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The right to health of the child: an analytical exploration of the international normative framework

Spronk, S.I.

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II. THE RIGHT TO HEALTH OF THE CHILD IN THE CHILDREN'S RIGHTS CONVENTION

2.1. INTRODUCTION

This chapter of the thesis seeks to investigate what priorities are set in relation to the right to the highest attainable standard of health of the child in the interpretation found in the international children's rights domain; the Convention on the Rights of the Child and the General Comments of the Committee on the Rights of the Child. Identified will be what the core elements of article 24 CRC are. The underlying presumption is that children have capabilities that can be best achieved when children are stimulated to engage in healthy behaviour from the very beginning. In looking at this question from the perspective of the international children's rights domain, investigated will be how the differential roles and legal responsibilities of parents, the State and medical professionals are balanced in realizing the core elements of children's right to the highest attainable standard of health. In that way the question will be answered how article 24 CRC can contribute to realizing the highest attainable standard of health of the child.

To answer the research questions, a historical overview of the development of the right to the highest attainable standard health in the CRC will be provided in paragraph 2, reflecting the initial priority setting of the right to the highest attainable standard of health of children during the drafting phase. Consequently paragraph 3 will present the key elements of article 24 CRC, paragraph 4 will discuss the relevance of other CRC articles for the right to health of children and paragraph 5 will describe the elaboration of the right to health of the child in the General Comments of the Committee on the Rights of the Child. The roles and responsibilities of the parents (or caretakers) and the State will be addressed throughout these paragraphs. Paragraph 6 will specifically focus on the translation of the core elements of article 24 CRC to medical ethics to elucidate the potential influence of the right to health of the child on the actual realisation of the right to the highest attainable standard of health of the child in the daily medical practice.

2.2. HISTORICAL DEVELOPMENT OF THE RIGHT TO HEALTH OF THE CHILD IN THE CRC

For centuries, little attention was paid to the rights of children as individual persons. Children were seen as little adults, their rights and needs being subordinate to the needs and values of their families. Not until the 18th century was particular attention paid to the special needs of children in the development of human rights treaties and only from the beginning of the 20th century several western countries did adopt legislation for the protection of children.¹⁸²

In 1924, instigated by a sense of urgency after the First World War, the League of Nations adopted the Declaration of Geneva, wherein children's rights were described at an international level for the first time. The large numbers of children suffering from the Second World War gave a second impulse to this development, which was reflected by the passing of the Declaration on the Rights of the Child¹⁸³ in the General Assembly of the United Nations on 20 November 1959. Inspired by the International Year of the Child in 1979 the discussion was raised whether this Declaration should be transposed into a binding treaty.¹⁸⁴ The Convention on the Rights of the Child was consequently drafted between 1978 and 1989 and entered into force on the 2nd of September 1990.¹⁸⁵ The initiative to adopt a Convention on the Rights of the Child was taken by Poland at the thirty-fourth session of the UN Commission on Human Rights, in early 1978. All countries of the world have signed the CRC, but which has not yet been ratified yet by Somalia, the United States and South-Sudan, although the last one is in the process of ratification.

The child's right to health as such, first appeared in the 1959 Declaration, formulated as:

‘The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and to his mother, including adequate prenatal and postnatal care. The child shall have the right to adequate nutrition, housing, recreation and medical services.’

Provisions in international human rights law instruments, predominantly the WHO Constitution, article 25 of the Universal Declaration of Human Rights (UDHR), article 12 of the International Covenant on Economic Social and

¹⁸² J. Dane et al., *Honderd Jaar Kinderbescherming (Hundred Years of Child Protection in the Netherlands)*, Edition on the occasion of the 100th Anniversary of the Council of Child Protection and Child laws. (1905–2005), First edition 2006, p. 7.

¹⁸³ UN Doc. A/RES/44/25, 20 November 1989.

¹⁸⁴ S. Meuwese, *Handboek Internationaal Jeugdrecht*, Nijmegen: Ars Aequi Libri, 2005, p. 1–3.

¹⁸⁵ UN Doc. E/CN.4/L.1366/Rev.1. This was 30 days after the 20th ratification of the CRC (see article 49–1 CRC).

Cultural Rights (ICESCR) and article 10 of the Protocol of San Salvador,¹⁸⁶ all contain specific references to the right of the (infant) child and her/his mother to health care. These general provisions have shaped the content of the right to health of the child in the CRC. The *Travaux Préparatoires* of the CRC show that article 12 ICESCR and the holistic vision on health as found in the 1978 Declaration of Alma-Ata have been especially influential.^{187, 188} This holistic vision is reflected in the broad interpretation including both health services and underlying determinants of health.

The inclusion of the right of the child to health in the CRC was first discussed in the 1980 meeting of the Open-Ended Working Group.¹⁸⁹ The basic working text recognized ‘the highest attainable standard of health care of the child for his physical, mental and moral development’, as laid down in article 12 ICESCR. Recommendations derived from the Declaration of Alma-Ata (1978),¹⁹⁰ such as the holistic vision on primary health care, have also influenced the development of the provision on the right to the highest attainable standard of health of the child in the CRC. This resulted in a focus in the discussions on the accessibility of health systems for all children, pre- and postnatal care and the lowering of the mortality index of babies. Proposals in the Working Groups in the following years included the prevention of the use of drugs by children,¹⁹¹ the development of preventive health care programmes for children¹⁹² and the support of action programmes for the benefit of international cooperation.¹⁹³

During the 1985 meeting of the Open-Ended Working Group, proposals on the interpretation of the right to health were submitted by Poland and Finland.¹⁹⁴ Discussion arose to replace the phrase ‘the state parties recognize’ by the term ‘shall ensure’ in article 24 sub 1 CRC to enhance the actual enforcement of the right to health, but it was decided to stay in line with article 12 ICESCR. Several issues were central in the debate, among which the introduction of the words ‘free of charge’ to the provision of medical assistance and health care by the

¹⁸⁶ Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, OAS. Treaty Series, November 17, 1988.

¹⁸⁷ See *Legislative History of the Convention on the Rights of the Child*, Volume II, United Nations, New York and Geneva, 2007, pp. 580–603.

¹⁸⁸ See also S. Detrick (ed.), *The United Nations Convention on the Rights of the Child. A Guide to the 'Travaux Préparatoires'*, Dordrecht/Boston/London, Martinus Nijhoff Publishers 1992, pp. 343–359.

¹⁸⁹ *Legislative History of the Convention on the rights of the Child*, Volume II, United Nations, New York and Geneva, 2007, pp. 580–603. See particularly U.N. Doc. E/CN.4/1349, pp. 4–5.

¹⁹⁰ The 1978 Declaration of Alma Ata was adopted during the UNICEF and WHO sponsored International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978. The UN General Assembly endorsed the Declaration by resolution 34/43 of 19 November 1979.

¹⁹¹ *Ibidem supra* note 187. See particularly U.N. Doc. E/1982/12Add.1, C.

¹⁹² *Ibidem supra* note 187. See particularly U.N. Doc. E/CN.4/1983/62, Annex II. This proposal was submitted by Canada and has been partly incorporated in the final text of article 24 CRC.

¹⁹³ *Ibidem supra* note 187. See particularly U.N. Doc. E/CN.4/1984/71, Annex II, p. 1. This proposal was submitted by Iran, but it was not considered.

¹⁹⁴ *Ibidem supra* note 187. See particularly U.N. Doc. E/CN.4/1985/64, pp. 3–8.

Soviet Union. The USA suggested that the term ‘whenever possible’ should be added, but Bangladesh and Senegal stated that this would lead to a situation of uncertainty. The issue reflected the notion that no child should be deprived of access to health care for financial reasons. In the final draft of the CRC this last phrase ‘for financial reasons’ has been omitted, suggesting that no reason justifies any deprivation of health care of children.

Also discussed in the 1985 meeting of the Open-Ended Working Group was the topic of the provision of Primary Health Care, objected by the Netherlands, but defended by Senegal, claiming that it was necessary to take into account the special needs of developing countries. The final text of article 24-2-b CRC now reads: ‘to ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care.’ Later topics discussed were the encouragement of infant feeding and breastfeeding¹⁹⁵ and the prevention of accidents.¹⁹⁶ The NGO Group proposed to include articles on the recognition of economic problems in realizing the right to the highest attainable standard of health of the child and to safeguard notions on breastfeeding and child health care deriving from Islamic law. An example of a provision on children’s right to health in Islamic law is the right for children to be breastfed during their first two years.¹⁹⁷

In the 1986 and 1987 meetings of the Open-Ended Working Group, the issue of ‘traditional harmful practices’ was central to the discussion.¹⁹⁸ The UK and the USA proposed to specifically refer to female genital mutilation (FGM), whereas Senegal emphasized the need for prudence in dealing with cultural values and the risk of forcing the practice of FGM into clandestinity. The decisive argument made by the representative of the International Movement for Fraternal Union Among Races and Peoples, held that no specific reference should be made to FGM, as other traditional practices, including preferential care for boys, can also be harmful to children.¹⁹⁹

¹⁹⁵ Ibidem supra note 187. The delegation of the USA included the subparagraph ‘including information about appropriate methods of infant feeding’, to which the NGO Ad Hoc Group on Drafting the Convention added the phrase ‘to actively promote and protect breastfeeding’, pp. 3–8.

¹⁹⁶ Ibidem supra note 187. The representative of the UK proposed to replace the word ‘safety’ by the phrase ‘prevention of accidents’, pp. 3–8.

¹⁹⁷ Rule of Islamic law as found in verse of Qur’an II: 233. This information was discussed in a lecture on children’s rights in Islamic Law at the University of Leiden on the 18th of September 2009. See for more information about children’s rights and the Islam ‘Covenant on the Rights of the Child in the Islam’ of the Organisation of the Islamic Conference. Doc. OIC/9-IGGE/HRI/2004/Rep.Final. www.oicun.org/uploads/files/convention/Rights%20of%20the%20Child%20In%20Islam%20E.pdf.

¹⁹⁸ Ibidem supra note 187. The proposal was made by the NGO Ad Hoc Group on Drafting the Convention, reading ‘The States Parties to the present Convention shall seek to eradicate traditional practices harmful to the health of children and shall take all appropriate action including necessary legislative, administrative, social and educational measures to ensure that children are not subjected to such practices. U.N. Doc. E/CN.4/1987/25, pp. 8–10.

¹⁹⁹ Ibidem supra note 187, pp. 8–10.

On the initiative of India, the 1988 meeting of the Open-Ended Working Group focused on low-cost measures and readily available technologies, such as oral rehydration and immunization against common childhood diseases.²⁰⁰ Thereupon, paragraph 2(e) was enriched with the elements ‘nutrition, including breastfeeding, hygiene and environmental sanitation’, though it was acknowledged that these elements of the right to health were already guaranteed in other human rights instruments.

Before the adoption of the final draft of article 24 CRC by the 1989 meeting of the Open-Ended Working Group, several additional topics were touched upon.²⁰¹ Australia suggested adopting the notion that treatment of children of an experimental nature should be guided by ethical guidelines and rules. Portugal and subsequent speakers emphasized that medical or scientific experimentation should be necessary for the individual child undergoing it and not only for children as a general group. The Soviet Union added that the consent of both the child and his parents (or legal guardians) must be sought when seeking consent for medical experimentation. Canada differentiated this by suggesting that the consent of the child should only be sought where appropriate. Examples were given that consent may not be possible in case of emergencies or in instances where the consent of parents cannot be asked for religious or privacy reasons. Finally, it was decided not to include a provision on medical experimentation for fear of abusive interpretations.²⁰² The Australian delegation concluded that other articles of the Convention protect children against medical experimentation that is not in the best interests of the (individual) child, such as article 19 CRC on the right of the child to protection and article 33 on the right of the child to protection against drugs.

2.3. KEY ELEMENTS OF THE RIGHT TO HEALTH OF THE CHILD IN THE CRC

2.3.1. SUBSTANCE OF ARTICLE 24 CRC

The final text of the right of the child to health is laid down in article 24 CRC. The article both encompasses the legal entitlement to services for the prevention and treatment of disease and to basic conditions necessary to ensure a minimum level of survival. The basic provisions explicitly mentioned in article 24 CRC include the entitlement of all children to nutritious food and safe drinking water (sub 2-c) hygiene and sanitary facilities (sub 2-e) and take into account the

²⁰⁰ Ibidem supra note 187. A proposal for revision of article 12 bis was made by India, U.N. Doc. E/CN.4/1988/WG.1/WP.14.

²⁰¹ Ibidem supra note 187, more particularly U.N. Doc. E/CN.4/1989/48, pp. 70–74.

²⁰² B.C.A. Toebes, *The Right to Health as a Human Right in International Law*, Intersentia 1999, p. 58.

risks of environmental pollution (sub 2-c). With a focus on health care, several priorities are set, namely the reduction of infant and child mortality (sub 2-a), the provision of necessary medical assistance, preferably primary health care for all children (sub 2-b), pre- and postnatal health care for mothers and their babies (sub 2-d). To enable children and their families to take responsibility over their own health the right to health education for both children and adults on basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene, environmental sanitation (sub 2-e), preventive health care, family planning (sub 2-f) are incorporated. The international orientation of article 24 becomes eminent in the general provision on the abolishing of harmful traditional practices (sub 3) and also in sub 4, which specifically encourages State Parties to engage in international cooperation. Hereto, particular attention must be paid to the special needs of developing countries (sub 4).

Altogether, these provisions constitute the broadest provision on the right to health in international human rights law.²⁰³ Several other articles in international law instruments do contain more elaborate elements on particular topics, such as the requirements for ensuring the right to health in the work environment,²⁰⁴ the (sexual and reproductive) health rights of women²⁰⁵ and the health rights of disabled persons²⁰⁶ and these issues can be directly relevant for children. For example, the sexual and reproductive health rights of young women have a direct impact on children's survival, because it influences both the age at which women have their first baby, the spacing between subsequent births and the education received by the mother to take good care of her children. Nevertheless, the right to the highest attainable standard of health as formulated in the CRC still covers the widest range of prioritized health topics. Namely, supplementary to the health provisions in other international health and human rights treaties, the CRC incorporates provisions for the elimination of traditional harmful practices, the development of primary health care and the provision of rehabilitation services.²⁰⁷ However, the phrase 'physical and mental health' as found in article 12 ICESCR, is not included in article 24 CRC. Other elements not included in article 24 CRC are the improvement of hygiene in the working environment and the prevention and treatment of infectious diseases and occupational diseases.²⁰⁸

²⁰³ S. Detrick, *A Commentary on the United Nations Convention on the Rights of the child*, The Hague: Kluwer Law International and Martinus Nijhoff Publishers 1999, p. 399.

²⁰⁴ Article 12 International Covenant on Economic, Social and Cultural Rights, entry into force 3 January 1976.

²⁰⁵ Article 12 Convention on the Elimination of Discrimination against Women, entry into force 3 September 1981.

²⁰⁶ Convention on the Rights of Persons with Disabilities, entry into force on 3 May 2008.

²⁰⁷ Ibidem supra note 185.

²⁰⁸ L. Ling, *Internationale regelgeving over de rechten van het kind, het VN-kinderrechtenverdrag vergeleken met andere mensenrechten documenten*, Amsterdam: Defence for Children International Afdeling Nederland 1993, p. 109.

Several elements of article 24 CRC leave room for further interpretation. First of all, sub 2a and 2d are strongly connected; in order to diminish infant and child mortality (2a), appropriate pre- and postnatal health care for mothers is essential (sub 2d). The health of the (unborn) child is to a large extent dependent on the health of the pregnant woman and the quality of her food when lactating.²⁰⁹ Whereas sub 2a focuses on the mere survival of infants and children, sub 2d extends this obligation to ensuring access to all health care required, thus not only for the survival but also for the general health of the unborn and the newborn child. The provision in sub 2a, on the other hand, also aims to ensure the survival of children and not only infants and unborn babies. Both elements thus emphasize different aspects of children's right to health.

Article 24 sub 2e and 2f both focus on the prevention of health problems; sub 2e mentions the education and involvement of the society as a whole, in particular parents and children in ensuring children's health, whereas sub 2f focuses on the preventive health care in general and family oriented measures and education for the prevention of health problems. Ideally in my opinion, a more transparent distinction between the two articles would have been recommendable, for example by distinguishing between society oriented and family oriented measures. The target groups and types of prevention now offer a blurred distinction. However, the close and explicated link between the health of mothers and their children in sub 2d and the explicit mentioning of the need to educate adults on children's health in subs 2e and 2f points to the central role of parents in ensuring their children's right to health. Also, the application of the term parents gives room for broadening the link between children and maternal health to also including the involvement of fathers in the healthy upbringing of their children. This notion of shared responsibility of both parents for the healthy upbringing of their children is also found in article 5 CEDAW, which specifically stipulates that 'family education must include a proper understanding of maternity as a social function and the recognition of the common responsibility of men and women in the upbringing and development of their children, it being understood that the interest of the children is the primordial consideration in all cases'.

States recognize the right of the child to the enjoyment of 'the highest attainable standard of health' and 'States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.' Both the term 'recognize' and the inclusion of the term 'to strive to' in sub 1 impose relatively weak legal obligations. However, sub 2 mentions that State Parties 'shall pursue full implementation' of children's right to health and that they 'shall take appropriate measures', being specified in the following subparagraphs. This second part allows for a stronger entitlement to the children's right to the highest

²⁰⁹ See also the Barker-hypothesis, which postulates that several common adult diseases may be related to impaired foetal growth or disrupted genes, caused by nutritional inadequacies or other environmental influences at particular stages of pregnancy. D.J. Barker, 'Fetal Origins of Coronary Heart Disease', *British Medical Journal* 1995, 311, pp. 171-174.

attainable standard of health under the CRC and thus also to more serious efforts by the State to be in compliance.²¹⁰ Karsten qualifies this obligation of States as proactive and prescriptive.²¹¹

However detailed article 24 CRC may be, the provisions remain broad enough to be applied world-wide and thus remain to be interpreted through a variety of contexts and conditions, changeable over time. Historically, the right to health has been differentiated by region, in time, by type, by age-group (e.g. infants over adolescents) and by technical or organizational level (such as primary health care over high-tech curative health care).²¹² Choices made in favour of one group, excluded others, raising legal, ethical and practical questions. Van Bueren²¹³ and Kasper²¹⁴ commented that article 24 CRC provides a framework for setting priorities in creating equitable health-policies.

Interpretation must be sought in other sources, such as the General Comments on the Committee on the Rights of the Child and its Concluding Observations on individual Country Reports.²¹⁵ The practice of the CESCR Committee on article 12 ICESCR and its General Comments is also considered as useful interpretation material on the basis of article 41 CRC, which stipulates that 'nothing in the CRC shall affect other provisions in international law that are more conducive to the realization of the rights of the child.'²¹⁶ Further attention must be paid to the implications of the different concepts of health across different countries and cultures: locally accepted, community-based priorities on ensuring the right to the highest attainable standard of health of the child may be in conflict with the generally accepted priorities as set in the CRC.

More research on this interaction between the general CRC provisions and interpretations in local contexts is required, using both medical-anthropological insights and a more in-depth study of the CRC Country Reports. In order to obtain a better insight into the interaction between the general CRC provision on the right to health of the child and the interpretations, I will present the results

²¹⁰ S.C. Bischoff, *The UN Convention on the Rights of the Child. A Comparative Study*, 2 March 1999, p. 197.

²¹¹ J. Kasper 'The Relevance of U.S. Ratification of the Convention on the Rights of the Child for Child Health: A Matter of Equity and Social Justice', *Child Welfare* 2010, No. 89, Volume 5, p. 30.

²¹² C. Sepulveda, 'The right to child health: the development of primary health services in Chile and Thailand', *UNICEF Innocenti Research Centre Occasional Paper Number 7*, April 1994 pp. 1–8.

²¹³ G. van Bueren, *The international law on the rights of the child*. Dordrecht: Martinus Nijhoff Publishers/Save the Children 1995a, p. 300.

²¹⁴ J. Kasper 'The Relevance of U.S. Ratification of the Convention on the Rights of the Child for Child Health: A Matter of Equity and Social Justice', *Child Welfare* 2010, No. 89, Volume 5, p. 32.

²¹⁵ A. Eide & W.B. Eide, 'Article 24, The Right to Health', in: A. Alen, J. Van de Lanotte, E. Verhellen, F. Ang, E. Berghmans & M. Verheyde (eds), *A Commentary on the United Nations Convention on the Rights of the Child*, Leiden & Boston: Martinus Nijhoff Publishers 2006, p. 1.

²¹⁶ *Ibidem supra* note 215.

of an in-depth study of the Concluding Observations of the Committee on the Rights of the Child on the CRC country reports in the next chapter.

2.3.2. PROVISIONS ON IMPLEMENTATION OF ARTICLE 24 CRC

Article 24 CRC obligates States Parties to ‘progressively’ (sub 4) achieve the ‘highest attainable standard of health’ (sub 1). Hereto, States have to take all appropriate measures ‘to the maximum extent of their available resources.’ These phrases imply a rather vague and flexible standard for assessing degrees of compliance, as the highest attainable standard of health varies among states and periods of time.²¹⁷ The notion of flexibility is also found in article 4 CRC, which says that ‘States Parties shall undertake measures for the implementation of the economic, social and cultural rights in the CRC to the maximum extent of their available resources and, where necessary, within the framework of international cooperation’. Regarding the provision of ‘available resources’, attention has been drawn to warn that the phrase could be used as an excuse for less-than-adequate performance.²¹⁸ Given the differing basic health conditions in different countries, ‘the highest attainable standard of health’ implies a different starting point for ‘achieving the right to health for different countries’; attainability will differ according to financial resources and situational challenges of a country. For example, after the 2005 tsunami in Southeast Asia, Indonesia could not be expected to meet the same infant mortality rate as the Netherlands or even neighbouring countries that had not been affected in that same year, as it had to deal with high casualties and limited resources.²¹⁹

It has been commented that article 24 CRC is especially geared to the health requirements of developing countries, being focused on prevention and basic health requirements.²²⁰ This seems to be true as most developed countries have high percentages of immunization coverage and special methods in place to ensure access to health care for poor families.²²¹ For example, the immunization coverage in the Netherlands for 2009 was at least 96% for the major childhood

²¹⁷ V.A. Leary, ‘The right to health in international human rights law’, *Health and Human Rights* 1994, 1 (1), p. 33, stating that ‘The phrase implies a reasonable, not an absolute standard.’

²¹⁸ *Ibidem* supra note 212, p. 1.

²¹⁹ Chapter 4 will elaborate on the basic principles of non-retrogression and progressive realization in international health law. When applied to the CRC body of law, this could lead to the obligation to demonstrate that all possible efforts to minimize the total number of casualties have been made, for example by allowing foreign NGOs to enter the country and to take all necessary measures to prevent further casualties due to an outbreak of infectious diseases, violence or malnutrition.

²²⁰ *Ibidem* supra note 213, p. 197.

²²¹ Immunization summary, A statistical reference containing data through 2009 (The 2011 Edition), UNICEF and WHO, pp. xii–xvii.

diseases.²²² However, the available resources of a country do not fully explain the status of children's right to health in a country. Budget allocation to specific child health policy domains has an enormous effect on children's health indicators, so that countries with a relatively low GDP may perform better on child health indicators than countries with a higher GDP, if they allocated larger percentages to health care for children.²²³ It appeared that there are great differences in per capita expenditure on health as a percentage of the total government expenditure, so that great differences are discerned between countries with similar levels of GDP in both infant and child mortality rates and immunization numbers.²²⁴

The phrase 'maximum available resources' in article 4 CRC also implies that progress must be made in realizing children's right to health when additional resources become available.²²⁵ It has been acknowledged that resource allocation in itself can be discriminatory, for example when no budget is allocated to healthcare that meets the particular needs of the Roma populations in Europe or the indigenous populations in the Americas, practically excluding them from access to health care.²²⁶ This is also reflected by the fact that health indicators can vary widely between different groups of children within a country and between countries with similar levels of GDP.

The questions thus arises how to determine what the highest attainable standard of health in a particular country should be and over what period of time the progress made should be measured, so that States can be held accountable for the progress they have made in achieving a better health status for children. One approach to measure the degree of compliance of countries as often used by UNICEF is to compare the performance on the realization of the right to the highest attainable standard of health of a child of a country (e.g. by assessing

²²² Ibidem supra note 221, p. 123.

²²³ Cuba is the famous example of a country with a low level of human development and very good health indicators, even comparable to those of developed countries. Many econometric studies have shown that, if used efficiently, health expenditures can have significant effects on immunization coverage and child mortality. For example, the African Development Bank's Study of 47 African countries showed that a 10 percent increase in per capita public health expenditure results in a reduction of 21–25% in under-five and infant mortality rates. Other factors included efficiency and resource utilization, institutional capacity of implementing agencies, the extent of resource leakage and skills and attitudes of workers. See for example Anyanwu & Erhijakpor, *Health Expenditures and Health Outcomes in Africa*, Economic Research Working Paper Series, African Development Bank, Tunis, 2007. See also: E. Anderson & Hague, *The impact of investing in children: Assessing the cross-country econometric evidence*, Working Paper 280, Overseas Development Institute, London, 2007. This information is reproduced from the 'The African Report on Child Wellbeing 2011: Budgeting for Children', inferior note 54, p. 65.

²²⁴ Report prepared by an expert team of the African Child Policy Forum *The African Report on child Wellbeing 2011: Budgeting for Children*, Intersentia, 2010, Addis Abeba, pp. 64–65. For example in 2008, Rwanda spent 20.4%, Burundi 18.1% and Madagascar 17.3% of government revenue on health in comparison to 2.7% by Libya, 3.0% by Congo Brazzaville and 4.2% by Equatorial Guinea.

²²⁵ Ibidem supra note 212, p. 15.

²²⁶ Ibidem supra note 212, p. 12.

the under-five-mortality rate or the percentage of children under five years who are underweight) with countries with similar levels of per capita income.²²⁷ This approach has been considered practicable for its simplicity, but it may also suffer from weak statistics of countries.²²⁸ In order to measure progress over time, it would be necessary to compare the outcome of this method between subsequent years.²²⁹ A complementary approach is to gain knowledge from historical and analytical analyses of particular country experiences over time.²³⁰ Given the increasing documentation on the status of children's rights in the *Concluding Observations* of the Committee on the Country Reports of individual Member States to the CRC, this can be used as a starting point for such an approach. Such an analysis will be presented in chapter 3.

2.4. THE RIGHT TO HEALTH AND ITS RELATION TO OTHER CRC ARTICLES

The Committee on the Rights of the Child has reaffirmed repeatedly that the CRC is to be applied holistically, taking into account the principles of universality, indivisibility and interdependence of all human rights.²³¹ Four of the CRC's articles are explicitly recognized as the umbrella articles of the CRC, namely the right to non-discrimination (art. 2 CRC), the duty to promote the best interests of the child as a primary consideration in all actions affecting children (art. 3 CRC), the right to survival and development (art. 6 CRC) and the right to be listened to and taken seriously (art. 12 CRC). In addition to the four key principles in the CRC, the Committee on the Rights of the Child has acknowledged that the articles 6.2 (life and survival), 23 (disabled children), 24 (health and health services), 18.3 (role of parents), 26 (social security) and 27 (standard of living) CRC are all essential to ensuring children's right to health.

2.4.1. ARTICLE 2: THE RIGHT TO NON-DISCRIMINATION

The principle of non-discrimination in article 2 CRC is key to ensuring access to health care for children. Discrimination can be defined as 'any distinction, exclusion or restriction made on the basis of various grounds having the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise

²²⁷ See the annual series of UNICEF reports entitled 'The Progress of Nations'.

²²⁸ Ibidem supra note 212, p. 2.

²²⁹ Ibidem supra note 212, p. 2.

²³⁰ Ibidem supra note 212, p. 2.

²³¹ See for example General Comment No.7, page 2. U.N. Doc. CRC/C/GC/7/Rev.1 20 September 2006.

of human rights and fundamental freedoms'.²³² Article 2 of the Convention of the Rights of the Child stipulates that children's right to health must be ensured without distinction on the basis of race, colour, sex, language, religion, political conviction, national, ethnic or societal origin, level of wealth, handicap, birth and neither if based on the beliefs, opinions, residence permit or activities of the parents of the child. This is especially important for (new-born) infants, who are fully dependent on their mothers care. Other grounds of discrimination include health status or sexual orientation.²³³ Special caution must be taken for preventing discrimination on the basis of two grounds at the same time, for example minor girls, minority children or children with an HIV/AIDS infection. Or refugee girls, disabled refugee children and more.

Groups of people that are traditionally marginalized, often bear a disproportionate share of health problems. Several forms of discrimination hinder the effective access of children to health facilities. Kasper has identified that article 2 on non-discrimination is leading in ensuring children's health.²³⁴ She elaborates that the principle of non-discrimination means that States need to actively protect children against discrimination and that they have to refrain from policies with a discriminative effect.²³⁵ The prohibition of discrimination thus means that States must make proactive efforts to treat (vulnerable) children and adolescents in a non-discriminatory manner. This may entail taking affirmative action to ensure equal access to health care for specific vulnerable groups, such as girls, migrant children, disabled children etc.²³⁶ An elaboration of the measures propagated by the CRC Committee to realize the right to the highest attainable standard of health for several particular vulnerable groups is found in paragraph 5.

Discrimination, or differential treatment occurs 'de iure', when legislation inhibits children to have access to health care or 'de facto', when legislation ensures access, but when individual agents practice discrimination on their own initiative or under the social pressure of colleagues or supervisors or by unawareness of the rules among receptionists, for example in face-to-face contacts for admittance in a hospital.²³⁷

The provision on non-discrimination of children contains three key elements that must be met in order to establish a violation of the principle of non-

²³² WHO Factsheet No. 31 on the Right to Health, prepared by the Office of the United Nations High Commissioner for Human Rights, p. 7.

²³³ See also the elaboration on discrimination of children infected with HIV/AIDS in General Comment 3 to the CRC. U.N. Doc. CRC/GC/2003/3, General Comment 3 on HIV/AIDS and the rights of the child, 17 March 2003.

²³⁴ Ibidem supra note 213, p. 27.

²³⁵ Ibidem supra note 213, p. 28.

²³⁶ WHO Factsheet No. 31 on the Right to Health, prepared by the Office of the United Nations High Commissioner for Human Rights, p. 14 and 15.

²³⁷ B. Abramson, 'Article 2 the right of non-discrimination', in the Series: *A Commentary on the United Nations Convention on the Rights of the Child*, Leiden/Boston: Martinus Nijhoff Publishers 2008, pp. 33 and 51.

discrimination: 1) a differential treatment on a *forbidden ground*, 2) which causes a *violation/injury*, 3) in protecting a *certain interest*.²³⁸

2.4.1.1. *Forbidden ground for discrimination*

The first element of the right to non-discrimination contains the phrase 'forbidden ground'. This phrase is integrated in the definition of non-discrimination as there is a distinction between justified and non-justified grounds for making distinctions between different people. Many (medical) situations occur in which differential treatments are justified, for example, a child with a broken leg requires a different treatment than a child needing a tonsil section or a child with leukaemia. The principle of non-discrimination is violated when distinction is made on any of the non-exhaustive forbidden grounds, such as age, race, gender, religion or political conviction, resulting in the unequal treatment between equal cases. Different medical conditions may thus justify different treatments. However, when two girls of different ethnic origin suffer from the same kind of lung infection, they are entitled to the same level and methods of health care on the basis of their right to non-discrimination.²³⁹

However, in providing for differential treatments, caution must be taken that the provision of adjusted health care does not become a source of discrimination in itself. For example, General Comment 9 provides that in order to ensure maximum inclusion of disabled children in society, the necessary medical services must be integrated into the regular public health system for all children to reduce the risk of discrimination.²⁴⁰

Also for other groups of vulnerable children, States are required to make proactive efforts to ensure that all children receive health care and that this does not constitute an (unintended) cause for discrimination of the specified groups. General Comment 6 contains a separate paragraph to ensure that unaccompanied and separated children outside their country of origin have the same level of access to health facilities as nationals do.²⁴¹ In order to realize this States must take into account the specific vulnerabilities of these children, such as separation from their families, the experience of (gender-based) violence, war, loss and trauma. These children may have lost their trust in others, in particular government authorities after experiencing torture or threats²⁴² in their country of origin or during their flight and they need special sensitivity and attention in their care and rehabilitation.²⁴³ They are entitled to health care

²³⁸ Ibidem supra note 237, pp. 18–30.

²³⁹ E.g. A.W. Musschenga & E. Borst-Eilers, 'Prioriteiten in de gezondheidszorg. Rechtvaardig verdelen, maar hoe?', *Medisch Contact* 1987, no. 1, pp. 13–19.

²⁴⁰ U.N. Doc. CRC/C/GC/9, GC 9: The rights of children with disabilities, 27 February 2007, § 52.

²⁴¹ U.N. Doc. CRC/GC/2005/5, General Comment 6 on the treatment of unaccompanied and separated children outside their country of origin, § 46–49.

²⁴² Ibidem supra note 173.

²⁴³ Ibidem supra note 240, § 47.

in the immediate period after resettlement.²⁴⁴ For indigenous groups of children, the CRC Committee has acknowledged in General Comment 11 that indigenous children in both developing and in developed countries often suffer poorer health than non-indigenous children due to inferior or inaccessible health services.²⁴⁵ By remaining without birth registration, they have a higher risk of remaining invisible to health professionals,²⁴⁶ there are disproportionately higher numbers of infant and child mortality rates, diseases, extreme poverty and malnutrition among indigenous children.²⁴⁷ Furthermore, indigenous communities often live in areas targeted for their natural resources or areas that because of remoteness serve as a base for non-state armed groups or disputes with foreign States in the vicinity of borders.²⁴⁸ These circumstances lead to significantly worse health indicators. Measures propagated by the CRC Committee to meet the health needs of these children are further specified in paragraph 5.

2.4.1.2. *Violation of the right to health*

The second element of the right to non-discrimination says that there must be a violation of the substantive right (in casu the right to the highest attainable standard of health), which means that the right to non-discrimination does not refer to positive instances of discrimination such as preferential treatment:²⁴⁹ one can not make a complaint for receiving exceptionally qualitative care. However, if other patients are excluded from quality care, that practice may amount to a situation of negative discrimination of those who are excluded from the right to the highest attainable standard of health. For example, if some children in a sub-Saharan village receive anti-malaria treatment whereas others do not and thus run the risk of being infected, this may amount to a violation of the right to health of the discriminated children. The question is how this element must be explained in situations of scarcity, when only half of the total number of patients can be given adequate treatment, for example in developing countries with extreme levels of poverty and in cases of sudden emergencies with high numbers of victims. Questions like these on triage have been dealt with from philosophical perspectives, aiming to find decisive principles that can be applied to make just choices.²⁵⁰ These perspectives include egalitarian (first in, first out), utilitarian (a doctor must be helped first in order to increase the medical capacity so that more

²⁴⁴ Ibidem supra note 173.

²⁴⁵ U.N. Doc. CRC/C/GC/11, General Comment 11: Indigenous children and their rights under the Convention, January 2009, § 49.

²⁴⁶ Ibidem supra note 245, § 41.

²⁴⁷ Ibidem supra note 245, § 34, 50.

²⁴⁸ Ibidem supra note 245, § 64. Therein, referral is made to UNICEF Innocenti Digest No. 11, *Ensuring the Rights of Indigenous Children*, 2004, p. 13.

²⁴⁹ Ibidem supra note 237, p. 23.

²⁵⁰ A. Richters, 'Arts en oorlog: ethische aspecten van triage', in: J. Bierense a., *Urgentiegeneskunde en Triage*, Maarssen: Elsevier Gezondheidszorg 2004, pp. 55–70.

people can be cured in the longer term) or evaluative decision-making schemes (the most serious cases must be treated first).²⁵¹ These instances demonstrate the tension that is encountered in realizing social rights such as the right to health between the amount of children in need of health care and the resources available. Priority measures could include the raising of budget allocated to children's health or cost reduction by enacting legislation to set aside patents for very expensive medicines. Secondly, policy decisions need to be taken on prioritizing whether focus is placed on ensuring basic health care access for all children or ensuring more qualitative health care access for a limited number of children. In both instances, the right to health and the right to non-discrimination of children require that additional efforts must be made by States to raise the health standard achieved to a higher level, until all children reach the highest attainable standard of health.

2.4.1.3. *Protection of a certain interest*

With regard to the third element of discrimination, the protection of a certain interest, the distinction between direct and indirect discrimination is relevant. Direct discrimination is defined as 'treating one person less favorably than another person on the ground of race (sex, etc.)'. An example is when a certain group of inhabitants such as refugee children or indigenous children is legally completely deprived of adequate health care. Indirect discrimination occurs when an 'apparently neutral provision' puts 'members of one group at a disadvantage in comparison to others' that 'can not be justified'.²⁵² For example, when children are formally entitled to right to the highest attainable standard of health care, they may still be indirectly discriminated when they are not provided with sufficient resources to pay for the medical care. Another example of indirect discrimination with respect to the right to the highest attainable standard of health is when children are not registered at birth. Both types of discrimination are prohibited, as they limit children's enjoyment of the right to the highest attainable standard of health.

The duty of the State to prevent discrimination thus applies to overt discrimination, such as discriminatory legislation directed at the discriminated group itself and to covert discrimination, such as actual practices benefiting one (major) group while being discriminatory to others or when a neutral looking law appears to result in discriminatory practices.²⁵³ In recognizing discriminatory legislation, it is important to realize that a discriminatory law often has a positively formulated objective, such as 'for the benefit of society', 'to maintain

²⁵¹ See for a discussion on the impact of different principles A.W. Musschenga & E. Borst-Eilers, 'Prioriteiten in de gezondheidszorg. Rechtvaardig verdelen, maar hoe?', *Medisch Contact* 1987, p. 13.

²⁵² *Ibidem* supra note 220, pp. 33 and 67.

²⁵³ *Ibidem* supra note 220, p. 50.

order’ or ‘to protect public health’, whereas simultaneously the right to non-discrimination may be violated.²⁵⁴ Webb has made a useful categorisation of the different forms of discrimination of children, being distinguished between direct (or overt)²⁵⁵ and indirect (or covert) discrimination.²⁵⁶ Given the strong specific focus on discrimination on children’s health issues, the elaboration is particularly relevant for this research. An overview of the different forms of child-specific discrimination with respect to their right to health is provided in table 1.

Table 1. Modes of discrimination of children in health care (based on Webb²⁵⁷)

Direct discrimination by:	Indirect discrimination:
1. <i>Exclusion</i> of children from adult spheres as a natural state of well-being (separateness of the child’s world).	1. <i>Girls/women</i> : Low pay of single-mothers and poor maternity provisions resulting in inadequate resources for health care for children.
2. <i>Marginalisation</i> : as ‘constructed otherness’. E.g. underrepresentation of children in funding for research and development, resulting in an inadequate evidence-base for paediatric practice.	2. <i>Parents</i> : No or little parental leave for child illness, inadequate or unaffordable childcare services and little attention of dual role of working parents, resulting in stress on care for (ill) children.
3. <i>Age-blindness</i> : Ignoring or denying differences in needs for children, for example in waiting areas or hospitals.	3. <i>Ethnic minorities</i> : Increased risk of growing up in poverty, having inadequate access to quality and culturally appropriate health care. Illiterate parents.
4. <i>Deficit model of childhood</i> : Perceiving children as immature/unfinished and therefore incapable of medical decision-making.	4. <i>Asylum seekers</i> : Ibidem number 3 and lack of health insurances, translation on and information on the health system, whereas many are traumatized.
5. <i>Victim blaming</i> : Blaming children for injuries or abuses instead of addressing the real underlying structural causes.	5. <i>Homeless families</i> : Ibidem number 3 and low compliance with health care treatments and suffering from stigmatization.
6. <i>Stereotyping</i> : Perceiving distressed and disadvantaged children as inherently bad, resulting in unbelief of reports of right violations.	6. <i>Disabled</i> : Children having difficulties in obtaining adequate access, being marginalized or overseen in public health policy because of their disability.
7. <i>Internalised discrimination</i> : Children seeing themselves as inferior, having nothing worth to listen to and thus not actively participating.	7. <i>Mentally and chronically ill carers</i> : Unsupported children take up caregiver roles or risk being neglected, abused or stigmatized by their carers.
8. <i>Exploitation</i> : Using children against their will for age-inappropriate activities, such as abuse, child labour or political goals.	8. <i>Poor families</i> : Risk of stigmatization and poor access to health care (insurances) and underlying determinants for children.

²⁵⁴ Ibidem supra note 220, p. 33 and 34.

²⁵⁵ E. Webb, ‘An Exploration of the Discrimination-Rights Dynamic in Relation to Children’, in: A. Invernizzi & J. Williams (eds), *The Human Rights of Children: From Visions to Implementation*, Ashgate 2011, pp. 287–306. Webb qualifies overt discrimination as ‘childism’, discrimination against children as children per se.

²⁵⁶ Ibidem supra note 255, pp. 287–306.

²⁵⁷ Ibidem supra note 255, pp. 287–306.

In the second paragraph of article 2, the element of prohibiting discrimination of children on the basis of their parent's characteristics is specific for the prohibition of discrimination in the Convention on the Rights of the Child. This means for example that when parents do not have an official residence permit and consequently do not have a health insurance, this should not impair the possibility of their children to have access to adequate health services. In the *travaux préparatoires* to the Convention on the Rights of the Child the proposal to refuse undocumented children to have access to health care was explicitly rejected.²⁵⁸ Also, it means that children may never be punished for actions, beliefs or the status of their parents or guardians. This includes for example children who were born out of wedlock, whose parents are incarcerated, members of subversive political parties, social movements, religious sects or illegal organizations (article 2-2a).²⁵⁹ This prohibition explicitly extends to State practices that try to punish or convince parents by harming their children (article 2-2b).

In order to address the different forms and consequences of discrimination, States may decide to take affirmative actions, special measures to remove barriers for children so that they can enjoy their right to the highest attainable standard of health. Non-discriminatory affirmative action can only be achieved when additional possibilities are created for groups of children, without reducing the opportunities of others.²⁶⁰ Thus, when additional possibilities are created for refugee children to have access to health care, this may not reduce the possibilities of other (vulnerable) groups of society to have access to health services. Whereas this is a laudable obligation, it is difficult to realize in practice, because in many circumstances, not all children can be reached at the same time. Furthermore, conflicting rights and values can complicate this.²⁶¹ For example, when the right to health care and the right to freedom of religion are at odds when Jehovah witnesses do not want their child to receive a blood transfusion, when sex education at schools is opposed by religious parents or when cultural practices lead to discussion on potential harm to the child.²⁶² Also, discrimination may occur unintended when a certain interest is pursued having consequences for the enjoyment of the right of the child.

The obligation of the State to prevent and eliminate discrimination against children extends to (state) sectors that fall within their authority. It does not include all actions of individuals and other private actors who may discriminate against sick children. For example, when parents forbid their child to play with another child who has an infectious disease or whose parents are very ill, the State

²⁵⁸ *Legislative History of the Convention on the Rights of the Child*, Volume II, United Nations, New York and Geneva, 2007, pp. 580–603. See particularly U.N. Doc. E/CN.4/1349, pp. 4–5.

²⁵⁹ *Ibidem supra* note 237, p. 129.

²⁶⁰ *Ibidem supra* note 237, pp. 33 and 77.

²⁶¹ *Ibidem supra* note 255, pp. 300–301.

²⁶² Usual examples include female genital mutilation, cupping or sending a child to bed without food as a punishment.

is not expected to intervene in this practice, whereas it may constitute an act of discrimination towards the child. When this kind of behaviour is practiced on a large-scale by parents towards all children with a particular disease, the State may be required to establish a public campaign aiming to reduce this widespread practice of discrimination of (sick) children. However, it is difficult to determine where to draw the line between (overt or covert) discriminatory practices in which the State should intervene or where this falls within the responsibility of the private actor. More research is needed to determine when such practices by private actors lead to practices of widespread discrimination requiring a public response.

2.4.2. ARTICLE 3: THE BEST INTERESTS OF THE CHILD

The best interests of the child in article 3 of the CRC provide that the best interests of the child shall be a primary consideration in *all* measures concerning the child.²⁶³ This implies that all children must be approached in the first place as being a child (of a certain age) and only in the second place as migrants, refugees, indigenous or ill children. In that respect, it may be argued that it is central in ensuring all individual children's rights. The downside of this principle is that it can be interpreted so broadly, that even prejudices and harmful traditional practices can be applied under the alibi of a legal instrument.²⁶⁴ Different cultures also use different concepts of what the best interests of the child are, as becomes rather clear in the discussion of the issue on the circumcision of boys which is propagated by certain religions, whereas it is discouraged by others. The same is true for the performance of abortions in teenage girls. In the Netherlands it is seen by many as being in the best interests of both the baby as of the child mother, whereas under several religions and life considerations it is strongly opposed, notwithstanding social exclusion of children and their mothers who give birth out-of-wedlock. Actually, some of the most difficult cases in taking the best interests of the child into account have been identified in medical decision-making by Freeman.²⁶⁵ In determining the influence of the best interests of the child in medical decisions, a large margin of appreciation must be assumed, being further divided in short-term and long-term considerations on the best interests of the child, which may be a source of conflict. Freeman has identified that 'current interests tend to be formulated in relation to experiential considerations,

²⁶³ G.C.A.M. Ruitenbergh, *Het Internationaal Kinderrechtenverdrag in de Rechtspraak*, Amsterdam: SWP 2003, p. 61.

²⁶⁴ I. Thèry, 'The Interests of the Child and the Regulation of Post-Divorce Family' in: C. Smart & S. Sevenhuijsen, *Child Custody and the Politics of Gender*, 1989, London: Routledge, p. 82.

²⁶⁵ M. Freeman, *A Commentary on the United Nations Convention on the Rights of the Child, Article 3: The Best Interests of the Child*, Martinus Nijhoff Publishers 2007, p. 3.

whereas future-oriented interests focus on developmental considerations'.²⁶⁶ For example, in operating upon a child to cure it from a disease the child may suffer from short-term consequences, such as pain, tiredness and immobility, but in the long term, it may protect the child against further deterioration or even death. The consideration of protecting children against fear of needles must be balanced against the potential benefits of vaccinations.

Article 3 sub 2 of the CRC is of particular importance for children's right to health, stating that State Parties have the obligation to ensure that 'institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety and health, in the number and suitability of their staff, as well as competent supervision.' In the context of the health sector, the best interests of the child therefore imply that there must be a multi-disciplinary team available to treat children, ensuring not only a qualitative medical treatment, but also taking into consideration their psychological and social well-being and their opportunities to maintain a relatively normal life. This paragraph also implies that staff must be well trained and appropriately qualified, especially now that in recent years many examples have been revealed of children who were abused in the residences where they were formally taken care of.^{267, 268} The timing and way in which a medical treatment is delivered must be balanced against the requirements of other important interests of a child, such as contacts with friends and family, development in school and social and psychological well-being. This holistic consideration of children's right to health reflects the interpretation of the role of the best interests of the child when explained as 'informed and constrained by the rights and other principles of the Children's Rights Convention', such as the right of children to play, the right to education and the right not to be separated from its family.²⁶⁹ It leads to the conclusion that children's in realizing children's right to health, their best interests must be taken into account.

The best interests of the child must also be balanced against the right to participation of the child. It can be argued that when an anorexic child refuses food it is still in her best interest to provide her with artificial feeding. However, on the basis of the child's right to participation, it could be argued that children's views must be taken seriously and acted upon. The question of protection versus autonomy of children is at stake here. In this context, an interesting comment has been made by Fortin, noting that 'there are respectable jurisprudential arguments for maintaining that children's rights do not prevent interventions to stop children making short-term choices, thereby protecting their potential

²⁶⁶ Ibidem supra note 265, p. 3.

²⁶⁷ Ibidem supra note 265, p. 72.

²⁶⁸ U.N. Doc.E/CN.4/1989/48, § 144.

²⁶⁹ Ibidem supra note 265.

for long-term autonomy'.²⁷⁰ This idea can also be applied for the medical sector, for example in deciding upon the extent of children's participation in their own treatment.²⁷¹

Problems in the interpretation of children's best interests in particular situations may arise when the best interests of the child may be in conflict with the best interests of the (juvenile) mother (for example during pregnancy or childbirth²⁷²) or when the best interests of one group of children conflict with those of other children.²⁷³ Freeman gives a clear example of two conjoined twins, of whom the stronger one would benefit from separation, whereas this would cause her sisters death.²⁷⁴ The judges decided that the weaker twin did not have a quality of life while being conjoined and that it was in her best interests to at least momentarily experience bodily autonomy.²⁷⁵ Another dilemma occurs when a teenage mother suffers from pregnancy complications that endanger her life. Whose interests should prevail then? Those of the juvenile mother or those of the baby yet to be born? For groups of children, related questions have been identified in allocating limited budgets to either a neonatal unit or to enforcing health care for school going children or adolescents.²⁷⁶

The best interests of the child must be considered in its social context. This is also the reason why the cultural and religious values of the community in which a child is raised play an important role in the interpretation of the best interests of the child. As elaborated in chapter 1, concepts and notions of health are strongly diverse between and within different communities. This will certainly influence the interpretation of what is in the best interest of the child. FGM is the most debated example, but other examples include different visions on vaccinations by certain religious communities, blood transfusions by Jehovah witnesses and western, symptom based medical treatments versus more holistic approaches such as acupuncture and reiki.

²⁷⁰ J. Fortin, 'Children's rights: are the courts taking them more seriously', *King's College Law Journal* 2004, Volume 15, p. 270.

²⁷¹ Some state that professionals tend to believe that children pay more attention to short-term than to long-term consequences, for example fear of pain when receiving immunization. However, this standpoint seems to be a bit too simplistic, especially for children who undergone many medical treatments and are well aware of their medical situation.

²⁷² U.N. Doc./E/CN.4/1989/48, § 121, reproduced in Freeman, M., *A Commentary on the United Nations Convention on the Rights of the Child, Article 3: The Best Interests of the Child*, Martinus Nijhoff Publishers, 2007, p. 61.

²⁷³ Ibidem supra note 265, p. 63.

²⁷⁴ Ibidem supra note 265, p. 62.

²⁷⁵ Case Re A.: Two judges (the trial judge and Robert Walker L.J. in the Court of Appeal) considered that the best interests of achieving bodily integrity outweighed the poor quality of life while conjoined, while giving the chance of life to the twin who would be capable of surviving. Available at: www.ncbi.nlm.nih.gov/pubmed/15069933.

²⁷⁶ Ibidem supra note 265, p. 64.

2.4.3. ARTICLE 6: THE RIGHT TO LIFE, SURVIVAL AND DEVELOPMENT

The right to life and development particularly envisages the obligation of states to reduce infant and child mortality and to increase life expectancy.²⁷⁷ As such, it relates to the obligation in article 24-1 CRC. The basis of this article was laid down in 1948 in article 3 of the Universal Declaration on Human Rights, stating that ‘Everyone has the right to life, liberty and security of person’²⁷⁸ and it was further elaborated in article 6 of the International Covenant on Civil and Political Rights (the ICCPR), as ‘Every human being has the inherent right to life and no one shall be arbitrarily deprived of his life.’ In the International Covenant on Civil and Political Rights the first outline of the protection of children’s right to life as laid down in article 6 of the ICCPR could be discerned in paragraph 5, specifying that any ‘sentence to death shall not be imposed for crimes committed by persons under the age of 18 nor shall it be carried out on pregnant women’, thereby also protecting the life of the unborn child. A more explicit prohibition of the death penalty is found in article 37. Article 6 of the Convention on the Rights of the Child does not speak of the relevance of sentences to death. However, its protection extends beyond the protection of life itself by not only recognizing ‘that every child has the inherent right to life’, but also that ‘States Parties shall ensure to the maximum extent possible the survival and development of the child’. In explicating the child’s right to development, the link between children’s right to life and children’s right to health becomes evident, as children with health problems often experience stagnation or setbacks in development concomitantly. Riedel even states that ‘without an effective guarantee of the right to life, all other rights would be meaningless’.²⁷⁹ Others memorize that the right to life has amounted to *ius cogens* and that it can not even be derived from in times of emergency.²⁸⁰ The relation between the right to life and the right to health is also reflected in the regularly published child mortality rates. Good health (care) is required to prevent high rates of children’s diseases and consequent high child mortality rates. The right to (emergency) health care, including care for women in labour, must be fulfilled in order to meet the requirements of the right to life. Without adequate perinatal care both the (unborn) child and the mother run

²⁷⁷ E. Riedel, ‘The Right to Life and the Right to Health, in particular the obligation to reduce child mortality’, in: A. Invernizzi & J. Williams (eds.), *The Human Rights of Children: From Visions to Implementation*, Ashgate, 2011, pp. 351–369.

²⁷⁸ Universal Declaration of Human Rights, General Assembly resolution 217A (III), U.N. Doc A/810 at 71 (1948). The UDHR was adopted with 48 votes in favour, none against and 8 abstentions (Belorussia, Czechoslovakia, Poland, Ukraine, USSR, Yugoslavia, Saudi-Arabia and South Africa).

²⁷⁹ *Ibidem supra* note 277.

²⁸⁰ M.J. Bossuyt, *Guide to the Travaux Préparatoires of the ICCPR*, Dordrecht: Martinus Nijhoff 1987, p. 121. See also Riedel, *supra* note 260.

increased risks of infections and other birth complications resulting in higher infant and maternal mortality rates.

The right to life, survival and development of the child also requires that children have access to continuous care throughout the different phases of their life and that the services provided should be adapted to changing circumstances, such as the child's age and living environment, cutbacks in budgeting and changes in environmental circumstances such as increased industrialization, armed conflicts and natural disasters. These adaptations are necessary to ensure the survival and development of children in all different phases of their lives.

The relevance of the right to life for children's right to health is also eminent in the discussion on the necessity to immunize children against the major childhood diseases and in the tolerance of high levels of malnutrition among groups of children, leading to serious growth disturbances and possibly even to death. When certain religious groups refuse to immunize their children against possibly lethal diseases, such a choice may be in conflict with children's right to health and development, because children run the increased risk of contracting seriously debilitating diseases. The counterargument to this standpoint is that the right to life only protects against actual infringements of children's health and life and not against potential risks to such infringements. However, this standpoint does not match with the focus in article 24 CRC on the prevention of health problems and on the important role of parents on ensuring their children's right to health.

Several issues related to the right to life of the child are particularly controversial, such as the rights of the unborn child to protection against (selective) abortions, the protection of (unborn) children against HIV/AIDS infections²⁸¹ and the protection of children against harmful traditional practices, such as preferential feeding and girl infanticide.²⁸² Also, modern reproductive technologies evoke discussions as to the extent to which life can be artificially created and how this affects the health of (unborn) children. For example, much is still unknown on the long-term safety of reproductive technologies.²⁸³ Growing

²⁸¹ Sexual education to prevent different modes of HIV/AIDS transmission, such as through sexual intercourse and mother-to-child transmission may be objected for religious or cultural reasons.

²⁸² High rates of abortions and (selective) infant and child mortality rates have led to numerous questions of both the Committee on the Rights of the Child as of the CESCR. For example, the CRC Committee questioned the Netherlands on the relatively high number of abortions of children with congenital defects in 2009, U.N. Doc. CRC/C/NLD/CO/3, 27 March 2009, § 31. India was questioned on the practices of sex selective abortions and infanticide of girls, India, U.N. Doc. CRC/C/15/Add.115, 23 February 2000, § 49. See also the Concluding Observations of the CESCR on India, U.N. Doc. E/C.12/IND/CO/5, 16 May 2008, § 73–79.

²⁸³ E. Blyth, 'To be or not to be? A critical appraisal of the welfare of children conceived through new reproductive technologies', *International Journal of Children's Rights* 2008, Issue 16, pp. 505–522.

evidence on the increased incidence and concomitant risks²⁸⁴ of artificially conceived twins and on the increased risk of congenital malformations is counterbalanced by the question whether ‘bringing children into the world can ever be regarded as contrary to their interests’.²⁸⁵ This may be the case for children who are conceived as ‘saviour siblings’; brothers or sisters who are conceived to donate stem cells or bone marrow to their seriously ill sibling or children who are deliberately selected for their gender, for example when a hereditary disease is linked exclusively to the Y or X chromosome (e.g. haemophilia, Duchenne Muscular Dystrophy). Although some claim that, ‘it may always be in the best interests of the child to be born, save for exceptionally rare instances, when the child would be exposed to a life that is not worth living’,²⁸⁶ a contrary proposition asserts that ‘children should not be knowingly or intentionally be brought into the world unless they will not be affected negatively in any foreseeable way’.²⁸⁷ This has even been drawn so far as to prohibit the conception of saviour siblings, siblings in one-parent families, parents of similar sex and post-menopausal mothers, possibly leading to instances of discrimination when such parents have a deep wish to have children.

These types of conception are all characterized by a potential discrepancy between the rights to life and health of the child and the rights of the parents to reproductive autonomy and possibly also the rights to life and health of siblings. This discrepancy is also at stake with regard to the rights of the unborn child when a pregnant woman considers a (selective) abortion or when she decides upon undergoing a natural delivery or an alternative medical operation for the baby to be born.²⁸⁸ The right to life of the unborn child must further be balanced against the rights to life and to health of the pregnant woman, for example when the pregnancy poses serious threats to the life or health of the mother.

As long as the child is in the womb, it is part of the mother’s bodily integrity. The crucial difference for the protection of the unborn child is then dependent upon its capacity to be born alive. In practice, this distinction is difficult, because ‘what may be seen as a heroic fight for life in one setting may be classified as a hopeless case in another’.²⁸⁹ Also, there are instances in which babies were kept alive against all expectations whereas others unexpectedly gave up.

²⁸⁴ Risks include health implications for both the children and the mothers, including increased perinatal and maternal death rates and neurological, respiratory and gastrointestinal problems. Economic, social and psychological challenges for the families and increasing pressures on neonatal, health and social services may also be augmented. *Ibidem supra note 283*, p. 508.

²⁸⁵ *Ibidem supra note 283*, p. 506.

²⁸⁶ J. Harris, *On cloning: thinking in action*, London: Routledge 2004. See also: J. Savulescu, ‘Deaf lesbians, ‘designer disability’, and the future of medicine’, *British Medical Journal* 2002, Issue 325, pp. 771–773.

²⁸⁷ *Ibidem supra note 283*, p. 515.

²⁸⁸ M. Cornock & H. Montgomery, ‘Children’s rights in and out of the womb’, *The International Journal of Children’s Rights* 2011, Issue 19, pp. 3–19.

²⁸⁹ *Ibidem supra note 288*, p. 15.

Fundamental in deciding upon such highly sensitive questions is the quality of life of the child when it survives. Again, the question is at stake, whether it is ever in conflict with a child's best interests to save its life. Quality of life refers to the conditions in which children live. It is an important concept for children with chronic or terminal diseases and it plays a central role in decisions on the continuation of medical treatments and the start of palliative care. According to the WHO, palliative care can be defined as 'The active total care of the child's body, mind and spirit, and also involving the support given to the family'.²⁹⁰ Palliative care is intended to provide relief from pain and other distressing symptoms; it affirms life and regards dying as a normal process; it intends neither to hasten or postpone death; it integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death and to help the family cope during the patients illness and in their own bereavement; it will enhance quality of life, and may also positively influence the course of illness.²⁹¹ With respect to children, it has been established that 'palliative care requires a multidisciplinary approach, including the family and making use of community resources'.²⁹²

In my opinion, in deciding upon these highly sensitive issues, children's resilience and capacity to recover should be the basic premise, although at some point, the continuance of medical treatment may become more painful than letting go of life. The decision of where this point lies should be left to individual discretion of the child and its parents. Support from medical practitioners, friends, family, religious and spiritual coaches should be family-sensitive and respectful of the choices made in the intimate family context.

2.4.4. ARTICLE 12: THE RIGHT OF THE CHILD TO BE HEARD

Children's right to participation is laid down in article 12 CRC. Dr Hart has defined the concept of participation as 'The process of sharing decisions which affect one's life and the life of the community in which one lives'.²⁹³ This definition implies active involvement that can be effectuated in decision-making. Others even argue that participation of children can transform practices that exclude

²⁹⁰ www.who.int/cancer/palliative/definition/en/.

²⁹¹ Ibidem supra note 288.

²⁹² Ibidem supra note 288.

²⁹³ R. Hart, *Children's participation: From tokenism to citizenship*, Florence: UNICEF International Child Development Centre: 1992. See also: R. Hart, *Children's participation, the theory and practice of involving young citizens in community development and environmental care*, London: Earthscan Publications Ltd. 1997.

them.²⁹⁴ On the other hand, whereas a focus on autonomy²⁹⁵ is central in bioethics as a whole, the opposite sometimes seems to be the case for children in the health care sector.²⁹⁶ Contrary to children's increasing capacities, it is often assumed that children do not have sufficient knowledge or insight to make well-founded medical decisions. However, this question can also be posed to adults.

Article 12 CRC has three elements which can be considered as the basis for child participation, although the actual word 'participation' is not explicitly mentioned in the provision. These elements are: the right to 'express views freely', 'the right to be given due weight to these views in accordance with the age and maturity of the child' and 'the right to be heard in official proceedings'. These elements are both relevant for individual children as for groups of children.²⁹⁷ The concept of participation is described in General Comment 12 of the Committee on the Rights of the Child as 'an ongoing process, including 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 to shape the outcome of such processes.'²⁹⁸ As the concept of participation refers to a range of different practices, a distinction has been made between the private or personal domain of participation, such as the household or family and the social or public domain, such as the school, the community and government.²⁹⁹

The element of expressing views freely means that children should not be pressured or manipulated in expressing their opinions.³⁰⁰ Specifically for the health sector, children must be given the opportunity of confidential counselling, for example by speaking to the health professional and/or to the parent in private, so that they will feel free and secure to express themselves.³⁰¹ It may also require adults to accept choices of the child that they do not support, for example when a terminally ill child wishes to terminate a medical treatment against the will of the parents or doctor. Lastly, it may even require affirmative action to enable children with very rare diseases to express themselves or to enable particularly vulnerable or discriminated children to express themselves without having to

²⁹⁴ C. Dedding, *Delen in macht en onmacht, Kinderparticipatie in de (alledaagse) diabeteszorg*, Academisch proefschrift, verdedigd op 30 september 2009 aan de Universiteit van Amsterdam, p. 31. Available at: <http://dare.uva.nl/document/146511>.

²⁹⁵ See paragraph 6 for a further discussion on the relation between the right to participation of children and the principle of autonomy in bioethics.

²⁹⁶ L.F. Ross, 'Health Care Decision Making by Children. Is it in their best interest?' in: *Children, Medicine and the Law*, Hastings Center Report, November-December 1997, p. 487.

²⁹⁷ U.N. Doc. CRC/C/GC/12, 20 July 2009, General Comment 12 on The right of the child to be heard, § 28, § 9 and 72.

²⁹⁸ Ibidem supra note 297, § 3.

²⁹⁹ S. Moses, 'Children and participation in South Africa: An overview', *The International Journal on Children's Rights* 2008, Issue 16, pp. 327-328.

³⁰⁰ Ibidem supra note 297, § 22.

³⁰¹ Ibidem supra note 297, § 101. Elaborated is that the right to receive confidential counseling is distinct from the right to give medical consent and that it therefore applies to children of all ages.

fear repercussions from the government or other groups in society.³⁰² Articles 16, 28 and 29 CRC further elaborate that education must ensure that children develop the ability to seek and understand information to participate meaningfully in medical decisions and health care in general by seeking access to the kind of health care that they wish to enjoy. Children's right to participation thus also requires the fulfilment of their right to information, as they can not participate meaningfully if they do not have all relevant information.

The second element means that the views of the child are given due weight according to the age and maturity of the child. According to article 5 CRC and General Comment 12, the evolving capacities of the child must be taken into account in the exercise of the right to participation. Children's capacities differ according to their age, level of development and comprehension and also according to children's experiences. In the healthcare sector, it has been acknowledged that children undergoing long-term treatments develop and mature throughout the process, so that their wishes and expectations of the healthcare provided will also change and develop.^{303, 304} Bluebond-Langner demonstrated that experiences of children were crucial in establishing maturity among children; children of 4–5 years old having experiences with medical treatments appeared to better understand their medical situation and prognoses than intelligent children of 9 years old without such experiences.³⁰⁵ This is proof of the central importance of experience of children on specific topics or in specific contexts for establishing their competency to make choices in their own health care.³⁰⁶ This finding also implies that age limits for determining children's legal ability to be involved in medical decisions, as laid down in Dutch health legislation for example,^{307, 308} may not

³⁰² Ibidem supra note 297.

³⁰³ U. Kilkely & M. Donnelly, *The Child's Right to be heard in the Healthcare Setting: perspectives of children, parents and health professionals*, The National Children's Strategy Research Series, October, 2006, p. 3.

³⁰⁴ See also *Children's consent to surgery*, Open University Press, Buckingham, 1993, pp. 154–163.

³⁰⁵ M. Bluebond-Langner, *The private worlds of dying children*, Princeton, New Jersey: Princeton University Press 1978.

³⁰⁶ D. Mannaerts, 'Minderjarigen en participatie in de gezondheidszorg', *Rechten van minderjarigen in de gezondheidszorg* 2004, Kinderrechtencoalitie Vlaanderen vzw, 1^e jaargang, nr. 2, pp. 23–37.

³⁰⁷ In the Netherlands, on the basis of article 7:465-1, 7: 450-2 and 7:447 WGBO a distinction is made between children between 0–12 years old, 12–16 years old and children older than 16. The first category has the right to be informed about their medical situation, possible decisions and consequences, but parents are primarily responsible. For children in the second category, parents and children have a joint responsibility and for children in the last category, children are responsible to decide for themselves. For more information on exceptions on this scheme, most predominantly in the case of 'common medical treatments for children between 12–16 years', highly controversial decisions and decisions to protect children under the age of 16 against irresponsible decisions of their parents see: V.E.T. Dörenberg, *Kind en Stoornis, Een systematisch onderzoek naar de rechtspositie van minderjarigen in de kinder- en jeugdpsychiatrie*, Den Haag: Boom Juridische Uitgevers 2010, pp. 76–81.

³⁰⁸ See also supra note 297, § 102.

always reflect the actual capacity of children to decide upon their treatment.^{309, 310} Giving due weight further implies that when a child communicates pain or sorrow, action should be undertaken to support the child or provide medicines, health care or other necessary actions and to provide feedback on those actions taken in response to comments made by the child.

The third element is that children have the right to be heard in official proceedings affecting the child. In my opinion, this should include the involvement of children in procedures of disciplinary law against medical practitioners who have violated the right to health of the child or of other rights in the provision of health care to children, such as inclusion of children in medical decision-processes, informed consent for participation in clinical research and the shaping and organization of children's health care. Also, in order to further improve and realize children's participation in healthcare, children must be fully informed and given the opportunity to give and receive feedback on the way their views were taken into consideration in the medical process, for example when the child makes a complaint against a medical treatment it has undergone. To ensure that children can participate meaningfully in the health care processes that affect them, they must be provided with clear and accessible information on their right to participation and the way in which it is effectuated.³¹¹ Furthermore, standards and indicators must be developed to assess the participation of children in health care.³¹² Last but not least, article 12 must be understood to mean that the child also has the right not to exercise his right to participation.³¹³

Participation can be effectuated directly or through a representative.³¹⁴ However, precaution must be taken to ensure that children can genuinely participate. Several levels of participation have been discerned, ranging from manipulation and tokenism, in which children's participation is mentioned but

³⁰⁹ This dilemma was also discussed during the preparation of the Dutch legislation on age limits. See *Kamerstukken II 1989/91*, 21 561, no. 6, p. 49 (MvA). Criticism included that strict age limits would not take into account the capacity of the minor child to oversee the extent of its medical treatment, notwithstanding its age. See *Brands & Brands-Bottema 1991 vs. Hermans 1990*, p. 95–96 [reproduced in *Dörenberg*], p. 81. However, it was eventually decided to stick to the strict age limits. Somewhat contradictorily, the Dutch government elaborated in the same document that if a severely sick patient of 11 years old consciously refuses certain treatments, he can not be forced to undergo that treatment. See document above, p. 58 and *Kamerstukken II 1991/92*, 21 561, no. 11, p. 31.

³¹⁰ *Ibidem supra* note 289. Mannaerts explains that using age limits to determine children's competency in medical decision making leads to both under inclusion of competent children and over inclusion of incompetent children (and adults).

³¹¹ *Ibidem supra* note 297, § 103 and 134.

³¹² *Ibidem supra* note 297, § 104.

³¹³ *Ibidem supra* note 297, § 16.

³¹⁴ *Ibidem supra* note 297, § 35–37.

not really effectuated, to participatory processes in which children initiate and develop programs in cooperation with adults.^{315, 316}

2.4.5. THE DILEMMA BETWEEN PROTECTION AND CHILDREN'S AUTONOMY

In the realization of children's right to be heard in health care the dilemma of weighing the importance of children's protection against their right to participation or individual autonomy arises. Children undergoing medical treatment have a fourfold vulnerability for being dependent in their position as a minor *vis-à-vis* adults, for being dependent on highly informed medical professionals for being ill, for being sick and suffering from lack of energy and lastly because treatments affect both their short and long-term health prospects. However, their dependency is an argument in itself to give explicit room for their right to be heard. Children in health care must be empowered to have a say in their own medical treatment, so that children will not only be protected against 'wrong' choices or choices based on incomplete information, but also against harm deriving from neglecting their personal wishes.³¹⁷ Especially when highly intrusive medical treatments are considered, it is important that vulnerable children can freely and safely express their views and fears independently of the persons they are dependent on: confidential counsellors should be available for these children and actively provide assistance when children are confronted with (serious) medical decisions.^{318, 319}

³¹⁵ See for a further elaboration of this concept the 'The Ladder of Children's Participation by Hart', supra note 264. Eight different levels of (non-)participation are discerned: 1. manipulation; 2. decoration; 3. tokenism; 4. assigned but informed; 5. consulted and informed; 6. adult-initiated, shared decisions with children; 7. child-initiated and directed; 8. child-initiated, shared decisions with adults.

³¹⁶ See also Shier, identifying 5 levels of participation, namely 1. children are listened to; 2. children are facilitated in expressing their views; 3. children's views are taken into account; 4. children are involved in decision-making processes; 5. children share power and responsibility for decision-making.

An overview of different typologies of children's participation is found in: N. Thomas, 'Towards a theory of children's participation', *International Journal on Children's Rights* 2007, Issue 15, p. 199.

³¹⁷ *Ibidem* supra note 306. Mannaerts discusses that children's involvement in their own medical treatment may be shaped as informed consent (legally binding) or assent (approval, though not legally binding).

³¹⁸ In a study conducted in the European Union among more than 2000 children from various countries, it was found that out of the top 10 recommendations of children on their involvement in health care, 4 concerned the importance of communication; 49.1% being able to understand the doctor; 47.3% being heard; 44.6% having the opportunity to ask questions and 44.1% explanation and preparation to treatment. 'The views and experiences of children and young people in Council of Europe Member States', 2011, Dr. U. Kilkelly, University of Cork.

³¹⁹ Other research has indicated that children's experiences improved with their age, that speaking to nurses was more favourable than speaking to doctors and that children in specialist hospitals reported a much better preparation for medical procedures than children

Other arguments in favour of participation include findings that participation of children in decision-making processes promotes their protection, enhances their skills, autonomy competences and self-esteem.³²⁰ Last but not least, children's involvement in medical decisions has been found to increase the understanding of their diseases and medical treatment and thereby also their adherence to the treatment.³²¹ On the other hand, it is also argued that children require a safe period in which they can develop without jeopardizing their future life chances and without being burdened with the responsibility to make difficult decisions.³²²

To justify violating children's short-term autonomy, the need to protect their long-term autonomy and chances in life is put forward.³²³ Children's legally enshrined incapacity to act proves that focus is structurally placed on their need for protection. The consequence is that children have a heavier burden of proof than adults to show that they are competent.³²⁴ This is especially problematic when (seriously) ill children suffer from tiredness, weakness, pain and a lack of focus and clear communication skills, especially when adults are convinced of the necessity to opt for a particular choice.

A second argument against children's participation concerns questions on children's competency and lack of life experience to fully oversee the consequences of any medical treatment. If factors such as age, maturity and experience in the medical sector concomitantly influence a child's perception of the medical treatment required, how can the individual competency of the child be determined? Appelbaum and Grisso discern four elements that are central in assessing children's competency,^{325, 326} namely:

in general hospitals. Kilkelly, U. and Donnelly, M., 'Participation in Healthcare: The views and experiences of children and young people', in: *International Journal on children's rights*, Issue 19, 2011, pp. 107–125.

³²⁰ G. Landsdown, *Promoting Children's Participation in Democratic Decision-Making*, Florence: UNICEF Innocenti Research Centre 2001.

³²¹ *Ibidem* supra note 320 Landsdown. For a discussion of the importance of developing autonomy of children in healthcare see also Dodds, S., 'Choice and control in feminist bioethics' in: C. Mackenzie & N. Stoljar (eds.), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*, New York: Oxford University Press 2000, p. 229. Reproduced in M. Donnelly & U. Kilkelly, 'Child-friendly healthcare: delivering on the right to be heard', *The Medical Law Review* 2011, 19 (1), pp. 27–54.

³²² L. Friedman Ross, 'Health Care Decision Making by Children. Is it in their best interest?' in: *Hastings Center Report* 1997, Vol. 27, No. 6, pp. 41–45.

³²³ P. Baines, 'Medical ethics for children: applying the four principles to paediatrics', *Journal of Medical Ethics* 2008, Issue 34, p. 142.

³²⁴ *Ibidem* supra note 306 Mannaerts pp. 23–37. Adults on the other hand, have greater difficulty in demonstrating that they are incompetent.

³²⁵ Appelbaum & Grisso, 'Assessing patient's capacities to consent to treatment', *New England Journal of Medicine* 1988, vol. 319, no. 25, pp. 1635–1638.

³²⁶ Similar (less elaborate) analyses have been made by Buchanan & Brock, 'Deciding for others: the ethics of surrogate decision making', *Cambridge University Press* 1989, and Mannaerts, supra note 280. Central in these analyses are the capacity to make and communicate rational choices.

- the capacity to communicate choices;
- the capacity to understand relevant information;
- the capacity to evaluate the information in the context of their own situation;
- the capacity to weigh possible advantages and risks of the different options available.

Central in the analyses of elements of competency are the capacity to make and communicate rational choices. Although these elements provide a structure for determining children's competency for participation in healthcare, the question remains who is capable of assessing the child's competency. Mannaerts convincingly argues that in practice, the establishment of children's competency is often motivated by their willingness to follow a doctor's advice.³²⁷ Incompetency is assumed, if children refuse to follow the advice. This means that the pre-existing ideas and values of the medical professional are replacing the actual assessment of children's competency to take medical decisions and thus that children are not truly given the opportunity to participate in their own healthcare. Therefore, in assessing children's competency for participating in health care, a distinction has to be made between their competency on the one hand and the willingness of adults to respect and accept children's choices in the second place. As mentioned before, realizing children's right to the highest attainable standard of health may require the acceptance of choices that are not supported by the parents or medical sector. Therefore, truly respecting children's right to participation in health care requires an independent and unprejudiced assessment of competency by an independent counsellor or health advocate for children.

A third argument critical of participation of children in their health care is that children's autonomy must be balanced against the autonomy of the parents to give direction to the child during its development. In several researches, it was suggested that parental opposition to their children's participation could pose a considerable barrier to effective participation.³²⁸ Some nervous parents transmitted their fears to their children.³²⁹ Others were reluctant to communicate serious diagnoses fully to their children.³³⁰ Others found that some children welcomed their parents' role in buffering threatening information.³³¹ Also, if

³²⁷ Ibidem supra note 289 Mannaerts, pp. 4–5.

³²⁸ M. Donnelly & U. Kilkelly, 'Child-friendly healthcare: delivering on the right to be heard', *The Medical Law Review* 2011, 19 (1), pp. 27–54.

³²⁹ Ibidem supra note 328.

³³⁰ E. Kübler-Ross, *On Children and death, how children and their parents can and do cope with death*, Touchstone, Simon & Schuster 1997. On the other hand, Young et al found that some children relied upon their parents to manage the communication and welcomed their parents' role in buffering potentially threatening information. B. Young and others, 'Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents', *British Medical Journal* 2003, p. 305. A study was conducted involving 13 families: 19 parents and 13 patients aged 8–17. All patients suffered from cancer or a brain tumour.

³³¹ Ibidem supra note 330.

parents face their child's choice to terminate a potentially life-saving medical treatment, they have a strong personal interest in the decision made. Given the questions on competency and lack of life experience of children to decide upon these issues, parents' hesitance to let the child decide on its own is understandable. Therefore, it would be both practically and legally unjust for medical practitioners to simply override parents' objections to their child's participation when they want to provide the child with information on their medical condition. Proper communication to both parents and children is essential in ensuring participation of children that is compliant with the best interests of the child. This is especially important given the insights that in a triad relationship between doctors, children and their parents, there is a tendency for the development of coalitions between two parties.³³² Therefore the role of the medical professional in responding to parents' or children's involvement in health care is crucial.

2.4.6. ARTICLES 5 & 18: THE ROLE OF THE PARENTS IN ENSURING THEIR CHILDREN'S HEALTH

On the basis of article 18 CRC, parents (or legal guardians) have the primary responsibility for the development and upbringing of their children. The role of parents in ensuring children's right to health can hardly be overestimated, especially for children in their early childhood, as they are fully dependent on the care and attention of their parents or caretakers. However, Freeman establishes that there are inconsistencies in the terminology on parents' responsibilities in upbringing their children versus those of the State and the extended family and local community.³³³ Terms such as 'parents', 'legal guardians', 'persons taking care of the child', 'others responsible for the child' and 'family environment' have been used inconsistently in the Convention on the Rights of the Child. This lack of clarity requires further work to establish who can be addressed when children require access to health care.

In the relation between children and their parents, children are seen as the right holders and parents as the duty-bearers. Parents have the primary responsibility to provide the child with healthy food and a safe and healthy environment. They also have a crucial role in deciding whether children are going to see a medical doctor. Parents are the first to decide whether health care is necessary for their children.³³⁴ Already during pregnancy and delivery they

³³² Gabe and others, 'It takes three to tango: a framework for understanding patient partnership in paediatric clinics', *Social Science Medicine* 2004, Issue, 59, pp. 1071 and 1074. See also M. Donnelly & U. Kilkelly, *supra* note 310.

³³³ *Ibidem supra* note 265, p. 65. See articles 3-2, 5, 7-1, 9, 10, 14-2, 18, 19, 20-3, 26-2, 27, 29-2 and 40-2.

³³⁴ K.L. Hanson, 'Is insurance for children enough? The link between parents' and children's health care use revisited', *Inquiry* (a journal of medical care organization, provision and financing) 1998, Volume 35, Issue 3, pp. 294-302.

decide whether and when a medical professional is contacted.³³⁵ The nutrition and health behaviour of the future mother is crucial in ensuring the healthy development of the foetus. When the child is born, the parents usually decide whether the child is breastfed, whether it receives healthy food and what choices are made with respect to the medical (non-)treatment of children. Even when excellent health facilities are available for children, negligent or over-burdened parents may postpone the decision to take their child to a doctor (see also the discussion on General Comment 13 in paragraph 5). For example, in a family with many (young) children in need of supervision, a single-parent may have great difficulties in reaching a doctor when the clinic is far away or when the family does not have a proper health insurance. On the other hand, situations in which parents make their children go to medical doctors more often than is beneficial to them also exist, as is the case with the Munchhausen by-proxy-syndrome, possibly resulting in unnecessary medical treatments and physical harm.³³⁶ Others refuse to immunize their children against the common childhood diseases.³³⁷ Whereas the particular role of mothers in ensuring their children's health is emphasized in article 24-1d and in article 12 of the Convention on the Elimination of All forms of Discrimination against Women on the basis of the intrinsic physical relationship during and after the pregnancy period, there is less attention for the influence of the daily health behaviour of both mothers and fathers on the health of their children.

In addition to the consequences of parents' decisions on their children's health, they also play a very important role in stimulating healthy behaviour of their children by daily providing examples of healthy behaviour and ensuring safety and good sanitary conditions in the living environment. The daily examples of parents' healthy behaviour, such as consumption patterns, sleep, amount and intensity of exercise and relaxation, sun-bathing, hygiene, smoking, alcohol and drug use, violent behaviour, work-related stress and time spent together with the family are important indicators in predicting their children's (future) health

³³⁵ 'De vrijheid en waardigheid van de zwangere vrouw en het ongeboren kind. Een gezondheidsrechtelijk dilemma' in: *Grondrechten in de gezondheidszorg*, Liber Amicorum voor prof. Mr. J.K.M. Gevers, onder redactie van A.C. Hendriks et al., Houten: Uitgeverij Bohn Stafleu van Loghum 2010, p. 6.

³³⁶ See for more information on this classified form of child maltreatment for example Medlineplus encyclopedia, available at: www.nlm.nih.gov/medlineplus/ency/article/001555.htm.

³³⁷ D.S. Diekema, 'Responding to Parental Refusals of Immunization of Children', *Pediatrics* 2005, Volume 115, Number 5, May, p. 1428-1431. Available at: <http://aappolicy.aappublications.org/cgi/reprint/pediatrics;115/5/1428.pdf>.

behaviour.^{338, 339, 340, 341, 342, 343} Especially for boys, the health behaviour of their fathers is a direct example for their own future health behaviour. These examples show that health is a living reality: notwithstanding the normative rules that parents like to abide by, their daily health behaviour of both mothers and fathers is crucial in guiding their children towards a healthy future.

The important role of parents in ensuring children's right to the highest attainable standard of health is reflected in the dominant role attributed to parents under article 24-2 e and f CRC in the prevention of health problems. Therein, explicated is that all segments of the society, *in particular parents and children*, must be 'informed, have access to education and be supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene, environmental sanitation and the prevention of accidents'. In sub f, it is propagated that preventive health care, guidance for parents and family planning education and services must be developed. As is made clear from the focus on basic health knowledge on child health, the empowerment of both parent and children through the provisions of health education is an essential building block in realizing children's right to the highest attainable standard of health. In doing so, parents are in a direct position to promote, support and enhance their children's health.

Based on the interdependence of the CRC articles, measures for health protection must be specifically tailored for different age groups, such as infants, small children and adolescent youth, taking into account the evolving capacities of the child (art. 5 CRC). Article 5 CRC also mentions the role of parents in providing for appropriate direction and guidance in the exercise of children's rights. In accordance with this provision, parents have to continuously adjust the ways in which they guide and direct their children as required by their continuous growth and development.

The role of parents as a possible barrier to realizing the right to the highest attainable standard of health of the child is especially relevant to children in early childhood, as they are entirely dependent on the care of their parents. For

³³⁸ S.T. Borra and others, 'Developing health messages: Qualitative studies with children, parents, and teachers help identify communications opportunities for healthy lifestyles and the prevention of obesity', *Journal of the America Dietetic Association* 2003, Volume 103, Issue 6, June, pp. 721-728.

³³⁹ S.J.H. Biddle, 'Health-enhancing physical activity and sedentary behavior in children and adolescents', *Journal of Sports Sciences* 2004, Volume 22, Issue 8, pp. 679-701.

³⁴⁰ R.L. Repetti and others, 'Risky Families: Family Social Environments and the Mental and Physical Health of Offspring', *Psychological Bulletin* 2002, Volume 128, Number 2, pp. 330-366.

³⁴¹ M. Okada and others, 'Influence of parents' oral health behaviour on oral health status of their school children: an exploratory study employing a causal modelling technique', *International Journal of Paediatric Dentistry* 2002, volume 12, number 2, March, pp. 101-108.

³⁴² C.L. Perry, 'Parent involvement with children's health promotion: the Minnesota Home Team', *American Journal of Public Health* 1988, Volume 78, Issue 9, pp. 1156-1160.

³⁴³ S. Golombok, *Parenting, what really counts?*, London: Routledge 2000.

example, when a baby has high fever, it is up to the parents or primary caretaker to assess whether and with what urgency it is necessary to contact a doctor.

In the implementation guide on General Comment 7 on the rights of children in early childhood provided by UNICEF and the Bernard van Leer Foundation,³⁴⁴ the implementation of child rights in early childhood is directly linked to the rights of families, being divided in several subsequent steps. The first step in realizing children's right to health is the necessary support and advice to the pregnant mother, ensuring healthy behaviour during pregnancy (nutritious food, no smoking, alcohol and drug consumption, stress etc.). The second step entails the conduct of childbirth, highly impacting upon the possible development of health problems resulting from birth complications and also upon the building of a loving mother-child relationship from the very beginning of a child's life. The third step underlines the importance of family-centred care, particularly when children need neonatal or intensive care and the provision of information and support to young parents on breastfeeding, vaccination programs, healthy nutrition and other preventive health measures. Last but not least, the well-functioning of child-friendly health facilities during the entire childhood is required.

Whereas parents (article 5 CRC) and at a certain age children themselves have the primary responsibility to ensure adequate conditions of living, the State has to provide additional assistance and support with regard to nutrition, clothing and housing and the State is also responsible for the establishment of preventive, curative and rehabilitative health care policies, institutions and measures.³⁴⁵ Furthermore, whereas parents are not directly bound by international human rights treaties, States Parties are required to adopt national legislation and measures to ensure the fulfilment of the provisions of the human rights treaties they are party to. The legal relation between parents and States has as such been beautifully interpreted as 'parents have a wide, but not unlimited margin of appreciation *vis-à-vis* the State concerning the ways to implement their responsibility towards the child.'³⁴⁶

A common avenue for States to fulfil its *secondary* responsibility to ensure children's right to health is by providing adequate health and social insurances and taking other measures to ensure an adequate standard of living. Furthermore, several examples can be given in which the State may take over the role of parents in taking care of the child, for example when disputing parents do not give permission for a medical treatment or when overanxious or attention seeking parents try to have their children examined more often or more vigorously than

³⁴⁴ 'A Guide to General Comment 7: Implementing Child Rights in Early Childhood', produced by Bernard van Leer Foundation and UNICEF, 2006, p. 75.

³⁴⁵ Ibidem supra note 215, p. 6.

³⁴⁶ A. Eide, 'Article 27: The Right to an Adequate Standard of Living', in Series: *A CRC Commentary on the United Nations Convention on the Rights of the Child*, Leiden: Martinus Nijhoff Publishers 2006, § 50.

is beneficial for them. In cases of child maltreatment, the State may need to step in the place of the parents or in more extreme cases even protect the child against the parents. However, conflicts may arise when parents and doctors disagree over the need to perform a potentially life-saving treatment on a child. It has been established that patients and their family often face a big challenge in refusing medical treatments not being in line with the usual practice in highly organized and technical medical institutions. It is important to ensure that both children and their parents are given the opportunity to express their views in medical decision-making and that these views are seriously considered. It would be highly counterproductive and ethically wrong if States take over the responsibility for children if parents do not act in accordance with standard medical practices. As laid down in article 18 CRC, parents have the primary responsibility over their children and only in exceptional circumstances should this be replaced by the State.

In summary, under article 24 CRC, parents (or other caretakers) have the primary responsibility to ensure the right to health of their children, whereas States must ensure the necessary health infrastructure to enable parents to take this responsibility. Only in exceptional circumstances; when parents neglect or abuse their children, when children do not have parents or when parents are incapable of taking good care of their children (for example when they are severely ill or severely and acutely injured) may the State (temporarily) take over this parental role for the children. Well-established legislation and criteria must be in place to avoid any instances of arbitrary decisions.

2.4.7. ARTICLES 26 & 27: SOCIAL SECURITY AND AN ADEQUATE STANDARD OF LIVING

The role of the family in ensuring the right to the highest attainable standard of health of the child is central to the implementation of articles 26 and 27 of the Children's Rights Convention. Articles 26 and 27 CRC ensure that the child benefits from social security, including social insurance and to an adequate standard of living for the child's physical, mental, spiritual, moral and social development. Social security plays a crucial part in ensuring children's right to have (financial) access to health.³⁴⁷ Therefore, this right it is categorized in the Reporting Guidelines in the cluster on basic health and welfare.³⁴⁸ As such, it has been mainly applied in an instrumental way, being required to fulfil other rights

³⁴⁷ Research Report by UNICEF, Defence for Children and Pharos, 'Undocumented children and access to hospital health care', June 2010.

³⁴⁸ UN Office of the High Commissioner for Human Rights, *Manual on Human Rights Reporting Under Six Major International Human Rights Instruments*, 1997, HR/PUB/91/1 (Rev.1), p. 406. available at: www.unhcr.org/refworld/docid/428085252.html.

in the CRC, such as the right to health.³⁴⁹ The Committee has even insisted that an adequate social security system particularly has to improve access to health care and health insurance for children.³⁵⁰ If possible, a social security system should lead to a reduction of the costs of health care or even establish free access to health services for children.³⁵¹

Delineation of the two rights in article 26 and 27 is sometimes difficult, but it has been suggested that the right to social security as laid down in article 26 CRC can be the avenue for guaranteeing the right to an adequate standard of living in article 27 CRC.³⁵² Furthermore, when read in conjunction with other human rights provisions on social security, article 26 constitutes a more concrete protection in practice than the more vague phrasing of ‘the adequate standard of living’.^{353, 354, 355}

Article 26 CRC elaborates that children have the right to *benefit from* social security.³⁵⁶ Whereas the definition entails a result obligation, namely that the child should actually benefit from the social security granted to his family or legal guardian, this does not directly imply that the child has the right to have a social insurance in its own right. The question then is what this provision means for children without families or other responsible caretakers, for children whose parents are not or not sufficiently insured or for children whose parents or other caretakers are not aware or who do not make an appeal on the social security necessary for the medical treatment of their children. In these situations, children may not be able to (indirectly) benefit from their parents’ or caretakers’ social insurance.

Paragraph 2 of article 26 CRC gives more insight in these more complicated situations, by stating that the application can be made *by or on behalf* of the child. This phrasing indicates that the child does also have a right to social security when his parents or legal representatives do not apply for him or when they use

³⁴⁹ U.N. Doc. CRC/GC/2003/3, General Comment 3 on HIV/AIDS and the rights of the child, 17 March 2003, § 6.

³⁵⁰ U.N. Doc. CRC/C/15/Add.174, 2002, § 54d; CRC Committee Concluding Observations on Malawi. See also: W. Vandenhole, ‘The right to benefit from social security’, in the Series: *A Commentary on the United Nations Convention on the Rights of the Child*, Leiden: Martinus Nijhoff Publishers 2007, p. 41.

³⁵¹ U.N. Doc. CRC/C/15/Add.171, 2002, § 52c; CRC Committee Concluding Observations on Gabon. See also Vandenhole, p. 41.

³⁵² *Ibidem supra* note 350 Vandenhole, p. 1.

³⁵³ See for example article 25(1) of the UDHR 1948, referring to an adequate standard of living for ‘himself and his family’ and to the right to social security in case of sickness or disability (amongst others).

³⁵⁴ See also article 3 CERD, guaranteeing the enjoyment of social security, notably in the enjoyment of the right to public health, medical care and social security. Article 10(2) CERD offers special protection for pregnant and lactating mothers.

³⁵⁵ The 1952 ILO Social Security Convention Number 102 covers nine predominant social risks, among which health care, sickness benefit, family benefit, maternity benefit, invalidity benefit and survivor’s benefit.

³⁵⁶ *Ibidem supra* note 202, p. 461. See also *Travaux préparatoires* U.N. Doc. E/CN.4/1984/71, 1984, § 81.

it for other purposes than the maintenance of the child. It may even imply that children do have the right to apply for social security. This also derives from the request of the CRC Committee to States in its General Reporting Guidelines to specify in what circumstances ‘children are allowed to apply for social security measures either directly or through a representative’.³⁵⁷ The Dutch reservation to article 26 that children do not have an independent entitlement to social security indicates that a possible interpretation of article 26 does entail such an independent entitlement for children.³⁵⁸

For vulnerable groups of children, especially those without parents, such as street children, internally displaced children, refugee and asylum-seeking children, an adequate social security system could be very beneficial in providing access to health care and in cases even in preventing them from becoming extremely vulnerable.³⁵⁹ The CRC Committee refers to this idea in General Comment 9 on children with disabilities.³⁶⁰ It elaborates that it vulnerable children should be informed about the existence of such a system of social security and of the way in which they can apply for benefits. Furthermore, the way in which such information is provided plays a crucial role in the actual efforts that people make to get health care. It has been found in the Netherlands, that even when financial compensation for health care is available for undocumented health care seekers, the way in which bills are handled and communicated by service desks and health care professionals may constitute a significant barrier to seeking adequate health care.³⁶¹ This could lead to a situation wherein social security for having access to primary health care is available, though not being used. Therefore, States are recommended to ensure that the system of social security is transparent and that it is clear for families and their children how they can apply for social security benefits.³⁶²

When article 26 CRC is read in conjunction with article 4 CRC it appears that children’s right to benefit from social security must be achieved progressively. In progressively developing this system, the need for cost-sharing between all different beneficiaries is highlighted, aiming to ensure that all disadvantaged population groups are included. The CRC Committee has highlighted (the risk of) exclusion of female-headed households,³⁶³ non-working parents,³⁶⁴ children

³⁵⁷ U.N. Doc. CRC/C/58/Rev.1, 2005, § 100.

³⁵⁸ Ibidem supra note 350, Vandenhole, p. 14.

³⁵⁹ Ibidem supra note 350, Vandenhole, p. 13.

³⁶⁰ U.N. Doc. CRC/C/GC/9, GC 9: The rights of children with disabilities, 27 February 2007, § 20.

³⁶¹ S.E. Duijs, ‘Het recht op zorg én de plicht om te betalen’, *Dokters van de Wereld*, July 2010.

³⁶² U.N. Doc. CRC/C/15/Add.192, 2002, § 40b, CRC Committee Concluding Observations on Moldova. See also supra note 350, Vandenhole, p. 39.

³⁶³ U.N. Doc. CRC/C/TTO/CO/2, 2006, § 57–58; CRC Committee Concluding Observations on Trinidad and Tobago. See also supra note 350, Vandenhole, p. 31.

³⁶⁴ U.N. Doc. CRC/C/15/Add.217, 2003, § 59; CRC Committee Concluding Observations on Pakistan and U.N. Doc. CRC/C/MEX/CO/3, 2006, § 54; CRC Committee Concluding Observations on Mexico. See also supra note 350, Vandenhole, p. 31.

with temporary residence permits³⁶⁵ amongst others and aims to achieve universal social security coverage of all children and their families.³⁶⁶ Measures to enlarge the amount of children reached by social security systems are therefore encouraged.³⁶⁷ All possible discrimination grounds for having access to social security must be eliminated.³⁶⁸ This is explicitly stated for children residing on the territory of a State without having a (permanent) residence permit, suggesting that this is also the case for illegally residing children.³⁶⁹

Article 27 CRC recognizes the child's right to an adequate standard of living to ensure the child's full and harmonious development, including at the physical, mental, spiritual, moral and social levels.³⁷⁰ It elaborates on article 6 CRC, confirming the child's right to survival and development. The standard of living must be ensured by healthy nutrition, adequate clothing and housing. Here again, the primary responsibility for providing for such a standard of living is attributed to the parents, who have a common responsibility to take care of their children (article 18 CRC). However, the responsibility of parents for the upbringing of their children is required 'within the limits of their abilities and financial capacities'. This phrasing leads to a situation in which the realization of children's right to health is dependent upon their parents, whereas the living conditions differ enormously between and within countries to an extent that is not always within the reach of parents or caretakers. Even good-willing parents may have limited (financial) means, resources and sufficient time available to ensure an adequate standard of living for (all of) their children.

Furthermore, the type and quality of care provided is dependent on the composition of the family in which a child lives, such as a single-parent family, a family with many children or even child-headed households.³⁷¹ Therefore, to ensure a certain minimum level of living, States have the duty to provide assistance to parents in addition to the primary role of parents themselves; on the basis of article 18 paragraph 2, States Parties have the duty 'to render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children'.

The involvement of both parents and the State leads to the question where the demarcation line lies; under article 27 CRC States have the duty to intervene, but at the same time they must respect the rights of parents in raising their own

³⁶⁵ U.N. Doc. CRC/C/15/Add.268, 2005, § 64, CRC Committee Concluding Observations on Australia, *Ibidem supra* note 350, Vandenhole, p. 31.

³⁶⁶ *Ibidem supra* note 350, Vandenhole, p. 31.

³⁶⁷ U.N. Doc. CRC/C/15/Add.172, 2002, § 55; CRC Committee Concluding Observations on Mozambique, *Ibidem supra* note 350, Vandenhole, p. 32.

³⁶⁸ *Ibidem supra* note 350, Vandenhole, p. 32.

³⁶⁹ U.N. Doc. CRC/C/15/Add.167, 2001, § 53; CRC Committee Concluding Observations on Uzbekistan. *Ibidem supra* note 350, Vandenhole, p. 34.

³⁷⁰ *Ibidem supra* note 202, p. 462.

³⁷¹ *Ibidem supra* note 346 Eide, § 11 and 12.

children. In the CRC Commentary on article 27 it is elaborated that children can make a claim in first instance upon their parents for ensuring an adequate standard of living and in the second place on the State.³⁷² Parents are primarily responsible for the daily care of their children: nurturing and dressing them, taking them to school, to bed, to the doctor or the dentist. Families are defined by the CRC as 'a family refers to a variety of arrangements that can provide young children's care, nurturance and development, including nuclear family, extended family and other traditional and modern community-based arrangements', provided these are consistent with children's rights and best interests.³⁷³ Important in such arrangements, is that there should be no distinction between biological children and other, adopted or foster children.³⁷⁴ It must also be acknowledged that reality is much more complex than the ideal type family of two parents living together with their children.³⁷⁵ There exist great variations in family arrangements in rural or urban environments and the role of the family is changing towards different compositions.

It is important to acknowledge (article 18-1) that the primary responsibility of parents to care for their children must be shared between both the father and the mother.³⁷⁶ All parents or caretakers involved, including adoptive parents, separated parents and foster parents, have the same responsibilities as the natural parents (article 21 CRC). This also requires that children are legally recognized by both of their parents and that they receive a birth certificate that will guarantee access to maintenance by the parents and receive primary health care for the child.³⁷⁷ Illegitimacy should not be a barrier to receive such access, not when children are born outside a marriage, outside the borders of their country of origin or conceived in a one-night stand or with single, marginalized women.³⁷⁸

The obligations of the State in ensuring an adequate standard of life for children can be divided into the obligation to *respect* the primary responsibility of the parents to raise their children, the obligation to *protect* the rights of the child if the parents neglect it or do not sufficiently fulfil their responsibility and thirdly, the obligation to fulfil the child's right to an adequate standard of living – especially if the parents don't or when the child does not have parents.³⁷⁹

The obligation to fulfil can be achieved directly or indirectly through the support of parents by subsidizing or providing (cost free) youth health care institutions, water and sewage systems, emergency care, housing and nutrition, if so required, accessible social insurances and by adopting legislation to ensure

³⁷² Ibidem supra note 346 Eide, §. 5.

³⁷³ U.N. Doc./CRC/GC2005/7, 2005, CRC Committee General Comment No.7: Implementing child rights in early childhood, § 15.

³⁷⁴ Ibidem supra note 346 Eide, § 55.

³⁷⁵ Ibidem supra note 346 Eide, § 68.

³⁷⁶ See also article 5 of the CEDAW.

³⁷⁷ Ibidem supra note 346 Eide, § 92–94.

³⁷⁸ Ibidem supra note 346 Eide, § 94.

³⁷⁹ Ibidem supra note 346 Eide, §. 6 and 7.

universal access for all children, including those marginalized and belonging to social minorities. In principle, parents are responsible for ensuring their children's right to have a standard of living and the State must ensure the required infrastructure to enable parents to fulfil this right. States are furthermore responsible to address the large scale consequences of societal problems, affecting children's right to health and standards of living on a large scale such as corruption, natural disasters and situations of violence.

The scope of the right to an adequate standard of living is phrased in article 27 CRC (2 and 3) mentioning 'the conditions of living necessary for the child's development' and 'the provision of support programs particularly with regard to nutrition, clothing and housing'. No particular mention is made of health care. However, in explanations of the separate elements of the right to an adequate standard of living by the CESCR, reference was made to its connection to the right to health.³⁸⁰ For example with regard to the right to *adequate* housing, it is elaborated that houses must not be built on polluted sites or in proximity to pollution sources that threaten the health of the inhabitants. More importantly in relation to the realization of the right to the highest attainable standard of health of the child is the specification that housing must be in a location that allows for access to health care facilities.³⁸¹

Another link between the right to an adequate standard of living and the right to health is found in the provision of breastfeeding. Nutritious food must be economically and physically accessible and culturally appropriate. This allows for the adoption of national guidelines and policies to adjust the work environment for lactating women. Another example is the duty of the State to assist parents to reconcile their responsibilities as parents and as employees,³⁸² because many parents are dependent on their daily work to be able to provide their children with an adequate standard of living.

2.4.8. PARTIAL CONCLUSION

The CRC provision on children's right to health has a clear focus on prevention of health problems and on ensuring basic health care for all children. Key elements are the prevention of infant and child mortality by providing for the underlying determinants of health and necessary health care, including emergency care, perinatal care and preferably also including primary health care for all and for ensuring coverage of all children by immunization programs. On the basis of articles 6 and 24 CRC the health services must be continuous and adapted to the changing circumstances in which children live. Also, starting from the concept of

³⁸⁰ U.N. Doc. E/1992/23, 1994, CESCR Committee, General comment No. 4: The right to adequate housing, § 41.

³⁸¹ Ibidem supra note 380, § 8d and f.

³⁸² Ibidem supra note 346 Eide, § 79.

children's evolving capacities in article 5 CRC, services must be responsive to the changing needs of children. Therefore, four levels of priority have been identified in the organization of health care for young children:

1. Provision of health care and information to the mother during pregnancy.
2. Obstetric health care around the birth of the child.
3. Neonatal health care for the mother and the child immediately after birth.
4. Quality health care during childhood.

In order to realize these key elements, measures must be taken to prevent children from being excluded from the health services and from the underlying determinants of health being provided. Secondly, in shaping the way in which health services are organized, the best interests of the child as a child in its own social context must be leading and not only the interests of the child as a sick person. This means that the right to the highest attainable standard of health not only encompasses the provision of health services, but it also requires to take into account children's needs in other aspects of their daily life, such as the continuation of school and leisure activities, contacts with family and friends and support for both the child and its family members in dealing with the consequences of a diagnosis for the daily life and future perspectives of the child. To meet the needs of the individual child, it is required to involve both children and their parents in the identification of the child's particular needs in healthcare and in other areas of life.

To enable the child and its parents to be involved in the selection of medical treatments, quality and age-adjusted health information must be provided. This includes information on medical decision making at the individual level and the provision of preventive health information to all parents and children. While the provision of health information is required, it is also required to maintain confidentiality and provide for confidential counselling for children of all ages. The CRC Committee has underlined that the obligation to inform and involve people in children's health must also be realized *vis-à-vis* very young children, because they are considered as rights holders from the very beginning of their lives. Stimulating children to become involved in their own health care from the very beginning gradually enhances their capacities to take ownership of their own health during the rest of their lives. Simply listening to children is not sufficient. Feedback must be given on what has been done with their input. Although adapted to the level of comprehension of the child, adults must respect children's views and communicate with children as equal partners. It is important to realize that disagreement with children does not justify the setting aside of their views. It may even be required to accept children's views that are highly contested.

The next paragraph will further investigate the elaboration and implications of the right to the highest attainable standard of health of the child and the respective role of parents and the State in ensuring this by the Committee on the

Rights of the Child as found in the relevant General Comments. The last paragraph will then discuss the implications of this legal framework for the work of medical professionals by taking the medical ethical framework as a point of reference for integrating the right to health of the child in the daily medical practice.

2.5. INTERPRETATION OF THE CHILD’S RIGHT TO HEALTH IN THE GENERAL COMMENTS

The UN Committee on the Rights of the Child regularly issues General Comments (GC) in which an interpretation is given of the content of children’s rights provisions. Specifically related to the right to health are GC no. 3 on ‘HIV/AIDS and the right of the child’³⁸³ and GC no. 4 on ‘adolescent health’³⁸⁴ and GC 15 on the right of the child to enjoy the highest attainable standard of health.³⁸⁵ Other GC’s contain passages referring to the right of the child to health in a particular context. For example, GC no. 10 contains a very brief reference to the right of juveniles to be examined by a physician on admission to an institution and to receive adequate medical care from the regular community health services during their stay in the institution.³⁸⁶ Also, GC no. 13 indicates that the right of the child to be free from all forms of violence is necessary to achieve good physical and mental health.³⁸⁷ In the following, further insight will be provided in the elaboration of the right to the highest attainable standard of health in the General Comments of the Committee on the Rights of the Child. Particular attention is paid to the right to health of children in their early childhood.

2.5.1. GENERAL COMMENT 3: HIV/AIDS AND THE RIGHTS OF THE CHILD

GC no. 3 on the prevention of HIV/AIDS draws attention to the fact that children are extremely vulnerable to infection. The majority of infections occur among adolescents and young people (15–24). Also, because of a lack of information on the prevention of AIDS among women, their children become unknowingly

³⁸³ U.N. Doc. CRC/GC/2003/3, General Comment 3 on HIV/AIDS and the rights of the child, 17 March 2003.

³⁸⁴ U.N. Doc. CRC/GC/2003/4, General Comment 4 on Adolescent health and development in the context of the Convention on the Rights of the Child, 1 July 2003.

³⁸⁵ U.N. Doc. CRC/C/GC/2013/15, General Comment 15 on the Right of the Child to the Highest Attainable Standard of Health, 17 April 2013.

³⁸⁶ U.N. Doc. CRC/C/GC/10, General Comment 10 on Children’s rights in juvenile justice, 25 April 2007, § 89, p. 23.

³⁸⁷ U.N. Doc. CRC/C/GC/13, General Comment 13 on the right of the child to be free from all forms of violence, 18 April 2011.

infected with HIV/AIDS, resulting in an increase in infant and child mortality ratios.

The Committee on the Rights of the Child has identified a large number of rights relevant to the prevention and treatment of HIV/AIDS among children and youth. Central to this is art. 24 CRC, but the Committee has stressed that the HIV/AIDS epidemic is more than a health problem. Other relevant CRC articles provide for further protection of children's health, including art. 9 (right not to be separated from parents), art. 16 (right to privacy), art. 17, 24-f and 28 (right to information and education, particularly on sexual health and family planning), art. 23 (rights of disabled children), art. 26 and 27 (right to an adequate standard of living and the right to social security, including health insurance) and art. 19 and 32–37 (right to protection against violence, abuse, abduction and sale, inhuman and degrading treatment). These provisions are particularly relevant in the context of the right to non-discrimination, as children infected with HIV/AIDS often suffer from stigmatization and a lack of access to health care. Several groups are mentioned to be particularly vulnerable to discrimination such as minority children, disabled children, orphaned children, children living on the street, children abusing drugs and children suffering from sexual exploitation.

The Committee sets several related priorities in the combatting of the HIV/AIDS epidemic, among which the access to age appropriate, child friendly information is considered essential to prevention, testing, counselling, treatment and care. The Committee stresses the importance of an open dialogue in families, schools and in the community to stimulate a positive and healthy attitude towards sexuality. These priorities correspond to article 24 CRC, particularly elaborating on sub 2a on the reduction of infant mortality, 2b on the right to access for children to health services. Sub 2d on pre- and postnatal health care and sub 3 on the importance of breastfeeding are reflected in an elaboration of the need for and the particular guidelines for breastfeeding in the case of an HIV infection of the mother and the prevention of mother-to-child-transmission.

In general, GC no. 3 on the prevention of HIV/AIDS among children aims to strengthen the understanding and promote the realization of all children's rights in the context of HIV/AIDS by promoting child-oriented laws, policies and programs.³⁸⁸

2.5.2. GENERAL COMMENT 4: ADOLESCENT HEALTH AND DEVELOPMENT

General Comment 4 elaborates upon a large number of health topics particularly relevant for adolescents.³⁸⁹ This General Comment is partly relevant for infants

³⁸⁸ Ibidem supra note 382, § 4.

³⁸⁹ Ibidem supra note 383, § 12, 23, 24.

and children as it addresses the prevention of teenage pregnancies and the need to support teenage mothers and their babies.

Much attention is drawn to the need to respect the views of the child and involve adolescents in their own health and development. Hereto, an elaboration is provided on the right to informed consent, privacy and confidentiality in the healthcare setting.³⁹⁰ In addition, adolescents must be given access to adequate information for health and development and participate meaningfully in society. It is stated that school programs must be targeted at the development of the child's fullest potential, that they should be given the skills to take good care of themselves, for example by cooking healthy meals, paying attention to hygiene, coping with stress and educating them about sexual and reproductive health to prevent sexually transmitted diseases and early pregnancies. No marketing activities are deemed allowed to promote unhealthy lifestyles.³⁹¹

Another important issue in General Comment 4 is the necessity to prevent violence to prevent health problems among adolescents. For example, it is stated that adolescents must be taught how to make decisions in a non-violent manner, that they should be involved in the development of programmes and measures to protect them against violence, abuse, neglect and exploitation and that adolescents must be raised in a safe and supportive environment and be given the opportunity to discuss (health) problems openly. Specific violence-related problems that must be targeted are violence in the family, interpersonal violence among peers, participation in gangs, the participation of child soldiers in armed conflicts, violence targeted at orphans and disabled children, harmful traditional practices and honour killings. Measures to be taken to prevent violence impacting on adolescents' health include the restriction of access to (light) weapons and to alcohol and drugs.

Several guidelines are given for the provision of health services for adolescents: qualitative services must be available, accessible and acceptable to vulnerable groups such as physically and mentally disabled children, homeless children, sexually exploited children, children with mental health problems, minority and indigenous children and former child soldiers.³⁹² For this last group, particular rehabilitation and reintegration services must be established.

In order to improve the health status of adolescents, a multi-sectorial approach is propagated, wherein linkages and partnerships are established between all relevant actors, including practitioners in public health and traditional health practices, pharmaceuticals, special organizations for vulnerable groups and international (UN) agencies and international NGOs.³⁹³

The empowerment of adolescents by providing with necessary health information is important for the prevention of health problems resulting from

³⁹⁰ Ibidem supra note 383, § 26–33.

³⁹¹ Ibidem supra note 383, § 17 & 25.

³⁹² Ibidem supra note 383, § 34–38.

³⁹³ Ibidem supra note 383, § 43.

sexually transmitted diseases, mental health problems, alcohol and drugs, injuries and violence. Educating adolescents about their sexual and reproductive health rights (SRHR) benefits young children, because it increases the age at which girls first become pregnant. This increases the chance that girls finish their education and obtain good jobs so that they can provide their children with quality care and food. Secondly, education on SRHR benefits young children because it influences the spacing between subsequent births. This in its turn influences the value of the care and nutrition given to the children.³⁹⁴

2.5.3. GENERAL COMMENT 7: CHILDREN'S RIGHTS IN EARLY CHILDHOOD

General Comment 7 particularly aims to contribute to the realization of children's rights in early childhood and 'to encourage recognition of young children as social actors from the beginning of life, with particular interests, capacities and vulnerabilities, and of requirements for protection, guidance and support in the exercise of their rights'.³⁹⁵ In an elaboration of the right to life (art. 6 CRC), State Parties are urged to improve perinatal care for mothers and babies, reduce infant and child mortality, and create conditions that promote the well-being of young children.³⁹⁶ Mention is made of the role of malnutrition and preventable diseases and the interaction between physical health and psychosocial wellbeing. Here again, the holistic approach to the enforcement of the right to health integrates the right to health and the right to adequate nutrition and a healthy and safe environment (art. 24-2c and 29 CRC). Explicit referral is made to the duty to empower young children to adopt a healthy and disease-preventing lifestyle. The notion to empower children to play an active role in their development has been further developed in General Comment 12 on the right to participation of the child.

The right to non-discrimination as elaborated in General Comment 7 assures that no child is refused access to health care (art. 24-2b). Explicit mention is made of disabled children, children infected with HIV/AIDS and girls, regularly suffering from selective abortion, infanticide, inadequate feeding in infancy and female genital mutilation. Vulnerable groups of children need extra attention to ensure their right to health, as they are more prone to health risks such as

³⁹⁴ For a further discussion on the advantages and disadvantages of birth spacing see for example the Report of a WHO Technical Consultation on Birth Spacing, Geneva, Switzerland, 13–15 June 2005, available at: www.who.int/maternal_child_adolescent/documents/birth_spacing.pdf.

³⁹⁵ U.N. Doc. CRC/C/GC/7/Rev.1, General Comment 7 on Child rights in early childhood, 20 September 2006, § 2.

³⁹⁶ *Ibidem* supra note 395, § 2.

malnutrition, infectious disease, injuries, abuse and neglect, substance abuse and unhealthy working conditions.

Among the comprehensive programs for young children is the provision to ensure health care.³⁹⁷ The highest attainable standard of health care must be ensured by States Parties in order to reduce infant mortality (art. 24-2a). This duty ranges from the provision of adequate drinking water, nutrition and sanitation to immunization campaigns, medical services and a stress-free environment. Education about healthy behaviour for both adults and children is also mentioned, including child-centred health education programmes. Finally, attention is drawn to the need for prevention of HIV/AIDS and early diagnosis, effective treatment and alternative forms of support for infected and orphaned children.

With respect to young children's capacities to engage in meaningful participation, the CRC Committee acknowledges in General Comment 7 that 'young children's agency – as a participant in family, community and society – is frequently overlooked or rejected as inappropriate on the grounds of age and immaturity.' They often suffer from social ideas that they first need training and socialization before they can make and communicate choices. Therefore, the Committee emphasizes that article 12 applies to younger children as much as it does to older children and that they are 'acutely sensitive to their surroundings and very rapidly acquire understanding of the people, places and routines in their lives, along with awareness of their own unique identity. They make choices and communicate their feelings, ideas and wishes in numerous ways, long before they are able to communicate through the conventions of spoken or written language.' Therefore, the CRC Committee underlines that the right to be heard of the child is implemented from the very earliest stage and that it must be fully integrated in the child's daily life, including in early childhood health.³⁹⁸

Parents play a crucial role in the realization of the rights of young children. Especially babies and toddlers are highly dependent on the good care of their parents or caretakers. However, they are not passive recipients of care and guidance, but they actively seek care, nurturance and direction and soon after their birth they recognize their parents. In this way, close relationships develop between children and their parents.³⁹⁹ In responding to their children's needs, parents must continuously adapt to the changing needs of their children. This should be seen as a positive and enabling process, in which parents are encouraged to provide guidance in a child-centred way. In that way, they are best able to enhance children's capacities to take increasing responsibilities for their own health. To enhance young children's opportunities to express themselves, parents and professionals must be stimulated to adopt a child-centred attitude, to listen patiently to children and respect their views and use creativity in 'adapting

³⁹⁷ Ibidem supra note 395, § 24.

³⁹⁸ Ibidem supra note 395, § 14b.

³⁹⁹ Ibidem supra note 395, § 16.

their expectations to the interests, levels of understanding and preferred ways of communication of young children.⁴⁰⁰

2.5.4. GENERAL COMMENT 9: THE RIGHTS OF CHILDREN WITH DISABILITIES

The Committee has stressed that disabled children have the right to an adequate standard of living, including adequate food, clothing and housing, and to the continuous improvement of their living conditions.⁴⁰¹ Adequate allocation of budgetary resources is recommended as well as ensuring that children with disabilities have access to social protection.⁴⁰² Herein, health is mentioned as a particular focus area to ensure maximum inclusion of children in society,⁴⁰³ further mentioning that care and assistance must be designed to ensure effective access to health services for disabled children. This means that special services are often required, whereas these necessary medical services must be integrated into the regular public health system for all children to reduce the risk of discrimination.⁴⁰⁴

In allocating the available financial means, the ultimate responsibility of the State to ensure the (physical) access of disabled children to health services is emphasized given the current developments of decentralization and privatization wherein private parties tend to take over or neglect this responsibility.⁴⁰⁵ In meeting this responsibility, States are encouraged to cooperate with international organizations such as UNICEF, the WHO and NGOs to ensure that they operate in full compliance with the convention.

Central in the approach to improve knowledge, skills and capabilities on the prevention and treatment of disabilities, is the recommendation to exchange information between countries.⁴⁰⁶ This can help to attain early identification of disabilities and enhance a community-supported approach to support families, as well as the systematic training of (medical) professionals working with children. Information must also be dispatched to the children and their families themselves, so that they are aware of causes, management and prognoses of their disabilities.⁴⁰⁷ The knowledge will also help to make informed medical decisions. Dependent on the type of disability, means of communication must therefore be adapted, for example by using Braille materials for blind children. Given the fact that disabled children often have multiple health issues, it is recommended to

⁴⁰⁰ Ibidem supra note 395, § 14c.

⁴⁰¹ U.N. Doc. CRC/C/GC/9, GC 9: The rights of children with disabilities, 27 February 2007, § 3.

⁴⁰² Ibidem supra note 401, § 20.

⁴⁰³ Ibidem supra note 401, § 11.

⁴⁰⁴ Ibidem supra note 401, § 52.

⁴⁰⁵ Ibidem supra note 401, § 59.

⁴⁰⁶ Ibidem supra note 401, § 22.

⁴⁰⁷ Ibidem supra note 401, § 37.

address the health issues in a team approach of professionals, such as neurologists, psychologists, psychiatrists, orthopaedic surgeons and physiotherapists.⁴⁰⁸

The identified causes of disabilities are multiple and prevention must therefore be targeted through different methods, including the prevention of inherited diseases due to consanguineous marriages, appropriate preconception testing, universal immunization campaigns to prevent communicable diseases causing disabilities, poor nutrition (e.g. blindness is caused by a Vitamin A deficiency), adequate assistance during delivery and the prevention of road accidents by traffic laws and guidelines on wearing safety belts.⁴⁰⁹ Education and support of pregnant women will be targeted to prevent disabilities such as the foetal alcohol syndrome due to alcohol or drug abuse. Policies to prevent dumping of hazardous materials and other means of polluting the environment, such as the prevention of radiation accidents must also be in place. Last but not least, the attention for prevention is drawn to the harmful effects of armed conflicts resulting from the massive spread of small arms and landmines.⁴¹⁰ The Committee recommends that laws and policies must be put in place to continue to locate and dismantle landmines, to keep children away from hazardous areas and to ensure access of affected children to rehabilitative health services.

With regard to the access of disabled children to health care, several aspects are predominant. In the first place, mention is made that disabled children are more vulnerable to non-registration at birth.⁴¹¹ This increases the risk that they become invisible to government officials and thereby are excluded from access to health services. Other barriers to effective access identified result from discrimination (disabilities are sometimes viewed upon as a bad omen), inaccessibility due to a lack of suitable information, necessary (extra) finances and physical access to health facilities. The requirement of physical access encompasses the need to ensure adequate means of transportation so that disabled children can actually reach health institutions.⁴¹² Recommended is therefore that health programs must be comprehensive and include early detection of disabilities, early intervention and rehabilitation measures (the provision of physical aids such as free of cost limb prostheses, mobility devices, hearing and visual aids).⁴¹³ Early detection and intervention require high awareness among parents, teachers and health personnel and an easy access of these services.⁴¹⁴

⁴⁰⁸ Ibidem supra note 401, § 58.

⁴⁰⁹ Ibidem supra note 401, § 53–54.

⁴¹⁰ Ibidem supra note 401, § 55.

⁴¹¹ Ibidem supra note 401, § 35.

⁴¹² Ibidem supra note 401, § 39.

⁴¹³ Ibidem supra note 401, § 51.

⁴¹⁴ Ibidem supra note 401, § 56.

2.5.5. GENERAL COMMENT 11: INDIGENOUS CHILDREN AND THEIR RIGHTS UNDER THE CONVENTION

Given the previously identified vulnerability of indigenous groups of children (see § 4), State Parties are urged to apply specific measures to ensure that indigenous children have access to culturally appropriate health services.⁴¹⁵ Central in this General Comment is the urge for respect for culturally sensitive and community based health services in the language of the indigenous children.⁴¹⁶ Particular attention is required to ensure access to health services for indigenous peoples who reside in rural and remote areas or in areas of armed conflict or who are migrant workers, refugees or displaced and for the culturally sensitive needs of disabled indigenous children.⁴¹⁷ Therefore, the Committee advocates that in the provision of health care, preference must be given to health care workers and medical staff from the indigenous community, as they could function as a bridge between traditional medicine and conventional medical services.⁴¹⁸ They should receive the necessary means and special training to fulfil this role in a way that is mindful of their culture and traditions.⁴¹⁹ This could also be effective in combating harmful traditional practices, furthermore supported by the implementation of laws and programs to change attitudes and address gender roles that contribute to these practices.⁴²⁰ To achieve these targets, States are stimulated to allocate additional financial and human resources to implement economic, social and cultural rights and where necessary seek help from the international community.⁴²¹

2.5.6. GENERAL COMMENT 12: THE RIGHT OF THE CHILD TO BE HEARD

The right of the child to be heard has been elaborated specifically for application in the health care sector.⁴²² It applies both to individual health decisions and to children's involvement in the development of health policy and services. This extends to the determination of the services needed, how and where they are best provided, the identification of discriminatory barriers to and attitudes of

⁴¹⁵ Ibidem supra note 245, § 25.

⁴¹⁶ Ibidem supra note 245, § 51.

⁴¹⁷ Idem, supra note 245.

⁴¹⁸ Ibidem supra note 245, § 52.

⁴¹⁹ In this context, the Committee recalls article 25(2) of the ILO Convention No. 169 and articles 24 and 31 of the United Nations Declaration on the Rights of Indigenous Peoples on the right of indigenous peoples to their traditional medicines, A/RES/61/295, Articles 24, 31.

⁴²⁰ Ibidem supra note 245, § 7.

⁴²¹ Ibidem supra note 245, § 34.

⁴²² U.N. Doc. CRC/C/GC/12 on the Rights of the Child to be heard, 20 July 2009, § 98–104.

professionals to have access to health care and the elaboration of ways to best involve children of different ages.⁴²³

In order to be able to engage in meaningful ways of participation, children must be provided with understandable information (art. 17 CRC) about proposed treatments, their (side-)effects and outcome in a manner consistent with their evolving capacities (art. 5 CRC). In fulfilling the right to information the Committee on the Rights of the Child states that States must ensure confidentiality. This right to confidential information and counselling applies to all children, irrespective of their age and maturity. It must therefore be distinguished from the right to informed consent, which usually has a certain age threshold beyond which children have the right to independent consent or refusal to any medical treatment without the approval of their parents and without an assessment of their capacities.

Often the criticism is made that the capacities of very young children are too limited to engage in meaningful participation. However, the CRC Committee has explicitly rejected this standpoint in its considerations on the right of children in their early childhood to be heard in all matters and procedures affecting them. The basis of its argumentation is that children should be approached as rights-holders from the very beginning of their lives and that ‘young children should be recognized as active members of families, communities and societies, with their own concerns, interests and points of view’.⁴²⁴

The CRC Committee considers that ‘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’, even ‘if the child is not yet able to verbally express itself’.⁴²⁵

While the CRC Committee discourages States to introduce age limits in its national legislation, it explains the concept of children’s evolving capacities as an obligation for States to ‘assess the capacity of the child to form an autonomous opinion to the greatest extent possible’.⁴²⁶ Particularly, this requires the ‘recognition of, and respect for, non-verbal forms of communication including play, body language, facial expressions, and drawing and painting, through which very young children demonstrate understanding, choices and preferences.’⁴²⁷

The CRC Committee furthermore considers that children don’t need to have a comprehensive understanding of all aspects of the matter affecting them; they only need to have ‘sufficient understanding to be capable of appropriately forming her or his own views on the matter’.⁴²⁸ States Parties are under the obligation to ensure that children have the required modes of communication at their disposal

⁴²³ Ibidem supra note 422, § 104.

⁴²⁴ Ibidem supra note 422, § 21.

⁴²⁵ Ibidem supra note 422, § 20–21.

⁴²⁶ Ibidem supra note 422, § 20.

⁴²⁷ Ibidem supra note 422, § 21.

⁴²⁸ Ibidem supra note 422, § 21.

to express their views and that all measures need to be in place to protect children from manipulation or pressure or in expressing their views and that they should not be interviewed too often.⁴²⁹ The CRC Committee particularly warns for the potentially negative consequences of inconsiderate practices in (not) hearing young children, especially on sensitive issues.⁴³⁰

Simply listening to children is not sufficient.⁴³¹ Their views must be seriously considered and feedback must be given on the ways in which children's views were weighed.⁴³² This must be done by a case-by-case examination, because different levels of information, experience, levels of support and social and cultural expectations all influence the capacities of children to form its own views.⁴³³

In principle, in assessing children's evolving capacities, States Parties shall also respect the responsibilities, rights and duties of parents, legal guardians, or members of the extended family or community to give direction and guidance to the child in her or his exercise of its rights'. In this way, the lack of knowledge or experience of the child is compensated by the guiding of its parents or caretakers.⁴³⁴ Whereas children should be approached as rights holders from the very beginning, their responsibilities increase as they grow older and mature.

2.5.7. GENERAL COMMENT 13: THE RIGHT OF THE CHILD TO FREEDOM OF ALL FORMS OF VIOLENCE

General Comment 13 focuses on the protection of children against all forms of violence.⁴³⁵ The Committee has considered that the extent and intensity of violence against children is alarming, violence being defined as 'all forms of physical and mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including abuse' as phrased in article 19-1 CRC and in conformity with the terminology as used in the 2006 UN Study on Violence against Children.⁴³⁶ Whereas the Committee recognizes that families have the greatest potential to protect children,⁴³⁷ it is acknowledged that the majority of violence takes place in the context of (extended) families so that intervention and support may therefore be required when children become victims of domestic violence or when violence is imposed upon families as a whole. Furthermore, the

⁴²⁹ Ibidem supra note 422, § 21.

⁴³⁰ Ibidem supra note 422, § 21.

⁴³¹ Ibidem supra note 422, § 28.

⁴³² Ibidem supra note 422, § 45.

⁴³³ Ibidem supra note 422, § 29.

⁴³⁴ Ibidem supra note 422, § 84.

⁴³⁵ U.N. Doc. CRC/C/GC/13 on Article 19: The right of the child to freedom from all forms of violence, 17 February 2011.

⁴³⁶ Ibidem supra note 435, § 3 and U.N. Doc. A/61/299, Report of the independent expert for the United Nations study on violence against children, 29 August 2006.

⁴³⁷ Ibidem supra note 435, § 65d.

public health sector is identified as having a significant role to play in the primary prevention of violence and in providing for recovery and social reintegration services.⁴³⁸ The 2006 UN Study on Violence against Children comes to a similar recommendation to provide for recovery and social reintegration services in calling for accessible, child-sensitive and universal health and social services, including pre-hospital and emergency care for children and their families.⁴³⁹

The impact of violence on children's (right to) health is elaborated in General Comment 13. In the first place, securing well-being, health and development of the child is identified as the ultimate goal of child care and protection.⁴⁴⁰ From this central premise, both the short and the long-term health consequences of violence on children's survival and development, as protected under article 27-1 CRC, are specified, including fatal injury and non-fatal injury, possibly leading to disabilities, physical health problems such as failure to thrive, lung, heart and liver problems, sexually transmitted diseases, mental health problems and health-risk behaviours.⁴⁴¹ In the explanation of the Committee on the Rights of the Child on the different forms of child maltreatment, several aspects relate to the impact of violence on children's health. For example, the Committee elaborates that neglect includes the failure to meet children's physical and psychological needs, such as basic necessities like food, water, clothing and essential medical care and failure to obtain medical and birth registration necessary to have access to health services.⁴⁴² It is further exemplified that physical violence, including corporal punishment and harmful traditional practices may lead to fatal or non-fatal injuries, possibly leading to lifelong physical and psychological harm, requiring medical care and recovery.⁴⁴³ This is particularly true for forced sterilisations (often inflicted upon disabled children), deliberate infliction of disabilities for the purpose of exploitation by begging on the streets, violence in the guise of treatment (electroconvulsive therapy to control children's behaviour), female genital mutilations, amputations, burning, scarring, binding and branding, force-feeding, virginity testing, exorcism of children accused of witchcraft, uvulectomy and teeth extractions.⁴⁴⁴ Self-harm, including eating disorders and substance abuse, automutilation and suicidal thoughts, attempts and suicides also result in violations of children's right to health.⁴⁴⁵ Failure to protect children against the different kinds of violence, including a lack of supervision, is qualified as neglect.⁴⁴⁶ On the societal level, both direct and indirect costs are identified,

⁴³⁸ Ibidem supra note 435, § 2 and § 38.

⁴³⁹ A/61/299, Report of the independent expert for the United Nations study on violence against children, 29 August 2006, p. 26.

⁴⁴⁰ Ibidem supra note 435, § 17 and 52.

⁴⁴¹ Ibidem supra note 435, § 14.

⁴⁴² Ibidem supra note 435, § 19.

⁴⁴³ Ibidem supra note 435, § 24.

⁴⁴⁴ Ibidem supra note 435, § 21–27.

⁴⁴⁵ Ibidem supra note 435, § 26.

⁴⁴⁶ Ibidem supra note 435, § 19.

including the costs of necessary medical care, social services and alternative care and social problems resulting from disabilities.

While the range of possible violations impacting upon children's right to health is broad and diverse, it is important to identify who can be held responsible for protecting children against violence and who is responsible for providing the necessary medical care to recover. General Comment 13 provides several indications to answering this question by elaborating on the concept of caregivers as defined in article 19 CRC, being responsible for the safety, health, development and well-being of the child.⁴⁴⁷ Such caregivers include the biological, foster or adoptive parents, the legal guardians of the child, extended family members, community members, school and early childhood personnel, child caregivers employed by parents, institutional and health care personnel, in short all persons caring for the child for a shorter or longer period. The settings where these caregivers are primarily expected to watch over the child include places where children reside permanently or temporarily, medical, rehabilitative and care centres and refugee camps for children who are displaced by conflict or natural disasters.⁴⁴⁸

The recommended measures to ensure the protection of children against violence and the recovery after suffering from it, include general measures such as budget allocation, social welfare programmes to support children and caregivers, academic teaching on children's rights, research programmes and the identification and prevention of hindered access for vulnerable groups of children to health services.⁴⁴⁹ Specifically related to health, recommendations are made to implement public health policies, improving access to health and ensure registration of children to ensure access to health and social services.⁴⁵⁰ The recommendations extend to the provision of pre- and postnatal services, home visitation programmes, strengthening the link between mental health services for adults, substance abuse treatments and child protection services and⁴⁵¹ the provision of medical, mental health and social services for children who have experienced violence and the establishment of help lines particularly aimed at offering public health and social support.⁴⁵²

When coming to measures to protect children's health and well-being at the level of individual children, the Committee on the Rights of the Child gives a very extensive enumeration of all groups of children who are particularly vulnerable to suffer from violence. It is acknowledged that babies and young children are most vulnerable due to their immaturity and complete dependency on adults.⁴⁵³

⁴⁴⁷ Ibidem supra note 435, § 31.

⁴⁴⁸ Ibidem supra note 435, § 32.

⁴⁴⁹ Ibidem supra note 435, § 38–40.

⁴⁵⁰ Ibidem supra note 435, § 40–43.

⁴⁵¹ Ibidem supra note 435, § 43.

⁴⁵² Ibidem supra note 435, § 45 and 48.

⁴⁵³ Ibidem supra note 435, § 65f.

Among the many other groups of vulnerable children, mention is made of children who are separated from their biological families, children living on the street, physically disabled children, children with congenital, acquired or chronic illnesses, malnourished children and children who are hospitalized without adequate supervision.⁴⁵⁴

All in all, General Comment 13 on the protection of children against violence pays extensive attention to the harmful effects of violence on children's health and the recommended measures to prevent these effects. A central role in protecting children is attributed to the primary caregivers, being responsible to take care of the child in both private and professional environments.

2.5.8. THE NEWLY ADOPTED GENERAL COMMENT 15 ON CHILDREN'S RIGHT TO HEALTH

In December 2011, the UN Committee on the Rights of the Child issued a call for submissions on the interpretation of children's right to health in preparation of the forthcoming General Comment on the right of the child to the enjoyment of the highest attainable standard of health. From all over the world, academics, NGOs, other interest groups and ombudspersons submitted contributions focussing on either the general principles underpinning the right of the child to the enjoyment of the highest attainable standard of health or zooming into a particular subtheme relating to this right.⁴⁵⁵

In March 2013, the UN Committee on the Rights of the Child issued General Comment 15 on the right of the child to the enjoyment of the highest attainable standard of health. This General Comment elucidates the interpretation by the Committee of the normative content of article 24 CRC, the resulting obligations of State Parties and the responsibilities of non-state parties and it provides for a framework for implementation and accountability for any intervention identified, political commitment and sufficient allocation of resources are deemed essential.⁴⁵⁶

⁴⁵⁴ Ibidem supra note 435, § 65g.

⁴⁵⁵ The 36 resulting submissions were published online: www2.ohchr.org/english/bodies/crc/calls/submissionsCRC_received.htm. Particular subtopics included in the submitted contributions deal with reproductive and sexual health rights of children, the health rights of lesbian, gay, bisexual, transgender and intersex children, disabled children, children born with drug addicted parents, parents who denied their pregnancy, children in need of palliative care, children in detention, children in out-of-home care, children without parental guidance or children as caretakers, children with mental health problems, children in hospitals, children participating in medical research, and children in rural areas.

⁴⁵⁶ U.N. Doc. CRC/C/GC/15 on the right of the child to the enjoyment of the highest attainable standard of health, 14th March 2013, § 2–4.

2.5.8.1. *Holistic approach to health*

In interpreting the right to the highest attainable standard of health, the Committee deliberately emphasizes the need to take a holistic approach to realizing the right to the highest attainable standard of health. General Comment 15 stipulates that children not only have a right to timely and appropriate prevention, health promotion, curative, rehabilitative and palliative health care but also that children have ‘the right to opportunities to survive, grow and develop to their full potential and to live in conditions that enable them to attain the highest attainable standard of health’.⁴⁵⁷ Healthy living conditions are thus deemed essential for the enjoyment of the highest attainable standard of health of the child.⁴⁵⁸ The approach taken in the General Comment is deliberately generic in order to be applicable to a wide variety of health problems, contexts and countries.⁴⁵⁹

The requirement to approach the right to health of the child holistically also follows from the identification of the broad range of stakeholders that should or can contribute to the realization of the right to the highest attainable standard of health of the child.⁴⁶⁰ It is not only children, parents, medical professionals and policy makers who can contribute, but in fact any participant in society whose activities directly or indirectly influence the realization of the right of the child. A further investigation into ways in which all potential stakeholders can contribute to the realization of the right to health of the child will be conducted in chapter 6 on the realization of the right to health of the child.

2.5.8.2. *Active involvement of all stakeholders*

In several instances, the need to involve all stakeholders in the different stages of the realization process of the right to the highest attainable standard of health of the child is highlighted. For example, in the organization of primary health care, health services must be organized around people’s needs and expectations, collaborative models of policy dialogue must be sought and stakeholder participation must be increased in the demand and appropriate use of services.⁴⁶¹ In order to empower young women to combat instances of gender discrimination such as female infanticide and preferential feeding their (political) participation is deemed necessary.⁴⁶² Most specifically, the central role of parents and other caregivers must be better recognized, for example in acknowledging the relation between the realization of the right to health of the mother and decreasing

⁴⁵⁷ Ibidem supra note 456.

⁴⁵⁸ Ibidem supra note 456, § 2, 5, 13, 17, 18, 43–50.

⁴⁵⁹ Ibidem supra note 456, § 3.

⁴⁶⁰ Ibidem supra note 456, § 3, 76–85.

⁴⁶¹ Ibidem supra note 456, § 4, 15, 19.

⁴⁶² Ibidem supra note 456, § 9.

rates of perinatal mortality and in improving breastfeeding practices.⁴⁶³ It is acknowledged that the socialisation process and thus the health behaviour of children is heavily influenced by the parents and parents are considered to be an important source for early diagnosis and primary care in small children.⁴⁶⁴ Therefore, participatory consultations must be held separately with parents and children in order to learn about children's health problems, developmental needs and expectations to improve the design of health programmes and interventions.⁴⁶⁵ The involvement of parents and other caregivers is also highlighted in preventing health problems.⁴⁶⁶

All participatory initiatives must take into account the age and evolving capacities of the children involved. Thereto, understanding of the life course is essential. Special consideration must be given to involving vulnerable children in the realization of the right to health of the child, because they often have the fewest opportunities to exercise their autonomy.⁴⁶⁷ The particular involvement of children in realizing their own right to health is highlighted by stating that children must be enabled to claim their own right to health and in the acknowledgement that children have the right to control one's own health and body with increasing maturity.⁴⁶⁸ General Comment 15 elaborates very precisely several issues in which children's views must be sought.⁴⁶⁹

- What services are needed?
- How and where are these services best provided?
- What barriers do children encounter in accessing or using these services?
- How do children assess the quality of the services available to them?
- How do children assess the attitudes of health professionals?
- How can children's capacities be strengthened to take increasing responsibility for their own health and development?
- How can children be more effectively involved in the provision of services as health educators?

In order to enable all stakeholders to participate meaningfully in decisions on their own health and on the provision of medical services, health education is essential. Article 24.2 (e) CRC and its elaboration in General Comment 15 establish that States must ensure an environment in which parents and children are encouraged to pursue health-seeking behaviour. Schools can play a constructive role in stimulating children and their families to healthy behaviour

⁴⁶³ Ibidem supra note 456, § 6, 15, 18, 67.

⁴⁶⁴ Ibidem supra note 456, § 67.

⁴⁶⁵ Ibidem supra note 456, § 19, 32.

⁴⁶⁶ Ibidem supra note 456, § 67.

⁴⁶⁷ Ibidem supra note 456, § 21.

⁴⁶⁸ Ibidem supra note 456, § 6, 24.

⁴⁶⁹ Ibidem supra note 456, § 19.

by providing healthy food, health education, establishing school gardens and training teachers to stimulate healthy behaviour in their pupils.⁴⁷⁰ This can be beneficial both in developing countries where the provision of (healthy) food can be a strong motivational factor for parents to send their children to school, but also in developed countries where the availability of healthy food in school canteens and the restrictions on marketing of unhealthy products are essential in reducing the alarming incidence of obesity among children.⁴⁷¹ Topics in health education should inter alia include healthy eating and promotion of physical activity, sports, recreation, accident and injury prevention, sanitation, hand washing and other personal hygienic practices and the dangers of alcohol, tobacco and drugs.⁴⁷²

Not only schools, but also private businesses and mass and social media have a role to play in stimulating healthy behaviour among children and adolescents. Mass and social media can play a role in this by exclusively promoting healthy lifestyles, providing free advertising spaces for health promotion, respecting privacy and confidentiality of children and providing access to health information.⁴⁷³

2.5.8.3. *Primary health care*

In line with article 24.1 and 24.2(b) CRC the provision of primary health care is prioritized as the main route to follow to achieve the right of the child to the enjoyment of the highest attainable standard of health.⁴⁷⁴ As an absolute minimum, the facilities provided for the treatment of illness and the rehabilitation of health should include prevention, promotion, treatment, rehabilitation and palliative care.⁴⁷⁵ The health care system also has a role in reporting violence and injustice.⁴⁷⁶

Whereas the Committee acknowledges that the exact configuration of health services varies per country, a few elements are qualified as essential, namely a robust financing system, a well-trained and adequately paid workforce, reliable information, well-maintained facilities and logistics systems to deliver quality medicines and technologies and strong leadership and governance.⁴⁷⁷ Very specifically, special reference is made to the usefulness of 'The essential interventions, commodities and guidelines on reproductive, maternal, newborn and child health' for establishing a system of primary health care that meets the

⁴⁷⁰ Ibidem supra note 456, § 46.

⁴⁷¹ Ibidem supra note 456, § 47.

⁴⁷² Ibidem supra note 456, § 59.

⁴⁷³ Ibidem supra note 456, § 84.

⁴⁷⁴ Ibidem supra note 456, § 4.

⁴⁷⁵ Ibidem supra note 456, § 25.

⁴⁷⁶ Ibidem supra note 456, § 25.

⁴⁷⁷ Ibidem supra note 456, § 27, 36.

minimum requirements deriving from the right to health of the child.⁴⁷⁸ Secondly, States have the obligation to make available all essential medicines for children as specified on the WHO Model Lists for Essential Medicines – Children. This list consists of a core and a complementary part, which respectively specify i) the list of efficacious, safe and cost effective medicines that are minimally required for a basic health care system and ii) the list of medicines for priority diseases that require specialized diagnosis, monitoring, treatment or training of professionals.⁴⁷⁹

The involvement of stakeholders in the provision of primary health care facilities is also required in the organization of primary health care, because the primary health care provided must be matched with community-based efforts, such as immunization programs, nutritional interventions, efforts to prevent health problems and injuries resulting from violence and traffic and provision of community-based health information.⁴⁸⁰ This can be optimized by undertaking an in-depth analysis of priority health problems, where appropriate with children and their families.⁴⁸¹

Universal access to primary health care should be achieved *inter alia* by setting up facilities in close proximity to children and families, for example by collaboration with or in close proximity to schools and by deploying mobile health clinics and health kits.⁴⁸² Mobile health clinics can be useful in areas where no permanent services are available due to a lack of resources (e.g. India), remoteness and low population density (e.g. Australia) or in emergency situations (Haiti after the earthquake).⁴⁸³ General Comment 15 establishes that the private sector could play a role in making such mobile arrangements available so that all children can gain access to health services.⁴⁸⁴

Whereas States have a responsibility to establish a comprehensive primary health care system for all children as an absolute minimum, secondary and tertiary systems should be provided to the largest extent possible, including functional systems of referral.⁴⁸⁵ Dependent on the age of the child, the care provided should adopt a i) baby-friendly, ii) child-friendly or iii) adolescent-friendly approaches, that are aimed at minimizing fear and suffering of children and their families.⁴⁸⁶

⁴⁷⁸ Ibidem supra note 456, § 37 and The essential interventions, commodities and guidelines on reproductive, maternal, newborn and child health, available at: www.who.int/pmnch/topics/part_publications/essentialinterventions14_12_2011low.pdf.

⁴⁷⁹ Ibidem supra note 456, § 37, 38 and WHO Model Lists for Essential Medicines – Children, 3rd list, March 2011, available at: http://whqlibdoc.who.int/hq/2011/a95054_eng.pdf.

⁴⁸⁰ Ibidem supra note 456, § 26, 35.

⁴⁸¹ Ibidem supra note 456, § 32.

⁴⁸² Ibidem supra note 456, § 36.

⁴⁸³ Ibidem supra note 456, § 40.

⁴⁸⁴ Ibidem supra note 456, § 41, 42.

⁴⁸⁵ Ibidem supra note 456, § 24, 28.

⁴⁸⁶ Ibidem supra note 456, § 53.

2.5.8.4. *Reduction of infant and child mortality*

General Comment further elaborates the requirements to reduce infant and child mortality as laid down in article 24.2(a). The Committee acknowledges that infant and child health is strongly related to maternal health. Therefore, timely and quality health care is required to prevent intergenerational transmission of health problems.⁴⁸⁷ General Comment 15 specifies the interventions that should be made to address the main health problems leading to infant and child mortality, including the provision of essential care before, during and after delivery, safe abortion services, the provision of sexual and reproductive health information and services and social protection such as universal coverage and paid parental leave to ensure access for mothers and children to essential health care. The Committee furthermore provides for a non-exhaustive list that qualifies the health issues that must be addressed within the continuum of care of reproductive, maternal, newborn and child health: stillbirths, preterm birth complications, birth asphyxia, low-birth weight, mother-to-child transmission of HIV/AIDS and other sexually transmitted diseases, neonatal infections, pneumonia, diarrhoea, measles, under- and malnutrition, malaria, the prevention of accidents and violence.⁴⁸⁸ Prevention of health problems is extensively elaborated and addresses not only communicable and non-communicable diseases, but also the prevention of health problems by combatting substance abuse and ensuring product and environmental safety.⁴⁸⁹

2.5.9. CONCLUDING OBSERVATIONS ON THE GENERAL COMMENTS

On the basis of the analysis in the preceding sections, we make the following concluding observations on the General Comments.

The achievement of the highest attainable standard of health must be realized for all children without discrimination. The General Comments emphasize that all groups of children must have access to age-adjusted, disability adjusted and culturally appropriate health services without discrimination. Several groups of children have been identified for being particularly vulnerable to violations of their right to health, including babies and very young children. It is acknowledged that vulnerable groups of children are more prone to health risks such as malnutrition, infectious diseases, injuries, (substance) abuse and neglect. Particular problems of discrimination in realizing the right to health of the child are identified when children are vulnerable in plural aspects. Measures required have to take into account the different aspects of all vulnerabilities present. These

⁴⁸⁷ Ibidem supra note 456, § 53.

⁴⁸⁸ Ibidem supra note 456, § 33, 34, 53.

⁴⁸⁹ Ibidem supra note 456, § 62–66.

examples underline that ensuring children's right to health requires measures beyond the limited environment of the health care sector. This requirement similarly follows from the need to ensure and enforce existing community-based health programs for children. Although different groups of vulnerable children require special attention in receiving health care, this care must be integrated in the general health care system to prevent stigmatization and discrimination as a result of the special attention they receive. Furthermore, multi-sectorial health approaches are required that can respond to the differential needs of children. This should include mental health facilities and possibly also home visitations.

The achievement of the highest attainable standard of health must be realized from the basis, which is the prevention of health problems and empowerment of young children and their parents. Prevention starts with combating malnutrition and easily preventable diseases. Secondly, prevention can be achieved by early detection and early intervention. This in its turn requires awareness of health risks among all people involved in the care of a child. The third way to prevent health problems must therefore be achieved by providing child-centred health education to young children, adolescents, pregnant women, parents and other caretakers and medical professionals. Additional efforts are required to enhance open communication about sensitive health topics. Through the provision of health education young children are stimulated in their direct environment to adopt healthy lifestyles from the very beginning of their lives. Fourthly, a safe and healthy environment adds to the prevention of health problems resulting from injuries, violence or poisoning with hazardous materials.

The role of families is central to the achievement of the right to the highest attainable standard of health by young children. Children are highly sensitive to their surroundings and imitate large parts of the (health) behaviour witnessed in their direct environment. Therefore, parents must be aware of their own health behaviour. In providing guidance they must continuously adapt to the changing health needs of their children and positively stimulate children to take increasing responsibility for their own health. This requires the adaptation of modes of communication to the preferred ways of communication of children and to their level of comprehension. The capacities of very young children are complemented by the guidance of their parents. This involvement of parents can contribute to better meeting the needs of children in the health sector by helping to identify what health services are required, how they should be provided, what discriminatory barriers and attitudes they encounter and how children can best be involved in their own health care.

The ambivalent role of the (extended) family in the prevention and infliction of violence is highlighted. It is acknowledged that violence impacts heavily on the health of children of all ages, either directly through the infliction of physical harm or indirectly through the destruction of medical facilities and the disruption of social structures including families, schools and infrastructure

for the distribution of food, water and medicines.⁴⁹⁰ Armed conflicts play a complicating role in realizing the right to the highest attainable standard of health of children in remote areas and war zones. The health sector has an important role in identifying and treating health problems resulting from violence in the private or in the public sector.

The recently adopted General Comment 15 on the right of the child to enjoy the highest attainable standard of health offers a valuable and concise elaboration of the Committee's interpretation of the right to health of the child. It concretizes the different aspects of the right to health to the operational level. With a focus on the provision of primary health care it specifies the levels of health care that must be provided for as a minimum, namely, prevention, promotion, treatment, rehabilitation and palliative care. In doing so, priority must be given to the establishment of services for the continuum of care to ensure good maternal, new born and child health. Useful tools are furthermore suggested to determine the key interventions that must be taken, the minimum essential medicines that must be provided for and the most pressing health problems that must be addressed. Last but not least, General Comment 15 refers extensively to the need to involve all stakeholders to the greatest extent possible in the interpretation of the right to the highest attainable standard of health of the child and the prioritization of measures that must be taken to achieve that level of health for all children.

2.6. THE BASIC PRINCIPLES OF MEDICAL ETHICS FROM A CHILDREN'S RIGHTS PERSPECTIVE

The articles of the CRC constitute a useful legal basis for analysing the application of medical ethical principles in children's health care.^{491, 492} Goldhagen and Mercer have developed a model that translates the principles of children's rights, social justice and health equity into children's health outcomes.⁴⁹³ This is useful, because many medical professionals are not used to working with children's rights concepts. Therefore, the potential contribution of a rights-based approach to children's health often remains confined to the legal sector. Translation to the medical practice is crucial for implementation.

Whereas attention is rightly paid to the social determinants on health outcomes instead of narrowly focusing on medical care for children as a way to

⁴⁹⁰ See for example General Comment 4 on adolescent health and General Comment 6 on the treatment of unaccompanied and separated children outside their country of origin.

⁴⁹¹ S. Nixon & L. Forman, 'Exploring synergies between human rights and public health ethics: a whole greater than the sum of its parts', *British Medical Journal on International Health and Human Rights* 2008, Volume 8, Issue 2.

⁴⁹² Goldhagen & Mercer, 'Child Health Equity: From Theory to Reality', in: A. Invernizzi, *The Human Rights of Children*, p. 313.

⁴⁹³ *Ibidem* supra note 492.

realize children's rights to health, the overall approach is rather untransparent.^{494,495} However, the component of health-equity ethics in which the four basic principles of the CRC⁴⁹⁶ are related to the core principles in medical ethics (see Table 1 below⁴⁹⁷) is useful for answering the question how the principles of the CRC that are relevant for ensuring children's right to health can be translated to medical ethical principles, being the more common normative framework for medical professionals.

Table 1. Relating the core principles of child rights and medical ethics

Children's rights principles	Ethics principles
Non-discrimination (art. 2 CRC)	Justice
The best interests of the child (art. 3 CRC)	Beneficence
Survival and development (art. 6 CRC)	Non-maleficence
Listened to and taken seriously (art. 12 CRC)	Autonomy

The four core principles of medical ethics have a strong focus on the individual and the self-determination of the subject. The principle of autonomy refers to the inherent dignity of the individual and of human life in itself. Although autonomy is related to children's right to participation, the two concepts are not identical. Children's autonomy entails that children can act completely independently from others. Children's right to participation on the other hand, means that children are involved to a certain extent, depending on the opportunity they are given to participate and to the weight that is attributed to their opinions.⁴⁹⁸ However, they are not granted the full responsibility to take (medical) decisions completely autonomously.⁴⁹⁹ Baines elaborates that 'Children do not develop the abilities

⁴⁹⁴ Several sets of principles are combined; I. Child rights principles are defined as 'establishing the prerequisites for the health and well-being of children'; II. Social justice principles as 'providing insight and instructing how to allocate and distribute finite resources to ensure non-discrimination (art. 2 CRC), the best interests of the child (art. 3 CRC) and survival (art. 6 CRC)'; III. 'Health-equity ethics uses the CRC articles to establish an expanded set of ethical principles as a lens through which to view and analyse the world of children and the decisions that impact upon them'.

⁴⁹⁵ Where the heading states that four themes of the CRC are translated to the core ethics principles, 5 themes are addressed, namely economic, social, cultural, protective and civil and political rights. Examples like these create confusion in reading the article.

⁴⁹⁶ [Www.unicef.org/crc/files/Guiding_Principles.pdf](http://www.unicef.org/crc/files/Guiding_Principles.pdf).

⁴⁹⁷ Ibidem supra note 492, p. 311.

⁴⁹⁸ M. Donnelly & U. Kilkelly, 'Child-friendly healthcare: delivering on the right to be heard', *The Medical Law Review* 2011, 19(1), pp. 27–54.

⁴⁹⁹ Donnelly and Kilkelly argue that two common aspects of participation and autonomous decision-making by children are the requirement of accessible information and the placing of the child at the heart of the decision-making process. However, as shown by the elaboration of the participation ladder by Hart and also the distinction made by Shier of different levels of children's participation, there are different levels of participation possible, that do not all place the child central. I would rather argue that truly placing the child central at the heart of the process is an essential condition for establishing their right to participation.

to act autonomously overnight.⁵⁰⁰ Therefore, the concept of children's right to participation with its varying degrees of involvement according to both the best interests (art. 3 CRC) and the evolving capacities of the child (art. 5 CRC), offers a very practical tool for medical practitioners to apply the principle of autonomy to children in the health care practice.

Following from the autonomy principle is the doctrine of informed consent, meaning that the subject has to receive sufficient and appropriate information to be able to give consent for a medical treatment. The amount of information that is actually provided, however, is determined by the parents or medical practitioners. As elaborated in paragraph 4 of this chapter, the role of the medical practitioner is crucial in shaping the degree of participation of the child that is achieved, especially when parents are objecting.

The principles of beneficence and non-maleficence are often viewed as different sides of the same coin, but there is a fundamental difference. Non-maleficence means doing no harm, which does not necessarily require action to be taken. Beneficence on the other hand, means that medical professionals have to make active efforts to do good to their patients. This can not be achieved by 'not taking action'. It would seem logical to relate the concept of non-maleficence to the right to protection of children and the principle of beneficence to the right to health. However, within the legal domain, protective rights also require proactive efforts to prevent children from being harmed, such as reporting mechanisms on situations of violence that are coupled with help-oriented services in the field of public health.⁵⁰¹ A legal translation of the principle of non-maleficence thus seems to lead to a broader scope than the strictly medical interpretation.

The last principle, justice, means that persons with equal characteristics must be treated equally and that health resources must be allocated equitably. The concept of equity, as further discussed in chapter 4 is central to this notion. Limiting access to health care on discriminative grounds is thus not in line with the justice principle.

With respect to the realization of children's right to health, several other CRC articles are also relevant for the interpretation and implementation of article 24 CRC.^{502, 503} Therefore, translation of these provisions to the domain of medical ethics will be useful as well for realizing children's right to health. On the basis

⁵⁰⁰ P. Baines, 'Medical ethics for children: applying the four principles to paediatrics', *Journal of Medical Ethics* 2008, Issue 34, p. 142.

⁵⁰¹ With respect to the protection of children against violence, see for example General Comment 13 of the Committee on the Rights of the Child, U.N. Doc. CRC/C/GC/13, 17 February 2011, § 36–51 for an enumeration of all appropriate protective measures. § 36 specifically emphasizes the proactive character of the protective measures enumerated.

⁵⁰² See for example the explicitly enumerated articles in the Treaty-specific guidelines regarding the form and content of periodic reports to be submitted by States parties under article 44, paragraph 1(4) of the Convention on the rights of the Child, § 18–21. [art. 6.2, 18.3, 23, 26 and 27].

⁵⁰³ See also the article mentioned in the Implementation Handbook for the Convention on the Rights of the Child, prepared for UNICEF by Rachel Hodgkin and Peter Newell, fully revised

of the articles identified as being relevant for ensuring children's right to health, in Table 2 an attempt is made to relate those articles to the common principles in medical ethics. The principles in italics are not mentioned in the treaty-specific guidelines, nor in the Implementation Handbook for the Convention on the Rights of the Child, but given the relevance of birth registration for having access to health care and the widespread discrimination of refugee children from having access to health care, are deemed relevant for this overview.⁵⁰⁴

Table 2. Relating the health related principles of child rights with medical ethics

Children's rights principles relevant to children's right to health care	Ethics principles
The role of the parents in children's health: i. The role of the parents/legal guardians to provide direction and guidance (art. 5 CRC) ii. The right not to be separated from the parents (art. 9 CRC) iii. Parents have dual responsibility for the upbringing and development of the child. (art. 18 CRC) iv. Children of working parents must have access to child-care services (art. 18 CRC)	Autonomy Non-maleficence Autonomy Justice
The right to privacy (art. 16 CRC)	Autonomy, confidentiality
The right to information (art. 12, 13 and 17 CRC)	Autonomy (informed consent)
The right to protection (art. 19 and 20 CRC)	Autonomy and non-maleficence
The right to special care for disabled children (art. 23 CRC)	Autonomy, justice, beneficence.
The right to health (art. 24 CRC)	Autonomy, beneficence, justice, non-maleficence.
The right to periodic review of treatment (art. 25 CRC)	Non-maleficence and beneficence.
The right to social security (art. 26 CRC)	Justice
The right to an adequate standard of living (art. 27 CRC)	Justice
The right to (health) education (art. 28 and 29 CRC)	Autonomy
The right to protection from exploitation, child labour, drugs, sexual abuse and trafficking (art. 32–36 CRC)	Non-maleficence
The right to physical and psychological recovery and social reintegration of child victims (art. 39 CRC)	Beneficence
<i>The right to birth registration and identity (art. 7 and 8 CRC)</i>	<i>Autonomy</i>
<i>The right to protection and humanitarian assistance for refugee children (art. 22 CRC)</i>	<i>Justice, beneficence, non-maleficence</i>

The previous translation of the articles of the CRC for the children's health domain can help to further specify the application of the core medical ethical principles in the child's health care domain. Translating the CRC articles to the medical domain gives rise to a broader interpretation of the medical ethical principles than the strict medical context, including the relevance and necessity of ensuring

third edition, September 2007, p. XI-XXI. Available at: www.unicef.org/publications/files/Implementation_Handbook_for_the_Convention_on_the_Rights_of_the_Child.pdf.

⁵⁰⁴ The relevance of birth registration for the right to health of the child is found in General Comment 15 to the CRC. This relevance will be further addressed in chapter 3 below.

socioeconomic determinants and a rights-based treatment of minor patients. Secondly, it provides a useful tool for further developing child-friendly working methods in the health care setting on the basis of an integrated approach based on both medical ethical and children's rights principles. The translation of children's rights to practical guidelines for medical professionals can further operationalize their implementation and realization.^{505, 506} Therefore, children's rights should be included in the education of all medical professionals working with children. This obviously includes paediatricians, gynaecologists and family practitioners, but it also extends to professionals who only occasionally encounter children in their daily work, such as radiologists, haematologists and others.

2.7. CONCLUSION

2.7.1. PRIORITIES IN INTERPRETING THE RIGHT TO THE HEALTH OF THE CHILD

Given the scarcity of resources, prioritization in ensuring children's right to health is necessary. This need is even more pressing in times of financial crisis and public debates over continuously rising health costs. This chapter has analysed what the key elements are of article 24 in interpreting the concept of the highest attainable standard of health of the child.

The priorities found in article 24 CRC, all contribute to children's survival in the first place (art. 24 sub 2a-2d), namely the reduction of infant and child mortality rates and secondly to leading a healthy life (art. 24 sub 2e-f). The achievement of the highest attainable standard of health must be realized from the basis, namely prevention of health problems, provision of basic health services and empowerment of young children and their parents to adopt healthy lifestyles.

⁵⁰⁵ Some progressive medical societies, especially in Anglo-Saxon countries, have established guidelines for guiding pediatricians in child-appropriate health care. These guidelines should be analyzed for their compliance with the Children's Rights Charter. See for example *Good Medical Practice in Paediatrics and Child Health: Duties and Responsibilities of Paediatricians* by the Royal College of Paediatrics and Child Health, London, 2002. See also the Child Friendly Health Care Initiative (www.cfhiuk.org), a Manual for health workers by Sue Nicholson and Andrew Clarke. The Manual is said to translate the CRC articles into simple CFH 'Standards' that are applicable to everyday healthcare practices. Available at: www.cfhiuk.org/publications/cfhi_manual/cfhi_manual.pdf.

⁵⁰⁶ An article on the implementation of the Child-Friendly Healthcare Initiative (CFHI) provided 12 standards for providing healthcare in accordance with the Convention on the Rights of the Child. The intention was expressed to implement the standards in six pilot countries in cooperation with the Department of Child and Adolescent Health and Development of the World Health Organization and UNICEF. Southall, D. P. (2000). 'The child-friendly health care initiative (CFHI): Health care provision in accordance with the United Nations Convention on the Rights of the Child', in: *Pediatrics*, 106(5), pp. 1054–1064.

Prevention must be achieved through the provision of underlying determinants of health, implementation of high coverage vaccination campaigns, combating malnutrition and easily preventable diseases, early detection and intervention of diseases and ensuring a healthy environment. Through the provision of child-centred and child-sensitive health education, children, parents and other caretakers are stimulated to adopt healthy lifestyles and take increasing responsibility for their own and their child's health.

In the provision of health care to children, the focus lies on basic health care. These services must be continuous and responsive to the changing circumstances in which children live and to the different developmental stages of children. Four different levels have been identified at which age-specific health care services should be provided:

1. Provision of health care and information to the mother during pregnancy.
2. Obstetric health care around the birth of the child.
3. Neonatal health care for the mother and the child immediately after birth.
4. Quality health care during childhood.

In the second place, health services must be responsive to the needs of different groups of (vulnerable) children and children from various sociocultural backgrounds. The right to the highest attainable standard of health entails that in providing for these health services, special attention must be given to include all groups of vulnerable children in the health care system by providing for age-adjusted, culturally and disability appropriate basic health services and information. Multisectoral health teams, home visits and mobile health clinics can contribute to integrating the particular needs of (vulnerable) children, including infants and very young children in the realization process of the right to the highest attainable standard of health.

An important avenue for identifying the best interests of the child is by involving both children and their parents in the different phases of the health care process. Furthermore, the right to the highest attainable standard of health requires that children's opinions on the impact of their health situation on other aspects of their daily life must be sought. Where young children have limited capacities to communicate their particular health needs, parents have a complementary responsibility in providing for guidance and communicating their children's needs. However, this must be done from the perspective of children as rights holders. Therefore, to the largest extent possible, children must be informed from the very beginning and in an age-appropriate way about their health status, options for treatment and prognosis. If necessary, this requires the application of creative and child-specific modes of communication. Involving children in their

own health care from the very beginning gradually enhances their capacities to take ownership of their own health.

2.7.2. RESPONSIBLE ACTORS

With regard to the responsibility to ensure the right to the highest attainable standard of health of the child, the provisions related to health constitute a dual responsibility between individual children and their parents on the one hand and States Parties on the other. The State has the overall responsibility to ensure the provision of non-discriminatory, accessible and acceptable health care facilities, the underlying determinants of health and the provision and implementation of legislation and national programs to ensure adequate health facilities and personnel. This responsibility includes the provision of affordable and accessible insurances for all children and protection of children against practices of overt and covert forms of discrimination in acquiring access to health care. The role of the State in ensuring children's right to health further focuses on enabling individuals and their families to take their primary responsibility to ensure their own health through the provision of health information. This requires the training of all medical professionals working with children in children's rights and in communicating with children.

Parents have the primary responsibility to ensure daily care and guidance to their children, thereby supporting them to develop in a healthy manner. The right to the highest attainable standard of health of very young children is directly related to the health of their families. Parents' role in ensuring their children's health contains several elements, related to their biological connection, behaviour of the mother during pregnancy and around the birth of the child as well as the health behaviour of both parents, the guidance given to the child on healthy behaviour. Central in the realization of the right to the highest attainable standard of health of the child is the need to continuously adapt to the changing circumstances in which children live and to take into account the evolving capacities of the developing child. Although young children are rights holders on their own, the capacities of very young children are complemented by the guidance of their parents. In providing guidance, parents must positively stimulate children to take increasing responsibility for their own health. This requires the adaptation of modes of communication to the preferred ways of communication of children and to their level of comprehension.

The primary responsibility for financing both the actual health care as the basic necessities in life lays with the parents. However, as specified in article 27, the responsibility of parents to take care of their children is limited to the abilities and financial capacities of the parents. This specification leaves room for a broad margin of appreciation to determine when the State should intervene. Special consideration must be given to children and families in difficult circumstances

such as orphaned children, refugees or families without a residence permit, children of indigenous and minority groups, child headed households, single parent families and parents who are unemployed or who otherwise have limited means for ensuring the right to the highest attainable health of their child.

A problem remaining in the determination of the responsible actors is that whereas the CRC provisions hold parents primarily responsible, it is the State that is directly bound by the Convention. This incoherence results in uncertainty over the legal enforceability of the provision to hold parents accountable for ensuring their children's right to health. The same is true for several other groups of actors that are discerned in the newly adopted General Comment 15 on the right of the child to the enjoyment of the highest attainable standard of health, that have capacity and resulting responsibility to contribute to the implementation of the right of the child to the highest attainable standard of health. More research into this aspect will be conducted in chapter 6 on realizing the right to the highest attainable standard of health of the child.

Medical professionals can play a valuable role in enabling children to be involved in medical decisions on their individual treatment and on the organization of health services. They can also contribute to streamlining the communication with and between parents and their children and guiding parents in ways to stimulate their children to adopt healthy lifestyles. Thereto, all medical professionals encountering children in their daily work or just occasionally, must be educated about children's rights in health and trained in communicating with children and families in the health care sector. Since the role of families in ensuring children's right to health can be both enabling and harming to the realization of the right to health of the child, the health sector has an important role in identifying and treating health problems resulting from violence in the private sector. The same is true for health problems resulting from public health problems, such as obesity or alcohol and drug abuse, from (structural) violence and in humanitarian situations. In order to increase awareness and professionalism of best practices in different countries, both states and medical professionals must share information with professionals in other, less developed countries.