Routledge International Handbook of Children’s Rights Studies

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Publication details

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Published online on: 27 Mar 2015

How to cite :- Ursula Kilkeley. 27 Mar 2015, Health and children’s rights from: Routledge International Handbook of Children’s Rights Studies Routledge
Accessed on: 25 Aug 2023

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13

Health and children’s rights

Ursula Kilkeany

1. Introduction

The importance of good health to all children is well recognised and under Article 24 of the UN Convention on the Rights of the Child (CRC), all children have the right to enjoy the highest attainable standard of health, to facilities for the treatment of disease and to access healthcare services. However, children face many, diverse challenges exercising their right to health and there is a huge gulf between the right to health and healthcare and its effective enjoyment by children around the world. The child’s right to health is frustrated by healthcare systems that are inaccessible, expensive, inequitable or poor in quality (Harris et al., 2011; Huber et al., 2008). Child mortality, although improving, continues to be a serious problem, especially in sub-Saharan Africa where children under five are 16 times more likely to die than children in the developed world (WHO, 2013). The fact that more than half of the world’s early child deaths (6.5 million in 2012) are due to conditions that could be prevented or treated with access to simple, affordable interventions, highlights the complexity of the problem (WHO, 2013). The challenge in implementing the right to health and healthcare thus varies from situations that frustrate the right to access health and healthcare, those that undermine the right to health and those that threaten the way in which the right is protected and realised.

In other ways too, children experience barriers to securing their right to health. For instance, healthcare is usually delivered to children in the presence of parents who frequently enable but sometimes frustrate the child’s involvement in healthcare decision-making (Kilkelly and Savage, 2013). The situation is complicated by the intimate involvement of health professionals such as doctors, nurses or therapists. Children may struggle to have their voices heard or their perspective represented adequately in this adult dominated setting (Gabe et al., 2004). Paternalism – where the focus is on the need to protect children from harm rather than enabling them to exercise their rights – is commonplace in children’s healthcare. Children’s lack of capacity – perceived or real – can sometimes undermine their involvement in healthcare decision-making and has implications for the development of the law relating to consent (Bainham, 1986; Eekelaar, 1986; Fortin, 2009).

The CRC has made a major contribution to the legal protection of children’s rights by articulating children’s needs and interests as legal claims and entitlements and giving children
and those who work with and for them a basis for legal advocacy (Freeman, 2007). In addition to enshrining health and healthcare as a legal right of the child, the indivisibility of rights means that children’s rights to education, play, contact with family, and to have a say must also be protected when children come into contact with the healthcare system. At the same time, the CRC says remarkably little about the scope of the child’s right to health and how to ensure that children’s healthcare is delivered in a rights compliant manner. Nor does the CRC direct states on the many sensitive and controversial issues in children’s health, including consent to medical treatment, involvement in medical trials and the impact of poverty on child health. The Committee on the Rights of the Child has provided important guidance to states on these and other contemporary issues of child health but many questions remain. Some of these questions arise from the fact that children are not a homogenous group – they differ not only in age and levels of maturity but in other ways too related to socio-economic background for instance. This complexity is not reflected in the CRC, as the Introduction to this Handbook notes, yet it is crucial to the effective implementation of the child’s right to healthcare as this chapter shows. Issues of capacity, perceptions of childhood and different professional attitudes and cultural traditions all add to the complex challenge of ensuring that every child enjoys their right to healthcare. Disparity in socio-economic circumstances also weighs heavily on the extent to which children enjoy their right to health. Poverty, famine and drought frustrate efforts to provide even basic healthcare to children in certain countries meaning that the children’s rights issues vary dramatically from the developed to the developing world. On a more positive level, healthcare is a hugely important setting in which to promote and protect children’s rights where children, families, health professionals and government agencies are necessary partners to effect children’s healthcare rights. Inter-disciplinarity and inter-agency co-operation – at the core of the implementation of children’s rights – is present here too. If made to work, however, the benefits are huge. Children’s health is not only a right in itself, it enables children to enjoy their other rights to the full and if children’s rights are effectively protected in the healthcare setting, the multiplier effects are significant.

Against the backdrop of this complexity, this chapter has two aims – first, it will sketch out the right of the child to health under the CRC. A summary of the key CRC provisions is provided and a brief analysis of the application of the CRC to some of the contemporary issues in child health is presented. Second, the chapter will then consider in more depth the challenges posed by children’s rights in healthcare, and will examine with reference to research, the extent to which these rights are being protected in practice. Particular regard is had here to the right of the child to participate in healthcare decision-making, as this is a key barometer of child’s rights compliant healthcare. The chapter concludes with an assessment of the challenges that prevent further implementation of children’s rights in healthcare.

2. The child’s right to health in international law

International law on the right to healthcare can be traced to the Constitution of the World Health Organisation of 1946 and shortly afterwards, the Universal Declaration of Human Rights in 1948. It was not until 1966, however, that the right to health was enshrined in binding international law in the form of the International Covenant on Economic, Social and Cultural Rights (ICESCR), Article 12 of which guarantees to ‘everyone’ the right to enjoy the highest attainable standard of physical and mental health. More specific to children, Article 12(2) of the ICESCR provides that states are specifically required to take steps to achieve the full realisation of this right including those necessary, inter alia, for ‘the provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child’.
In 2000, the UN Committee on Economic, Social and Cultural Rights adopted a General Comment on the right to health where it expanded upon the duty to protect, respect and fulfil the right without discrimination (UN Committee on Economic, Social and Cultural Rights, 2000). According to the General Comment, the right to health has four components – availability, accessibility, affordability and quality. The Committee's commentary on the child's right to health relies heavily on the CRC in highlighting the duty to ensure that, in all policies and programmes on the right to health, the child's best interests are a primary consideration. Specific mention is also made of the need to provide a safe and supportive environment for adolescents that enables them to participate in decisions affecting their health and acquiring information and counselling that helps them to negotiate health-behaviour choices (UN Committee on Economic, Social and Cultural Rights, 2000).

### 2.1. Convention on the Rights of the Child

In 1989, the adoption of the CRC by the General Assembly of the United Nations recognised explicitly the child's right to healthcare in international law. Article 24 of the CRC makes provision for the child's right to 'the highest attainable standard of health and to facilities for the treatment of illness and the rehabilitation of health' and provides that States shall 'strive to ensure that no child is deprived of his or her right of access to such healthcare services.' Thereafter, the provision focuses on what could be considered basic, minimum standards of child health in that states are required to take appropriate measures in respect of infant and child mortality; the development of primary healthcare; disease and malnutrition; pre- and post-natal care for mothers and health promotion. The emphasis on the needs of children in developing countries is accentuated by the final paragraph, which requires states to 'promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article', with particular account being taken of the 'needs of developing countries'. Interestingly, the African Charter on the Rights and Welfare of the Child, which was adopted in 1990 and came into force in 1999, contains very similar provisions to the CRC. Article 14 of the Charter also focuses on the core minimum health standards for children including: primary care, prevention, healthcare for mothers and health promotion.

Article 24(3) of the CRC requires states to take 'all effective measures' to abolish traditional practices prejudicial to the health of children (see also Leye and Middelburg, Chapter 17 in this Handbook). The CRC recognises that traditional cultural practices have an impact on children's health and steps must be taken to eliminate them, but it stops short of naming various forms of mutilation or cutting carried out for religious, cultural or social reasons (Fortin, 2009). The Committee on the Rights of the Child has also been slow to define such practices and it is notable that the General Comment on the Right to Health does not deal with Article 24(3), while only a passing reference is made to the elimination of the practice of genital mutilation in the General Comment on Adolescent Health (UN Committee on the Rights of the Child, 2003b: 3). In the absence of explicit protection of the child's right to health in this context, legitimate concerns prevail about the dominance of competing rights claims – including parents' rights and religious/cultural rights – over those of the child in this area (DeLaet, 2012).

Article 24 of the CRC is not the only Convention provision relevant to child health. Also relevant is Article 6, which recognises the right of the child to life, and requires states to secure to children the right to survival and development to the maximum extent possible. This provision – one of the four general principles of the Convention (UN Committee on the Rights of the Child, 1991) – makes it clear that children are entitled to a standard of health that is commensurate with their healthy development. The UN Committee on the Rights of the
Child has carefully linked Articles 6 and 24 to the body of evidence on social determinants of health (Commission on the Social Determinants of Health, 2008). In particular, the Committee has highlighted that the ‘many risks and protective factors that underlie the life, survival, growth and development of the child need to be systematically identified in order to design and implement evidence-informed interventions that address a wide range of determinants during the life course’ (UN Committee on the Rights of the Child, 2013b: 6).

The CRC’s three other general principles – under articles 2, 3 and 12 – resonate loudly in the healthcare setting too. Article 2, which requires states to ensure CRC rights to all children without discrimination on the grounds of ‘origin’ and ‘property’ makes it clear that poorer health or disadvantaged access to healthcare services derived from social origin, geographical location or poverty is contrary to the Convention. Conversely, it is argued that child rights and equity principles can help to deliver more effective child health in practice globally (Goldhagen and Waterston, 2007; Goldhagen and Mercer, 2011). But like socio-economic rights more generally, equal enjoyment of the right to health is a huge challenge that is far from met in reality (Marmot et al., 2008; Berry et al., 2010). Significantly though, as Tobin has noted, the drafters of the CRC recognised that the health of children is not compromised merely ‘by gaps in medical knowledge, a lack of resources, or inadequacies in the social determinants of health such as housing and food’ (Tobin, 2009: 374).

Article 3, which requires the best interests of the child to be a primary consideration in all actions concerning children, reinforces that healthcare policy and the organisation of healthcare must be informed by what is in children’s interests, while also highlighting that healthcare must meet the needs of individual children (UN Committee on the Rights of the Child, 2013b: 12). The key question of course is how are the child’s best interests or needs to be determined in the healthcare setting (Fortin, 2009). Some health professionals and health systems use a solely medical framework (the ‘diagnose and treat dialectic’) for determining what treatment or approach to apply to child health (Goldhagen and Mercer, 2011). However, under the CRC, individual children’s best interests must be assessed in a holistic manner, based on their ‘physical, emotional, social and educational needs, age, sex, relationship with parents and caregivers, and their family and social background, and after having heard their views according to article 12 of the Convention’ (UN Committee on the Rights of the Child, 2013b: 13). The Committee on the Rights of the Child has made it clear that hearing the views of children and taking them into account in the decision-making process is the only way to ensure a rights-compliant approach to the implementation of Article 3 (UN Committee on the Rights of the Child, 2009: 15). To aid this process, the Committee has advised that states should develop ‘procedures and criteria to provide guidance to health workers in this area’ (UN Committee on the Rights of the Child, 2013b: 14).

Article 12 is pivotal to healthcare decision-making concerning children in two ways: the first concerns the involvement of the child in decisions about their individual healthcare treatment and the second requires that children’s views are taken into account in healthcare policy and the planning, delivery and improvement of healthcare services (UN Committee on the Rights of the Child, 2009: 20). In relation to the former, views about the limits of children’s capacity – specifically in the case of younger children who have no legal entitlement to consent – can inform professionals’ attitudes towards them with the result that children may not be involved in any meaningful way in decisions about their healthcare. Yet, as the Committee on the Rights of the Child has pointed out, children should be included in decision-making processes in line with their evolving capacities (UN Committee on the Rights of the Child, 2009: 20). Moreover, children themselves want to be listened to, want more information about their healthcare and want to understand the information they are given (Kilkelly, 2011). To this
end, children should be provided with information about ‘proposed treatments and their effects and outcomes’ (UN Committee on the Rights of the Child, 2009: 20).

There is recognition in Article 5 of the CRC that the role of the parent to support the child’s exercise of his/her rights changes with the child’s evolving capacity and maturity. At the same time, even very young children are capable of expressing their views if adults develop the skills to listen to them (Alderson, 2007; UN Committee on the Rights of the Child, 2009: 7). This is true for healthcare professionals too who should receive training in this area (UN Committee on the Rights of the Child, 2009: 12). Older children also have the right to be able to participate in healthcare decision-making and respect for their right to privacy under Article 16 requires professionals to create safe spaces to this end (UN Committee on the Rights of the Child, 2003b: 3). Children are not a homogenous group, however, and children who come into contact with the healthcare system have different needs and circumstances (Alderson, 2014). Depending on their age and understanding, their level of familiarity with their health and the healthcare system in which they are treated, children will have different levels of capacity to understand and participate in healthcare decision-making.

Taken together, the provisions of the CRC prescribe healthcare for children that is informed by equitable access, the best interests of the child and children’s views and perspectives. This approach applies to individual healthcare decision-making as well as to the way in which healthcare policy and services are developed and implemented. Children of all ages have much to contribute to the development of healthcare policy and efforts to improve service delivery. Respect for children’s right to participate requires their voices to be heard in this context also and for this reason, the Committee on the Rights of the Child has recommended that states introduce measures enabling children to ‘contribute their views and experiences to the planning and programming of services for their health and development’ (UN Committee on the Rights of the Child, 2009: 21). A broader approach requires children’s involvement in policy making that has implications for children’s health, like in the area of environmental health for example (Spady et al., 2008).

More generally, a children’s rights approach to healthcare requires states to put in place a healthcare system that respects not only the child’s right to health, but all the child’s other rights too. Child-friendly healthcare, as defined by the Council of Europe Guidelines, is ‘health care policy and practice that are centred on children’s rights, needs, characteristics, assets and evolving capacities, taking into account their own opinion’ (Council of Europe, 2011). A child rights approach to healthcare means that under the CRC, children who come into contact with the healthcare system have a right to access education (Article 28), to enjoy play, rest and leisure (Article 31), to enjoy their right to privacy (Article 16) and to have contact with and the support of their parents and carers (Articles 9, 18) throughout this process. Children continue to have the right to be protected from all forms of harm (Article 19) and exploitation (Article 36) and they are entitled to religious freedom (Article 14) and freedom of expression (Article 13). The child’s right to information is particularly important in the healthcare context. Children have a general right to access information and material from a diversity of sources, especially information aimed at the promotion of the child’s social, spiritual and moral well-being and physical and mental health (Article 17). In addition, the Committee on the Rights of the Child has encouraged states to adopt and implement ‘a comprehensive strategy to educate children, their caregivers, policymakers, politicians and professionals working with children about children’s right to health, and the contributions they can make to its realization’ (UN Committee on the Rights of the Child, 2013b: 19). Healthcare decision-making requires that children are provided with ‘adequate and appropriate information’ to inform the choices being made are in the child’s best interests and to
enable them to provide their consent in an informed manner, when possible (UN Committee on the Rights of the Child, 2013a: 17).

3. Contemporary challenges in child health

3.1. Consent

Although the CRC could not be expected to deal with every eventuality and issue affecting child health, it is remarkably silent on a large number of the contemporary dilemmas and controversies. For instance, it makes no explicit reference to what is arguably the key question in child health, i.e. the age at which children can consent to medical treatment without the consent of their parents or carers. Nor does it consider when children should be entitled to refuse such treatment or the limits that might be placed on such decisions (e.g. with regard to euthanasia, organ donation or non-therapeutic research). Although Article 5 recognises the role of parents in providing guidance to children in the exercise of their rights in line with the principle of evolving capacity, the CRC does not stipulate at what age children should be allowed to take responsibility for decision-making in healthcare or what say children should have where their legal consent is not required. Article 12 of the CRC requires that children’s views are taken into account in matters that affect them and the Committee on the Rights of the Child has recommended that ‘supportive policies are in place and that children, parents and health workers have adequate rights-based guidance on consent, assent and confidentiality’ (UN Committee on the Rights of the Child, 2013b: 7). At the same time, health professionals, whose ‘decisions and actions’ ‘impact on children’s lives in profound, intimate, and powerful ways’ (Lansdown, 2000) are not mentioned in the CRC, which is also silent on whether parents or health professionals should have the final say when consensus cannot be reached.

The CRC announced the recognition of the child’s independent status as a rights-holder, making it clear that the traditional dynamic – whereby parents and health professionals alone took the decisions about children’s health – had to change (Fortin, 2009). Recognition of children’s rights has begun to increase awareness of children’s capacity and competence in healthcare decision-making, with the criteria moving from age to understanding (Alderson, 2007). At the forefront of this shift was the 1986 judgment by the House of Lords in Gillick v West Norfolk and Wisbech Area Health Authority ([1986] AC 112), which decided that children under the legal age of consent can have capacity to consent if they are considered mature enough to understand the implications of the decision. A judgment still needs to be made as to whether the child is ‘mature enough’ and so such developments have not necessarily led to more widespread exercise of autonomy by children in the healthcare process. What autonomy does exist more frequently applies to children’s right to consent to, rather than their right to refuse medical treatment (Gilmore and Herring, 2011) and adult-formed views of what is in a child’s best interests continue to influence children’s involvement in healthcare decision-making (Kilkelly and Donnelly, 2006). Admittedly, the CRC presents a somewhat cloudy picture here in requiring under Article 3 that the best interests of the child be a primary consideration in all actions (including healthcare). This, it is suggested, hands the power back to the adults to make this determination, notwithstanding the requirement under Article 12 that the child’s views be taken into account. In this way, the issue of consent to or refusal of medical treatment must be distinguished from the right of the child to have a say in the healthcare decision-making process (Donnelly and Kilkelly, 2011) if greater compliance with children’s rights is to be achieved.

Regardless, it is arguable that consideration of what is in a child’s best interests outweighs the interference with bodily integrity that proceeding without consent would normally
involve. The ‘best interests’ principle and sometimes even the public interest can outweigh the child’s exercise of his/her autonomy in this area (Ribot, 2013). Aside from the many ethical issues here, the question of why it is legitimate to proceed without the consent of a child – indeed faced with the child’s opposition to an intervention – when the same standard is not applied to an adult remains unanswered. Freeman has argued, based on Dworkin’s theory of ‘future orientated consent’, that such restrictions on the child’s autonomy can be justified because they enable children to mature to independent adulthood (Freeman, 1992). This approach clearly applies only where the autonomy is being limited to preserve life; it does not assist when the decision is to refuse life saving treatment or to hasten death. Should children’s exercise of their right to health include a right to refuse medical treatment with the ultimate consequence? Situations like euthanasia (Vrakking et al., 2005) are clearly much more difficult to resolve than where the child is choosing between two different types of life sustaining treatment (Gilmore and Herring, 2011). Similarly, where the medical treatment results in no benefit to the child – such as in areas like non-therapeutic research or organ or bone marrow donation – the search continues for a satisfactory framework to determine its legitimacy and its compliance with children’s rights (Fortin, 2009; Lyons, 2011; Alderson, 2014).

3.2. Sexual health

Although Article 24 makes reference to pre- and post-natal care for mothers, it makes no explicit reference to when children themselves become mothers and what entitlements they have to autonomy over their bodies in this context. The Committee on the Rights of the Child has acknowledged the reality of ‘high rates of pregnancy among adolescents globally’ and recommended that health systems and services are able to ‘meet the specific sexual and reproductive health needs of adolescents, including family planning and safe abortion services’, ensuring that girls can make autonomous and informed decisions on their reproductive health (UN Committee on the Rights of the Child, 2013b: 13). Although the issue of confidential access to information and counselling on matters of sexual health might be considered too controversial for a binding international treaty, it is disappointing that the Committee’s guidance is not more specific. For instance, although the Committee states a preference for privacy and confidentiality with respect to advice and counselling on medical matters, it reserves the right to privacy and confidential services, including treatment, to those ‘adolescents deemed mature enough to receive counselling without the presence of a parent’ (UN Committee on the Rights of the Child, 2003b: 4). The controversy that this has generated in the courts suggests, perhaps, that the Committee is correct not to establish minimum universal standards in this area (e.g. Bridgeman, 2006; Gilmore and Herring, 2011).

3.3. Health promotion

The importance of health promotion is specifically mentioned in Article 24(2)(e) of the CRC, which highlights the need to equip parents and children with basic knowledge on child health and nutrition. This links in with Article 17 also, which recognises the importance of children having access to information and material 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’. The importance of providing health information to children in accessible, age appropriate forms and formats, is well recognised in the General Comments also (UN Committee on the Rights of the Child, 2003b, 2013b), where it is linked to preventive healthcare and promotion of healthy life choices. The relevance of ‘nutrition’ in contemporary times can be
linked to obesity as the most significant health risk to children in both developed and increasingly developing countries (WHO, 2014).

The CRC is equally silent on other crucial aspects of child health promotion including children’s involvement in medical trials and their access to life-saving medicines and vaccinations. Also unclear is how the CRC would apply when the risk to the child – say of HIV infection or foetal alcohol syndrome – comes from his/her mother (Dabis and Ekpini, 2002; Scott, 2000). Would the child’s best interests and his/her right to health trump a mother’s right to autonomy and bodily integrity in these circumstances? This issue has been addressed in the Committee’s General Comment on HIV/AIDS and the Rights of the Child where states are encouraged to take steps to prevent mother to child transmission of HIV/AIDS including via the provision of essential drugs and medical intervention (UN Committee on the Rights of the Child, 2003a: 8). Given the scale of these threats to children’s health and development, it is surprising that they have not been addressed much more directly in the Committee’s guidance on the child’s right to health.

4. Implementing children’s rights in healthcare

In addition to these challenges to children’s right to health, multiple barriers also prevent the realisation of children’s rights in healthcare. Research provides a useful insight into the extent to which children’s rights are implemented in the healthcare setting and multiple small studies on children’s experiences and views on healthcare inform international compliance with children’s rights norms in this setting. This next section considers this evidence in an effort to examine the progress made in the implementation of children’s rights in health by focusing in detail on the specific aspect of children’s right to participate in healthcare decision-making.

4.1. Children’s right to participate in healthcare decision-making

As already noted, international law is clear about children’s right to have a say in decisions that affect them. Healthcare clearly affects children and the centrality of Article 12 to healthcare is confirmed to be the most important right to children across all age groups (Bensted et al., 2014). However, the research presents a complex picture as to the extent to which children enjoy this right in practice (Moore and Kirk, 2010; Coyne, 2008; Martenson and Fagerskiold, 2007; Worrall-Davies and Marino-Francis, 2008).

Several studies show that children are often marginalised from the decision-making process across a range of settings including: hospital inpatient units (Lambert et al., 2008, 2010b; LeFrancois, 2007; Coyne et al., 2006; Alderson, 2014); outpatient departments (Savage and Callery, 2007) and community healthcare (Kilkelly and Donnelly, 2006; Tates et al., 2002). One study (Lambert et al., 2008, 2010b) noted that during healthcare consultations, children were either positioned as ‘passive bystanders’, as healthcare professionals communicated directly with parents or ‘active participants’, as healthcare professionals communicated directly with them. The impact of the ‘passive’ position was that children were left ‘overshadowed’, eavesdropping in the background, whereas children in the ‘active’ role were more prepared to ask questions. Observations made in the outpatient departments of two Irish hospitals found that the communication style of healthcare professionals – closed conversations and interrogative questioning – contributed to the largely marginalised position of children (Savage and Callery, 2007). These researchers found that parents’ accounts of their children’s health (cystic fibrosis) were often privileged over those of their children, and some children spoke of healthcare professionals not believing what they had to say. Staff were friendly towards the children and talked to them
about social aspects of their lives, but conversations with them about their health were limited (Savage and Callery, 2007).

Although children have the right to participate in the healthcare process under Article 12 of the CRC, they have no obligation to do so. Striking the right balance between supporting children to be involved, but not requiring that participation can be difficult as children’s needs and preferences vary. Apart from the differences between children, a child may move along the spectrum from active to passive involvement in the process requiring health professionals to be constantly attuned to their wishes and their development to ensure that the choice about what role they play lies with the child. Children’s preferences about their level of involvement during consultations can vary with age, with younger children preferring their parents to communicate to health professionals, whereas older children mostly prefer to take the lead (Gibson et al., 2010; Garth et al., 2009; Savage and Callery, 2007; Kilkelly and Donnelly, 2006; Coyne et al., 2006). For the health professionals, age and cognitive ability can determine a child’s level of involvement in consultations (Garth et al., 2009; Martenson and Fagerskiold, 2007). According to one Irish study, however, professionals were influenced more by a child’s age, than his/her capacity to understand or be directly involved (Kilkelly and Donnelly, 2006), implying a belief that younger children are less capable of being involved during healthcare consultations compared to older children. Conversely, research has found that young children have a greater capacity to communicate about their health and well-being than adults are willing to believe (Garth et al., 2009; Savage and Callery, 2007; Alderson and Montgomery, 1996). The reality that one size does not fit all is reinforced by the fact that additional factors – illness experiences, social experiences of communicating with adults and a willingness to be involved – may influence the level of involvement that children want during consultations (Gibson et al., 2010; Alderson et al., 2006). Training and education to deal with the variety of situations that may arise is clearly vital in ensuring that all health professionals have the capacity to respond appropriately to the needs of the child in each individual case (UN Committee on the Rights of the Child, 2003c).

In some studies, children differentiate between making ‘small’ (those relating to everyday aspects of care, like diet and medication) and ‘serious’ decisions (relating to surgery for example) (Coyne et al., 2006; Coyne and Gallagher, 2011), presenting mixed views as to whether the latter are made by them alone or shared with carers. These findings suggest that children’s participation in decision-making is a matter of degree and accordingly, there is a need for a flexible and individualised approach that meets the needs, choices and desires of the children concerned.

Access to information is important both to facilitate meaningful participation by children in healthcare decision-making and as a right in itself. Research shows that children appreciate the importance of information in the healthcare context. For example, in a survey of young people undertaken for the Council of Europe, 80.9% of the respondents considered it important that children should be given information about what is going to happen to them in the healthcare setting (Kilkelly, 2011; Bensted et al., 2014). In other studies (Kilkelly and Donnelly, 2011; Alderson, 2014), children readily identified that having things (e.g. proposed treatment) explained to them in advance made them less afraid. For children, therefore, there are important, practical reasons for ensuring that they have information that they can understand.

Participation in healthcare decision-making presupposes that children will be informed and will understand the issues being discussed, but providing information in a way that is understood by children and that is relevant to their needs is not straightforward. Using age appropriate language and props has been described by children as a component of their ‘ideal model of participation’ (Kilkelly and Donnelly, 2006); a finding supported in communication.
frameworks for working with children (Jaaniste et al., 2007; Alderson and Montgomery, 1996). Yet, this component of an ‘ideal model of participation’ is not often experienced by children (Buckley and Savage, 2010; Lambert et al., 2010b; Savage and Callery, 2007; Coyne et al., 2006). Regarding language, children have identified the importance of professionals using child-friendly terminology when medical or healthcare information is being communicated to them. Studies have found that the use of ‘simple’ language in the child’s own terms and the avoidance of medical ‘jargon’ better equips children to understand health information communicated to them (Mitchell-Lowe and Eggleston, 2009; Kilkeely and Donnelly, 2011; Coyne et al., 2006). However, it is evident that as children get older, they want information in terminology that is more age appropriate (Gibson et al., 2010).

There have been surprisingly few studies on information sharing practices with children in healthcare. Some studies – mainly relating to children’s hospital experiences – have shown that children want information on what to expect especially in relation to procedures and medical treatments (Coyne and Gallagher, 2011; Migone et al., 2008; Coyne et al., 2006). One general study analysed unsolicited information requests made by children and young people to the Children’s First for Health website in the UK, which is an online information resource for this population group (Franck et al., 2008). Over an 18-month period, there were 2,865 hits for general information and 924 hits for specific inquiries. There were more hits from adolescents than younger children. The most common queries related to psychosocial issues, hospital and health services, and normal growth and development. These researchers, along with others (e.g. Gray et al., 2005), illustrate that children are active agents in seeking out information about health and healthcare matters in their own time and space.

There is evidence that children are dissatisfied with the information received from healthcare professionals. One study found that children aged 5 to 11 years were generally dissatisfied with how they were informed about impending procedures such as injections and x-rays (Kilkeely and Donnelly, 2006). Although there was some evidence of procedures being explained, the practice of informing children was found to be sketchy overall and not a planned process. According to Jaaniste et al. (2007), healthcare professionals often experience uncertainty about informing children in relation to medical procedures. These researchers offer a framework on the scope of providing children with health-related information: content – what to tell them; format – how to convey information; personnel – who provides information; and timing – when to provide information. Using this framework, Buckley and Savage (2010) explored the pre-operative information needs of children (aged 6 to 9 years) undergoing tonsillectomy in one general teaching hospital in Ireland. Children, who were interviewed on the eve of surgery, spoke of having received little information in advance of admission for surgery. One consequence of children having limited information is that they may construct inaccurate mental representations of what might happen and these could be frightening.

Effective communication depends not only on the approach taken, it also depends on the nature of the relationship between those communicating. Children want healthcare professionals to be sympathetic towards them; children in one Irish study identified this quality as definitive of ‘a good health professional’ (Kilkeely and Donnelly, 2006, 2011). Children need healthcare professionals to empathise with them and their situation and to show some appreciation of what they are going through (Buckley and Savage, 2010; Coyne et al., 2006; Smith and Callery, 2005). Communicating with children in the healthcare context differs from everyday social discourse because private, emotional, or intimate matters may need to be discussed such as talking about stigma around mental health or worrying about the seriousness of illness. In order to deal effectively with children’s distressing situations, individual professionals need to exercise ‘interpersonal sensitivity’ i.e. affective behaviours that pay attention to, and interest in,
the child’s feelings and concerns (Levetown et al., 2008). Based on a review of evidence of clinical communication in paediatric settings, Levetown et al. recommended general behaviours for effective communication practices with children among which are: begin conversation with a broad, non-threatening topic; pay attention to body language and tone of voice; listen actively; use creative communication tools such as drawings and games; talk with the child not at them; and use language that they can understand. The importance to children of their healthcare professional being child-friendly – in the sense of connecting with them through language and approach – is a hugely dominant one across all the literature.

5. Children’s participation in policy making and service design

The CRC Committee advocates children’s involvement in consultation on healthcare policy (UN Committee on the Rights of the Child, 2013b: 7). In contrast to the growing body of knowledge on children’s participation in clinical consultations and decision-making regarding their health, there is less known about the role of children in health service planning, governance, and policy formulation. It is only in recent years that attention has focused on the ‘service user’ in the healthcare context and the idea of children being service users in healthcare is now slowly gaining momentum internationally. This is partly due to international law obligations under Article 12 of the CRC, and partly due to a wider political agenda concerning democratisation, citizenship and choice – all of which are applicable to all service users (Coad and Shaw, 2008). The evidence available to date on children as service users mostly relates to health service planning, especially children’s views and expectations of services. A growth of interest in this area is particularly notable in the UK (Koller et al., 2010; Hoole and Morgan, 2010; Robinson, 2010; Mainey et al., 2009; Coad and Shaw, 2008; Day, 2008; National Children’s Bureau, 2005; Dogra, 2005; Boylan, 2004). These reviews or studies collectively draw on children’s views across a range of services – acute hospital care, long-term care, community, mental health, and intellectual disability (Spady et al., 2008).

Taken together, the findings indicate a number of key areas that are important to children in service planning: service organisation and access; care delivery processes; staffing (qualifications and communication style); and environment. On service organisation and access, children want accessible, flexible and integrated services that allow for continuity of care. In addition, they want wider access to information about health matters and related services made available to them; the need for community drop-in centres was highlighted in one review (National Children’s Bureau, 2005). A specific call for fairness and equality has been made by young people with intellectual disabilities (Hoole and Morgan, 2010). In this study, young people expressed the view that they were not being afforded the same rights to services as their counterparts without disabilities; this reference was specific to social care provision such as housing. Areas highlighted in relation to processes of care delivery have included provision of information and shared decision-making. In addition, children have highlighted that services need to be holistic in perspective to include emotional and social care and not just physical aspects of care; a point made specifically in relation to general and acute healthcare services (Koller et al., 2010; National Children’s Bureau, 2005; Goldhagen and Mercer, 2011).

5.1. Children’s views on healthcare services

Studies have found that children connect their experience of a quality healthcare service strongly with their views on the qualities of healthcare professionals. In particular, they want staff to be knowledgeable, skilled, competent, and to have expertise specific to a child’s health
condition or problem (Robinson, 2010). Their relationships with their professionals are important – as noted above, the evidence clearly points to children wanting professionals that are friendly, good communicators, good listeners, empathetic and non-judgemental (Robinson, 2010; Mainey et al., 2009; Coad and Shaw, 2008; Dogra, 2005; National Children’s Bureau, 2005; Boylan, 2004). Significantly, these qualities have also been identified as important for others working in the healthcare system, like receptionists (National Children’s Bureau, 2005).

Regarding the environment, the evidence points to a number of facilities and resources that children would like to see built into service planning. Play and recreation resources and activities have been highlighted as important to children across a range of healthcare settings (Lambert et al., 2010a; Koller et al., 2010; National Children’s Bureau, 2005; Boylan 2004). This is an area reported by children to be inadequate (Migone et al., 2008; Kilkelly, 2011). Play is not only important as a right of the child under Article 31 of the CRC, it is also a vital part of the child-friendly approach to healthcare in that it aims to secure healthcare services to children in a manner that respects their rights. Although there is little published research on the role of play specialists in promoting a culture of respect for children’s rights in healthcare settings, there is evidence that organised and supervised play activities by such professionals help to alleviate children’s distress and anxieties in relation to procedures such as day surgery (Fereday and Darbyshire, 2008). Their work clearly facilitates the fulfilment of the child’s rights to health and to play in the healthcare setting.

Children and young people have also identified the need for developmentally appropriate facilities such as separate adolescent units, bright and colourful décor and age appropriate furniture (Lambert et al., 2010a; National Children’s Bureau, 2005; Boylan, 2004). For example, children’s (5–8 years) views on the design of the new children’s hospital in Ireland includes some important child-focused recommendations such as: quiet reading areas; stepping stone paths leading to play areas; open spaces to allow for physical activities e.g. jumping and dancing; bikes to move around on, and information and communication technology including game consols for playing games (Lambert et al., 2010a). The many specially designed children’s hospitals around the world are testament to how seriously this is now viewed. Children’s needs regarding facilities and resources are not just recreational and aesthetic but also directly relate to the protection of their rights. For example, older children, in particular, have called for healthcare settings to be designed in ways that promote their privacy during consultations and treatment procedures (Tylee et al., 2007; National Children’s Bureau, 2005; Boylan 2004). The need for distinct child-friendly settings for different categories of children is also applicable to younger children (Lambert et al., 2010a) and is an important illustration of the indivisibility of children’s rights in the healthcare context.

Children’s needs across all areas (e.g. organisation of and access to services; care delivery processes; staffing and the environment) have been highlighted (Boylan, 2004; National Children’s Bureau, 2005). In order to promote respect for children and their rights, health services need to be planned and implemented in accordance with children’s own identified needs. In reality, this aspiration is far from realised (Hoole and Morgan, 2010; Coad and Shaw, 2008; Dogra, 2005) and there is little substantive evidence on the long-term impact that children’s views have on changing and improving services to meet their needs. If children are to be respected as service users, however, it is important to go beyond recording their views about services and their recommendations for how this should be changed. Although this is an important baseline, respect for children’s rights in healthcare, and indeed the spirit of service user involvement, demands that children need to be supported to actively engage in service organisation, governance and policy formulation. Children’s participation at this level is now beginning to emerge (e.g. Coad and Shaw, 2008; Godfrey, 2003; Owens, 2010; Burke et al., 2010).
5.2. Challenges implementing children’s rights to participate in healthcare decision-making

Progress is being made in the implementation of the child’s right to participate in healthcare decision-making, but this is a complex and sensitive process. Barriers identified by the research include: poor communication skills among professionals who use medical jargon rather than child friendly language; lack of time and appropriate facilities; ignoring or disregarding children’s preferences and professional and parental attitudes and beliefs about age and competence of children (Moore and Kirk, 2010; Kelsey et al., 2007; Runeson et al., 2007; Kilkelly and Donnelly, 2006). The absence or inadequacy of training for those who work with and for children in the healthcare setting is a dominant concern, identified by both health professionals and children themselves (Kilkelly and Donnelly, 2006). A range of measures are necessary to address these barriers and given their mutual dependency, the measures must be addressed simultaneously to: health professionals, parents and carers and children. While resources may be required to ensure that the healthcare environment and infrastructure (hospitals, waiting areas, equipment, materials, etc.) enables respect for children’s rights, cultural and traditional barriers to children’s rights are arguably more difficult to dismantle. For instance, parents opposed to having their child involved in healthcare decision-making – perhaps because they want to protect them from a negative prognosis (Coyne and Gallagher, 2011; Kilkelly and Donnelly, 2006; Runeson et al., 2002; Tates et al., 2002) – may not be aware of the benefits to children of being informed and supported to take on a greater role in decision-making. Education will help parents to understand the importance of listening to children in this context and what they can do to support their child to realise his/her rights. At the same time, parents who wish to promote their child’s participation in decision-making may face obstacles in doing so, such as where the healthcare professional is the controlling influence (Hallstrom and Elander, 2004). Healthcare professionals need to find better ways to navigate through what can be a delicate process in order to ensure that children are spoken to directly, understand what is going to happen to them and agree to any interventions proposed (Moore and Kirk, 2010). They need to understand the significance of treating the child as a rights-holder in the healthcare process and to develop special skills to balance the right of parents to decide what is in their child’s interests with their own professional understanding of the child’s needs and rights. Child-friendly healthcare requires respect for children as the primary rights-holder; what children seek is accessible information and safe spaces in which they can express themselves freely and be supported to understand their health and healthcare better. Parents and professionals, on the other hand, should be made aware of the strength of children’s ability to reflect on their experiences and to contribute in a meaningful way to decisions about their healthcare (Alderson and Montgomery, 1996; Alderson, 2014). Addressing the attitudes, roles and competencies of all three groups is thus necessary to maximise respect for the rights of the child in healthcare.

Implementing children’s rights to healthcare depends to a large extent on the attitudes, skills and competence of those providing healthcare services at primary, secondary and tertiary levels. The scope and nature of professional training and ongoing development in child development, children’s rights and communication with children will influence the extent to which children are treated as individuals with the capacity to understand information about their health and healthcare and to participate, directly or indirectly in healthcare decision-making (Kilkelly and Donnelly, 2006). For this reason, the Committee on the Rights of the Child has recommended that all healthcare professionals receive systematic training on children’s rights and child development (UN Committee on the Rights of the Child, 2003c: 66–70, and 2010: 49). Raising awareness about children’s rights among adults, notably parents and carers, and among children
themselves is also vital to the implementation of children’s rights (see Article 42). Research shows that the awareness of children’s rights must also be generated among healthcare managers and policy makers in order to ensure that those who set the priorities for the development of the healthcare system and who decide how and where to deliver children’s healthcare services are sensitive to the needs and rights of those most affected by their decisions (Kilkelly and Savage, 2013).

According to the Committee on the Rights of the Child, translating rights into good healthcare practice requires the adoption of legislative, administrative and other measures, expending the maximum extent of available resources (Article 4). The implementation of the Convention thus requires the adoption of relevant law and policy to promote the full enjoyment of children’s rights in healthcare. It also requires the establishment of institutions, services and facilities responsible for the care or protection of children, and these must conform to the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision (Article 3(3)). Data collection on the extent to which children are enjoying their rights in healthcare is vital to monitor progress and ensure on-going implementation of the Convention (Alderson, 2014). States are encouraged to develop indicators to this end and to ensure that children have the opportunity to feed their experiences into the evaluation process (UN Committee on the Rights of the Child, 2003c: 12). Similarly, the establishment of effective monitoring bodies will ensure that targets are being met and progress maintained in the delivery of child-friendly healthcare (UN Committee on the Rights of the Child, 2003c: 3).

Ensuring that children’s rights are fulfilled in the healthcare system is thus a challenging process. It requires that:

- Healthcare law and policy and the organisation and delivery of health services recognises children as rights-holders, focuses on the child’s best interests and on the full realisation of the child’s right to health and healthcare while respecting the child’s rights to family support, protection from harm, access to education, rest and play and privacy;

- Decision-making on matters that affect the child is informed by children’s views and perspectives including individual clinical decisions and healthcare policy development and improvement to services;

- Services are organised and implemented in a manner that recognises children’s special needs, circumstances and vulnerability, with reference to their evolving capacity and changing needs.

6. Conclusion

This chapter set out the international law on children’s rights in healthcare, by providing an overview of the CRC provision on the right to health and the guidance of the Committee on the Rights of the Child and the Council of Europe Guidelines on Child-friendly Healthcare. Attention was drawn to several contemporary challenges of child health: consent, sexual health and health promotion and these complex issues were discussed from the perspective of children’s rights.

The case study of the child’s right to participate in healthcare illustrates the depth and range of research that identifies both the barriers to the implementation of children’s rights in this setting and the lessons that show that healthcare is informed by children’s interests, views and perspectives. Healthcare is a hugely important setting in which to promote and protect children’s rights. Children’s health is not only a right in itself, it enables children to enjoy their own
Implementing children's rights in healthcare brings with it a range of challenges – from traditional attitudes to the availability of resources – that must be addressed if children are to be treated as rights holders in the healthcare system.

Questions for debate and discussion

• To what extent does the CRC provide a framework for responding adequately to contemporary challenges in child health?
• What does research tell us about children's right to have a say in healthcare decision-making?
• What are the barriers to the realisation of CRC rights in healthcare?
• What measures should be taken to promote greater compliance with children’s rights in healthcare settings?
• What challenges does the specific context of healthcare bring to children’s rights?

Acknowledgements

With thanks to all of the children who contributed to all of the studies cited here and to the Department of Children and Youth Affairs, the Ombudsman for Children and the Council of Europe who have supported my work in this area. This piece draws from research undertaken with my colleague Professor Eileen Savage, Head of the School of Nursing and Midwifery at University College Cork. All mistakes remain my own.

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