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

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IV. THE RIGHT TO HEALTH OF THE CHILD IN INTERNATIONAL HEALTH AND HUMAN RIGHTS LAW: ADDING A HUMAN VOICE?

4.1. INTRODUCTION

The right of the child to enjoy the highest attainable standard of health is laid down in article 24 of the Convention on the Rights of the Child (CRC). In addition, article 41 CRC provides that 'Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of the child and which may be contained in (a) The law of a State party; or (b) International law in force for that State.' This means that provisions in other (international) law sources that provide for a more extensive guarantee of children's right to health should be taken into account when applying children's right to health. This chapter seeks to investigate the additional value of the provisions in international health and human rights law other than the CRC for interpreting the right to the highest attainable standard of health of the child as enshrined in article 24 CRC. After an analysis of the key sources on children's right to health in international law in section 2, the key features of the general right to health with be discussed in section 3. Specifically, the framework of **A**vailability, **A**ccessibility, **A**cceptability and **Q**uality as laid down in General Comment 14 to the ICESCR will be assessed for its child-specificity. In section 4, participation is discussed as a key constituent element of the right of the child to the highest attainable standard of health. Section 5 recognizes the importance of the international dimension of the highest attainable standard of health. In section 6, the key features of child's rights-based health system will be identified.

4.2. AN ANALYSIS OF THE KEY SOURCES ON CHILDREN'S RIGHT TO HEALTH IN INTERNATIONAL HEALTH LAW

4.2.1. THE RIGHT TO HEALTH IN THE UDHR, ICESCR, WHO CONSTITUTION

Several international legal documents have qualified the right to health as a fundamental human right.[689] The language of the declarations and treaties varies widely, but it has become customary to refer to the provisions collectively as 'the right to health'.[690]

The preamble of the WHO Constitution states that the enjoyment of the highest attainable standard of health is 'one of the fundamental human rights of every human being without distinction of race, religion, political belief, economic or social condition'.[691] Article 25.1 of the Universal Declaration of Human Rights[692] locates the right to health in its context, as it declares that the standard of living is determinative for fulfilling the right to health by stating that 'everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care and necessary social services.' The right to health as laid down in international law thus encompasses both the right to health care services and the right to a wide range of factors conducive to leading a healthy life; the underlying determinants of health, such as safe and potable drinking water, adequate nutrition, sanitation, housing, healthy working and environmental conditions and health related education and information.[693]

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689 See article 25 of the Universal Declaration of Human Rights (U.N. Doc. A/810, 1948), and article 12 of the International Covenant on Economic, Social and Cultural Rights and article 12 of the Convention on the Elimination of Discrimination against Women.

690 V.A. Leary, 'The right to health in international human rights law', *Health and Human Rights* 1994, Volume 1, no. 1, p. 26.

691 The WHO Constitution was adopted by the International Health Conference held in New York from 19 June to 22 July 1946, signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, 2, 100), and entered into force on 7 April 1948. Amendments adopted by the Twenty-sixth, Twenty-ninth, Thirty-ninth and Fifty-first World Health Assemblies (resolutions WHA 26.37, WHA 29.38, WHA 39.6 and WHA 51.23) came into force on 3 February 1977, 20 January 1984, 11 July 1994 and 15 September 2005 respectively and are incorporated in the present text.

692 The Universal Declaration on Human Rights was initially a 'common standard of achievement for all peoples and all nations'. However, it has become an instrument exerting strong moral, legal and political influence on the development and implementation of fundamental human rights, for example by serving as a model for the development of domestic constitutions, laws, regulations and policies. Also, many of the UDHR's provisions have become part of international customary law. See for example: H. Hannum, 'The UDHR in national and international law', *Health and Human Rights* 1998, Volume 3, Number 2, pp. 145–158.

693 WHO Factsheet No. 31 on the Right to Health, Office of the United Nations High Commissioner for Human Rights, Geneva, June 2008, p. 1.

The right to health does not mean that States must ensure that their citizens are healthy, because they are not in a position to fully influence and be responsible for the biological make-up of persons nor for the level of health risks they take in their behaviour.[694] At best, they can undertake public campaigns to make people aware of the risks of for instance smoking and alcohol abuse and various measures to prevent these risks e.g. by a prohibition of smoking in public places and limitations on the sale of tobacco and alcohol. Furthermore, they can provide for vaccination campaigns for children and stimulate safe traffic behaviour. Article 25.1 UDHR establishes that the right to health of the individual (e.g. the child) is explicitly related to the health of his family. Although not explicated in the article itself, this relation may for example become visible in the role that parents have in providing examples of (non-)healthy behaviour to their children, in deciding for the child to go to the doctor and also in the distribution of underlying determinants of health among the different members of the (extended) family. The right to health of the child may also be at stake when other family members have health problems. This is for example the case when parents or other caregivers have serious health problems, such as HIV/AIDS, psychiatric diseases or chronic and terminal diseases, seriously reducing their capacity to ensure their children's right to health. Also, the relation between the health of the child and his or her family becomes clear when a sibling has a serious health problem demanding much attention from the parents or other primary caregivers. Lastly, other family issues, such as unemployment of one or both of the parents, may significantly reduce the family budget to be able to afford nutritious foods, clothing and access to medical care.

Some scholars commented that the right to health does not belong to the body of international customary law, as there is little domestic or international jurisprudence on the implementation of the right to health that would constitute an indication of the existence of an *opinio iuris*.[695, 696] However, others have provided a clear overview of the right to health in national and international jurisprudence, mounting to different sets of core state obligations to respect, protect and ensure the right to health.[697] More importantly, the Committee

694 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 8 and 9.

695 H. Hannum, 'The UDHR in national and international law', *Health and Human Rights* 1998, Volume 3, Number 2, p. 153.

696 Sandhu argues that there are three levels of rights: moral, aspirational and legal. Problems at the legal level concerning the right to health are, according to Sandhu, threefold: indeterminacy (how to characterize it?), justifiability (how to enforce it?) and progressive realization (how to raise the standard over time?). Sandhu argues that the right to health does not go beyond the aspirational level, stating that 'I have a right to health care, but no means of enforcement.' See: P.K. Sandhu, 'A legal right to health care: what can the United States learn from foreign models of health rights jurisprudence?', *California Law Review* 2007, Volume 95, Issue 115, p. 1158.

697 A. Hendriks, 'The right to health in national and international jurisprudence', *European Journal of Health Law* 1998, Volume 5, pp. 389–408. See for a further discussion of state obligations deriving from the right to health paragraph 4.4 of this contribution.

on Economic, Social and Cultural Rights has established that the provision of 'essential primary health care is part of the minimum core obligations deriving from the right to health' and is as such applicable to all member states to the International Covenant on Economic, Social and Cultural Rights.[698] Riedel argues that although 'strictly speaking the international instruments providing for the right to health are not legally binding, the mere fact that these instruments have been followed by states as if they were binding,[699] has illustrated that they form an important component within the international movement to promote and protect the physical and mental health of all persons worldwide'.[700] The growing link between health and human rights and the growing appreciation of the right to health itself is increasingly recognized for its humanitarian importance as well as for its national security interest and its interdependence with global public health interests.[701]

Article 12.1 of the International Covenant on Economic, Social and Cultural Rights[702] elaborates on the fundamental right to health by stating that 'States Parties recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health'. The concept of 'the highest attainable standard of health' is first introduced here in an international treaty. Article 12.2 specifies four targets to be realized out of which two are particularly relevant for realizing children's rights to health, namely (a) the provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child and (d) the creation of conditions which would assure to all medical service and medical attention in the event of sickness.[703]

The central notion of 'the highest attainable standard of health' in article 12 of the ICESCR has been further elaborated in General Comment No. 14 of the Economic and Social Council.[704] The highest attainable standard of health of

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698 Committee on Economic, Social and Cultural Rights, General Comment No. 3 (1990), reprinted in *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies*, U.N. Doc. HRI/GEN/1/Rev.3 (1997), § 10.

699 Some states have included the right to health in their domestic legislation, such as South-Africa and India. See: C.F. Kinney & B. Clark, 'Provisions for Health and Health Care in the Constitutions of the Countries of the World', *Cornell International Law Journal* 2004, Issue 37, pp. 285–355.

700 E. Riedel, 'The Human Right to Health: Conceptual Foundations', in: A. Clapham & M. Robinson, *Realizing the Right to Health*, Swiss Human Rights Book 2009, Volume 3, Ruffer & Rub, pp. 21–39.

701 L. Oldring, 'Advancing a Human Rights Approach on the Global Health Agenda', in: A. Clapham & M. Robinson, *Realizing the Right to Health*, Swiss Human Rights Book 2009, Volume 3, Ruffer & Rub, p. 101–102.

702 International Covenant on Economic, Social and Cultural Rights, Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966 entry into force 3 January 1976.

703 The other two specified targets in article 12.2 ICESCR are (b) the improvement of all aspects of industrial and environmental hygiene and (c) the prevention, treatment and control of epidemic, endemic, occupational and other diseases.

704 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR.

an individual depends on personal factors, such as genetics, susceptibility to ill health and unhealthy or risky lifestyles, on socio-economic preconditions and on a State's available resources.[705] The individual factors may play an important role in an individual's health, but they are generally beyond a State's control. The right to the highest attainable standard of health must therefore be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions that are necessary for the realization of the highest attainable standard of health.[706]

4.2.2. THE RIGHT TO HEALTH OF THE CHILD IN INTERNATIONAL HEALTH LAW

The Preamble of the World Health Organization (the WHO)[707] states that 'the healthy development of the child is of basic importance' and that 'the ability to live harmoniously in a changing total environment is essential to such development' is one of the basic principles for the happiness, harmonious relations and security of all people'. Article 2-l, furthermore, specifies that one of the key functions of the WHO is 'to promote maternal and child health and welfare and to foster the ability to live harmoniously in a changing environment'. Although not explicitly directed at children, the provision in article 2-e elaborates that the WHO shall assist in providing health services and facilities to special groups. Given the specific requirements necessary for ensuring access to healthcare for children[708] and the fact that children are identified as special groups in need of specific attention,[709] this article is also relevant for understanding the children's right to health. This relevance is further reflected in the elaboration that the right to health should be exercised without discrimination of any kind.[710] Children, as reflected in the WHO Constitution, are thus seen as vulnerable actors in need of protection in light of the 'changing circumstances'. Not specified is what these changing circumstances are exactly, but it is logical to assume that this phrase covers at least the regular economic and political developments in a country,

705 Ibidem supra note 685.

706 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 9.

707 The WHO Constitution was adopted by the International Health Conference held in New York from 19 June to 22 July 1946, signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, 2, 100), and entered into force on 7 April 1948. Amendments adopted by the Twenty-sixth, Twenty-ninth, Thirty-ninth and Fifty-first World Health Assemblies (resolutions WHA26.37, WHA29.38, WHA39.6 and WHA51.23) came into force on 3 February 1977, 20 January 1984, 11 July 1994 and 15 September 2005 respectively and are incorporated in the present text.

708 See chapter 2.

709 See for example General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 12b.

710 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 30.

including those in times of economic recession. Furthermore, this provision is particularly relevant for children, since they are heavily affected by poverty.

The principle of non-retrogressive measures is relevant in this context, namely that States Parties have the burden of proving that any retrogressive measures – in casu with respect to children's right to the enjoyment of the highest attainable standard of health – deliberately taken, have been introduced after the most careful consideration of all alternatives and that they are duly justified by reference to the totality of the rights provided for in the Covenant in the context of the full use of the State party's maximum available resources.[711] Although the highest attainable standard of health differs according to available resources and situational circumstances, it has been elaborated that retrogressive measures are not permissible, notwithstanding the financial resources available in a country.[712] This means that once a certain standard of health has been achieved, only exceptional circumstances, such as the 2011 earthquake, tsunami and nuclear threat in Japan, are accepted as an excuse by the Committee on Economic Social and Cultural Rights for any setbacks in the standard of health in a country. If retrogression in the realization of the right to health occurs, governments have the burden of prove to demonstrate that all possible alternatives have been considered and that all efforts are made to reduce the impacts of such extreme circumstances and try to restore the earlier achieved health status as soon as possible.[713] Therefore, even in changing circumstances, the promotion of maternal and child health as laid down in article 2.1 of the WHO Constitution and in article 12.2a ICESCR should remain a priority that can not be easily derogated from. The need to protect children in changing circumstances is especially important, since children are disproportionally affected by poverty, environmental pollution, natural disasters and conflict.[714] The reasons for this are that children have less capacities to flee from a disaster area and that any harmful consequences affect not only their actual health status but also their future development and opportunities. In many developing countries, children make up more than 40% of the total population.

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711 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 32.

712 Ibidem supra note 694.

713 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 32.

714 See for example the documentary 'Children of the tsunami' on the 2011 disaster in Japan and the effects of the meltdown of Fukushima on the health of children http://vimeo.com/40005340. Furthermore, as a result of the 2010 earthquake in Haïti 1.5 million children were affected (dead, injured, displaced, deprived of basic necessities and schools), out of which 720.000 between 6 and 12 and 494600 under 5. Office of the UN Secretary-General's Special Advisor on community medicine and special lessons form Haïti, available at: www.lessonsfromhaiti.org/relief-and-recovery/key-statistics/. Thirdly, in Syria it was estimated in late 2012, that 2 million out of 4 million affected people were children and 800.000 out of a total of 2 million were displaced. Syria's children: a lost generation? UNICEF Crisis Report March 2011-March 2013.

The most detailed and authoritative source further elaborating on children's right to health in international health law is General Comment 14 of the CESCR. Article 12.2 (a) ICESCR specifies that States have to take steps to ensure 'the provision for the reduction of the stillbirth rate and of infant mortality and for the healthy development of the child' as laid down in article 12.2. According to the CESCR this may be understood as 'requiring measures to improve child and maternal health, sexual and reproductive health services, including access to family planning, pre- and postnatal health care, emergency obstetric services and access to information, as well as to resources necessary to act on that information'. The relevance of the Convention on the Rights of the Child is mentioned in paragraph 22 of General Comment 14 to the CESCR, dealing with the right to health of children and adolescents. It focuses on the duty of States to ensure access to essential health care services for the child and his or her family. Interestingly, General Comment 14 to the CESCR refers to the presumed link in the Convention on the Rights of the Child between access to essential health care and access to child-friendly information about preventive and health-promoting behaviour and support to families and communities in implementing these practices.[715] In this phrasing, the General Comment explicitly introduces and explains the term child-friendly (health) information.[716] More importantly, the requirement of child-friendly health information as a prerequisite to ensure access to essential health services for the child and his family is made even more explicit than it is in the children's rights domain. Whereas the CRC does make mention of the right of children to be informed and supported in the use of basic knowledge of child health and nutrition, the explicit link between the need to receive child-friendly health information to acquiring access to health services is not mentioned. General Comment 4 only addresses the need to provide information on access to sexual and reproductive health services. General Comment 15 significantly elaborates on the requirement to inform and educate children within the regular school curriculum and in medical settings 'in all aspects of health to enable them to make informed choices in relation to their lifestyle and access to health services'.[717] The information required extends 'to a broad range of health issues, including: healthy eating and the promotion of physical activity, sports and recreation; accident and injury prevention; sanitation, hand washing and other personal hygiene practices; and the dangers of alcohol, tobacco and psychoactive substance use.' With regard to sexual and reproductive health, 'education should include self-awareness and knowledge about the body, including anatomical,

715 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 22.

716 U.N. Doc. CRC/GC/2003/A, 1 July 2003, General Comment 4 to the Convention on the Rights of the Child on adolescent health, § 11 and 26–33. See also paragraph 2.5 for a further discussion on children's right to information in health.

717 U.N. Doc. CRC/C/GC/2013/15, General Comment 15 on the right of the child to enjoy the highest attainable standard of health, § 58–61.

physiological and emotional aspects and it should include content related to sexual health and well-being, such as information about body changes and maturation processes.' Education should also include information about how and where to access health information and services. However, in practice, it has been found that the basic knowledge on the opportunities to obtain access to health care for (minor) patients and the way in which referrals are communicated, is crucial in ensuring that these patients do actually reach the referred medical professional.[718] Unawareness of these opportunities jeopardizes the continuity of care for children, because subsequent steps in the medical treatment cannot be (adequately) followed. The explicit connection mentioned in General Comment 14 ICESCR between ensuring access to essential health services for children and families on the one hand and the requirement to ensure access to child-friendly information about preventive and health promotional behaviour is thus of additional value to the interpretation of the children's right to health.[719]

The concept of child-friendly information on health care is thus highlighted in General Comment 14. Age-friendly health care for minors is also put forward in relation to the provision of adequate health services for adolescents. Specifically referred is to youth-friendly health care, requiring at least respect for confidentiality and privacy and the 'opportunity to participate in decisions affecting their health, build life skills, acquire appropriate information, receive counselling, and negotiate health-behaviour choices.[720] Although the specific focus on adolescents seems to exclude younger children from these principles of 'youth-friendly' health care, referral in the following paragraph to the best interests of both children and adolescents as a primary consideration in health care gives room for the application of these principles to children of all ages. This could lead to the conclusion that young children must also have the opportunity to have their privacy respected and have the opportunity for confidential counselling, and participate in health-related decisions, if this is in their best interests.[721] However, especially for younger children, the role of parents is usually more dominant, given the direct dependence of children on their care.

A third element that is central in article 12.2 ICESCR in General Comment 14 is the principle of non-discrimination that is highlighted in ensuring access to

[718] For example in the Netherlands, it was documented that children, their parents and health professionals are not always aware of the way in which they can acquire access to health services. Also letters of referral are required for children without a residence permit though doctors sometimes forget to give these or patients are unaware of the importance and do not understand at all that they were referred to another doctor. See Report of Pharos Foundation, 'Undocumented children and access to hospital care', June 2010. Available at: www.medimmigrant.be/uploads/Gezondheidszorg%20per%20verblijfsstatuut/Eindrapport_Ongedocumenteerde_kinderen_en_de_toegang_tot_ziekenhuiszorg.pdf.

[719] See again article 41 CRC on the application of provisions in international law that are more conducive than the provisions in the CRC.

[720] General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 23.

[721] See for a further discussion on this topic § 2.5.

both the underlying determinants of health as well as physical and mental health services for children. Specific mention is made of the rights of girls to have equal access to all components of the right to health, their need to be protected against harmful traditional practices and the need to provide children with disabilities the opportunity to enjoy a decent and fulfilling life and participate meaningfully in their community.[722]

It thus becomes clear from the elaboration of the right to health in the WHO Constitution, the ICESCR and General Comment 14, that access to essential health services for children and adolescents without discrimination forms part of the minimum core content of the international right to health.[723] This legal obligation is further explained as requiring access to child-friendly health information, involving the need to ensure respect for privacy and provide for the opportunity to have confidential counselling and to participate in health-related decisions, particularly if this in the best interests of the child. In a later chapter, it will be investigated whether and if so when and why, the child-friendly aspect of health care is an essential component of acquiring access to health care in general.[724]

Read in conjunction, the priorities mentioned in § 43-a of General Comment 14, ensure the right to have access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups and in § 44-a, ensure reproductive, maternal (pre- as well as postnatal) and child health care, almost literally phrase this core obligation deriving from the general right to health. Non-discriminative access to health care is thus focused upon as one of the relatively small amounts of core obligations deriving from the right to health, because this is resource-independent.[725] Toebes discusses the fact that articles 2(2) and 3 ICESCR on non-discrimination have immediate effect, given the fact that they contain the terms 'to ensure' and 'to guarantee'.[726] However, Klerk

722 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 22.

723 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 43-a and 44-a.

724 Not only is assumed that child-friendliness is always in the best interests of the child, but that under circumstances child-friendliness is an essential requirement for acquiring adequate access to health care, for example when children are not taken care of by adults at all, as may be the case with orphans, unaccompanied minor asylum seekers, children living in child-headed households and children living in the streets. It may also be the case that children hold important health information that their parents and other caretakers are unaware of (for example acquired or experienced in peer-to-peer contacts), or that an adult tries to conceal information (for example on child maltreatment, abuse or neglect) that the child is only able to communicate in the absence of this adult. The term child-oriented health care may therefore be more appropriate then child-friendly health care, as child-friendliness assumes some level of voluntariness, whereas child orientation can be interpreted as an essential prerequisite to obtaining adequate access to health care.

725 Riedel, supra note 700, p. 30.

726 See also B.C.A. Toebes, *The Right to Health as a Human Right in International Law*, Groningen/Oxford: Intersentia/Hart, pp. 292 and 296.

distinguishes between de iure and de facto modes of discrimination, arguing that legislative measures may have discriminative effect, but that non-legislative measures may need to be taken gradually, obliging States to take affirmative action to prohibit practices of discrimination in horizontal relations.[727] Examples of such discriminative situations are when families tend to systematically prioritize sons or fathers in acquiring access to health facilities or when unmarried pregnant women are not provided with the nutrition and drinking water that they need.

The environmental component of the definition of health can be met by acknowledging that one of the key targets of the right to health is 'to live harmoniously in a total environment' and that this must be achieved in light of any 'changing circumstances'. These circumstances may include climate change, emergency situations due to conflict or natural disasters, financial hardship or economic crises, processes of privatization and decentralization and other policy measures such as the building of roads, railways, chemical factories or nuclear power-stations in the vicinity of children's living environments, potentially impacting upon the realization of the highest attainable standard of their health. Therefore, any measures or developments that have potential negative consequences for the realization of children's right to the highest attainable standard of health should be preceded by health impact assessments, elucidating the effects on the realization of the highest attainable standard of health of children.

4.3. KEY FEATURES OF THE RIGHT TO HEALTH OF THE CHILD IN INTERNATIONAL HEALTH LAW

The concept of 'the highest attainable standard of health' is highly debated, because it is questionable whether one universal standard can be applied across different countries, regions, cultures and situations.[728, 729] Another criticism is whether defining a minimum core content of the right to health, would instigate governments and other actors involved in realizing the right to health to stop investing as soon as that minimum standard of health has been achieved. Therefore, it is important to clarify that the minimum core content of the right to

727 Y. Klerk, 'Working on Article 2(2) and Article 3 of the International Covenant on Economic, Social and Cultural Rights', *Human Rights Quarterly* 1987, Volume 9, pp. 250–267.

728 For a further discussion on the universality of the right to the highest attainable standard of health, see chapter 5 on the right of the child in Europe.

729 See for a discussion on the challenge for child rights advocates to 'achieve universal protection of children's rights and at the same time preserve the cultural integrity of the communities that subscribe to the normative order' T. Kaime, ''Vernacularising the Convention on the Rights of the Child: Rights and Culture as Analytic Tools', *International Journal on Children's Rights* 2010, Volume 18, pp. 637–653.

health is only a first step in a continuing process,[730] being followed by intermediate stages in ensuring the right to health, until the highest attainable standard of health has been achieved.[731]

The first level of 'minimum essential levels of goods and services' has been clearly established in international law, including as a minimum core content 'certain categories of primary health care services, including immunizations and nutritional programs; the obligation to provide certain free services where necessary; adequate information; the availability of skilled health professionals; essential medicines and technologies; and the adoption and implementation of a national strategy and plan of action' these minimum essential levels will necessarily evolve in accordance with increased budget made available, medical and scientific developments and situational developments.[732,733,734,735] Furthermore, the principle of non-discrimination has immediate effect as well as the obligation of States to adopt national health plans.[736] This means that the allocation of (limited) resources must be done in an equitable manner, in a transparent and participatory process in which particular attention is given to marginalized and disadvantaged groups of children. The principle of non-discrimination must be taken into account in States' acts as well as in processes of privatization and decentralization.[737]

730 See General Comment 3 to the International Covenant on Economic, Social and Cultural Rights on the nature of States' Parties obligations, 14 December 1990, § 10.

731 See General Comment 3 to the International Covenant on Economic, Social and Cultural Rights on the nature of States' Parties obligations, 14 December 1990, § 9. It states that 'the fact that realization over time, or in other words progressively, is foreseen under the Covenant should not be misinterpreted as depriving the obligation of all meaningful content. It is on the one hand a necessary flexibility device, reflecting the realities of the real world and the difficulties involved for any country in ensuring full realization of economic, social and cultural rights. On the other hand, the phrase must be read in the light of the overall objective, indeed the *raison d'être*, of the Covenant which is to establish clear obligations for States parties in respect of the full realization of the rights in question. It thus imposes an obligation to move as expeditiously and effectively as possible towards that goal.'

732 See General Comment 3 to the International Covenant on Economic, Social and Cultural Rights on the nature of States' Parties obligations, 14 December 1990.

733 United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health, initial report on sources and content of the Right to Health U.N. Doc. E/CN.4/2003/58.

734 United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health, report on progress and obstacles to the health and human rights movement, in addition to cases on the right to health and other health-related rights U.N. Doc. A/HRC/4/28.

735 See also various training toolkits on the right to health, such as the Manual on the right to the highest attainable standard of health of the Human Rights Centre of the University of Essex and the International Federation of Health and Human Rights Organisations, available at: www.paho.org/hr-ecourse-e/assets/_pdf/Module2/Lesson1/M2_L1_4.pdf. See also *The Right to Health: a Resource Manual for NGOs* Asher, Judith, 2004, available at: www.shr.aaas.org/Right_to_Health_Manual/index.shtml.

736 See U.N. Doc. E/C.12/GC/20, General Comment 20 to the International Covenant on Economic, Social and Cultural Rights on the nature of States' Parties obligations, 2 July 2009, § 7.

737 See for a discussion of the relation between privatization of the Dutch health care system and the key elements of the right to the highest attainable standard of health: B.C.A. Toebes, 'The

The right to health as identified in the CESCR contains certain freedoms, such as the right to be free from non-consensual treatment and medical research and the right to be free from torture and other cruel, inhuman, degrading treatments.[738, 739] This includes child maltreatment, sexual abuse and traditional harmful practices such as female genital mutilation. The right to health also contains certain entitlements, such as the right to prevention, treatment and control of diseases, equal and timely access to basic health care, access to essential medicines and participation of the population in health related decisions at national, community and individual level.[740] The identified requirement to arrange for child-friendly health information is crucial for ensuring children's right to meaningfully participate in health decisions.

General Comment 14 to the ICESCR identifies four key elements that must be established in realizing the right to health in the provision of (basic) health services, goods and facilities: availability, accessibility, acceptability and good quality.[741] The approach of identifying key elements for interpreting a social right was initially developed by Katarina Tomasevski, the UN Special Rapporteur on the right to education.[742] However, the list of four was slightly different and not considered to be definitive. The list included the concept of adaptability, which is defined as 'the ability to evolve with changing needs of society, contribute to challenging inequalities, be locally applied and adapted to the specific context'. The element of adaptability is very useful for the interpretation of the right to health, since health needs differ widely across different regions and localities. Furthermore, in the context of the interpretation of the right to health, additional elements have been suggested including accountability, participation, patient satisfaction and effectiveness,[743] although this last one has also been identified as

right to health and the privatization of national health systems: a case study of the Netherlands', *Health and Human Rights* 2006; Volume 9, Issue 1, pp. 102–127.

738 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 34–37.

739 Riedel (supra note 683, p. 26) distinguishes between the 'freedom dimension' and the 'entitlement dimension'. These issues are highly relevant for structuring the right to health of the child, as the tension between children's autonomy, i.e. their right to participation, always has to be balanced against their right to health and their right to protection, aiming to result in the best possible outcome with regard to the best interests of the child.

740 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 34–37.

741 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 12.

742 K. Tomasevski, *Human Rights Obligations: Making Education. Availability, Accessibility, Acceptability and Adaptability*, Gothenburg: RTE Primers, January 2001.

743 See B. Toebes, A. Hendriks & K. Stronks, 'Health inequalities and the social determinants of health', in: *Health and Human Rights in Europe*, edited by Toebes, Hartlev, Hendriks and Herrman, Groningen: Intersentia 2012, pp. 227–247, particularly p. 218.
See also example the submissions of E. Kabengele Mpinga and P. Chastonay of the University of Geneva and of Nolan, E. Yamin, and B.M. Meier for the preparation of General Comment 14 to the CRC on children's right to health, available at: www2.ohchr.org/english/bodies/crc/callsubmissionsCRC_received.htm.

an element of the principle of quality.[744] All elements relate to both the underlying determinants of health and to the health care services itself. Below, the identified factors included in General Comment 14 to the ICESCR are specifically explained for interpreting children's right to health.[745] Consequently, the other elements are discussed for their usefulness in interpreting the right to the highest attainable standard of health.

4.3.1 AVAILABILITY

Availability means that underlying determinants of health and functioning health services must be available in sufficient quantities.[746] This refers to the absolute number of health institutions and professionals in a country and also to the distribution of infrastructure and medical services over geographical areas. A high number of hospitals in the capital does not mean that sufficient medical services are available in rural areas nor in all areas of the city. For example, it may occur that certain areas can benefit from high quality medical services, whereas others lack even the most basic services. Applied to children, the requirement of availability also means that there must be sufficient health services and health professionals specifically trained for delivering child-appropriate health care available. Given the explanation of the provisions in article 12.2a ICESCR to ensure pre- and postnatal health care, as well as emergency obstetric care, this means that pregnant women should be able to reach such health facilities within a limited period of time. Research in the Netherlands has indicated that when pregnant women have to travel more than 20 minutes to a hospital, infant mortality rates significantly increase.[747] Therefore, the distance to obstetric health care should maximally be 15 minutes and that women should be treated promptly upon arrival in the hospital.

The principle of availability also refers to the availability of appropriate drugs and to the underlying determinants of health for children. With respect to the availability of drugs that are appropriate for children, it must be noted that even

744 See for example the submissions of Harm Reduction International: www2.ohchr.org/english/bodies/crc/docs/CallSubmissions_Art24/HRI_YouthRISE_EHRN.pdf.

745 The Committee on the Rights of the Child has endorsed the AAAQ-framework in U.N. Doc. CRC/GC/2003/A, 1 July 2003, General Comment 4 to the Convention on the Rights of the Child on adolescent health, § 41.

746 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 12a.

747 In May 2012, the Dutch media reported on the closure of hospitals in some rural parts of the Netherlands, thereby increasing the travel time for women in labour to more than 40 minutes. This is a serious violation of children's right to health, as it poses increased risk to infant death in case of emergencies during pregnancy or delivery. See: www.ad.nl/ad/nl/4560/Gezond/article/detail/3252971/2012/05/09/Kleinste-ziekenhuis-van-Nederland-boos-over-sluiting-geboortezorg.dhtml.

in developed countries, limited research is done on the child-appropriateness of drugs for children, resulting in limited availability of appropriate drugs.[748, 749]

4.3.2. ACCESSIBILITY

4.3.2.1. No de iure and de facto discrimination

The second factor of the right to health is accessibility, consisting of four dimensions.[750] The first dimension entails that accessibility of health services means that there should not be any *de iure* or *de facto* discriminative barriers in place, excluding certain (vulnerable) groups such as disabled children, girls, children from minority groups or children without official residence permits from having access to health care services. Specifically for children, the prevention of any instances of discrimination may entail the provision of age-adapted services and waiting areas. For example, children have indicated that they value low reception desks, so that they can see the person they are talking to.[751] Also, as children often have school hours to adhere to, the opening hours of health are influential to their inclination to visit a doctor.[752] Lastly, as children are largely dependent on their parents or caretakers, they should not be blamed for any actions of their parents, for example when the family resides illegally in a country or when parents are in jail and are not able to take their children to a doctor. Also, the ability of parents to take their children to a doctor during working hours contribute to better accessibility of health services for children.

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748 In order to tackle the problem of the limited availability of information on child-appropriate drugs and in line with EU Regulation 1901/2006, an expert group of pediatricians has been established in the Netherlands in 2006. Also, the Dutch Ministry of Health has funded the Dutch Knowledge Centre for Pharmacotherapy in children (NKFK-Nederlands Kenniscentrum voor Farmacotherapie bij kinderen) to develop national guidelines for prescribing medicines for children and developing a teaching module on pharmacotherapy in children for pediatricians. See for more information on the NKFK: http://nkfk.nl/.

749 It was recognized by the Dutch Minister on Health in January 2011 that pharmaceutical companies do also have a responsibility in ensuring sufficient research on the appropriate medicines for children. See letter of the Minister of Health of the 21st January 2011 in reply to parliamentary questions on medicine use in children, reference GMT-U-3036517. This standpoint is in line with the recommendations in paragraph 55 and 56 in General Comment 14 of the Committee on Economic, Social and Cultural Rights, specifying that States Parties should take steps to ensure that the private business sector considers the importance of the right to health in their activities.

750 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 12b.

751 U. Kilkelly & M. Donnelly, 'The Child's Right to be heard in the Healthcare Setting: perspectives of children, parents and health professionals', Office of the Minister of Children of Ireland, The National Children's Strategy Research Series, October 2006, pp. 37–46.

752 M. Whitehead, 'The concepts and principles of equity and health', *Health Promotion International* 1991, Volume 6, no. 3, Oxford University Press, p. 221.

4.3.2.2. Economic accessibility

The second dimension of accessibility is economic accessibility. This dimension requires that all health services must be affordable to all, including socially disadvantaged groups. With respect to children, the prevention of *de facto* or substantial discrimination in having economic accessibility requires specific attention for children without official birth registration or residence permits limiting access to health insurances, for children whose parents are not adequately insured and may therefore lack the necessary documents to gain access to health facilities and last but not least for children who don't have parents or guardians at all to ensure the payment for their health care services. In conjunction with the dimension of non-discrimination, the dimension of economic accessibility thus entails that financial support systems should not exclude certain groups of children from health care insurances, thereby indirectly limiting access to health care services.

As phrased in General Comment 14 on the right to the highest attainable standard of health 'Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.'[753, 754, 755, 756] Whitehead has identified seven determinants of health 1. natural variation, 2. health-damaging behaviour such as high risk sports, 3. health-promoting behaviour of one group over another (eating fruit and vegetables and sporting), 4. health-damaging behaviour resulting from limited choices, for

753 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 12.

754 The WHO definition of equity in health is that this 'implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that no one should be disadvantaged from achieving this potential, if it can be avoided.' WHO 1986a Social Justice and Equity in Health: Report on a WHO Meeting, Leeds, United Kingdom, 1985.

755 Whitehead defines the concept of equity in health care as 'Differences or variations in health statistics that are unnecessary and unavoidable and in addition are also unfair and unjust.' See: M. Whitehead, 'The concepts and principles of equity and health', *Health Promotion International* 1991, Volume 6, Number 3, Oxford University Press, pp. 219–220.

756 Ernest Gruenberg argued in 1968 that there is in our society 'a pattern in which the prevalence of illness is an inverse function of family income, while the volume of medical care received is a direct function of family income'. Whereas governments in the west have increasingly recognized that such inequalities, give rise to inequities, they are now faced with the almost unbearable costs of their health systems. For example, in the Netherlands, the expenditure on health constitutes the largest post on the governmental budget for 2012. Also in the USA, health care spending as a share of U.S. Economic Output has been rising steadily over the past 45 years (5% of GDP in 1960 – 15% of GDP in 2002), so that increases in income between 2020–2009 have been almost completely wiped out by increases in health costs. See: D.P. Goldman, E.A. McGlynn, *U.S.Health care, Facts about costs, access and quality*, 2005, p. 3. Available at: www.rand.org/pubs/corporate_pubs/2005/RAND_CP484.1.pdf.
Between 2001–2010, health insurance premiums in the USA increased by 178%. See for example: S.S. Jones, J. Caloyeras & S. Mattke, *Power to the People: The Role of Consumer-Controlled Personal Health Management Systems in the Evolution of Employer-Based Health Care Benefits*, p. iii. Available at: www.rand.org/content/dam/rand/pubs/occasional_papers/2011/RAND_OP352.pdf.

example limited available services in ones living environment 5. unhealthy living or working situations, 6. inadequate access to health services, 7. health-related social mobility, involving the tendency of sick people to move down the social scale.[757] Whitehead argues that the first three factors are generally not considered as inequities, whereas the last four are considered to be either avoidable or unjust. However, healthy behaviour (#3) is also influenced by a lack of resources and by the level of education of people. Therefore, it can be argued that also this factor contributes to the level to which the right to health of the child is attained.

It appears from these health determinants that having a free choice and structural vulnerability are thus crucial aspects that guide the qualification of health related practices as equitable. This leads to the suggestion that actions to improve the right to health of children must focus on enhancing both their, and their parents capacity, to adopt healthy lifestyles. In order to achieve this, three different pathways must be involved. In the first place, it must be ensured that families with lower incomes are provided with sufficient resources to pay for their medical costs and for the underlying determinants necessary to engage in healthy lifestyles, either directly or indirectly through medical and other social insurances.[758] Secondly, children and their families must be provided with health related information to actually enable them to understand their health status and make healthy choices.[759] Thirdly, they must be given the structural opportunity to participate in medical program development so that they can indicate what the most important (health) challenges encountered in their daily lives are, supported by indicators on the actual health status of (vulnerable) groups of children.[760] Only through active involvement of seemingly helpless or vulnerable children and families, will they be able to take ownership of their own health status and

757 M. Whitehead, 'The concepts and principles of equity and health', *Health Promotion International* 1991, Volume 6, no. 3, Oxford University Press, p. 219.

758 Szasz argues that the State can protect and promote the interests of the sick either by coercing physicians to serve patients or by creating moral, economic and political circumstances to provide the conditions necessary for the exercise of free and responsible individual choices. According to Szasz, these modes of operation reflect underlying presumptions about the role of the State in ensuring the right to health being either highly dominant and directive or on the other hand limiting its own power to provide room for society to fill in this duty. See: T.S. Szasz, 'The Right to Health', *The Georgetown Law Journal* 1968–1969, Volume 57, pp. 734–751.

759 In addition to the rights-based arguments to enhance children's and families' level of basic health knowledge, arguments are also found on the economic level; as a response to the rising costs of health care in many wealthier countries, the costs and potential benefits of personally controlled health management systems are increasingly investigated. See for example: S.S. Jones, J. Caloyeras & S. Mattke, *Power to the People: The Role of Consumer-Controlled Personal Health Management Systems in the Evolution of Employer-Based Health Care Benefits*. See also the initiative: *Helping families raise healthy children*, available at: www.rand.org/health/projects/healthy-children.html.

760 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 57–58.

develop into independent actors in improving their own and their community's health status.[761]

The concept of economic accessibility extends to making a balance between budget allocation to respond to individual health claims and financing public health programs. General Comment 14 elaborates that the principle of economic accessibility entails that 'health resource allocations should not favor expensive curative care at the expense of preventive public care, benefiting a larger population.[762] In this respect, MacNaughton distinguishes the concepts of one-to-one equality, applicable to every individual identically, such as the right to have a name and bloc equality, requiring equality between blocs such as boys and girls or different groups of vulnerable children having the right to equal access to health, but not necessarily within the different blocs.[763]

A common institutionalization of bloc discrimination is seen in the dichotomy between public and private insurance systems, sometimes resulting in entirely separate health care systems wherein the wealthier benefit from more extensive health services than the poor do, being dependent on the public system. Whitehead even states that 'in general, those most in need of medical care, including preventive care, are least likely to receive high standards of services'.[764] Especially with respect to children, there is no legal basis to justify such discriminatory health care systems.[765]

In international human rights law, focus is usually placed on bloc equality, for example equality between children from different socio-economic groups.[766] Violations of one-to-one equality may arise before a Court when an individual claimant receives a benefit that others do not receive.[767] When such benefits are structurally granted on the basis of individual claims for the right to health, this may also lead to violations of bloc-equality, as wealthier families usually have better access to the judicial system through both financial and social resources and therefore have a better chance of obtaining individual benefits for ensuring their right to health at the expense of health costs being allocated to public health

761 L. London, 'What is a human-rights based approach to health and does it matter?', *International Journal on health and human rights* 2008, Volume 10, no. 1, p. 68.

762 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 19.

763 MacNaughton, 'Untangling equality and non-discrimination to promote the right to health care for all', *Health and Human Rights* 2009, Volume 11, no. 2, p. 47–63.

764 M. Whitehead, 'The concepts and principles of equity and health', *Health Promotion International* 1991, Volume 6, no. 3, Oxford University Press, p. 218.

765 In unifying the benefits of the different health systems, the Court of Colombia decided that priority had to be given to children and then progressively to adults. See: *Corte Constitutional de la República de Colombia, Sala Segundo de Revisión* (2008), Constitutional Court of Colombia, Sentencia, No. T-760 de 2008.

766 Ibidem supra note 763, MacNaughton.

767 General Comment 14 states that any person or group victim of a violation of the right to health should have access to effective judicial or other appropriate remedies at both national and international levels through reparation, such as restitution, satisfaction or guarantess of non-repetition.

programs for poor families, 'given that resources are always scarce in relation to the health needs of the population as a whole'.[768] Therefore, individuals who manage to get access to the court and who are on that basis granted access to health services are privileged over others who do not manage to start a litigation procedure.[769] This is especially troublesome for children without parents taking care of them, as they often have no opportunity to go to Court at all, even if they are aware of the possibility. Some therefore argue that claims based on the right to health should only be undertaken collectively.[770] Motta Ferrez argues that such actions would lead to enormous numbers of claimants and consequently to unmanageable costs and that it would be more effective to prevent that individual claims rise to an unlimited level of medical care seems to be more in line with reality.[771] Given the seemingly limitless growth in medical opportunities and concomitant medical costs, this option seems to give room to a more equitable solution, in which the core content of the right to health, namely access to primary health care for all can and should be achieved as a priority. Current debates on the price-setting for highly specific, though scarcely used medicines are relevant in this context,[772] because extremely high costs for individuals may pose an enormous barrier to ensuring economic accessibility to basic levels of health care for many others.

MacNaughton argues that protecting one-to-one equality provides 'the balance between the collective right to equality in health care and individual claims for health benefits by requiring that benefits available to one be available to all'.[773] Interesting about this standpoint is that it places individuals and their actual enjoyment of health care at the heart of the health system. Unclear however

768 O.L. Motta Ferraz, 'The right to health in the courts of Brazil: worsening health inequities?', *International Journal on Health and Human Rights* 2009, Volume 11, no. 2, p. 33.

769 Ibidem supra note 768. Motta Ferraz demonstrates that this phenomenon is widespread in Brazil and growing to 'significant levels in terms of volume and costs', (p. 36). He concluded that such a model of litigation therefore has potential negative effects on health equity. The result is a 'lack of opportunity to achieve good health because of factors beyond individual control such as discrimination and severe poverty, as opposed to personal free choices'. This is exemplified by higher infant and child mortality rates in families with lower incomes.

770 F. Hoffman & F. Bentes, 'Accountability for social and economic rights in Brazil', in: V. Gauri & D. Brinks, *Courting Social Justice: Judicial Enforcement of Social and Economic Rights in the Developing World*, Cambridge University Press 2008, pp. 100–145.

771 Ibidem supra note 768, p. 41.

772 In the Netherlands, the discussion over the price-setting of extremely expensive medicines was instigated after the appearance of two concept-advices to the Dutch Minister of Health by the College for Health Insurances the 'College Zorgverzekeringen', on the financing of medicines for the Pompe and Fabry diseases. See: http://content1a.omroep.nl/3dfedaca6f6328b38f6fbc84d3840caf/501fafa4/nos/docs/290712_pompe.pdf. See also the comments made by professor in ethics Dupuis on the Dutch Radio, stating that it is necessary to draw lines in the public financing of medicines, because many new and highly expensive medicines will appear on the market in the near future, whereas the costs for these medicines would significantly increase the total costs of health care and thereby subvert the functioning of the entire society. Interview in 'Dichtbij Nederland' on 3 August 2012, available at: http://dichtbijnederland.nps.nl/page/detail/794371/%27In+Nederland+was+Friso+al+opgegeven%27.

773 Ibidem supra note 746, MacNaughton, p. 56.

remains how poor, orphaned children are informed about their right to get such a benefit for individual health.

4.3.2.3. Physical accessibility

The third dimension of accessibility, namely physical accessibility, requires that the location of the health services can be easily and safely reached by all. This means that health services must be within a reasonable distance from families and their children, also in rural, mountainous or distant regions, that transport is physically accessible (e.g. for children in wheelchairs, blind children) and affordable to take (sick or injured) children timely to a health facility and that parents or other caregivers are given the opportunity to take their child to hospital when they are ill. This requires for example that parents are allowed to leave work when their child needs to go to a health facility, especially when no other persons are available to take them there.

4.3.2.4. Information accessibility

The fourth dimension of accessibility is information accessibility. This dimension provides that people have 'the right to seek, receive and impart information and ideas concerning health issues.'[774] Specifically for children, this means that leaflets are written in understandable language and supported by age-appropriate pictures, so that they will be able to understand their medical condition and prognosis and support them in making choices for the preferred medical treatment. It is also required to directly speak to children to explain their medical conditions, prognosis and options available for them. The right to information accessibility however, should not limit children's right to medical confidentiality and privacy; whereas children's medical data must be easily available for the children themselves, the provision must be done with high prudence, so that only the children (and their parents or caretakers) obtain access. Information accessibility is thus limited to the actors that are directly involved with a child's medical treatment.

As clarified from the analysis of General Comment 14, child-friendly, or child-oriented information often is an essential requirement to ensure access to health care at all: without understandable and relevant information, many children will not be able to reach their doctor.

[774] General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 12.

4.3.2.5. Organizational accessibility

In 2008, the World Health Organization renewed its interest in the importance of the primary health care approach as laid down in the Declaration of Alma-Ata (1978).[775] As part of the Declaration, the WHO developed the concept of 'organizational accessibility'. This concept refers to convenient office hours, out-of office hours, the possibility to have distance consultations and consultations by phone or through internet, short waiting times and the possibility of home visits. Although not included in General Comment 14 to the ICESCR, the practical value of these aspects of the element of access, makes it highly relevant for the interpretation of children's right to health, although it does need adaptation to meet the particular needs of children. For example, office hours should be adapted to school hours. Another suggestion is to ensure the location of medical services in close proximity to schools and day care facilities for children.

4.3.3. ACCEPTABILITY

The factor of acceptability requires respect for medical ethics and cultural and gender-sensitive aspects of health care.[776] Interestingly, § 12 of General Comment 14 of the ECOSOC Committee specifically mentions the requirement that health facilities must be sensitive to 'life-cycle requirements'. This unmistakably involves the requirement to ensure that health services respect the rights and needs of children of all ages, especially since the 'right to maternal, child and reproductive health' is explicitly mentioned in § 12.2 (a). This can be interpreted as such that health facilities must be responsive to the needs of children of different ages and also as such that they must be responsive to the needs of children in different phases of a chronic or terminal disease. For example, a 7-year old that is infected with HIV/AIDS or a 5-year old who suffers from leukaemia, may be at the end of his or her entire life cycle. Therefore, health facilities must simultaneously apply for both 'age- ánd stage (or phase)' associated needs of children. Secondly, given the particular mentioning of the need to respect for confidentiality in health care, it can be concluded that health care that is sensitive to life-cycle requirements, must also ensure children's right to informed consent and that this may require additional efforts to enable children to be effectively involved. Thirdly, § 12 establishes that all health facilities, goods and services must be respectful of the culture of individuals, minorities, peoples and communities. Girls must preferably be examined by female doctors or at least in the presence of female employees in order to prevent any risks of abuse. Furthermore, the health care offered to

775 *The World Health Report 2008, Primary Health Care – Now More Than Ever*, Geneva, World Health Organization, 2008. Available at: www.who.int/whr/2008/en/index.html.

776 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 12-c.

children must take into account as much as possible the wishes and traditions of (parents of) children from different cultures and religions, as long as these do not harm the best interests of the child, as may be the case with female genital mutilation. Sensitive discussions arise when alternative views on (children's) health in a society clash with more dominant health views as is the case when parents in the Netherlands refuse to vaccinate their children against the major childhood diseases as is laid down in the National Vaccination Program.[777]

Last but not least, the element of acceptability requires that health facilities must be designed to improve the health status of those concerned. This provision is in line with the medical ethical principle of 'primum non nocere', or 'doing no harm', which brings about that medical treatments may only be performed for improving the individuals' health status. It is thus not permitted to perform medical treatments that have no beneficial effect to the individual undergoing the treatment in order to acquire academic insights that potentially benefit the treatments of others with similar medical conditions (in the future), as this would not improve the health status of the individual concerned.

4.3.4. QUALITY

The fourth factor requires that health facilities, goods and services are of good quality. In the phrasing of § 13 of General Comment 14 to the ECOSOC Committee, this means that health facilities, goods and services must be scientifically and medically appropriate and of good quality. The key elements of this factor of health have been identified as effectiveness, efficiency, safety and patient-satisfaction.[778]

Applied to the provision of health care for children, the element of quality requires that professionals are adequately trained to diagnose, treat and communicate with children of all ages, that drugs are unexpired and scientifically tested and approved for children and that hospitals have adequate equipment, drinking water and sanitation.

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[777] The National Vaccination Program for children in the Netherlands (het Rijksvaccinatieprogramma) was established by the Dutch Government in 1957 and aims to protect all children from dangerous or deadly infectious diseases. Vaccinations against 12 major diseases are offered without any costs for the parents: 1. cervical cancer for girls, 2. mumps, 3. diphtheria, 4. disease due to Haemophilus influenza type B (Hib), 5. hepatitis B, 6. pertussis (whooping-cough), 7. measles, 8. Meningococcal disease due to serogroup C, 9. pneumococcal disease, 10. poliomyelitis, 11. rubella, 12. tetanus. While participation is not compulsory, over 95% of parents consent to having their children vaccinated. See for more information: www.rivm.nl/Onderwerpen/Onderwerpen/R/Rijksvaccinatieprogramma/National_Immunisation_Programme.

[778] Lecture of Director UNICEF Europe, Steven Allen on the occasion of the adoption of the Guidelines on child-friendly healthcare by the Council of Europe Member States in Lisbon, September 2011.

With respect to the applicability of medicines for children, it was found in the Netherlands that 40–80% of the drugs are not specifically tested for children.[779] The exact percentage differs per age group, mode of admission and type of disease and is the lowest for newly born children and infants.[780] Even if medicines are specifically registered for children, the form in which they are registered (e.g. relatively big capsules) may only be suitable for older children, whereas younger children prefer other modes of admission (small and tasteful capsules). Unavailability of such pills affects therapy compliance and the effectiveness of therapies prescribed.

For now, doctors often prescribe medicines as a percentage of the adult body weight. There is as such not an evidence-based, but an experience-based medical treatment applied. Exemplified by the expression that 'Children are no small adults', this establishes the risk that children suffer from unforeseen side-effects and ineffective treatments. This can lead to longer hospital stays, additional treatments to reduce negative (side-)effects, ineffective treatments as well as preventable infant deaths.[781] Therefore, more research is required upon the potential (side-effects) of medicines on children. In doing so, it is necessary to find a better balance between the need to protect minors against the potential harmful effects of unregistered medicines on the one hand and the need to increase knowledge on the other hand.[782, 783] Although recent developments are intended to create more room to undertake research on the appropriateness of medicines for children, medical professionals have urged that it remains crucial to minimize any potential negative effects for children, especially when a treatment proposed

779 Report ZonMw 'In-depth study 'Goed Gebruik Geneesmiddelen', 11 June 2010 carried out for the Ministry of Health subsequent to a preliminary report of 20 July 2009.

780 Ibidem supra note 779.

781 It was found in the Netherlands that 2,5% of the hospital admissions of children are caused by medicine intake, of which an estimated 30% was preventable. Ibidem supra note 78.

782 In the Netherlands, the Commission Doek came to the conclusion that the actual Dutch legislation poses too many limits for conducting research on medicines for children. It proposed to change the basic principle from 'no, unless' to 'yes, unless'. In deciding upon a potential intervention for children, the potential risks for the individual child must be balanced against the potential benefits of the research. The Commission suggested that intervention research with children should be allowed if there is to be expected any direct advantage for the test person or the group of children with a similar medical condition. See: Commissie-Doek, *Advies medisch-wetenschappelijk onderzoek met kinderen*, Den Haag, 26 November 2009.

783 In the European Union, the Pediatric Regulation came into force on 26 January 2007. The new paediatric legislation comprises Regulation (EC) No 1901/2006 and the amending Regulation (EC) No 1902/2006 and obliges pharmaceutical companies to specifically test medicines for children. Aims of the regulation are 1) to facilitate the development and availability of medicines for children aged 0 to 17 years, 2) to ensure that medicines for use in children are of high quality, ethically researched and authorised appropriately and 3) to improve the availability of information on the use of medicines for children, all without subjecting children to unnecessary trials. The regulation has resulted in an increase in applications to the pediatric committee of the European Medicines Agency (PDCO) and in an increase in registrations of medicines for children. For more information see: www.ema.europa.eu/ema/index.jsp?curl=pages/special_topics/general/general_content_000302.jsp&mid=WC0b01ac058002d4ea.

does not directly benefit the health of the child who undergoes the treatment.[784] Only when such stringent requirements are respected, can individual children be protected against heavily burdensome medical treatments.

4.4. PATIENT INVOLVEMENT AS A KEY CONSTITUENT ELEMENT OF THE RIGHT TO HEALTH

The identification of the 'AAAQ-structure' as a basis for analysing the right to health has been established in General Comment 14 to the ICESCR.[785] Increasingly, the principles of 'accountability' and 'participation' are recognized as constituting key elements of the right to the highest attainable standard of health.[786] Accountability has been described by Potts as 'the process that requires the government to show, explain and justify how it has discharged its obligations regarding the right to the highest attainable standard of health. It is thus about holding all responsible actors accountable for their human rights violations, but also, and more constructively about assessing the progress made in realizing the highest attainable standard of health. Five distinct forms of accountability have been distinguished, namely judicial, quasi-judicial, administrative, political and social.[787] All these forms are interlinked and thereby lead to a community wide process for involving all stakeholders in the realization of children's right to health. A further discussion of the role of all relevant stakeholders in the realization of the right to health of the child will be presented in chapter 6.

The principle of participation aims to involve the individual patients and the population at large in the health-decision making process. Potts argues that 'an important purpose of participation in the context of the right to health is to recognise and respect differences and diversity within the population, and to ensure inclusiveness in the development of health policy'. As such, involving children in a participatory manner in their own health care is an essential step in revealing and including their particular needs in the organisation of their

784 F. van Agt, L. Damen & F. Huysmans, 'Jonge proefpersonen zijn kwetsbaar' [Young test persons are vulnerable], *Medisch Contact* 2010, 65 no. 13, 1 April, p. 629. The authors advocate for a twofold ethical basis that 1) it is authorized to involve children in research if it can only be exercised with children and if the risks and negative side-effects are minimal. 2). This condition is not applicable if participation in the clinical research directly benefits the children, for as far as negative (side-)effects are part of the regular treatment. This means that terminally ill children may undergo a new medical treatment, if there is a chance that this treatment will be beneficial to their medical condition and prospects.

785 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 12.

786 H. Potts, *Participation and the Right to the Highest Attainable Standard of Health* and *Accountability and the Right to the Highest Attainable Standard of Health*, University of Essex, Human Rights Centre/Open Society Institute, 2008. See also Riedel, supra note 678.

787 See supra note 769, Potts and Riedel supra note 683, Riedel.

health care and in the health-care decision making process. Potts gives several examples of how this element of participation can be realized in practice, including interviews, focus group discussions, forums, conferences, local health committees and public meetings.[788] Other options would be to allow children to create children's newspapers, perform role or theatre plays, poems, songs, photos, drawings and other ways of artistic expression.

General Comment 15 has included the AAAQ-structure for the children's rights domain, as was suggested by various experts in the preparation phase of this General Comment.[789] It therefore is a valid structure to follow in analysing the level of realization of the right to health of the child. In addition, the principle of 'patient-satisfaction' has been introduced as a key element of the right to the highest attainable standard of health of the child in the contribution of the University of Geneva.[790] This principle of 'patient-satisfaction' has been analysed for its applicability to measure the realization of the right to the highest attainable standard of health.[791] It was found that there is a high correspondence between the recommended or collected items for patient satisfaction and the other four key constituent elements (AAAQ) of the right to health as defined by General Comment 14 to the ICESCR. The authors therefore conclude that patient satisfaction could prove a 'natural' right to health indicator, covering all other key constituent elements of the right to health.[792]

Applying patient satisfaction as a key element of the right to health has several advantages. In the first place, it tackles the problems of limited or contradicting data collection on the other constituent elements of the right to health and of inadequate monitoring or reporting by States, because 'patient satisfaction studies are frequently implemented in health services throughout the world'.[793] Furthermore, integrating the component of 'patient satisfaction' as a constituent element in the AAAQ-structure of the right to health, allows for applying a patient-centred approach to health care, involving the views, experiences and psychological dimensions of patients in assessing and improving the right to the highest attainable standard of health. Such a patient-centred approach could be translated to a child-centred approach in children's health care. In such a way, ensuring the best interests of the child and the right to participation of children

788 Ibidem supra note 769.

789 See for example the submissions of the Royal Australian College of Physicians, the submission of Professor A. Nolan a.o., the Committee for Human Rights Sweden, Harm Reduction International a.o., the International Planned Parenthood Federation and Spronk. www2.ohchr.org/english/bodies/crc/callsubmissionsCRC_received.htm.

790 See the contribution made by Professor E. Kabengele Mpinga and Professor P. Chastonay of the University of Geneva to the call for submissions on the interpretation of children's right to health, available at: www2.ohchr.org/english/bodies/crc/docs/CallSubmissions_Art24/UniversityofGeneva.pdf.

791 E. Kabengele Mpinga, & P. Chastonay, 'Satisfaction of patients: A Right to health indicator?', *Health Policy* 2011, 100, pp. 144–150.

792 Ibidem supra note 774.

793 Ibidem supra note 774.

in medical care can be integrated in the general framework of the right to health of the child.

Kabengele Mpinga and Chastonnay present several arguments in favour of applying patient satisfaction as a right to health indicator:[794]

> '– From a *legal point of view*, patient satisfaction has become a legal obligation in many states and is often considered as an element of the quality of care.'
>
> '– From *the point of view of implementing the right to health* in the health systems, patient satisfaction does integrate the recommended "participative approach" as identified by the Special-Representative on the Right to Health Paul Hunt.[795]'

Criticisms on applying patient satisfaction as a constituent element of the right to health point to the lack of consensus on the concept of patient satisfaction, the intrinsic subjectivity and the strong clinical orientation of patient satisfaction studies.[796] International consensus on the concept of patient satisfaction as an element of the right to health should be reached in order to allow for international comparison of studies on patient satisfaction and thereby possibly on assessing the level of realization of the right to the highest attainable standard of health of patients. Defining such a concept should account for any possible unpredictability due to the intrinsic subjectivity of the concept of patient satisfaction. However, it is exactly the acceptance of a certain degree of unpredictability that allows for patient involvement in assessing and raising the standard of the right to health. By taking the voice of the patient into account in the setup of medical services and in the selection of medical treatments, the concept of the highest attainable standard of health will be more responsive to patient needs. Whereas it has previously been acknowledged that the highest attainable standard of health is dependent upon

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794 Ibidem supra note 774. Other arguments presented include: 'From *a political point of view* it is a democratic necessity to listen to the opinions of patients in accordance with the concept of participation as a central feature to the harmonious functioning of modern societies. Some argue that participation of patients is assumed to restore confidence in health services and that it strengthens the power of patients and facilitates their integration into the decision making process.' See also: H. Vuori, 'Patient satisfaction – does it matter?', *International Journal of Quality in Health Care* 1991, 3, pp. 183–189. See also: R. Chambers, C. Drinkwater & E. Boath, 'Involving patients and the public: How to do better?', *Radcliffe Medical Press* 2003, Abingdon, p. 158. 'From a sociological point of view, the technical, social and economic evolutions have transformed the relationship between patients and health professionals with new expectations from both parties; therefore integrating the opinion of patients into the therapeutic strategy strengthens the partnership dimension of care weakening the obsolete paternalistic approach, which once was (too often still is) the key feature of the therapeutic relationship.' See also: K. Taylor Paternalism, 'Participation and partnership-the evolution of patient centeredness in the consultation', *Patient Education and Counseling 2009*, 74, pp. 150–155.

795 P. Hunt & G. Backman, 'Health systems and the right to the highest attainable standard of health', *International Journal on Health and Human Rights* 2008, Volume 10, no. 1.

796 Ibidem supra note 791. See also: K.D. Hekkert, S. Cihangri a.o., 'Patient satisfaction revisited: a multilevel approach', *Social Science and Medicine* 2009, pp. 68–75. See also: L. Gill & L. White, 'A critical review of patient satisfaction', *Leadership in Health Services* 2009, 22(1), pp. 8–19.

financial and human resources, political will to realize such a standard and local circumstances, the individual perceptions and health choices of patients play a significant role in defining and achieving the highest standard of health.[797] For example, some terminally ill people wish to continue their medical treatments to prolong life with some months or years. Others, on the other hand, choose for a termination of medical treatments and accept the risk of more rapid deterioration of their physical health status. Individual health choices therefore do certainly impact upon the attainment of the highest attainable standard of health that is actually reached in terms of for example, infant, child and maternal mortality rates and life expectancy. The central role attributed to the individual patient (and his/her parents) is specifically acknowledged in the definition of health as introduced by Huber (see chapter 1), in which self-management by the individual and adaptability are two constituent parts.

The standard of health that is attained can be measured on the basis of objective criteria, such as number of available health services, staff and medicines, but this may still lead to unsatisfied patients. When, on the other hand, objective criteria are combined with the subjective element of patient satisfaction, seemingly less favourable health outcomes may be better assessed by the patients that have (not) undergone certain treatments, because, e.g. there was more attention and time available for personal consultations or palliative care and more room for discussing issues of concern to the patient. Items that could be measured in patient-satisfaction assessments could include timely provision of health care,[798] having enough time and attention during the care provided, transparency and coherency in the health care process and in the communication, having the opportunity to ask questions, to discuss alternative medical treatments, fears and hesitations, value for money, availability of supportive care such as massages,[799] counselling and palliative care,[800] having the opportunity to stay with or see

797 General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 9.

798 See for an example of possible items for measuring patient satisfaction the Patient Satisfaction Questionnaire of Rand Health, available at: www.rand.org/health/surveys_tools/psq.html. 'The PSQ-III is a 50-item survey that taps global satisfaction with medical care as well as satisfaction with six aspects of care: technical quality, interpersonal manner, communication, financial aspects of care, time spent with doctor, and accessibility of care.' The original version was developed by Ware and colleagues in 1974 and it has been repeatedly validated and adapted since then. RAND aims to collect and analyze health data to assess and follow health conditions in the USA and worldwide. 'RAND research on children covers the prenatal period up to age 18 and includes areas such as child health and the role of the family unit, neighborhoods, and communities in influencing child well-being.'

799 For a further motivation of the importance of providing massages as a way to improve children's health and well-being see the submission of the Massages in School Association to the UN Committee on the Rights of the Child to the development of a General Comment on children's right to health. www2.ohchr.org/english/bodies/crc/callsubmissionsCRC_received.htm.

800 For a further motivation of the need to ensure palliative care for children see the submission of the International children's palliative care network to the UN Committee on the Rights of the

family and friends in private and to refuse treatments or hospitalization if the individual does not wish to undergo a certain (series of) medical treatments. These items are by no means exhaustive and could be further developed by taking a look at previously conducted patient-satisfaction assessments in the medical sector. Particularly for children, the proposed element of patient satisfaction can be further interpreted by taking the body of law of the Convention on the Rights of the Child into account and any applicable regional treaties and medical guidelines, such as the Guidelines of the Council of Europe on Child-Friendly Health Care.[801]

4.5. A SYNTHESIS

In ensuring health facilities, several key elements are useful for assessing the level of realization of the right to the highest attainable standard of health in a given context. General Comment 14 to the ICESCR establishes several key elements that concomitantly provide for a useful legal framework to shape, assess and improve the realization of the right to the highest attainable standard of health. This framework consists of the elements of availability, accessibility, acceptability and quality, applying to both the underlying determinants of health and to the actual health care services itself. The concomitant structure that arises is strongly focused upon the requirements of the right to health to ensure 'physical health'. However, as discussed in introductory chapter 1, the WHO-definition of health goes beyond the strictly physical dimension of health by defining health as 'a state of complete physical, psychological ánd social well-being and not merely the absence of disease or disability'.[802] Therefore, the identified legal framework of the right to health as laid down in the ICESCR is deficient when comparing this to the definition of health of the WHO and the definition of Huber. In order to allow for the integration, assessment and improvement of the 'highest attainable standard of health', it would be necessary to incorporate a constituent element that allows for assessing the psychological and social well-being of patients. Hereto, it is recommendable to include the concept of patient-satisfaction as an additional key constituent element of the right to health. This allows for a more nuanced assessment of the 'highest attainable standard of health' by taking both objective criteria and personal experiences into account. The resulting highest attainable standard of health should fulfil all separate elements in the model below. For as

Child to the development of a General Comment on children's right to health. www2.ohchr.org/english/bodies/crc/callsubmissionsCRC_received.htm.

801 The Guidelines on child-friendly health care were adopted in Lisbon on 28 September 2011 in the context of the Strategy 'Building a Europe for and with children' 2009–2011.

802 Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

long as States Parties to the ICESCR have not fulfilled the requirements of the constituent elements of the right to health, there remains room for improvement. Furthermore, new insights and developments may urge a continuous redefinition of the highest attainable standard of health of the child.

Figure 1. Key constituent elements of the right to the highest attainable standard of health of the child

	Underlying determinants of health	**Health services**
Availability	# and regional spread of safe drinking water, nutritious foods, sanitation and infrastructure (e.g. transport): within reasonable distance of living environment.	# and regional spread of health professionals, medical facilities and medicines
Accessibility	Non-discrimination: de facto and de iure access, economic, physical and information accessibility	Non-discrimination: de facto and de iure access, economic, physical and information accessibility
Acceptability	drinking water, nutritious foods, sanitation and infrastructure must respect traditional and cultural norms of local inhabitants.	Care and medicines provided must be respectful of medical ethics, culture, gender and life-cycle requirements.
Quality	drinking water, nutritious foods, sanitation and infrastructure must be of good quality and safe.	Care and medicines provided must be scientifically and medically tested and safe, well-trained medical professionals.
Patient-Satisfaction/ Participation	Patients indicate that they are satisfied with the drinking water, nutritious foods, sanitation and infrastructure that they use.	Patients indicate that they are satisfied with the health care received ánd with other factors relevant to their well-being, e.g.: – information, privacy and involvement in (medical) decisions – timely provision of health care – having enough time and attention – transparency in health care process and communication – coherency of health care process – opportunity to ask questions, discuss alternative treatments, fears and hesitations – supportive care and counselling (e.g. massage and palliative care) – contact with friends and family – provide health education – right to refuse medical treatments and hospitalization – value for money

	Underlying determinants of health	Health services
Adaptability	Provision of Underlying Determinants is adapted to changing needs and circumstances	Provision is adapted to changing needs and circumstances: – individual needs of children and family (beliefs and experiences, health knowledge, family composition, culture, religion) – life course (age, level of development) – stage of disease (prevention, curation, rehabilitation, palliative) – medical knowledge – needs of different groups of children – changing circumstances
Accountability	The government has shown how it meets its obligations through judicial, quasi-judicial, administrative, political and social procedures.	The government has shown how it meets its obligations through judicial, quasi-judicial, administrative, political and social procedures.

Applying a legal framework on the basis of which both objective and subjective elements can be assessed, creates the opportunity to acquire additional insights into potential mismatches between the objective elements of the right to health that are realized and the experiences of patients in receiving health care. This is of vital importance to ensuring the right to the highest attainable standard of health, because it is the physical, psychological and social well-being of the individual patients that is the primary object of the right to health. Also for children, the need to integrate children's experiences in health care assessments is crucially important, since they are generally less involved in shaping and organizing health care than adults are. Integrating the voice of children as an element of the right to health of the child, will therefore allow for rights-based improvements of the health services provided in the future and place children at the heart of the health care provided to them.

4.6. KEY FEATURES OF A HEALTH SYSTEM FOR CHILDREN BASED ON THE RIGHT TO HEALTH

In April 2002, the mandate of the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health was established by the Commission on Human Rights.[803] In 2008, this Rapporteur presented a report in which the key features of an effective and integrated health

[803] U.N. Doc. E/2002/23- E/CN.4/2002/200, Commission on Human Rights resolution 2002/31 on the right to the highest attainable standard of physical and mental health. The mandate was endorsed and extended by the Human Rights Council by its resolution 6/29 of 14 December 2007. For more information on the activities of the UN Special Rapporteur on the Right to Health see: www.ohchr.org/EN/Issues/Health/Pages/SRRightHealthIndex.aspx.

system were identified.[804, 805] This report provided for the translation of the right to health to essential building blocks of a human rights based health system and therefore poses a useful structure for translating the right to health of children as laid down in the children's rights domain into essential building blocks of health systems. The Rapporteur (Paul Hunt) claims that a health system that is based on human rights lies at the heart of the right to the highest attainable standard of health, being responsive to both national and local priorities and accessible to all.[806] More specifically, he claims that 'Health systems are central to children's right to health'.[807] According to Nolan and others, 'Health systems can too frequently exacerbate inequalities, stigmatization, and marginalization, and these forms of exclusion disproportionately affect children.'[808] The realization of the right to the highest attainable standard of health is thus largely dependent on the way in which health systems are structured.

In the Report, it is recommended that the key features of a rights based health system must be applied across the different building blocks of a health system.[809] All building blocks must be assessed for the separate key features of a rights-based health system. In the following, the key aspects that are most relevant for involving children in their own health care will be discussed, namely person centeredness (1), transparency (3), participation (4), respect for different (youth) cultures (6), equity (5) and continuous health care (11).[810]

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804 U.N. Doc. No. A/HRC/7/11, 2008, Report of the UN Special Rapporteur on the right of everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health. All key features identified are already found in some health systems, recognized in international legal documents or advocated for in health literature.

805 It is interesting to realize that the highly organized level of health systems is barely 100 years old, even in industrialized countries. See Everybody's Business: Strengtening Health Systems to Improve Health Outcomes, WHO, 2007, p. 2, available at: http://who.int/healthsystems/strategy/everybodys_business.pdf).

806 Ibidem supra note 778, p. 2. The importance of an effective health system for the realization of the right to health is compared to the importance of a fair justice system and accessible courts for the realization of the right to a fair trial.

807 P. Hunt & G. Backman, 'Health systems and the right to the highest attainable standard of health', *Health and Human Rights* 2008, 10; and Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN Doc. A/HRC/7/11, 31 January 2008.

808 Ibidem supra note 778.

809 Ibidem supra note 778. p. 18. The building blocks of a rights-based health system have been identified as i. the health services, ii. the health workforce, iii. the health information system, iv. medical products, vaccines and technologies, v. health financing, vi. leadership and governance.

810 In total, 17 key features of a rights-based health system are identified in the Report: 1. the well-being of people at the centre; 2. not only outcomes, but also processes; 3. transparency; 4. participation; 5. equity, equality and non-discrimination; 6. respect for cultural differences; 7. medical care and the underlying determinants of health; 8. progressive realization and resource constraints; 9. core obligations (i. national health plan, ii. access to health-services on a non-discriminatory basis, iii. equitable distribution of health services, iv. mechanisms of accountability); 10. quality; 11. a continuum of prevention and care; 12. disease-specific or integrated health interventions; 13. coordination between sectors; 14. international

The principal element identified of a rights-based health system is its focus on the well-being of individuals, communities and populations: key feature 1 is to put patients at the centre of the health care system. Stressed is that health systems should not become 'impersonal, top down and dominated by experts'.[811] Thereto, the influence of health professionals on determining the medical treatment for children should be balanced by the voice-raising of children and their families. In achieving this, medical professionals must be able to step back and provide meaningful opportunities for children to speak up and have their say over their own bodies and treatments. Secondly, focus should not be placed only on diseases, as is now often the case, but on the patient as a whole. This element is especially important for the provision of health care to children, as children face a fourfold vulnerability: in the first place in their capacity as being a child, often being subordinate to the will and directives of their parents or other adults and in the second place as being subordinate in their capacity as being a patient with – presumably – less technical medical knowledge than their doctors.[812] Furthermore, sick children often lack the energy to stand up for their rights during their medical treatment. Lastly, medical treatments affect not only their present but also their future medical condition. The right to health of the child therefore is a good pretext to ensure that children are placed central in the health care process. Hereto, several other elements identified are supportive, such as transparency, participation, a focus on processes in addition to outcomes and respect for different (youth) cultures.[813]

The additional principles can add to a child-oriented way of organizing health care; transparency requires that children have access to health information (for example at school), so that they can become involved in promoting their own good health by eating healthy, stop smoking and start sporting.[814] This requires that the information is understandable for children of different ages and that different modalities of information transmission are used, e.g. cartoons or explanations with teddy bears and dolls. Transparency is also relevant for the continuum of prevention and care: a health system should have an appropriate mix of primary, secondary and tertiary care, including effective referrals between these different phases in the health care system and between the alternative and mainstream health sector.[815] Especially for children, the feature of transparency requires supportive guidance and patience in explaining about possible referrals that they may undergo during the health care process. It would therefore be very useful if

cooperation; 15. balances between different human rights; 16. monitoring and accountability; 17. legal obligation.

811 P. Hunt & G. Backman, 'Health systems and the right to the highest attainable standard of health', *International Journal on Health and Human Rights* 2008, Volume 10, no. 1, p. 83.

812 G. Brichner, 'Children in the Hospital: Issues of Power and Vulnerability', *Pediatric nursing* 2000, May-June; 26(3), pp. 277–82.

813 Ibidem supra note 810.

814 Ibidem supra note 810, p. 83.

815 Ibidem supra note 810, p. 85.

special health care coaches would guide children through the entire health care process, be it necessary for just a few visits in case of temporal medical problems or for many more sessions in the course of treatment of chronic or long-term diseases. Such a coach should guard the best interests of the child, being broader than only the physical and emotional well-being, but also involving the interests of the child in other life domains, such as family life, school life and maintaining contacts with friends and continuing leisure activities if they wish to.

Transparency enables children to participate in their own health care process. Only if they have clear and understandable information, can they make solidly motivated choices concerning their health and treatment. Through this active participatory process in which children's ideas and experiences are central, the interests of the child as a child are placed at the heart of the health care process, as is required under the first and principal element of a rights based health system.[816] This would furthermore ensure that not only the outcome of the health treatment (namely curation or not), but also the process itself is attentive of children's interests (key feature # 2). The need to ensure children's rights during the entire health care process is especially relevant for children who can not be cured completely, such as children with chronic diseases, disabled children and children with life-threatening diseases.[817] For example, in many, especially developing countries, there is no or insufficient palliative care for children, especially babies and neonates.[818] The reason given for this situation is that 'most adults have an inherent disbelief that children should not die and therefore ignore the needs of these children.'[819] Secondly, it is identified that because (young) children have limited communication skills, 'their pain and suffering are often left unnoticed and untreated'.[820] Though it is important to ensure a child-appropriate health care process for its own sake, it may be assumed that such a process will also result in a better outcome, as children and their parents will be more inclined to follow the treatment if their wishes are taken into account. Also, attention for the interests and opinions of the child during the treatment will likely reduce feelings of anxiety and helplessness over their own health.

Another important aspect of a child centred health care system is derived from the key feature of respect for different cultures.[821] It has been observed that cultural sensitivity leads 'to higher levels of programme acceptance and ownership by the community, and programme sustainability'. It can be assumed that including features of specific child and youth cultures has a beneficial effect

816 Ibidem supra note 810.

817 See the submission of the International children's palliative care network in response to the call for submissions of the UN Committee on the Rights of the Child for the development on a General Comment on children's right to health.

818 Ibidem supra note 810.

819 Ibidem supra note 810.

820 Ibidem supra note 810.

821 Ibidem supra note 810.

on the likelihood that children and youth will feel more attracted to such health information materials and advices from medical professionals.

A rights based health care system requires effective coordination among various sectors and departments such as health, environment, water, sanitation, food, shelter, transport and education.[822] The equal distribution of health services could be done on the basis of demographic statistics: the more children live in a specific area, the more child health services must be available. It could also be spread in coordination with the regional distribution of schools: many examples have shown that when children are provided with healthy meals, they are more likely to go to school. A similar connection could be achieved by locating primary health services in or near the schools they are going to. Problems of accessibility of schools and health care services can thereby be solved in conjunction, for example by building a road from a village to another where children can go to school and visit a doctor when they are sick. In doing so, however, children's right to privacy must be guaranteed, in order to avoid issues of stigmatization, for example, in the case of HIV/AIDS tests for children.

Last but not least, a health system that is based on children's right to the highest attainable standard of health should progressively realize the priorities that can be derived from that right. Remarkable is that the basic components of the right to the highest attainable standard of health, such as access to health care and to the underlying determinants of health concomitantly focus on achieving health for as many individuals as possible. Therefore, the social justice (or horizontal) component is much stronger than the vertical component, aiming at progressive achievement of a better health status for just a limited number of people. As this key characteristic of the right to health calls for involving *all people*, and thus *all children* without discrimination, it is necessary to determine who is actually responsible for ensuring health for all. It has been identified that community participation is crucial, given the extent of the legal obligation, which is far beyond the reach of governmental institutions. Community participation, for a start, is partly dependent on the initiatives taken within the community. A government can evoke and stimulate communities to take responsibility and be involved in the realization of the health of its children. However, it cannot and should not force communities to do so, since this would result in a top-down process, that thus does not address the capabilities of individuals to make their best contributions.

How should the responsibilities of adults, i.e. parents or other caretakers be balanced against the responsibilities of the State and other actors involved? Secondly, in order to measure progress in achieving the highest attainable standard of health over time, it is necessary to use indicators and benchmarks on children's right to health. Thirdly, to assess the level of progress in achieving the highest attainable standard of health over time, independent monitoring

[822] Ibidem supra note 736.

and accountability mechanisms are crucial elements of a rights-based health system. These questions on accountability will be discussed in chapter VI on the realization of the right to health of the child.

4.7. CONCLUSION

In this concluding section the question is addressed what the additional value of the right to the highest attainable standard of health as formulated in international health and human rights law is for interpreting the right to the highest attainable standard of health of the child in the children's rights domain. Article 24 and 41 CRC concomitantly create the opportunity for elaborating the right to the highest attainable standard of health of the child in the CRC by looking at legal documents other than those in the children's rights domain.

The concept of the highest attainable standard of health of the child cannot be easily defined, because it depends on continuously moving, sometimes even conflicting conditions:

- Individual needs and viewpoints of children and their families: e.g. based on personal beliefs and experiences, level of health education, religion, culture and family composition vary. This influences the health seeking behaviour.
- Children's health needs change continuously based on their life course, age and levels of development. These varying needs require consequent health services that are adaptive to those needs: maternal, antenatal, obstetric, newborn, infant and child healthcare.
- The varying stages of diseases require primary, secondary or tertiary prevention, curation, rehabilitation and palliative care.
- The developing insights of medical science and available technologies constantly create new opportunities for medical treatment and therefore raise the highest attainable standard of health.
- The varying needs of (vulnerable) groups of children: e.g. children in early childhood, girls, immigrant children, indigenous children, orphaned children, street children require different modes of communication and adaptation of health education to their living world and level of understanding. This is reinforced by the requirement to stimulate community participation: to be able to respond to the plurality of community initiatives, health services must be flexible.
- The circumstances in which children live: e.g. socioeconomic conditions, economic crisis, humanitarian situation and climate change require continuous restructuring and re-evaluation of existing health services.
- Changing health challenges due to increasing numbers of international travellers, awareness of health problems and solutions in other areas of the world instigate continuous development.

Although it follows from the identified factors of uncertainty that one universal standard for the highest attainable standard of health is impossible to establish, several elements are considered as priorities, deriving from international health and human rights other than the CRC domain, of the right to health of the child.

1. Right to underlying determinants of health, including:
   - safe drinking water;
   - adequate nutrition;
   - sanitation;
   - housing;
   - healthy living environment;
   - health information and education;
   - vaccination campaigns.
2. Right to a variety of facilities, goods, services and conditions that are necessary for the attainment of the highest attainable standard of health:
   - Child and maternal health measures;
   - Sexual and reproductive health services, including:
     a. Access to family planning;
     b. Pre- and postnatal health care;
     c. Emergency obstetric services;
     d. Access to health information;
     e. Resources necessary to act on the health information.
   - Access to essential health care services for children and their family.
3. Child-friendly health information for prevention and promotion.
4. Inclusion of vulnerable groups through community participation.
5. Skilled health professionals.
6. Essential medicines and technologies.
7. Adoption of a national strategy or plan of action.

The provision of underlying determinants can be better met by increasing the available budget. General Comment 14 further establishes that the identified health services should be in line with the key constituent elements of the right to health in order to achieve the highest attainable standard of health: availability, accessibility, acceptability and quality. The AAAQ structure for structuring and assessing the level of realization of the general right to health offers significant insight into the way in which the highest attainable standard of health of the child can be achieved. The framework applies to both the underlying determinants of health and to the provision of medical care itself. The steps that must be taken should therefore progressively realize all the identified aspects of the key constituent elements of the AAAQ structure as depicted in figure 1. Also, in case of retrogressive measures with respect to a particular constituent element of the realized right to health in a country, alternative options must be considered in order to restore the previously realized health status of children.

However, several new trends have been discerned, which require a further development of the traditional AAAQ structure as laid down in General Comment 14 to the ICESCR: inclusion of the elements of adaptability, accountability and participation (or patient-satisfaction) in the traditional AAAQ framework. Such inclusion would be responsive to the current trend to better involve patients in their own health process. It would furthermore allow for a more flexible and adaptive health system that places the best interests of the child and its family at the heart instead of the functionalities of medical organizations. This requires approaching the child as a whole and not only as an object in need of medical physical treatment. Secondly, it allows for focusing not only on the health outcome of the medical care provided, but also on the health process. Such an approach to health care would be in line with the right to participation and with the best interests of children as laid down in articles 12 and 3 of the CRC.

So how can such a flexible and adaptive health system be realized in practice? Paragraph 12 of General Comment 14 particularly establishes the link between ensuring child friendly health information about preventive and health-promoting behaviour for children and their families in order to gain access to essential health services. Having access to understandable health information enables both children and their families to become personally involved in improving and ensuring their own level of good health. In this way, every individual gradually becomes an active participant in achieving the right to the highest attainable standard of health of children.

Secondly, a rights-based health system for children must ensure effective coordination between health services, schools and the provision of safe drinking water, food, sanitary facilities and housing. Access to those facilities must be non-discriminative, transparent, sensitive to the particular needs and (youth) cultures of different children and targeted to individual children, communities and populations. Such inclusive access requires the involvement of all community members, so that children's needs can be identified by their caretakers living in their direct vicinity.

Last but not least, the highest attainable standard of health is not confined to the limited borders of States. States have extraterritorial obligations to ensure the right to the highest attainable standard of health for children in developing countries. Key requirements for meeting these obligations are the identification of shared international health standards and indicators and the assessment of foreign policies through child health impact assessments. Coordination and realigning of existing health structures can be instigated by engaging into health diplomacy: identifying and negotiating mutual health needs and finding common grounds on which health policies can be based. The minimum requirements deriving from the right to the highest attainable standard of health as identified above are legally grounded and offer a useful starting point for engaging with such international coordination.