The Child’s Autonomy in Decision-making on Medical Treatment: Theoretical Considerations

1. Introduction

With the adoption of the United Nations Convention on the Rights of the Child (CRC), children were given a voice. Article 12 of the CRC stipulates that ‘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 coin has another side, however, as the second part of the sentence reads thus: ‘the views of the child being given due weight in accordance with the age and maturity of the child’. It is an inherent paradox of children’s rights that they address subjects ‘who, on the one hand[,] lack the full autonomy of adults but, on the other, are subjects of rights’, as the matter is characterised in a statement from the Committee on the Rights of the Child (CRC Committee)*1 that is included in said committee’s General Comment 12*2. The gradual shift toward full autonomy that is conceptualised in the CRC as ‘evolving capacities’ renders it a challenge to establish legal norms that address the legal capacity of children in real-world situations.

That setting may explain why the theories surrounding Article 12 have conceptualised this as ‘participation’; i.e., children participate in decision-making but are often not themselves the decision-makers. According to the CRC Committee, the term ‘participation’ is ‘widely used to describe ongoing processes, which include information-sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes’*3. It is also the reason children’s participation has been criticised; their participation can easily remain in a ‘virtual box’, consisting of activities that run in parallel with those of adults*4:

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1 The Committee on the Rights of the Child is a treaty body created under Article 43 of the CRC. According to rule 73(1) of its ‘ Provisional Rules of Procedure’, said committee may prepare general comments based on the articles and provisions of the convention, with a view to promoting its further implementation and assisting States Parties in fulfilling their reporting obligations.
2 CRC Committee, General Comment No. 12: The Right of the Child To Be Heard (UN Doc CRC/C/GC/12, 2009).
3 Ibid.
a ‘separate process of representation tends toward tokenism, placing an inherent distance between representation and real power’.5

But why is the topic of the child’s autonomy in health care important? It is vital because it is bound up with very fundamental questions pertaining to children’s rights: Do children have the right to self-determination and autonomy as adults do? And are children competent to decide on their own health and life? According to Farson, ‘[t]he issue of self-determination is at the heart of children’s liberation. It is, in fact, the only issue, a definition of the entire concept. The acceptance of the child’s right to self-determination is fundamental to all the rights to which children are entitled.’6

In this article, I analyse the theoretical framework for the child’s autonomy in decision-making related to medical treatment. The principles of children’s rights are derived from the CRC; therefore, the CRC and the general comments of the CRC Committee are analysed in sections 2–4, below, as the main source of interpretation of the concept of the child’s autonomy. However, as the CRC does not give detailed guidance on how to assess children’s autonomy, the concept of competence is elaborated upon from a philosophical perspective in Section 5.

2. A child’s right to health

In health care, the autonomy of a child should be reflected in honouring the principle of the child patient’s consent to medical treatment. The patient’s autonomy (exercised through informed consent) is a core principle of contemporary medical ethics.7 In the case of children, however, the application of this anchoring principle is not so clear.

A child’s right to health is stipulated in Article 24 of the CRC, according to which

States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

The CRC Committee has explained that children’s right to health encompasses both freedoms and entitlements, where the freedoms, ‘which are of increasing importance in accordance with growing capacity and maturity, include the right to control one’s health and body, including sexual and reproductive freedom to make responsible choices’.8

The child’s right under Article 24 does not explicitly include the right to give free consent to medical treatment. However, it has been argued that,

although the CRC Committee did not mention this principle in its general comment on children’s right to health, it is a derivative of the established principle that the right to respect for private life, which includes bodily integrity, requires that informed consent [...] be obtained before any medical procedure can be performed lawfully.9

In recent years, the CRC Committee has taken steps toward stronger emphasis on autonomy, stating in its General Comment 20 that ‘the voluntary and informed consent of the adolescent should be obtained whether or not the consent of a parent or guardian is required for any medical treatment or procedure’.10

Although the analysis here concentrates on the principles of the CRC, it is worth mentioning the principle of the patient’s autonomy, following from what is enshrined in the Council of Europe’s 1997 Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application

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7 Jonathan Herring, Medical Law and Ethics (7th edn, Oxford University Press 2018) 24–25. DOI: https://doi.org/10.1093/he/9780198810605.001.0001.
of Biology and Medicine: Convention on Human Rights and Biomedicine (or Oviedo Convention), which is the only binding international legal instrument on the subject of bioethics. The principle of ensuring the ability to give free and informed consent to medical treatment and interventions is anchored in Article 5 of the Oviedo Convention. Article 5 specifies that an intervention in the health field may only be carried out after the person concerned has given free and informed consent.

Article 6 of the Oviedo Convention addresses those persons who are not able to consent, including children, stipulating that where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided by law. The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity. Thus, the Oviedo Convention leaves it open to the signatory states to determine the relevant threshold of capacity of minors.

The following can be stated in conclusion on the child’s right to health: the boundaries of this right have to be analysed in combination with other articles and principles stemming from the CRC, foremost in conjunction with the child’s right to be heard (per Article 12) and the principle of evolving capacities (enshrined in Article 5).

3. A child’s right to be heard

“The right of all children to be heard and taken seriously constitutes one of the fundamental values of the Convention,” the committee has stated. According to Article 12 of the CRC, ‘all 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’. For this purpose, the CRC requires that the child be heard in any proceedings affecting him or her. Article 12 articulates this assurance as one of the four general principles of the CRC, together with the right to non-discrimination, the right to life and development, and granting of primary consideration to the child’s best interests. It is evident that Article 12 must be applied to a child’s decision-making with regard to medical treatment, because such decisions affect the child directly.

With specific regard to the child’s right to be heard in health care, the CRC Committee has expressed the need to:

(i) involve even young children in decision-making processes (para 100);
(ii) introduce legislation to ensure that children have access to confidential medical counselling and advice without parental consent being required (para 101);
(iii) provide clear and accessible information to children (para 103);
(iv) introduce measures enabling children to contribute their views and experiences to the planning and programming of health services (para 104).

Most importantly, in the context of children’s autonomy, the CRC Committee has welcomed the introduction in some countries of a fixed age at which the right to consent transfers to the child, and the committee encourages other states to introduce such legislation but at the same time to ensure that a child younger than this age limit could demonstrate capacity to express an informed view.

As Article 12 refers to the child ‘who is capable of forming his or her views’, it is important to ask whether the wording of said article limits the scope of its application in stating that this right must be assured (only) for the ‘capable’ child. The CRC Committee has explained that ‘[t]his phrase should not be seen as a limitation, but rather as an obligation for States parties to assess the capacity of the child to form an autonomous opinion to the greatest extent possible. [...] States parties should presume that a child has the capacity to form her or his own views and recognize that she or he has the right to express them’.

Hence, ‘for the purposes of article 12 the requirement that a child be “capable” does not impose a requirement that he or she must be competent, accomplished, or skillful in the formation of their views’.

11 CRC Committee’s General Comment No. 12 (see Note 2).
12 Ibid.
13 Ibid, para 20
14 John Tobin (see Note 9), 404.
The key aspect of Article 12 pertains to how due weight shall be given to the opinion of the child. According to its text, age and maturity are the determining factors in the weight to be accorded to the child’s opinion. The CRC Committee has explained that age alone must not be taken to determine the significance of a child’s view; rather, there is research showing that ‘information, experience, environment, social and cultural expectations, and levels of support all contribute to the development of a child’s capacities to form a view. For this reason, the views of the child have to be assessed [on the basis of] case-by-case examination’.15 The second criterion to be used when one is assessing what weight to give a child’s view is the child’s maturity. The CRC Committee defines maturity as the ‘capacity of a child to express her or his views on issues in a reasonable and independent manner’.”16 Acknowledging the challenges that such assessment entails, the CRC Committee has articulated the need to develop good practice for assessing the child’s capacity accordingly.17 In light of this, the concept of maturity is analysed in detail in Section 5 of this paper.

The key elements addressed by Article 12 of the CRC are expressed comprehensively in the model Laura Lundy developed for conceptualising said article.18 Lundy’s model comprises four elements, which all must be established, in the following order:

- **Space**: Children must be given safe, inclusive opportunity to form and express their views.
- **Voice**: Children must be facilitated to express their view.
- **Audience**: The view must be listened to.
- **Influence**: The view must be acted upon, as appropriate.

The model presented above serves as a useful framework via which professionals who work with children, health practitioners included, can more readily think through the steps that are necessary for enabling meaningful participation of the child.

It is important to stress that Article 12 focuses on the right to express one’s views and participate in decision-making, not on the right to decide. In the framework of Article 12, there is always an adult who decides how much weight the child’s view is to be given. Therefore, it is difficult to agree unreservedly with those authors who contend that Article 12 ‘expresses true respect for the child as an autonomous person’.19 By criticising the above statement, it is not argued that children should always be given the right to decide regardless of their age, maturity and circumstances. Rather, the contention in this paper is that precision is necessary in specifying what we mean with the concept of autonomy, as a right to participate in decision-making is not synonymous with the right to decide, and this distinction has direct legal implications. In the health-care systems of those jurisdictions in which a child may be deemed capable of deciding, once a qualified doctor finds the child capable of forming a rational and considered opinion about treatment, that doctor is obliged to honour the child’s decision. The CRC supplies little, if any, guidance on the autonomous decision-making of children. Therefore, a more elaborate analysis of the autonomy of children is given in section 5 of the article.

4. **A child’s evolving capacities**

The CRC Committee has explained that a child’s autonomy with regard to health issues is dependent on the child’s evolving capacities.20 The concept of evolving capacities is presented in Article 5 of the CRC, where the convention stipulates a right and duty of a parent to provide appropriate direction and guidance to the child, in a manner consistent with the evolving capacities of the child. The concept is mentioned also in the CRC’s Article 14, in the context of parental responsibility related to the freedom of thought of a child:

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15 CRC Committee’s General Comment 12 (Note 2), para 29.
16 Ibid, para 30.
17 Ibid, para 44.
20 CRC Committee’s General Comment 15 (see Note 8), para 21.
parents have to provide direction to the child in the exercise of his or her right to freedom of thought, in a manner consistent with the child’s evolving capacities.

The CRC Committee has defined the concept of evolving capacities in its general comments as follows:

The Committee defines evolving capacities as an enabling principle that addresses the process of maturation and learning through which children progressively acquire competencies, understanding and increasing levels of agency to take responsibility and exercise their rights. (General Comment 20, para 18)

The more the child himself or herself knows, has experienced and understands, the more the parent, legal guardian or other persons legally responsible for the child have to transform direction and guidance into reminders and advice and later to an exchange on an equal footing. This transformation will not take place at a fixed point in a child’s development, but will steadily increase as the child is encouraged to contribute her or his views. (General Comment 12, para 84)

The language above nicely illustrates the dynamics of the concept – positioning the child’s right rather than that of a parent at its core. As one commentary has noted, ‘Article 5 is therefore best characterised as the right of a child to receive appropriate direction and guidance from his or her parents to secure the enjoyment of his or her rights rather than a right of parents to have their rights regarding their parenting respected by the state’.21 Appropriate guidance of this sort must be given to a child for every facet of his or her life. Therefore, it has been argued that the principle of evolving capacities should have been laid down as one of the general principles of the CRC, possessing relevance for the interpretation of all rights enshrined in the convention.22

The principle of evolving capacities ties in closely with the ‘best interests’ principle derived from Article 3 of the CRC, which expresses the ideal that the child’s best interests be a primary consideration in any action or decision concerning the child. Both principles respond to the fact that the child, although granted certain autonomy under the convention, cannot exercise his or her rights autonomously and that there is a need for protection and guidance – a need conditional to the age and maturity of the child. Thus, the convention encourages the emancipation of children (per articles 12–17), hand in hand with their optimal development (see Article 6) while, on the other hand, also requiring their protection (see Article 19 and provisions further on in the CRC), to be guaranteed primarily by the parents or those acting with equivalent responsibility (see Article 18).

The above is reflected in Lansdown’s23 three dimensions of the concept of evolving capacities: it is described as (i) a developmental concept, emphasising the child’s right to development; (ii) a participatory or emancipatory one focused on the shift wherein rights are transferred from adults to the child; and (iii) a protective concept acknowledging the child’s right to protection while his or her capacities are still evolving.

With this framing, the concept of evolving capacities clearly addresses the gradual shift from dependence to independence/autonomy, and parents (or other legal guardians, as the case may be) have a crucial role in enabling the capacities of their children to evolve.

5. The meaning of competence

The key question in the debate over a child’s autonomy (autonomous decision-making) with regard to medical treatment pertains to competence. Laws provide for autonomy of individuals who are deemed to be or proved to be competent/capable.24 Children are generally not deemed competent but may be judged so by adults. This places an enormous responsibility on adults and on professionals charged with making such decisions, and it confirms the necessity of understanding what competence as a prerequisite for autonomy actually means. Laws, the CRC among them, determine only general principles for such assessment. Therefore, addressing it in greater depth demands another framework. With the following subsections, the
meaning of competence is analysed from a philosophical perspective, through the lens of David Archard’s approach to competence of children. Archard posits that a right to self-determination may be viewed as a capacity to make sensible choices, most frequently described as rational autonomy. According to Archard, rational autonomy comprises at least three elements – rationality, maturity, and independence.

### 5.1. Rationality

Archard defines rationality as the ability to form generally reliable beliefs about the world, doing so requires cognitive competence. He contends that an inability to form reliable beliefs or take well-founded decisions has been ‘the most fundamental, recurring argument against autonomous rights for children’. Indeed, cognitive competence, as necessary for ‘well-founded’ or ‘generally reliable’ decision-making, may be one of the most challenging factors in assessment of someone’s rational autonomy or competence in the broader sense. One of the most influential experts in child cognitive development, Jean Piaget, associated certain levels of cognitive competence with certain stages of development and saw children’s intellectual development as ‘progression through a series of qualitatively distinct stages of intellectual ability’.

According to Piaget’s findings, children would be capable only from around 12 years old as this is the age at which they attend the concrete operative stage where they have the cognitive competence to make their own rational and moral judgements. However, we now have accumulated enough evidence to conclude that children’s competence does not hinge on their physical (biological) development alone. Rather, it may depend just as much on the characteristics of the adults living and working with them, such as each adult’s competence, training, support, willingness, and generosity.

As rationality is connected with knowledge and experience, both elements that must be acquired, one can rightly conclude that rationality increases with age. Therefore, age can be seen as only one of many criteria by which a child’s competence may be assessed.

Rationality comes under particularly close scrutiny in the context of informed consent in health care. A child’s decision is often assessed in terms of rationality: is the child’s decision rational in the eyes of others (physicians, parents, etc.) or is it irrational in others’ eyes and therefore not ‘well-founded’?

### 5.2. Maturity

Archard talks about maturity, with regard to which he borrows from the theory of John Stuart Mill, who most likely employed the term to mean ‘fully developed, where this implies [the individual being] settled and unlikely significantly to change’. He also refers to maturity as emotionally balanced. This is probably the most common approach to maturity, as we often hear someone being described as mature because he or she does not make decisions fired by the heat of emotions. Small children are known for not being fully able to separate themselves from their emotions and, therefore, letting emotions direct their decisions.

In the context of this article, it is important to refer to maturity in the sense of accumulated life experience. As research shows, children’s understanding of their health and treatment issues depends far more on their experience than on age or aptitude. The Ethics Working Group of the Confederation of Euro-

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25 David Archard (see Note 6), 88–91.
30 David Archard (see Note 25).
31 Ibid.
European Specialists in Paediatrics notes that ‘competence has often been associated with cognitive capacity, rationality and age. However, it is now regarded to be also a function of a child’s experience of the illness in question’. Priscilla Alderson offers an example wherein a child’s long-term condition may confer ‘maturity’ with regard to his or her health very early in life:

Everyday evidence of children aged 3 and 4 years, with such conditions as cystic fibrosis or type 1 diabetes, shows how responsible they can be when adults are not present. For example, children with diabetes refuse sweets, which their friends enjoy, and cope in sophisticated ways with being different yet sustaining friendships.

The above illustrates the danger of considering children solely on a general single-dimension scale of mature–immature. Therefore, it is hard to agree entirely with Woodhead’s statement that ‘immaturity remains one of the most distinctive features of the young of the human species (Bruner, 1972), whether constructed in terms of nurturance and vulnerability, teaching and learning, socialization and development or respect for their rights’. Since maturity is connected with life experience, a child with a long-term health condition and related experience may be much more mature with regard to the accompanying health issues than an adult having only little or no experience with the same.

‘Maturity’ is a central term in the language of the CRC. Article 12, being one of the four general principles of the CRC, states that the views of the child must be given due weight in accordance with age and maturity, yet, as Freeman rightly points out, ‘the Convention gives no indication as to how to judge the maturity, or indeed what is meant by maturity’. As noted above, the CRC Committee has characterised the concept of maturity, in its General Comment 12, as the ‘capacity of a child to express her or his views on issues in a reasonable and independent manner’ (para 30). In this, we can see that the committee links maturity with independence and reasonability. Independence is the third of the key concepts applied by Archard.

5.3. Independence

Proceeding from Kantian philosophy, Archard states that ‘the strongest sense of independence or “self-maintenance” is self-sufficiency, that is, an ability to sustain oneself physically by providing for one’s own food, clothing and shelter’. Of course, Archard accepts that in modern societies this definition is inapplicable, as societies and economies are much more complex than in Kantian times. Archard therefore concludes that a ‘broader interpretation of self-maintenance is that people are self-maintaining when they can actually act out their choices’. It is in this connection that one of the main challenges of a child’s participation and implementation of children’s rights is best reflected upon:

Presumed unable to do something, children may simply not be allowed to show that in fact they can. More subtly, it may be the case that a competence can only be acquired in the exercise of the appropriate activity. A child may display incompetence just because she has been prevented from doing what would give her the ability.

Allowing children to practise independence/independent decision-making and, thereby, autonomy is key to more meaningful and effective implementation of children’s rights. Naturally, this practice cannot be completed overnight, and independence and autonomy are acquired gradually. Freeman agrees with the assessment of Virginia Morrow, who explains that autonomy requires ‘not the straightforward delegation

34 Priscilla Alderson (see Note 29).
37 David Archard (see Note 6).
38 Ibid, 90.
39 Ibid, 90.
40 Ibid, 91.
of decision-making to children, but rather enabling children to make decisions in controlled conditions, the overall intention being to enhance their capacities for mature well-founded choices’. Freeman also cites John Eekelaar, who defines the same process of gradual maturation as ‘dynamic self-determinism’, the goal of which is ‘to bring a child to the threshold of adulthood with the maximum opportunities to form and pursue life-goals which reflect as closely as possible an autonomous choice’.

Independence could be viewed equally as physical autonomy or freedom. With regard to this type of independence, a large contrast can be seen between the children of the Global South and the Global North. In Lancy’s description of the issue, typically children in the Global South are granted considerable agency in the form of physical autonomy but little efficacy, in the sense of effect on others and responsiveness from adults. In the Global North, the opposite is true: children are granted little physical autonomy but a large amount of efficacy. This illustrates how much independence, as a component of autonomy, depends on the context.

One can sum up the matter of competence thus: the competence of a child depends on many factors, and there is no universal criterion for determining whether a person is competent to decide on a certain matter or not. The complexity of the issues related to the element of competence are summarised well by De Lourdes Levy, Larcher, and Kurz:

Competence depends on the context which may involve the physical surroundings of the child. It also depends on the relationship between the child, the parents and the health professionals and must be seen within the child’s experience of their illness. Competence also varies over time and with the state of the illness. For example a child who is in severe pain may not be competent to make decisions which they could otherwise make. [...] There is a complex relationship between competence and information. It would be difficult for a child to be competent if they had not been adequately informed.

However, there is a position among many child-rights specialists that one must presume the competence of children, not absence of competence, and that the burden of proof lies with those who wish to deny rights to children.

6. Conclusion

With the adoption of the CRC, especially Article 12, a whole new approach evolved, one that promotes children’s participation and the right of children to be heard. Starting in the 1990s, within this participation framework, step-by-step movement toward recognising the autonomy of children, from a certain age and maturity level, can be identified. That incremental process is illustrated by the shift whereby the CRC Committee’s general comments have changed over time toward acceptance of adolescents’ full autonomy in health care. As discussed above, the committee expressed the need to include children in decision-making processes in health care in 2009, whereas in 2016 it invited states to introduce minimum-age thresholds that ‘recognize the right to make decisions in respect of health services or treatment’ and emphasised that ‘voluntary and informed consent of the adolescent should be obtained whether or not the consent of a parent or guardian is required for any medical treatment or procedure’.

Even though the CRC Committee, in its current interpretations of the convention, recognises a right of the adolescent to make autonomous decisions (though without specifying the threshold age for this), it clearly accepts the existence of a need to assess the maturity of the child in question. In paragraph 44 of General Comment 12, the committee refers to the need to develop good practice for assessing the capacity of the child to form his or her own views.

There is not much theory to be found in the CRC or in the General Comment materials by the CRC Committee on the subject of the criteria for regarding a child as competent for autonomous decision-making.

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41 Michael Freeman (see Note 36).
42 Ibid.
44 See the Ethics Working Group statement (Note 33).
45 See notes 26, 28, and 36.
Neither does the Oviedo Convention offer any clarification, stating only, in Article 6, that 'where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided by law'. Both the CRC and the Oviedo Convention leave it open to the ratifying states to specify the age from which children should be able to make decisions in respect of health services or treatment.

The key question in the debate over children’s autonomous decision-making with regard to medical intervention is competence. In this article, competence was analysed through the lens of Archard’s (2015) division of rational autonomy into rationality, maturity, and independence. These three are also key words the CRC Committee has employed when discussing children’s competence. All three qualities – rationality, maturity, and independence – are acquired by children gradually. This is precisely why the concept of evolving capacities, introduced in Article 5 of the CRC, is so important. Parents have a right and duty to provide appropriate direction and guidance to a child, in a manner consistent with the evolving capacities of that child. The concept of evolving capacities addresses the gradual shift from dependence to independence/autonomy, and parents (or other guardians) have a crucial role in enabling the capacities of the children in their care to evolve. It is important that children be given opportunities to practise decision-making and weighing among options, so that they eventually become autonomous.

As long as there is no universal set of guidelines clarifying how one might assess children’s competence, health practitioners could benefit from protocols and guidelines articulating appropriate consent procedures developed by health-care institutions. Archard’s breakdown of rational autonomy could guide institutions in developing such best practice.

In summary, the autonomy of a child depends on the attitudes and understandings of all participants in the decision-making process related to medical intervention. This proves the necessity of research to study the associated attitudes and understandings among children, parents and equivalent persons, and medical practitioners.