Providing medical care for children has several distinguishing features. The first is that most children lack the capacity to make healthcare decisions for themselves. This means that others, typically parents in consultation with the child’s healthcare provider, must decide. At the same time, children usually develop greater capacities for decision-making as they mature and so can play a greater role in deciding about their healthcare as they get older. Another feature is that the government, exercising its power of parens patriae, intervenes more frequently to protect the interests of children than it does to protect those of adults. The result is a set of dynamic interactions, among parents, clinicians, the government, and the child, which is unique to pediatrics.

This chapter proceeds by addressing the United Nations Convention on the Rights of the Child 1989 (CRC), which lays out two critical frameworks: (1) the importance of promoting children’s best interests in decisions that affect them; and (2) the need to create opportunities for children’s views to be informed, to be heard, and ultimately for their decisions to be honored. The second section outlines some of the challenges that arise when the child’s best interests may be compromised by the interests of others or where stakeholders disagree about the child’s interests. The next section is devoted to exploring the roles of parents, clinicians, the state, and the child in healthcare decision-making, addressing, in particular, situations in which the various participants conflict. This discussion focuses primarily on the law of the United States but considers at length the Gillick case from the United Kingdom. The fourth section illustrates ways in which advances in technologies can challenge understandings of how the child’s interests are to be promoted, using the case of exome and genome sequencing.

5.1 The United Nations Convention on the Rights of the Child

5.1.1 The role of the best interests of the child

The best interests of the child (BIC) is the framework most commonly used for decision-making. This standard applies because, unlike many adults who become incompetent, children, particularly when they are younger, have never had an established set of values that can form the
basis of substituted judgment. In the international *Convention on the Rights of Child*, which is the most widely adopted international convention, rights and responsibilities are shared between parents, the state, and the child. While parents typically make decisions on behalf of their children, the Convention provides rights of the child that can be asserted against parents, typically by the state. Article 3 of the CRC, which sets forth a framework for allocating this decision-making authority, states that:

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

(1989)

Close attention reveals that this article leaves room for interpretation. The use of the term ‘a primary’ implies that the BIC principle is ‘not the only factor to be considered in the actions of institutions, authorities and administration’ (UN Committee on the Rights of the Child 2009: para. 71) or even the only important one. Exactly what weight is due is debated. Hammarberg, for example, writes the BIC should be ‘among the first aspects to be considered and … given considerable weight in all decisions affecting children’ (2008: 5). Some worry that the BIC gives inappropriate weight to the child, at times to the child’s detriment, as well as to the interests of the parents and the family (Iltis 2010; Cherry 2010). By contrast, others, including the World Medical Association (WMA) in its *Declaration of Ottawa on Child Health*, state that the child’s best interest is the primary consideration (2009: General Principle 3a).

The UN Committee on the Rights of the Child, the enforcement body for the CRC, expanded upon the BIC in its General Comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health (art. 24) (2013) in which it interpreted the child’s right to health as:

an inclusive right, extending not only to timely and appropriate prevention, health promotion, curative, rehabilitative and palliative services, but also to a right to grow and develop to their full potential and live in conditions that enable them to attain the highest standard of health through the implementation of programmes that address the underlying determinants of health.

(2013: para. 2)

The Committee went on to ‘underscore the importance of the best interests of the child as a basis for all decision-making with regard to providing, withholding or terminating treatment for all children’ (2013: paras 12–14), and directed states to develop criteria to help healthcare providers to determine the child’s best interests.

With regard to the responsibilities of parents, the Committee opined that:

Parents should fulfil their responsibilities while always acting in the best interests of the child, if necessary with the support of the State. Taking the child’s evolving capacity into

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1 The United States has signed, but not ratified this Convention and so is not bound by it. For a recent consideration of the United States’ position, see Bartholet (2011).

2 I am heavily indebted to Ma’in H. Zawati, David Parry and Bartha Maria Knoppers for their analysis of international law in ‘The Best Interests of the Child and the Return of Research Results: International Comparative Perspectives,’ submitted to *BMC Medical Ethics* for publication.
account, parents and caregivers should nurture, protect and support children to grow and develop in a healthy manner …

(2013: para. 78)

The Committee later discussed at length the many ways that parents can and should shape the child’s health and development and urged states to assist parents in these endeavours (2013: para. 67).

5.1.2 The rights of the child to be heard, to be informed, and to make their own decisions

Complementing its discussion of BIC, the UN Committee on the Rights of the Child also addressed the role of the child, insisting on the right of children to be heard as a general principle (2009: para. 74). Article 12 of the Convention, which for the first time codified this right, reads:

States Parties shall 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 … (1989)

The UN Committee insisted that children have the right to information (2013: para. 13) and should be presumed to have the capacity to form their own views (2009). The right of children to express their views, embodied in article 12, has three elements: they must be allowed to decide whether they want to speak (UN Committee on the Rights of the Child 2009: paras 35–42); if they do wish to speak, they must be free from undue pressure (Lücker-Babel 1995); and finally, according to the UN Committee on the Rights of the Child’s statement in 2013, children’s views should be ‘seriously taken into account, according to age and maturity’ (para. 19). As a result, sufficiently mature adolescents may be able to provide adequate consent for their own healthcare. The Committee expanded upon the state’s obligation to honor the developing capacity of the child, explaining that:

In accordance with their evolving capacities, children should have access to confidential counselling and advice without parental or legal guardian consent, where this is assessed by the professionals working with the child to be in the child’s best interests … States should review and consider allowing children to consent to certain medical treatments and interventions without the permission of a parent, caregiver, or guardian, such as HIV testing, sexual and reproductive health services, including education and guidance on sexual health, contraception and safe abortion.

(2013: para. 31)

The Committee has been more ambivalent about preserving adolescents’ confidentiality. In a report focused on adolescent health, the Committee concluded that confidential ‘information may only be disclosed with the consent of the adolescent, or in the same situations applying to the violations of the adult’s confidentiality’ (UN Committee on the Rights of the Child 2003: para. 7), but later stated that such information can be disclosed to parents if it is in the child’s best interests (para. 28). Nonetheless, the picture that emerges from the discussion of BIC and of the child’s participation in decision-making is child-centered, with the interests of parents playing a secondary role.
5.2 Challenges to the best interests of the child in clinical practice

The best interests of the child, while clearly elevated above those of the parents in the CRC, at times may be redefined or even subordinated in order to accommodate other interests. This conflict of interest is perhaps most obvious when one child is a potential donor of a kidney or bone marrow to his or her sibling, procedures that pose risks to the donor. The cases that most frequently reached court were those in which the potential donor is developmentally delayed or quite young. In many cases, courts in the United States objected to the procedure, concluding that it was not in the donor’s best interest (see, for example, Curran v. Bosze, 566 NE 2d 1319 (1990)), or exceeded the court’s authority (In re Richardson, 284 So.2d 185 (1973)). The few courts that permitted the donation did so specifically on the ground that the benefit to the donor from the survival of the sibling/organ recipient was so great that it outweighed the risks to the donor of the procedure to harvest the organ, recasting organ donation as a primary benefit to the donor. (See, for example, Little v. Little, 576 S.W.2d 493 (1979); Hart v. Brown, 289 A.2d 386 (1972)).

Another area where questions can arise about the BIC and from whose perspective it is assessed is childhood immunizations, which are required to protect the child and others from a wide array of communicable diseases. Some parents, however, feel that their children’s best interests are compromised by state immunization requirements, reasoning that their child’s risk of contracting the disease does not warrant exposure to the perceived risks of vaccines. These differences in understanding of ‘best interest’ have led to enormous controversy.

In the discussion that follows, which will focus on US law while making some comparisons to the laws of other countries, we will examine the roles of parents, clinicians, the state and the child in making healthcare decisions for minors to address the extent to which legal systems protect the best interests of the child and their rights to health, to be heard, and to decide.

5.3 Who decides about the healthcare of children?

5.3.1 The role of parents

Parents are literally the primary care providers for their children. Parents decide, after all, whether to give chicken soup and an antipyretic to an ailing child or whether to take the child to the clinician for care. In addition, even if the child is seen by a healthcare provider, most medications are delivered in the home, whether by the parent or by the child, in the latter case often with parental supervision. More generally, parents are thought to be most likely to act in their child’s interest and, in accordance with the classic liberal tradition (Ross 1998), are given broad deference in how they raise their children. This presumption of deference to parental decision-making in many domains, including healthcare, is deeply embedded in US law, embodied in such federal constitutional cases as Meyer v. Nebraska, 262 US 390 (1923), Pierce v. Society of Sisters, 268 US 510 (1925), Prince v. Massachusetts, 321 US 158 (1944), Wisconsin v. Yoder, 406 US 205 (1972), and Parham v. J.R., 442 US 584 (1979). Within this domain, parents are not required to focus solely on the best interest of the child, but rather may, and often do, take into account competing needs and goals. Other countries which have ratified the CRC also acknowledge deference to parents in childrearing (UN Committee on the Rights of the Child 2001: para. 217; UN Committee on the Rights of the Child 2002: para. 58).

3 The issue of religious objection to immunization is addressed in section 5.3.4 below.
5.3.2 The role of the clinician

Parental discretion, however, is not unlimited. In responding to parental requests for medical care, the United States Supreme Court in *Parham* noted that in earlier decisions, the Court had ‘asserted that parents generally have the right, coupled with the high duty, to recognize and prepare [their children] for additional obligations [cits. om.]. Surely, this includes a “high duty” to recognize symptoms of illness and to seek and follow medical advice’ (1979: 602; emphasis added). Nor are parents able to obtain whatever medical interventions they desire. Many medical interventions, such as prescription medications and many diagnostic procedures, are available only on physician’s orders. In *Parham*, for example, parental requests for commitment of their children were subject to physician approval. This type of physician control, of course, is applicable to the healthcare of both adults and children. From an ethical perspective, however, the focus on the best interest of the child provides the clinician with greater discretion than is warranted in the care of competent adults, where the guiding values of the individual patient have greater weight.

Legal issues typically arise only when parents do not agree with the clinician on a course of care. In such cases, a variety of responses may be appropriate. In cases where the course of care desired by the parents is adequate, even if not the one preferred by the clinician, the healthcare provider can simply defer to the parents’ wishes. If the physician is unwilling to accede, then he or she must effectively terminate the physician–patient relationship in order to avoid liability for abandonment and, in most cases, help the family to find another healthcare provider.

5.3.3 Medical neglect and state intervention

Things become more complex when clinicians reasonably believe that the parents’ failure to provide recommended care poses a threat of substantial harm to the child. All states have laws requiring that clinicians report such suspicions of ‘medical neglect.’ If the state agency concludes that this level of harm will occur more probably than not, the state may go to court seeking an order to intervene to protect the child. If the court agrees, it has a variety of tools available, ranging from simply ordering treatment to removing the child from the home as a last resort. Issues of medical neglect most commonly arise when parents fail to deliver the ongoing care for a child with a chronic medical condition such as cancer (*Jensen v. Cunningham* 250 P.3d 465 (2011)), diabetes (*In re Shawndel M* 824 NYS 2d. 335 (2006)), or cystic fibrosis (*In Re Stephen K* 867 NE2 81 (2007)). These cases are particularly challenging since ensuring treatment may require removing the child from the home, a disruption that may harm the child in other ways, as well as profoundly affecting the remaining family. Concerns about medical neglect also arise when parents fail to seek medical care for an acute illness or injury (see *Walker v. Superior Court* 763 P.2d 852 (1988) (failure to seek care for child with meningitis)).

5.3.4 Parental religious objection

Parents often object to medical interventions on religious grounds. Examples include the Old Order Amish who refuse state-run newborn screening and immunizations, Christian Scientists who refuse all allopathic medical treatment, and Jehovah’s Witnesses who refuse blood products. The Nixon administration briefly required states to enact statutes allowing people to opt out of medical care for religious reasons as a condition of receiving federal funds for Medicaid, the insurance program for the poor. As a result, most states enacted statutes allowing parents to refuse medical treatment for religious reasons. However, not all countries respond to medical neglect in the same way. See, for example, Ertem et al. (2002); Raman and Hodes (2012); Pinnock and Crosthwaite (2005).
some medical interventions for their children for religious reasons, statutes that have largely remained in place despite the fact that the federal requirement was quickly rescinded.

The state religious objection laws vary significantly in their language, with some written to apply to only one or two established religious groups (e.g. New Hampshire Statutes §169-C.3. XIX.(c) 2013; Colo. Rev. Stat. Ann. § 19-3-103(2) (2013)), while others are quite broad and extend to conscientious or philosophical objection even in the case of public health emergencies (e.g. Ore. Rev. Stat. § 431.264(2)(d) (2013); Maine Rev. Stat. 22 § 820.1.B.(3)(a) (2013)). Many statutes address specific topics, such as newborn screening and immunizations, while others apply to medical care generally.

Although an important function of these laws is to ensure that parents who follow their religious beliefs in refusing medical care for their children are not deemed neglectful, their freedom to refuse care for religious reasons, however, is not unlimited. Nor is the state powerless to intervene to protect the child from serious harm, despite the parents’ religious beliefs. Alabama, in its provision dealing with parental objection, states:

(a) … This exception [for parental religious objection] shall not preclude a court from ordering that medical services be provided to the child when the child’s health requires it.

(b) The department may, in any case, pursue any legal remedies, including the initiation of legal proceedings in a court of competent jurisdiction, as may be necessary to provide medical care or treatment for a child when the care or treatment is necessary to prevent or remedy serious harm to the child, or to prevent the withholding of medically indicated treatments from infants with disabilities and with life-threatening conditions.

(Alabama Code § 26-14-7.2 (2013))

Colorado’s statute provides that ‘the religious rights of a parent, guardian, or legal custodian shall not limit the access of a child to medical care in a life-threatening situation or when the condition will result in serious disability’ (Colo. Rev. Stat. Ann. § 19-3-103 2013). Provisions such as this put the parents at risk if they do not seek medical attention once the child becomes seriously ill, whether they recognize the seriousness of the situation or not. A number of cases over the years have addressed the question of whether parents can be criminally liable for failing to seek and provide medical care for their children for religious reasons, despite the presence of exemptions within the child protection laws. (See, for example, Walker v. Superior Court, 763 P.2d 852 (1988); State of Wisconsin v. Neumann, 832 NW 2d 560 (2013) (upholding convictions). But see Hermanson v. State of Florida 604 So.2d 775 (1992) (striking down conviction); Commonwealth v. Twitchell 617 NE 2d 609 (Mass. 1993) (striking down convictions but permitting prosecution of cases in the future).)

5.3.5 The ability of the minor to make their own choices about medical care

The general rule is parental permission is required for medical evaluations and treatment of minors. Failure to obtain this permission in the absence of a medical emergency can give rise to a claim for both the parent and the child for battery, that is unconsented touching of the child (Bonner v. Moran, 126 F.2d 121 (1941); Rogers v. Sells, 61 P.2d 1018 (1930); Miller v. HCA, Inc., 118 S.W.3d 758 (2003)). Under a number of circumstances, however, the law permits minors to make their own healthcare choices.

The United States Constitution protects healthcare decision-making by minors about a narrow range of issues, providing them with rights to choose contraception (Carey v. Population
Statutes, therefore, are a major source of minors’ rights to make other healthcare decisions. All states have laws allowing minors to obtain certain types of medical care without parental permission (English et al. 2010). These frequently include treatment for drug and alcohol abuse, mental health, and pregnancy, which generally accords with the UN Committee on the Rights of the Child’s recommendations (2013: para. 31). States may also allow minors who have attained a certain status to make all healthcare decisions on their own, although states vary dramatically in their criteria for which minors qualify. Some of the qualifying events are marriage, emancipation, living independent and apart, enlistment in the military, pregnancy, and parenthood.

Common, or judge-made, law is the primary source of the ‘mature minor’ exemption to the requirement of parental permission (Slonina 2007). This doctrine allows clinicians under certain circumstances to rely on the consent of minors for clinical interventions, protecting clinicians from liability in the case of parents whose permission was not sought or of minors who subsequently want to disaffirm their prior consent to treatment. This doctrine is most often invoked in cases involving an older teen who has decision-making capacity and where the care provided was within the mainstream, met the standard of care, and was not high risk (English et al. 2010). Few states have specifically rejected this doctrine, but a small number of states have passed statutes essentially codifying the mature minor doctrine, allowing minors to give effective consent if they are above a certain age or have ‘sufficient intelligence to understand and appreciate the consequences of the proposed surgical or medical treatment or procedures’ (Arkansas Code Ann. § 20-9-602(7) 2010).

5.3.6 Confidentiality

Confidentiality is often important to minors who are making their own healthcare decisions. The Health Insurance Portability and Accountability Act of 1996 (HIPAA), the primary federal law addressing confidentiality, relies primarily on state law and regulation for guidance. In this regard, some states protect the child’s confidentiality more completely than others. Some states provide clinicians with discretion, for example, to notify the child’s parents in certain situations. HIPAA does require that the child’s confidences be honored when parents agree that their child’s relationship with the clinician will be confidential (Office for Civil Rights HIPAA 2003, Personal Representatives 45 CFR 164.502(g)). Some institutions deny access to health records to both parents and minors to avoid problems.

5.3.7 The Gillick case

In a much more expansive decision than is embodied in the US mature minor doctrine, the House of Lords addressed the question of the role of minors and parents at length in the case of Gillick v. West Norfolk and Wisbech Area Health Authority 3 All ER 402 (1985), which addressed the question of whether a mother could prevent her daughter under the age of 16 from obtaining contraception.

5 States, however, may require that the child’s request be reviewed by a judge.

6 See also Alabama Code § 22-8-4 (2013)(‘14 years of age or older, or has graduated from high school, or is married, or having been married is divorced or is pregnant’); Alaska Stat. § 25.20.025(a)(2) (2013) (if parents unavailable or unwilling to give permission); Kansas Stat. Ann. § 38-123b (2013) (16 years old if parent not readily available); La. Rev. Stat. Ann. § 40:1095 (2013) (limited to a minor ‘who is or believes himself to be afflicted with an illness or disease’); Oregon Rev. Stat. § 109.640 (2013) (15 years old); South Carolina Code Ann. § 63-5-340 (2013) (16 years old but can consent to surgery ‘only if such is essential to the health or life of such child in the opinion of the performing physician and a consultant physician if one is available’).
At the time, applicable law encouraged physicians to urge minors to involve their parents in such decisions, but recognized that in some ‘unusual’ cases, it could be necessary to protect minors’ confidentiality in order to encourage them to seek care. In a complex opinion, Lord Fraser held that:

Provided the patient, whether a boy or a girl, is capable of understanding what is proposed, and of expressing his or her own wishes, I see no good reason for holding that he or she lacks the capacity to express them validly and effectively and to authorise the medical man to make the examination or give the treatment which he advises.

(pp. 6–7)

In regard to the mother’s claim that her parental rights were infringed by allowing her child to obtain medical care without her consent, Lord Fraser held that ‘parental rights to control a child do not exist for the benefit of the parent. They exist for the benefit of the child and they are justified only in so far as they enable the parent to perform his duties towards the child, and towards other children in the family’ (p. 8). He explicitly rejected the notion that the child’s age is the only factor to be considered or that the parent has an absolute right of veto, even saying that, at times, physicians are better decision-makers.

Lord Scarman, in a separate opinion, wrote ‘[t]he principle of the law … is that parental rights are derived from parental duty and exist only so long as they are needed for the protection of the person and property of the child’ (p. 22), citing ‘the law’s recognition of the parent as the natural guardian of the child [as] a warning that parental right[s] must be exercised in accordance with the welfare principle and can be challenged, even overridden, if it be not’ (p. 22). Lord Scarman ultimately held that:

as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed … Until the child achieves the capacity to consent, the parental right to make the decision continues save only in exceptional circumstances. Emergency, parental neglect, abandonment of the child or inability to find the parent are examples of exceptional situations justifying the doctor proceeding to treat the child without parental knowledge and consent but there will arise, no doubt, other exceptional situations in which it will be reasonable for the doctor to proceed without the parent’s consent.

(p. 27)

Two Lords dissented in large part on the grounds that intercourse with a female under the age of 16 was a crime at the time. Concern that females under 16 were not competent to make a decision about contraception suggested that their primary concern was about sexual activity and not decision-making per se. Thereby, little emphasis was placed on the impact on parents’ rights in these dissenting opinions.

5.4 Emerging ethical and legal issues

New technologies affect our understanding of the best interests of children and how and by whom those are to be protected. In this section, we will discuss developments in genetics and genomics as an example of these effects. Not only is more understood about the role genetic
variation plays in health, but new technologies, such as multiplex testing and exome and genome sequencing, make it possible to assay much more of this variation at one time. In pediatrics, the question of what tests should be done typically arises in state-run newborn screening and in testing symptomatic children more generally. Until recently, there has been a general consensus that the goal of genetic testing was to provide information that would assist in the children’s immediate care. In newborn screening, this has meant disorders should be screened only if near-term treatment is required, and in testing of the child after the newborn period that it is generally inappropriate to test for adult-onset disorders that do not require intervention prior to adulthood (Ross et al. 2013; van El et al. 2013).

Recently, however, the American College of Medical Genetics (ACMG) directly challenged the centrality of the child’s best interests and delicate balance of decision-making when they recommended that laboratories that are performing genome or exome screening for a particular clinical condition analyze an additional 56 genes that are not implicated in the clinical question and return results to the ordering clinician who is then responsible for ‘contextualizing’ the results for the patient (Green et al. 2013). The ACMG recommended that neither patients, regardless of age, nor in the case of children, their parents be given the opportunity to reject this extra analysis, even though some of the variants sought are predictive only of adult-onset disorders.

Although the ACMG subsequently rejected mandatory testing and return, it never addressed the best interests of the child (ACMG Update Recommendation, 2014). Rather, they were concerned that patients and family members may not otherwise have the chance to learn of their own risks if children’s results were not returned. In the case of children, this means that children’s interests are only one factor to be considered and may be secondary to the interests of parents and other relatives. This formulation flies in the face of the definition of the child’s best interests in the Convention on the Rights of the Child as well as general norms of decision-making for children, and is particularly surprising given the weak support of a ‘duty to warn’ of genetic risk in US jurisprudence. At this point, the ACMG’s recommendations regarding exome and genome sequencing have no independent legal weight and raise legal issues only insofar as they influence clinicians’ practice and thereby the standard of care. A potential concern, however, is the ACMG’s redefinition or subordination of the child’s interests to those of parents and other relatives may be expanded to state-run newborn screening programs, which are under pressure to use exome and genome analysis. The challenge, ethically and legally, will be ensuring the primacy of the child’s interests in the face of these and other new technologies.

5.5 Conclusion

While promoting the best interests of the child is a governing framework in pediatric ethics, implementing this principle in practice remains a challenge. Jurisdictions vary in allocating who decides the best interest of the child. In general, parents are the default decision-makers, but both clinicians and the government can override parental choices in areas ranging from medical abuse or neglect to public health interventions such as immunizations. Jurisdictions also vary in the extent to which they honor the rights of minors to participate in or to make their own healthcare decisions as rights-bearing individuals, a discourse parallel to the debate about best interests. New technologies present challenges for the interests of children as well. Understanding these tensions may guide the evolution of laws to ensure more adequate protection of children’s interests.
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