales at any rate, decisions may be overridden by the courts on the basis of the 'best interests' of the child or young person.¹⁶

Participation in decision-making is different from autonomous decision-making in a number of ways. First, the former concept is more flexible and allows for a range of meanings. Harry Shier outlines five levels of participation by children in decisions.¹⁷ These are, first, children are listened to; second, children are facilitated in expressing their views; third, children's views are taken into account; fourth, children are involved in decision-making processes; and fifth, children share power and responsibility for decision-making. Thus, unlike autonomous decision-making, participation is not restricted to children who meet the designated standards for

¹³ For a sample of the extensive discussion of this topic, see A Bainham, 'The Balance of Power in Family Decisions' (1986) 45 CLJ 262; J Eekelaar 'The Emergence of Children's Rights' (1986) 6 OJLS 161; M Brazier and E Cave, *Medicine, Patients and the Law* (4th edn Penguin, London 2007), Ch 15; J Fortin, *Children's Rights and the Developing Law* (3rd edn Cambridge University Press, Cambridge 2009), Ch 5.

¹⁴ Family Law Reform Act 1969, s 8 (EW); Non-Fatal Offences against the Person Act 1997, s 23(1) (Irl).

¹⁵ [1986] A.C. 112. It is probable that the Irish courts would endorse a *Gillick*-type approach to consent: see Law Reform Commission Consultation Paper, *Children and the Law: Medical Treatment* (LRC CP 59, Dublin 2009), paras 4.05–4.07.

¹⁶ See *Re R (A Minor)* [1991] 4 All E.R. 177; *Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* [1992] 3 WLR 758. The question has not arisen in Ireland, although note the finding of Laffoy J in *Fitzpatrick v K* [2008] I.E.H.C. 104, at p 19 of the transcript (in the context of adults) that the refusal of life-saving or sustaining treatment constitutes a waiver of the right to life and that, accordingly, a higher standard of capacity should be required. For a critique of the distinction drawn between consent to and refusal of treatment, see G Douglas, 'The Retreat from *Gillick*' (1992) 55 MLR 569; M Brazier and C Bridge, 'Coercion or Caring: Analysing Adolescent Autonomy' (1996) 16 LS 84; *Brazier and Cave*, above n 13, pp 405–6.

¹⁷ 'Pathways to Participation: Openings, Opportunities and Obligations: A New Model for Enhancing Children's Participation in Decision-making in line with Article 13.1 of the UNCRC' (2001) 15 *Children and Society* 107. See also RA Hart, 'Children's Participation: From Tokenism to Citizenship' (1992) *Innocenti Essays*, No 4 (UNICEF Innocenti Research Centre, Florence 1992). A helpful summary of different typologies may be found in *Thomas*, above n 4, 204–6.

competence but is important in respect of all children, albeit to differing degrees depending on their age and maturity.¹⁸

Second, as Shier's typology illustrates, even at the highest level of participation, children do not have the full power (or responsibility) for decision-making. Rather, power is shared between children and adults. Ultimately, this means that a participating child's decision may be overturned on the basis of what is in his or her 'best interests' in a way which an autonomous child's decision may not. However, if participation as a right is to be respected in a meaningful way, it must change the nature of the 'best interests' test. This is because participation introduces a subjective element into what was traditionally an objective assessment.¹⁹ It requires that the views of the child be sought and that the child's preferences be listened to in making an assessment of his or her best interests. As the Committee on the Rights of the Child explains in the context of the CRC, 'there can be no correct application of article 3 (the best interests standard) if the components of article 12 (the right to be heard) are not respected'.²⁰ In England and Wales, this view of best interests is, of course, also reflected in the Children Act 1989.²¹ However, it is less clear that this view prevails consistently in the healthcare context. Here, most assessments of 'best interests' have tended to take place in the context of treatment refusal.²² While the views of the child have sometimes been noted by the courts, there is little evidence that they have substantially influenced the decisions reached.²³

Participation arguably requires that if, having taken account of the child's own views as part of the assessment of 'best interests', the child's views are to be overridden, the reasons for this are explained to the child in language which the child can understand. Furthermore, it might be argued that this approach to participation requires that efforts must be made to act in a way which most closely accords with the

¹⁸ Note, for example, the arguments regarding participation rights of babies in P Alderson, J Hawthorne and M Killen, 'The Participation Rights of Premature Babies' (2005) 13 Intl J Children's Rights 31.

¹⁹ For a similar argument in respect of participation by patients lacking capacity under the Mental Capacity Act 2005, s 4, see M Donnelly, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 Med L Rev 1, 20–1.

²⁰ Committee on the Rights of the Child, *The Right of the Child to be Heard*, above n 5, para 74.

²¹ Children Act 1989, s 1(3) sets out the factors to be taken into account in deciding whether to make, discharge, or vary an order under the Act. These include the 'ascertainable wishes and feelings of the child concerned (considered in light of his age and understanding)'.

²² See S Elliston, *The Best Interests of the Child in Healthcare* (Routledge-Cavendish, Abingdon 2007) 127–39.

²³ See, for example, *Re E (A Minor)* [1993] 1 FLR 386; *Re M (Child: Refusal of Medical Treatment)* [1999] 2 FLR 1097.

child's views. Thus, for example, if an alternative treatment approach might be adopted which would be more in line with the child's views, it would seem reasonable that this should be considered in the light of the child's views, again with reference to the child's maturity.

While autonomous decision-making and participation in decision-making are different, the concepts also have a good deal in common. Both require the information about the healthcare decision to be provided to the child in an accessible manner. Both concepts also place the child or young person at the heart of the decision-making process. In respect of many, though by no means all, healthcare decisions involving children, it will not make a substantial practical difference whether the decision would be categorised legally as an autonomous one made by the child with the support of his or her parent/s or healthcare professionals or as a decision made by adults in which the child participated. If the parties are broadly in agreement, the decision-making experience may well be the same from the child's perspective, regardless of the legal principles which underpin the process.

B. The Importance of Participation

Participation in healthcare decision-making is important for a number of reasons. First, the right to participate in decision-making is a core right under the CRC. Article 12 requires States Parties to 'assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'.²⁴ This right has been identified by the Committee on the Rights of the Child as a general principle, with which all CRC provisions must be read.²⁵ Of particular significance in this respect is Article 13, which recognises the child's right to freedom of expression which includes the freedom 'to seek, receive and impart information ... either orally, in writing or in print, in the form of art, or through any other media of the child's choice'.²⁶ Also significant is Article 24, which requires States Parties to recognise the right of the child to the

²⁴ *Shier*, above n 17, 114, argues that the CRC protects participation to level three of his five-level typology (see text to n 17 above), requiring that children's views be taken into account (although he also notes the importance of developing participative practices to all five levels).

²⁵ See Committee on the Rights of the Child, *General Guidelines regarding the form and contents of Periodic Reports to be submitted by States Parties under Article 44, paragraph 1(b) of the Convention*, CRC/C/58, 1996.

²⁶ This provision is supplemented by Article 17 which recognises the role of the mass media in disseminating information to children and requires States Parties to ensure that children have access to information from a diversity of sources, 'especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health'.

enjoyment of the highest attainable standard of health.²⁷ Thus, state compliance with this most highly ratified instrument in international law²⁸ requires the development of mechanisms for participation.²⁹

Second, there are broader policy reasons why the child's right to participate in healthcare decision-making should be secured. In general terms, it is recognised that facilitating the participation of children in decision-making promotes children's protection and enhances children's skills and self-esteem.³⁰ Participation from an early age also assists in developing autonomy 'competencies', facilitating better decision-making not just in children but in the adults they become.³¹ In the healthcare context, Priscilla Alderson's interviews with children preparing for surgery showed that many children, especially children who because of illness or disability have had long-term exposure to the healthcare system, have a very high degree of maturity and a profound understanding of the issues involved in making choices about their health.³² Participation in healthcare decision-making also has other instrumental benefits. There is evidence that increased involvement in decisions about treatment increases children's adherence to prescribed treatments as well as their adaptation to and understanding of their illnesses.³³ Participation also minimises conflict between children,

²⁷ Note also the comments of the Committee on the Rights of the Child regarding the significance of the right to express views freely and to have these views taken into account in realising adolescents' rights under Article 24: Committee on the Rights of the Child, General Comment No 4 (2003) *Adolescent health and development in the context of the Convention on the Rights of the Child*, CRC/GC/2003/4, para 8.

²⁸ The Convention has been ratified by 194 members of the United Nations, some with stated reservations or interpretations, and only the USA and Somalia have failed to ratify. For a discussion of the impact of non-ratification on children's participation in healthcare decision-making in the USA, see W Mohr and S Kennedy, 'The Conundrum of Children in the US Healthcare System' (2001) 8 *Nurs Ethics* 196.

²⁹ Mechanisms for delivery on Article 12 are discussed in text following n 97 below.

³⁰ See *Lansdown*, above n 4; *Sinclair*, above n 4.

³¹ The importance of developing autonomy 'competencies' (i.e. improving individuals' abilities to make autonomous decisions) is key to the relational view of autonomy: see D Meyers, *Self, Society and Personal Choice* (Columbia University Press, New York 1989). For application in the specific context of children and healthcare, see S Dodds, 'Choice and Control in Feminist Bioethics' in C Mackenzie and N Stoljar (eds), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford University Press, New York 2000) 229.

³² See *Children's Consent to Surgery* (Open University Press, Buckingham 1993) 154–63.

³³ See J Angst and D Deatrick, 'Involvement in Healthcare Decisions: Parents and Children with Chronic Illness' (1996) 2 *J Fam Nurs* 174. Note also that the way in which adolescents are treated by healthcare professionals is an important predictor of their satisfaction with healthcare: see L Freed

parents, and healthcare professionals. Thus, from a perspective of therapeutic jurisprudence, participative decision-making represents an ideal.³⁴

Perhaps most significantly, participation in healthcare decision-making should be secured because it is important to children who present cogent and persuasive arguments as to why this is so. These reasons, together with other aspects of participation in practice, are explored in the next section.

III. PARTICIPATION IN PRACTICE

In recent years, there has been a 'paradigm shift' within healthcare law, reflected in a move away from reasoning from abstract principles to instead paying attention to the experiences of those receiving healthcare.³⁵ At the same time, there is a growing literature on children's participation in healthcare decision-making.³⁶ Although not directly concerned with participation rights, Priscilla Alderson's groundbreaking study of children's consent to surgery in a number of English hospitals provides valuable evidence of children's views on a range of issues, which are also of relevance in respect of participation.

Alderson interviewed 120 children aged between 8 and 15 years awaiting surgery as well as the adults caring for them.³⁷ Of these children, the vast majority considered that doctors should inform both

and others, 'Determinants of Adolescent Satisfaction with Health Care Providers and Intentions to Keep Follow-up Appointments' (1998) 22 J Adolesc Health 475. One might reasonably expect a similar finding in respect of children.

³⁴ An approach based on 'therapeutic jurisprudence' recognises the 'need for an assessment of the therapeutic impact of legal rules': see B Winick, 'The Right to Refuse Mental Health Treatment: A Therapeutic Jurisprudence Analysis' (1994) 17 Intl JL Psychiatry 99, 100.

³⁵ J Bridgman, 'After Bristol: The Healthcare of Young Children and the Law' (2003) 23 LS 229, 233.

³⁶ For a summary of studies, see A Franklin and P Sloper, 'Listening and Responding? Children's Participation in Health Care within England' (2005) 13 Intl J Children's Rights 11, 18–20. In addition to the work discussed in the text, see B Beresford and P Sloper, 'Chronically Ill Adolescents Experiences of Communicating with Doctors: A Qualitative Study' (2003) 33 J Adolesc Health 172; I Hallstrom and G Elander, 'Decision-making During Hospitalization: Parents' and Children's Involvement' (2004) 13 J Clin Nurs 367; C Battrick and A Gasper, 'The Views of Children and their Families on Being in Hospital' (2004) 13 Br J Nurs 328; I Coyne and others, *Giving Children a Voice: Investigating Children's Experiences of Participation in Consultation and Decision-Making in Irish Hospitals* (Office of the Minister for Children, Dublin 2006) and A Buckley and E Savage, 'Pre-operative Information Needs of Children Undergoing Tonsillectomy' (2010) 19 J Clin Nurs 2879.

³⁷ For details of methodology, see Alderson, above n 32, pp 3–6.

parents and children in advance of surgery.³⁸ The children identified a range of reasons regarding why they wanted to be informed about their surgery.³⁹ These included a desire for answers to questions; a need to relieve anxiety and avoid unnecessary distress and a view that information would help them to cope with the treatment. Children also associated the provision of information with a feeling of respect, and children who were under-informed felt under-respected.⁴⁰ Alderson also found that most children were not interested in being the 'main decider'. By far the most common response from children to the question of who should be the 'main decider' in respect of a decision about surgery was that children, parents, and doctors should decide together.⁴¹ Interestingly, however, most children felt that, in their own case, the main decider had been the adults.⁴² Asked how they would deal with disagreement about a decision, most children said that they would accept their parents' view while the second most popular option was to negotiate.⁴³

In a study into children's participation in healthcare decision-making in Ireland, we sought to record the views of children, parents, and healthcare professionals in a context which was overtly focussed on the delivery of children's right to be heard under Article 12 of the CRC.⁴⁴ Many of the views expressed by the children resonate with those recounted by Alderson. The study is also of interest because of the barriers to participation which were identified. Again, these resonate beyond the Irish context.

A. Framework for the Irish Study

The legal context for children's participation in Ireland is in most respects similar to that in England and Wales. Ireland has ratified the CRC without making any declarations or reservations although, as with the UK, Ireland has not incorporated the CRC into domestic law. There is, however, a distinctive aspect of Irish law in respect of children which derives from the Constitution of Ireland 1937 (*Bunreacht na*

³⁸ Ibid, p 118. Ninety-nine out of 120 children endorsed this view; sixteen believed only parents should be informed and four that only the child should be informed (one was unsure).

³⁹ See Alderson, *ibid*, pp 130–8.

⁴⁰ Ibid, p 132.

⁴¹ Ibid, p 164.

⁴² Ibid, p 164. Half of the 120 children considered that the adult had been the main decider in their cases although only thirty-two of the parents of these children considered this to be the case.

⁴³ Ibid, p 165.

⁴⁴ For full details of the methodology employed, see *Kilkelly and Donnelly*, above n 11, Ch 4.

hÉireann).⁴⁵ Articles 41 and 42 protect family and parental rights, including an express protection of the parental right to provide for the religious and moral, intellectual, physical, and social education of their children.⁴⁶ These articles have been held to limit the circumstances in which the state may interfere with parental healthcare choices.⁴⁷ The applicable test for when state interference is permissible ‘involves the weighing of all the circumstances, including parental responsibility, parental decisions, the child’s personal rights’, as well as the rights of the family in order to determine what is in the best interests of the child.⁴⁸ There is also a strong presumption that ‘the welfare of the child is to be found in the family exercising its authority as such’.⁴⁹ The implications of the dominance of parental rights under the Constitution for children’s participation in practice will be explored further below.⁵⁰

As part of the research study, we interviewed a total of fifty-one children, aged between 5 and 14 years. The choice of age reflected our goal of evaluating the broader concept of participation in decision-making as opposed to a focus on the question of decision-making competence.⁵¹ The children interviewed had varying levels of exposure to the healthcare system.⁵² Our concern was to include children who had limited exposure alongside children who had had considerable engagement.

⁴⁵ Note the current proposal to amend the Constitution to include express protection for children’s rights. The proposed amendment would include a specific provision vindicating the child’s right to be heard in ‘any judicial and administrative proceedings affecting the child, having regard to the child’s age and maturity’. See *Joint Committee on the Constitutional Amendment on Children: Third Report: Proposal for a Constitutional Amendment to Strengthen Children’s Rights* (February 2010) <www.oireachtas.ie>

⁴⁶ The conservative ideology underpinning these provisions is recounted in G Hogan and G Whyte, *JM Kelly: The Irish Constitution* (4th edn Lexis Nexis Butterworths, Dublin 2003) 1829–30. For the impact of these articles on children’s rights in Ireland, see U Kilkelly, *Children’s Rights in Ireland: Law, Policy and Practice* (Tortel Publishing, Dublin 2008), Ch 3.

⁴⁷ *North Western Health Board v HW* [2001] I.E.S.C. 90. The Supreme Court held that the state could not interfere with parents’ refusal to have a routine diagnostic procedure (the PKU or heel test) performed on their infant son. For a discussion, see U Kilkelly and C O’Mahony, ‘The Proposed Children’s Rights Amendment: Running to Stand Still?’ (2007) 2 *Irish J Fam L* 19.

⁴⁸ [2001] I.E.S.C. 90, [182], *per* Denham J. The sole dissenting judge, Keane CJ, applied a test based solely on the best interests of the child.

⁴⁹ [2001] I.E.S.C. 90, [289] *per* Hardiman J.

⁵⁰ See text following n 140 below.

⁵¹ The choice of these age perimeters for this purpose is supported by the literature in this area: see N King and A Cross, ‘Children as Decision Makers: Guidelines for Paediatricians’ (1989) 115 *J Paediatrics* 10; S Sartain, C Clarke and R Heyman, ‘Hearing the Voices of Children with Chronic Illness’ (2000) 32 *J Adv Nurs* 913.

⁵² Fourteen interviews were carried out, of which ten were group interviews and four were individual interviews. The individual interviews were with children who had considerable experience of the healthcare system.

We also interviewed thirty parents. Individual interviews were conducted with parents whose children had had a good deal of exposure to the system and we also interviewed some groups of parents, including one small group from the Traveller community.⁵³ Finally, we interviewed a total of fifty healthcare professionals, of which twenty-two were individual interviews with professionals in practice⁵⁴ and three were group interviews.⁵⁵ The primary goal of the individual professional interviews was to establish how participation operated in practice from the professional perspective, while the group interviews were concerned with assessing levels of training provided to professionals.

B. Participation in Practice: Children's Views

The study replicated Alderson's findings regarding the importance which children attribute to participation in healthcare decisions.⁵⁶ Many of the children articulated a strong sense of why direct and clear communication and explanations were important. Some children felt better placed than their parents to explain what was wrong with them.⁵⁷ Other children commented on their need to be involved so as to understand what was happening to them.⁵⁸ For younger children especially, understanding what was happening was seen as important in allaying their fears.⁵⁹ While clearly expressing a preference for greater involvement, many of the children also felt that it was important to include their parents in the conversation. One girl, aged 10, noted the practical reasons for involving her mother, 'if the doctor just talks to us children and he doesn't tell your mum, then your mum won't know what to look for [if something goes wrong]'.⁶⁰

⁵³ The Traveller Community is an ethnic, minority group comprising approximately 0.5% of the Irish population. Travellers have poorer health outcomes, higher rates of infant mortality, and a lower life expectancy than the rest of the population: see *The Travellers Health Status Study: Vital Statistics of Travelling People 1987* (Department of Health, Dublin 1987).

⁵⁴ Professionals interviewed included general practitioners, anaesthetists, ENT consultants, dentists, nurses, and specialists in children's healthcare. It must be recognised that there is an extent to which the individual interviewees were self-selecting; professionals who agree to be interviewed for a project like this are likely to be inherently more committed to the ideal of children's participation.

⁵⁵ These were with the (mainly) nursing staff of a children's unit in a general hospital; a group of hospital interns; and professionals involved in the education of healthcare professionals.

⁵⁶ See further U Kilkelly and M Donnelly, 'Participation in Healthcare: The Views and Experiences of Children and Young People' (2011) 19 *Intl J Children's Rights* (forthcoming).

⁵⁷ *Kilkelly and Donnelly*, above n 11, p 41.

⁵⁸ *Ibid.*

⁵⁹ *Ibid.*

⁶⁰ *Ibid.*

The children interviewed reported mixed experiences of participation in practice. Some patterns do emerge however. First, by and large, it seems clear that communication improves as children get older.⁶¹ Second, overall, the children's experiences of nurses were more favourable than their experience of doctors.⁶² Third, there was a clear distinction between the experiences of children who spent time in a specialised children's hospital and those who were treated in general hospitals or at general practitioner (GP) level.⁶³ Children in specialist hospitals reported a much higher degree of preparation for procedures and a better follow-up explanation afterwards.⁶⁴

In contrast, the majority of children who did not attend specialist hospitals were rarely offered explanations either before or after procedures.⁶⁵ Children in this category also felt less able to ask questions or seek explanations from their doctors.⁶⁶

None of the children recorded the use of physical force in the imposition of treatment and the healthcare professionals interviewed were generally very conscious of the difficulties to which the use of force would give rise. In the words of one nurse (whose views were typical of the professionals interviewed), 'you've got no consent, the child is screaming, you've got to think, long-term, are you providing this child with the most horrific memory that's going to keep them awake every night for the next six months?'.⁶⁷ However, given that the professionals participating in the study were self-selected, the extent to which this attitude is widely shared is not clear.

C. Barriers to Participation in Practice

The study sought to identify the practical barriers to participation from the perspectives of children, parents, and healthcare professionals. As with the children's views, the barriers identified would seem to be replicated beyond the specifics of the Irish context.⁶⁸ For some children, the language used by healthcare professionals constituted a clear barrier to

⁶¹ *Ibid*, p 40.

⁶² *Ibid*.

⁶³ This view was confirmed by parents whose children had spent time in both specialist and non-specialist hospitals: see *ibid*, p 51.

⁶⁴ Note however evidence which suggests that the experience of children in specialist hospital also varied considerably: see V Lambert, M Glacken, M McCarron, 'Visible-ness: The Nature of Communication for Children Admitted to a Specialist Children's Hospital in the Republic of Ireland' (2008) 17 *J Clin Nurs* 3092.

⁶⁵ *Kilkelly and Donnelly*, above n 11, p 51.

⁶⁶ *Ibid*, p 43.

⁶⁷ *Ibid*, p 67.

⁶⁸ See the barriers listed in *Alderson and Montgomery, Health Care Choices*, above n 12, 9, pp 58–61.

communication.⁶⁹ This feeling was shared by some parents, particularly parents from the Traveller community. One Traveller woman explained 'they should know that there is a language barrier between Travellers, and these are Traveller children, and doctors do come out with big words, not just to children. Like even when I go in to see the doctor, it is very hard to understand'.⁷⁰ Although we did not interview parents from other ethnic backgrounds, it is not unlikely that similar issues would arise in respect of language usage. From a Traveller perspective, literacy was also identified as a barrier to communication, especially in respect of information leaflets and medication prescriptions.⁷¹ Thus, for children from a background which was already disadvantaged, the possibility of further marginalisation was clear.⁷²

Health professionals identified a number of practical barriers to their delivery of effective participation. These included a lack of resources, especially in non-specialist hospitals;⁷³ a lack of proper space for communication; and a lack of time.⁷⁴ Professionals also noted a lack of education or training in communicating with children⁷⁵ and the problems created by the lack of a common approach to participation among the professionals involved. In the words of one nurse manager, 'You could spend some time winning confidence, having a child who is consenting, quite happily, to have an injection or procedure done . . . and it can be undone in a flash by a third party coming in saying the wrong thing'.⁷⁶

From a legal perspective, the most interesting of the barriers to participation identified by the health professionals was the attitude of parents. Parents who were themselves nervous were seen as transmitting their fears to their children.⁷⁷ Some professionals also described reluctance on the part of parents to let their children know that they have a serious condition. A paediatric oncologist explained 'When you have parents who come up here for investigation and we discover their child has cancer, the problem we often face is the reluctance on the part of parents to allow us to inform the child'.⁷⁸

⁶⁹ *Kilkelly and Donnelly*, above n 11, p 42.

⁷⁰ *Ibid*, p 52.

⁷¹ *Ibid*, p 52–3.

⁷² This experience of 'double marginalisation' in a range of contexts of disadvantage has been highlighted by other commentators: see *Franklin and Sloper*, above n 8, 19.

⁷³ *Kilkelly and Donnelly*, p 63.

⁷⁴ *Ibid*.

⁷⁵ *Ibid*.

⁷⁶ *Ibid*, p 64.

⁷⁷ *Ibid*, p 65.

⁷⁸ *Ibid*.

Our interviews with parents confirmed that there are tensions between healthcare professionals and parents about communicating with children. Parents' assertion of their own right to be involved in the process was clearly evident in many of the interviews while, for the most part, parents appeared to be less conscious of the child's right to participate. A substantial number of parents we interviewed were critical of health professionals who sought to communicate directly with their children.⁷⁹ For some parents, this was because of a desire to protect their child from anxiety. Other parents described their own feelings of marginalisation which were enhanced by the doctor's efforts to deal directly with their child. In the words of one woman, 'I had to stop them and ask them had I no mouth or something that they couldn't ask me? ... They shouldn't just ... ask the child without letting the parent know exactly what they are doing'.⁸⁰ These parents felt that they were better placed than professionals to determine the level of consultation which was in their child's interests and that the involvement of their child diminished their own contribution.⁸¹

The study suggests that parental opposition can effectively prevent children's involvement in the decision-making process. The professionals interviewed indicated that they generally respected parental views about the extent of their children's involvement. The approach taken was summarised by one haematology nurse as follows: 'You can only tell a child as much as a parent allows you to tell them and if they ask you to please don't mention it or please don't tell them, you have to respect that'.⁸² It is unclear whether this response is linked in any way to the elevated position of parents under the Constitution of Ireland. Certainly, it would seem that the professional attitude was that parental views automatically took priority over the right of the child to participate and that this was not a matter open to negotiation.

The impact of parental opposition on participation levels has also been noted in several UK-based studies.⁸³ In Young et al's study of communication with children with a potentially life-threatening illness, the substantial majority of parents expressed a desire that they should be told about their child's diagnosis without their child being present.⁸⁴

⁷⁹ Ibid, p 49.

⁸⁰ Ibid.

⁸¹ Ibid.

⁸² *Kilkelly and Donnelly*, p 66.

⁸³ See studies cited in J Gabe, J Olumide and M Bury, "It Takes Three to Tango": A Framework for Understanding Patient Partnership in Paediatric Clinics' (2004) 59 Soc Sci Med 1071, 1074.

⁸⁴ B Young and others, 'Managing Communication with Young People who have a Potentially Life Threatening Chronic Illness: Qualitative Study of Patients and Parents' (2003) 326 Br Med J 305, 306. The study involved thirteen families, comprising nineteen parents (thirteen mothers and six fathers)

Some also opted to dilute or delay what their child was subsequently told.⁸⁵ Young et al noted that many parents assumed an 'executive role... managing what, when, and how, their children were told about their illness'.⁸⁶

Parents' feelings of protectiveness towards their sick children are understandable as are feelings of alienation or marginalisation, especially for parents who are already disadvantaged. It is also undoubtedly the case that parents will very often have a depth of knowledge and insight in respect of their child which healthcare professionals cannot match.⁸⁷ As Young et al describe, in some instances, children often relied on their parents to assist in managing the burden of communication and, at times, welcomed the role of their parents as 'buffers' in respect of threatening information.⁸⁸ For these reasons, from both an instrumental and a principled perspective, it would not be appropriate for health professionals simply to override parental views and provide information to children in circumstances where parents are actively opposed.

However, the difficulty with acceding to parental views that the child should not be involved is that this approach can result in the marginalisation of the patient as well as, in some instances, increasing the trauma experienced by the child. An ENT surgeon we interviewed recounts an indicative instance:

I had a child recently who was in for an operation and the parent said "We've told the child they had to come to have their photograph taken" (nod, nod, wink, wink), wanting me to take part in the process. And that's obviously a bit disconcerting for everybody and then, of course, the child becomes hysterical when they find they're in hospital.⁸⁹

Gabe et al highlight how in any encounter involving three actors, there is a tendency for two of them to enter a coalition in order to advance a preferred agenda.⁹⁰ In a paediatric context, this is what happens where the agenda is set by the adults, and the healthcare professionals simply accede to parental views.

It is, of course, also possible for the professional to form a coalition with the patient to resist pressure from a parent to follow a particular

and thirteen patients aged 8–17 years. All patients suffered from cancer or a brain tumour.

⁸⁵ Ibid.

⁸⁶ Ibid.

⁸⁷ See *Bridgman*, above n 35, 236.

⁸⁸ *Young and others*, above n 84, 308.

⁸⁹ *Kilkelly and Donnelly*, p 66.

⁹⁰ Above n 83, 1077.

course of action and to ensure that the child has time to come to his or her own decision. Thus, in the event of a resisting parent, the response of the professional plays a pivotal role in the delivery or non-delivery of participation.⁹¹ Some of the healthcare professionals we interviewed outlined strategies which they use to deal with parents who wanted to limit the amount of information their child received. One paediatric oncologist described how, for younger children, he informed the parents first and asked them to talk the matter over with their child while with children aged over 10 or 11, he would tell the child that the news was bad and give them a choice as to whether to hear full details either with or without their parents.⁹²

More research is undoubtedly needed on how coalitions between professionals, parents, and children operate in practice.⁹³ From a legal perspective, however, a question arises regarding the perimeters of the child's right to be heard. In particular, to what extent does the law recognise parental opposition as a barrier to children's right to participate in healthcare decision-making? Legal recognition of a parental right to prevent participation would be detrimental for participation rights, not just in those situations where parents actively oppose the child's involvement, but also more generally. The possibility of a legal barrier to participation would inevitably inhibit the development of participative policies and practices. The next section will consider the strength of legal support for children's participation rights and the legal status of parental objections.

IV. DELIVERING PARTICIPATIVE PRACTICES: THE ROLE OF LAW

The child's right to participate in healthcare decision-making is protected under both the CRC and the ECHR, both of which require that steps be taken to deliver participation in practice. However, the effectiveness of both measures in the practical delivery of participative practices is limited and, accordingly, the introduction of legislation should be considered.

A. Delivering on Participation in the CRC

Article 12 of the CRC provides the foundational basis for children's participation rights. While the CRC is sometimes portrayed as being 'anti-family' on the basis that respecting children's rights must involve taking rights from adults, there is nothing in the CRC to support these

⁹¹ Ibid.

⁹² *Kilkelly and Donnelly*, p 67.

⁹³ See *Gabe and others*, above n 83, 1078.

conclusions.⁹⁴ In fact, several articles in the CRC emphasise the role of the family and of parents.⁹⁵ The wording of Article 5 indicates the shifting balance envisaged as the child matures. Article 5 requires States Parties to respect the responsibilities, rights, and duties of parents (and where appropriate extended family or community) to provide, in a manner consistent with the evolving capacities of the child, appropriate direction, and guidance to the child in the exercise of his or her rights. Read together with Article 12, Article 5 demonstrates the gradual way in which parents' direct role in the protection of children's rights transfers to children as they acquire the maturity to take on this role for themselves.

As John Eekelaar notes, the symbolic significance of a formal legal recognition of children's rights in an international human rights instrument should not be underestimated.⁹⁶ At a more practical level, the clear language of Article 12 offers potential for benchmarking law, policy, and practice.⁹⁷ In this respect, the periodic reports which States Parties must make to the Committee on the Rights of the Child provide an opportunity not just for external evaluation by the Committee but also for internal evaluation by citizens, civic organisations, and academia within the state.⁹⁸ In addition, the Committee's monitoring role allows it to direct States Parties on the extent to which implementation of the CRC has been achieved, and the measures necessary for more effective delivery of CRC rights.

The Committee has directed that, in the preparation of periodic reports, details must be provided regarding how Article 12 is enshrined in legislation.⁹⁹ It also requires States to report on the specific measures taken to raise the awareness of families and of the public in general of the need to encourage children to exercise their right to express their views and to train professionals working with children to encourage children to express their views and to give their views due weight.¹⁰⁰ In particular, details of the number of courses about the CRC provided

⁹⁴ See *Kilkelly*, above n 46, p 28.

⁹⁵ See for example, Article 7 (the child's right to know and be reared by her parents); Article 9 (right to direct contact with parents following separation); Article 18 (statement of parents' common responsibility to child).

⁹⁶ 'The Importance of Thinking that Children have Rights' (1992) 6 *Intl J Law Policy Fam* 221.

⁹⁷ See U Kilkelly and L Lundy, 'Children's Rights in Action: Using the Convention on the Rights of the Child as an Auditing Tool' (2006) 18 *Child Fam L Q* 331.

⁹⁸ Article 44(6) requires States Parties to make their reports widely available to the public within their own countries.

⁹⁹ *General Guidelines regarding the form and contents of Periodic Reports to be submitted by States Parties under Article 44, paragraph 1(b) of the Convention*, CRC/C/58, 1996, para 42.

¹⁰⁰ *Ibid.*

to various categories of professionals, including healthcare professionals, must be provided.¹⁰¹

In the specific context of healthcare, the Committee has issued a General Comment on adolescent health and development.¹⁰² This states that the CRC requires States Parties to ensure that young people have opportunities to participate in decisions affecting their health and to obtain adequate and age-appropriate information.¹⁰³

The Committee has been less specific in respect of participation by younger children in healthcare decisions. However, in a *General Comment on Implementing Child Rights in Early Childhood*, it emphasised that the right under Article 12 ‘applies both to younger and older children’.¹⁰⁴ It also emphasised that all decision-making concerning, *inter alia*, a child’s health must take account of the ‘best interests’ principle.¹⁰⁵ The Committee highlighted that the right to express views and feelings should be ‘anchored in the child’s daily life at home and in his/her community; within the full range of early childhood health, care and education facilities’.¹⁰⁶ In this context, the Committee noted that achieving the right of participation requires adults to adopt a child-centred attitude, listening to young children and respecting their individual points of view. It stipulated that adults must show ‘patience and creativity by adapting their expectations to a young child’s interests, level of understanding and preferred ways of communicating’.¹⁰⁷

In its most recent General Comment, issued in 2009, the Committee further explored the implications of Article 12, including in the healthcare context.¹⁰⁸ In addition to recommending the introduction into law of an age at which children can consent to medical treatment, it has also strongly recommended that States parties ensure that, where a younger child can demonstrate capacity to express an informed view on her or his

¹⁰¹ Ibid.

¹⁰² Committee on the Rights of the Child, General Comment No 4 (2003) *Adolescent health and development in the context of the Convention on the Rights of the Child*, CRC/GC/2003/4.

¹⁰³ Ibid, para 39. The Committee also emphasised (para 28) that, regardless of whether their parents or guardians consent, young people should have access to information about family planning and contraceptives as well as about the dangers of early pregnancy, the prevention of HIV/AIDS and the prevention and treatment of sexually transmitted diseases.

¹⁰⁴ Committee on the Rights of the Child, General Comment No 7 (2005) *Implementing Child Rights in Early Childhood*, CRC/C/GC/7/Rev., para 14.

¹⁰⁵ Ibid, para 13.

¹⁰⁶ Ibid, para 14.

¹⁰⁷ Ibid.

¹⁰⁸ Committee on the Rights of the Child, General Comment No 12 (2009) *The Right of the Child to be Heard*, above n 5.

treatment, this view is given due weight.¹⁰⁹ The Committee also recommended that States parties introduce legislation or regulations to ensure that children have access to confidential medical counselling and advice without parental consent, irrespective of the child's age, where this is needed for the child's safety or well-being (for example, in cases of conflict between parents and the child over access to health services).¹¹⁰ In this context, it explained that the right to counselling and advice is distinct from the right to give medical consent and should not be subject to any age limit.¹¹¹

The CRC is clear in its recognition of the participative rights of all children, not just children who have decision-making capacity. The approach of the Committee also provides support for the argument that parental opposition should not be permitted to limit the development of participative practices. However, while the clarity of the CRC approach and the level of detailed guidance provided is undoubtedly helpful in framing policy, as Jane Fortin notes, the absence of direct methods of formal enforcement is a weakness in the CRC.¹¹² Notwithstanding this, courts in England and Wales have begun to accord an increased degree of significance to the state's obligations under the CRC, in general,¹¹³ and under Article 12, in particular. This is in some contrast to Ireland, where, to date, Article 12 has not been instrumental in judicial decisions.¹¹⁴

Article 12 was cited by Thorpe LJ in *Mabon v Mabon* in the context of the child's right to be heard in family law proceedings.¹¹⁵ Thorpe LJ found that the applicable Rules must be applied in a way which focuses on 'the sufficiency of the child's understanding'.¹¹⁶ He noted that judges, in measuring that sufficiency, must 'reflect the extent to which, in the 21st Century, there is a keener appreciation of the autonomy of the child and the child's consequential right to participate in decision-making processes that fundamentally affect his family life'.¹¹⁷ This comment is interesting not least because Thorpe LJ appears to have

¹⁰⁹ Ibid, para 102.

¹¹⁰ Ibid, para 101.

¹¹¹ Ibid.

¹¹² *Children's Rights and the Developing Law*, above n 13, p 46. Contrast the position in respect of the United Nations Convention on the Rights of Persons with Disabilities where ratification of the Optional Protocol by the UK allows for a direct right of petition to the Committee on the Rights of Persons with Disabilities.

¹¹³ See *R (on the application of Williamson and Others) v Secretary of State for Education* [2005] UKHL 15, [80].

¹¹⁴ See A Parkes, 'Children Should Be Seen and Not Heard: A Reflection on the Proposed Constitutional Amendment' (2008) 11(3) *Irish J Fam L* 58.

¹¹⁵ [2005] EWCA Civ 634; [2005] FLR 1011.

¹¹⁶ Ibid, [26].

¹¹⁷ Ibid, [26].

regarded the right to participate as consequential on the child's autonomy. However, as has been argued throughout this article, the two concepts are different and the fact that a child does not have the degree of maturity necessary for autonomous decision-making does not diminish the child's right to participate.

The requirements under Article 12 were noted in the more immediate context of the duty of confidentiality owed to young people in respect of aspects of healthcare in *R (Axon) v Secretary of State for Health*.¹¹⁸ Drawing on Article 12, Silber J found that, while the facts of *Mabon* were very different to those in the case in question, they served to 'illustrate that the right of young people to make decisions about their own lives by themselves at the expense of the views of their parents has now become an increasingly important and accepted feature of family life'.¹¹⁹ It would, he considered, be 'ironic' if, in this changed 'landscape of family matters', the law were to impose additional duties on healthcare professionals to disclose information to the parents of their younger patients.¹²⁰ As with *Mabon*, a striking feature of the case is the equation of Article 12 with the right to autonomous decision-making.

For present purposes, perhaps the most important aspects of the decisions in *Mabon* and *Axon* are the extent to which they show Article 12 beginning to play a greater role, not just in directing state policy but in determining the outcome of legal disputes. However, the decisions also give some cause for concern because of the narrow conception of Article 12 adopted by the judges. It is important that the narrow view of Article 12, as solely protecting children's autonomy rights rather than their broader participation rights, is not perpetuated and that the scope of Article 12 as a right of all children to participate in decision-making is recognised.

B. ECHR Rights

In contrast to the CRC, the protections afforded by the ECHR can be accessed at national level.¹²¹ Although it is clear that the ECHR applies to children as well as to adults, the absence from the ECHR of explicit protection for children's rights has undoubtedly limited its potential in this area.¹²² At the same time, Article 8 of the

¹¹⁸ [2006] EWHC 37 (Admin). See also *Re Roddy (a child) (identification: restriction on publication)* [2003] EWHC 2927 (Fam).

¹¹⁹ *Ibid.*, [79].

¹²⁰ *Ibid.*, [80].

¹²¹ The ECHR has been incorporated in domestic law by the Human Rights Act 1998 (in the jurisdictions of the United Kingdom) and the ECHR Act 2003 (in Ireland).

¹²² See U Kilkelly, *The Child and the ECHR* (Ashgate, Aldershot 1999) 1–17; G Van Bueren, *Child Rights in Europe: Convergence and Divergence in*

ECHR, which protects ‘the right to respect for private and family life’, has been shown to provide considerable protection for the rights of children, both with respect to the family and in other contexts.

In this regard, an important development in the jurisprudence of the European Court of Human Rights (ECtHR) has been its interpretation of Article 8 to include procedural and participation rights as an ‘add-on’ to the determination of substantive ECHR rights.¹²³ Although this began with the Court protecting the procedural rights of parents as part of their respect for family life under Article 8, steps have been taken in recent years to recognise the importance of the views of children in proceedings that affect them. This was first evident in the cases of *Sabin* and *Sommerfeld* against Germany,¹²⁴ where the ECtHR acknowledged the importance of judicial willingness to hear children and take their views into account in family law decision-making. While stopping short of requiring that children should be heard in every case, the Grand Chamber noted that the issue depends ‘on the specific circumstances of each case, having due regard to the age and maturity of the child concerned’.¹²⁵ The Court’s approach reflected concern that the decision-maker would be able to base his/her decision on all the available information, perhaps suggesting an emphasis on the integrity of the process as a whole rather than on the individual right of the child to be heard. Nonetheless, the judgment indicated the impact on the ECHR case law of the increasing practice in national courts of hearing children directly.¹²⁶

The complexity of determining what weight should be attached to the views of a child, especially when those views are opposed to those of the child’s parent, is reflected in *C v Finland* where a father sought to challenge the national courts’ exclusive reliance on his child’s views that she did not want to remain in his custody.¹²⁷ Although the ECtHR found the decision of the national courts had violated the applicant’s family

Judicial Protection (Council of Europe Publications, Strasbourg 2007); J Fortin, above n 15, pp 60–2.

¹²³ See U Kilkelly, ‘Article 8: the Right to Respect for Private and Family Life, Home and Correspondence’ in DJ Harris and others (eds), *Harris O’Boyle & Warbrick: Law of the European Convention on Human Rights* (Oxford University Press, Oxford 2009), 361–424.

¹²⁴ *Sabin v Germany* [GC] (2003) 36 EHRR 765 and *Sommerfeld v Germany* [GC] (2004) 38 EHRR 35.

¹²⁵ *Sabin v Germany* [GC] (2003) 36 EHRR 765, para 73.

¹²⁶ See further Kilkelly, *Children’s Rights in Ireland*, above n 46, pp 225–9. See also the ECtHR’s recognition of the right of children to understand decisions made about them in the context of criminal proceedings: see *T v UK* (1999) 30 EHRR 121, para 84; *SC v UK*, ECtHR 15 June 2004, para 29.

¹²⁷ *C v Finland*, Application No. 18249/02, May 9 2006.

life rights under Article 8, in so doing, it did not reject the right of the child to be heard. Rather, the Court considered that it was the absolute weight attached to the child's views, which took the form of an unconditional veto, which was problematic in this instance. Thus, while recognising the importance of hearing children's views, the judgment stopped short of giving children full responsibility or autonomy to decide such matters on their own.¹²⁸

There is little modern ECtHR jurisprudence on children's rights in the healthcare context. However, jurisprudence of the ECtHR in other respects demonstrates the expansive nature of the concept of 'private life' under Article 8 in the context of healthcare. The ECtHR has recognised that the right to private life encompasses a right of autonomy¹²⁹ as well as a right to physical and psychological integrity which is not dependant on the subject's decision-making capacity.¹³⁰ The recognition of the child's personal right to physical integrity in *Glass v United Kingdom*¹³¹ emphasises the child's role as a rights-subject. Although in *Glass*, vindication of the child's right required enhanced parental involvement in the decision-making process,¹³² it is striking that the court's preferred approach was to locate the decision within the ambit of the child's rights under Article 8 rather than within the rights of the 'family'.¹³³

Although not concerned directly with children's rights, the decision in *Storck v Germany*¹³⁴ is also supportive of an approach to rights which is not focussed on the capacity of the rights-holder.¹³⁵ The ECtHR found that the applicant's rights under Article 8 had been breached by the administration of medication to her against her will while she was being detained, also against her will, at a psychiatric clinic. The Court was not concerned with whether or not the

¹²⁸ J Fortin, above n 13, p 313; Kilkelly, *Children's Rights in Ireland*, above n 46, p 214.

¹²⁹ See *Pretty v United Kingdom* (2002) 35 EHRR 1, para 61.

¹³⁰ See *Glass v United Kingdom* (2004) 29 EHRR 341, para 70.

¹³¹ (2004) 29 EHRR 341.

¹³² The ECtHR found, *ibid*, para 83, that the child's mother's views should not have been overridden in the absence of authorisation by a court. See R Huxtable and K Forbes, 'Glass v UK: Maternal Instinct vs Medical Opinion' (2004) 16 Child Fam LQ 339.

¹³³ Mrs Glass had also brought proceedings in respect of her own rights under art 8. However, the ECtHR did not address this matter, considering *ibid*, para 72 that it was required only to consider the matter from the first applicant's standpoint.

¹³⁴ (2005) 43 EHRR 96. Although she was first detained in a psychiatric clinic at the age of 15, the applicant's case was concerned with detention in the period following her eighteenth birthday (*ibid*, para 24).

¹³⁵ See M Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, Cambridge 2010), 220–1.

applicant had capacity at the time the treatment was administered.¹³⁶ Rather, it found that ‘even a minor interference with the physical integrity of an individual must be regarded as an interference with the right to respect for private life under Article 8, if it is carried out against the individual’s will’.¹³⁷ There is no reason in principle why this approach should not extend to children. The decision in *Storck* is also significant because of the ECtHR’s recognition of the positive obligations which Article 8 imposes ‘to take reasonable and appropriate measures to secure and protect individuals’ right to respect for their private life’.¹³⁸ Thus, the decision lends support to the argument that the State has a positive obligation to ensure the development of participative practices.¹³⁹

Although the tenor of the judicial approaches might be said to provide support for participation rights, there is very limited modern ECtHR jurisprudence regarding a direct conflict between children’s rights and parental or ‘family’ rights. Accordingly, as Fortin notes, the 1988 decision in *Nielsen v Denmark*¹⁴⁰ ‘cannot be ignored when considering the boundaries between parents’ rights and those of their uncooperative children’.¹⁴¹ In *Nielsen*, the ECtHR (by a nine–seven majority) found that a 12-year-old boy’s right to liberty as protected under Article 5 had not been violated by the actions of his mother at whose request he had been detained in a psychiatric hospital for over 5 months, notwithstanding that he did not have a psychiatric disorder. In reaching this conclusion, the majority of the ECtHR recognised the protection afforded to family life under Article 8. In the words of the majority, ‘family life in the Contracting States encompasses a broad range of parental rights and responsibilities in regard to care and custody of minor

¹³⁶ Although capacity was not central, the ECtHR, *ibid*, para 76, stated that it was proceeding on the basis of a presumption that the applicant had been capable of refusing consent to admission at the time she was admitted against her will although it also acknowledged the possibility that, having been medicated, she may subsequently have lost capacity.

¹³⁷ (2005) 43 EHRR 96, para 143.

¹³⁸ *Ibid*, para 149.

¹³⁹ Support for the need for positive action from a children’s rights perspective may also be found in *Mikulic v Croatia*, Application No 53176/99, [2002] 1 FCR 720 where the state was found (para 65) to have failed to provide an appropriate mechanism to balance the applicant’s right to have uncertainty as to her personal identity eliminated without unnecessary delay and the right of her supposed father not to undergo DNA tests. On the development of positive rights under art 8, see A Mowbray, *The Development of Positive Obligations under the European Convention on Human Rights* (Hart Publishing, Oxford, 2004), 127–88. See also U Kilkelly, ‘Protecting Children’s Rights under the ECHR: the Role of Positive Obligations’ (2010) 61 Northern Ireland LQ 245.

¹⁴⁰ (1988) 11 EHRR 175.

¹⁴¹ *Children’s Rights*, above n 13, p 101.

children'.¹⁴² On the matter of the child's own views, the majority considered that 'he was still of an age at which it would be normal for a decision to be made by the parent even against the wishes of the child'.¹⁴³ As Fortin notes, given that the child was 12 years old, this reflects a 'peculiarly authoritarian view of the parental role'.¹⁴⁴

The decision in *Nielsen* could be used to support the argument that parents have the right to determine the extent to which their children should be permitted to participate in healthcare decision-making. However, there are a number of reasons why *Nielsen* is unlikely to be persuasive authority. First, the current status of *Nielsen* is questionable. In *R (Axon) v Secretary of State for Health*, Silber J restricted the application of *Nielsen* to circumstances involving where the child should reside and as relevant only in respect of Article 5.¹⁴⁵ Silber J's 'reading down' has been criticised as based on 'rather implausible reasons'.¹⁴⁶ Rachel Taylor argues that a 'more convincing reason' for Silber's reading of *Nielsen* is the approach taken by the ECtHR to precedent.¹⁴⁷ Taylor notes that the Convention is a 'living instrument' and that *Nielsen* is over 20 years old and out of line with more recent case-law. Accordingly, she argues that *Nielsen* can no longer be said to represent the position in respect of parental rights under the ECHR.¹⁴⁸ The increased significance accorded to the CRC (which *Nielsen* pre-dated) in judicial reasoning would also lend support to this view.¹⁴⁹

Second, even in the context of elevated parental rights, some degree of balancing is required. In *Nielsen*, the majority of the ECtHR appeared to recognise that the views of a child aged more than 12 years would have to be listened to. Moreover, the Court also warned that parental responsibility was not unlimited and reminded the State that it should provide children with protection from potential abuse of parental authority.¹⁵⁰ The necessary balancing of the rights of children and their parents is also clear in Irish constitutional jurisprudence in respect of family rights. Notwithstanding the superior status afforded to parental and family rights under the Constitution of Ireland,¹⁵¹ the Supreme

¹⁴² (1988) 11 EHRR 175, para 61.

¹⁴³ *Ibid*, para 72.

¹⁴⁴ *Children's Rights*, above n 13, p 101.

¹⁴⁵ [2006] EWHC 37 (Admin), [126].

¹⁴⁶ *Fortin*, *Children's Rights*, above n 13, p 102.

¹⁴⁷ R Taylor, 'Reversing the Retreat from *Gillick*?: *R (Axon) v Secretary of State for Health* (2007) 19 Child Fam LQ 81, 89.

¹⁴⁸ *Ibid*. See also *Fortin*, *Children's Rights*, above n 13, p 102.

¹⁴⁹ See U Kilkelly, 'The Best of Both Worlds for Children's Rights? Interpreting the European Convention on Human Rights in the Light of the UN Convention on the Rights of the Child' (2001) 23 Human Rights Q 308.

¹⁵⁰ See *Kilkelly*, *The Child and the ECHR*, above n 122, p 37.

¹⁵¹ See text following n 45 above.

Court of Ireland has recognised that the views of a young woman (aged almost 18) were ‘very relevant’ in determining whether her health records should be released to her father.¹⁵² When the case was remitted to the Information Commissioner for determination, the Commissioner found that the strong constitutional presumption that parental actions are in accordance with the best interests of the child had been rebutted by the direct evidence of the young woman that she did not wish the information to be disclosed.¹⁵³ Thus, even if *Nielsen* were considered still to represent the law, it is difficult to see that parental rights could represent a legal barrier to participation at least in respect of older children.

On the basis of the preceding discussion, a reasonable case may be made that there is an ECHR basis for children’s participation rights and that parents do not have the right to limit children’s participation in healthcare decision-making. Further, if the precedent established in *Storck* is adopted in the context of children, there may be scope for a positive duty to protect the rights of children lacking decision-making capacity, including their right to participate in healthcare decision-making. However, any development of the law in this area will inevitably be dependent on courts having the opportunity to consider the issues at stake. A difficulty here is that children are not well placed to assert their participation rights and that adults, whether parents or health professionals, may have limited motivation in asserting children’s rights in this context.¹⁵⁴ Ultimately, therefore, if the law is to make an effective contribution to the delivery of participation rights, a mechanism that is more immediately accessible must be found. The introduction of legislation represents an obvious way forward in this regard.

C. Using Legislation to Enhance Participation

Article 4 of the CRC makes it clear that states parties must take all appropriate measures to implement CRC rights and the Committee on the Rights of the Child has noted the contribution of legislation to the delivery of the child’s right to be heard.¹⁵⁵ In this vein, Alderson and Montgomery advocate the use of a statutorily-based Code of Practice as a suitable mechanism for the delivery of children’s rights in the

¹⁵² *McK v Information Commissioner* [2006] I.E.S.C 2, [15.3].

¹⁵³ *Decision under the Freedom of Information Acts 1997–2003 in relation to Case Number 000137: Mr N McK and a Dublin Hospital*. The young woman had said that ‘thinking that he might get my personal information makes me physically sick’.

¹⁵⁴ *Fortin, Children’s Rights*, above n 13, pp 67–9, recounts the limited number of assertions of ECHR rights by children themselves.

¹⁵⁵ Committee on the Rights of the Child, *The Right of the Child to be Heard*, above n 5, para 8.

healthcare context.¹⁵⁶ They suggest that such a Code should set out fundamental principles, including that children should receive detailed relevant information; that children have a right to share in making decisions by expressing views if they have them; that children may grant or withhold consent to proposed treatment if they are competent to do so, subject to the supervisory role of the courts and that children's privacy, dignity, and confidentiality should be respected.¹⁵⁷

The use of legislation as a way of enhancing children's participation in healthcare decision-making offers several advantages. It provides clear guidance for professionals as well as for children and parents. It also raises the profile of the issue of participation and opens public space for debate. Law reform bodies in a number of jurisdictions have advocated the introduction of legislation specifically directed at children's healthcare decision-making.¹⁵⁸ The recent proposals of the Irish Law Reform Commission present an interesting example of a possible framework for such legislation.¹⁵⁹

The Irish Commission proposes that a tiered approach to capacity to consent to and refuse treatment should be enshrined in legislation.¹⁶⁰ Children aged more than 16 years should be presumed to have capacity to consent to treatment (as is currently the law). For children aged between 14 and 16 years, the Commission proposes a functional approach based on a legislative statement that it is lawful for healthcare professionals to provide treatment where, in the opinion of the healthcare professional, the patient understands the nature and consequences of the proposed treatment; the healthcare professional has considered the best interests of the patient; and the healthcare professional has had due regard to any public health concerns. While the Commission recommends that the legislation should require healthcare professionals to encourage the patient to inform his or her parents, it does not propose

¹⁵⁶ *Healthcare Choices*, above n 9, p 86.

¹⁵⁷ *Ibid.*

¹⁵⁸ See, for example, the recommendations of the Queensland Law Reform Commission *Consent to Healthcare of Young People* (QLRC R 51, Brisbane 1996); the New South Wales Law Reform Commission, *Young People and Consent to Healthcare Report 119* (NSWLRC, Sydney 2008).

¹⁵⁹ See *Children and the Law: Medical Treatment* (LRC CP 59, Dublin 2009) (available at www.lawreform.ie). Appropriately, given the subject matter under discussion, the Commission engaged in a consultative process with children and young people: see para 1.60.

¹⁶⁰ Although the Commission favours the adoption of a largely similar approach to refusal as to consent, it recommends (*ibid.*, para 5.150) that, in respect of life-saving or sustaining treatment, the matter should be considered by the High Court. This approach, it argues (*ibid.*, para 5.149), would protect minors against 'choices which irreversibly limit their future choices'.

the imposition of a requirement that parents be informed or consulted.¹⁶¹

For children aged between 12 and 14 years, the Commission also proposes the adoption of a functional approach to capacity to consent. However, for children in this age group, the Commission recommends that the healthcare professional must inform the patient's parents and take account of their views (although these views are not to be determinative).¹⁶² For all children, the Commission recommends that a requirement should be enshrined in law that healthcare professionals, when treating children, should grant children an opportunity to express their views and give these views due weight in accordance with the child's age and maturity.¹⁶³

There is little doubt that the introduction of legislation along the lines proposed by the Irish Law Reform Commission would raise the profile of children's participation in healthcare decision-making. While clearly not addressing all of the current obstacles to fuller participation, this approach would represent a clear statement of children's rights in the healthcare context. If accompanied by a Code of Practice which sets out in more detail the requirements of best practice for healthcare professionals working in the area, it could make a genuine difference. This, of course, is why such legislation may be controversial and why Irish legislators may prefer to avoid the issue. It is interesting that, although a number of Australian law reform bodies have recommended broadly similar legislative models, legislation has not been forthcoming there. For this reason, while legislation may represent an ideal, it is not necessarily one which will be delivered upon in the short term.

V. CONCLUSIONS

Healthcare decision-making involving children can be a difficult process, especially in situations of serious illness. When children are ill, adults have an understandable desire to protect them from difficult decisions and to shield them from unpleasant information. Yet, as the children we spoke to remind us, children want and need to be heard by healthcare professionals and to be provided with age-appropriate explanations and information in order to help them cope with the consultation and treatment processes. In the words of one 12-year-old girl we interviewed, 'children want to understand if they're sick ... what's

¹⁶¹ *Ibid*, para 4.127.

¹⁶² *Ibid*, para 4.128.

¹⁶³ *Ibid*, para 4.115.

wrong with them, and if what their doctor is going to do will help them'.¹⁶⁴

Recognising the complexity and the depth of the barriers to participation is a necessary first step to improving the delivery of participation in practice. In the words of Alderson and Montgomery, '[t]he greatest obstacles arise from prejudices about children's inabilities, and beliefs that it is unwise or unkind or a waste of time to listen to children'.¹⁶⁵ In this respect, there is a need to engage with adults' attitudes towards children. Better information needs to be put in place which draws attention to children's capacities and to their legal rights. There is also a need for better training for professionals in dealing with both children and parents.¹⁶⁶ In addition, more research is needed into how participation works in practice and into the impact of factors such as social exclusion or other forms of disadvantage on participation.¹⁶⁷

While the law is just one component in the development of participative mechanisms, it has a valuable role to play in improving participation in practice as well as in changing attitudes. The CRC provides both symbolic and practical support for the child's right to participate, and the Council of Europe is seeking to build on this gold standard by drafting guidelines on child-friendly healthcare in 2011. The ECHR, and especially the more modern jurisprudence of the ECtHR, offers the possibility of directly enforceable protection. This article has argued that the ECHR requires the recognition of the child's right to participate and that the fact of parental objections does not represent a legal barrier to the protection of the right. However, given the limitations of reliance on the ECHR, it has been argued that legislation, combined with a Code of Practice, represents the most effective legal mechanism for delivering on the child's right to participate in healthcare decision-making. While legislation on its own cannot deliver participation, a clear statement that participation is to be valued and that children's rights are to be respected represents an important first step.

¹⁶⁴ *Kilkelly and Donnelly*, above n 11, p 41.

¹⁶⁵ *Healthcare Choices*, above n 9, p 58.

¹⁶⁶ See *Franklin and Sloper*, above n 8, 22; *Kilkelly and Donnelly*, above n 11, p 90.

¹⁶⁷ See *Franklin and Sloper*, *ibid*, p 19.

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