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

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I. INTRODUCTION

1.1. INTRODUCTION

Every woman giving birth to a child wishes her baby is born and raised in good health. This single factor, health, plays a crucial role in the viability of the newborn. It is a matter of daily concern and it has a major impact on the well-being of the individual and its opportunities to go to school, work, participate in family and community activities. The Preamble of the Constitution of the World Health Organization (WHO) specifically mentions that the healthy development of the child is of basic importance and that the ability to live harmoniously in a changing environment is essential to such development.¹ The WHO even considers health as our most basic and essential asset.² Similarly, Navi Pillay, the United Nations High Commissioner for Human Rights commented that the right to health is the foundation for all other human rights.³

Last but not least, the health condition of babies and young children lays down the fundamentals of health in later life.⁴ Article 24 of the Convention on the Rights of the Child (CRC) provides for the right of children to the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. Furthermore and in order to achieve the highest attainable standard of health, article 24 CRC provides that 'States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services'. However, unclear is what the right to the highest attainable standard of health of children entails, what obligations States and parents have to ensure this right to the highest attainable standard of health of children and how it can be enforced.

¹ Preamble to the Constitution of the World Health Organization, as published in World Health Organization, *Basic documents*, 45th edition, Geneva, 2006. The WHO Constitution was signed in 1946 and entered into force on 7 April 1948.

² WHO Factsheet No. 31 on the Right to health, Office of the United Nations High Commissioner for Human Rights, Geneva, June 2008.

³ 4 March 2013, Report in preparation to the Day of General Discussion on Human Rights on the right of the child to the enjoyment of the highest attainable standard of health.

⁴ See also the Barker-hypothesis, which postulates that several common adult diseases may be related to impaired foetal growth or disrupted genes, caused by nutritional inadequacies or other environmental influences at particular stages of pregnancy. D.J. Barker, 'Fetal Origins of Coronary Heart Disease', *British Medical Journal* 1995, 311, p. 171–174.

The basic importance of children's health has been laid down and reassured in many international documents.^{5, 6} During the 1990 World Summit for Children, a 10-point programme was adopted that focused on enhancing children's health, promoting prenatal care and lowering infant and child mortality.⁷ This commitment was reaffirmed in the Report 'A World Fit for Children', which speaks of the need to ensure 'the best possible start in life' for children by 'making concerted efforts to fight infectious diseases, tackle major causes of malnutrition and nurture children in a safe environment that enables them to be physically healthy, mentally alert, emotionally secure, socially competent and able to learn'.⁸ In the field of health, the Report established 25 priorities, which concomitantly lay down the fundamentals for the Action Plan that is intended to 'break the intergenerational cycle of malnutrition and poor health'.⁹

Goal 4 of the Millennium Development Goals aims to reduce by two thirds the mortality rate among children under five by the year of 2015.¹⁰ This goal, consisting of infant (0–1) and under-five (0–5) mortality rates, constitutes one of the most important indicators to assess the degree to which the right to health of children is prioritized within a country.¹¹ However, promising infant and under-five mortality rates in a country do not reveal the underlying disparities in health between different subgroups in that country.

Taking a look at the Concluding Observations of the Committee on the Rights of the Child for several countries of the last five years, it becomes clear that different groups of vulnerable children lack (sufficient) access to basic health care facilities and/or underlying determinants of health, such as safe drinking water,

⁵ See 'The World Declaration on the Protection, Survival and Development of Children' and 'The Plan of Action for Implementing the World Declaration on the Protection, Survival and Development of Children in the 1990s', adopted by the World Summit for Children, New York, 30 September 1990. In § 10, 'enhancement of children's health and nutrition is qualified as a first duty, because infant and child mortality are unacceptably high and readily preventable. In § 11 and 12, specific attention is demanded for ensuring care and protection for 'disabled children, girls and children in very difficult circumstances'. Furthermore, safe motherhood must be promoted in all possible ways, including family planning and birth spacing, § 14.

⁶ See the Report 'A World Fit for Children', adopted by the United Nations General Assembly Resolution A/RES/S-27/2, 11th October 2002. Available at: www.unicef.org/specialsession/docs_new/documents/A-RES-S27-2E.pdf.

⁷ Ibidem supra note 4, § 20.

Measures promulgated included the provision of clean drinking water, ensuring universal access to sanitation, eradicating hunger, malnutrition and famine, promotion of family planning, child spacing, safe motherhood and breastfeeding. In the concomitant Action Plan, focus is placed on preventing childhood diseases and strengthening primary health care and basic health care services in all countries.

⁸ Ibidem supra note 5, § 7, point 4.

⁹ Ibidem supra note 5, § 35–37.

¹⁰ See the UN Millennium Development Goals Report, New York, 2010, p. 26. Available at: www.un.org/millenniumgoals/pdf/MDG%20Report%202010%20En%20r15%20-low%20res%2020100615%20-.pdf.

¹¹ A. Eide & W.B. Eide, *A Commentary on the UN CRC Article 24: The right to health*, Leiden: Martinus Nijhoff Publishers 2006, p. 17.

nutritious food, housing and health education.¹² Similar observations have been done by paediatricians in both high-income and low-income countries.^{13, 14} Great differences have been observed in access to health care, including preventive medicine such as immunization between and within developed and developing countries, particularly impacting upon children in war zones and countries affected by sanctions.¹⁵

In high-income countries there are vulnerable groups of children who suffer from significant health problems and who have limited access to primary health care facilities, such as refugee children, children of minority groups and children who are confronted with domestic violence.^{16, 17, 18, 19} For example, the infant mortality rate in the Netherlands in 2008 was 4/1000 and the under five mortality rate was 5/1000.²⁰ However, these excellent youth health indicators disguise the fact that many refugee children suffer from infectious diseases, diarrhoea, malaria and mental health problems, because they remain deprived of the basic necessities for good health.^{21, 22, 23} Also within low-income countries, there are big differences between health indicators for different groups of children, reflecting the differences in political will, organizational capacity and dissemination of knowledge to ensure children's right to health.²⁴ General Comment 15 on the right of the child to the enjoyment of the highest attainable standard of health

¹² See for example the Concluding Observations of the Committee on Argentina (2010), § 31 en § 58, Australia (2005), § 72 en § 88, Uganda (2005), § 242c, § 258, § 267, § 276, Lebanon (2006), § 409b, § 432, § 433–437, Bulgaria (2008), § 45–46, the Netherlands (2009) Doc. CRC/C/NLD/CO/3 27 March 2009, § 51–52.

¹³ T. Lindberg, 'The Child's Right to Health and Treatment', *Medicine, conflict and survival* 1999, Volume 15, p. 336. Published by Frank Cass, London.

¹⁴ D. Southall et al., 'The Child-Friendly Healthcare Initiative (CFHI): Healthcare Provision in Accordance With the UN Convention on the Rights of the Child', *Pediatrics* 2000, Vol. 106 No. 5 November 1, p. 1054–1064.

¹⁵ Ibidem supra note 4.

¹⁶ A. Hjern & P. Bouvier, 'Migrant children – a challenge for European paediatricians', *Acta Paediatrica* 2004, Volume 93, pp. 1535–1539. Stockholm.

¹⁷ R. Romero-Ortuño, 'Access to health care for illegal immigrants in the EU: should we be concerned?' *European journal of Health Law* 2004, Volume 11, p. 245–272, Martinus-Nijhoff Publishers.

¹⁸ N. Davidson e.a., 'An issue of access: delivering equitable health care for newly arrived refugee children in Australia', *Paediatric Journal Child Health* 2004, Volume 40, p. 569.

¹⁹ F.S. Mendoza, 'The health of Latino children in the United States', *Critical health issues for children and youth* 1994, Volume 4, number 3.

²⁰ UNICEF Statistics by country, At a glance: Netherlands. See website: www.unicef.org/infobycountry/netherlands_statistics.html.

²¹ 'Medical care of underage refugees', *Nederlands Tijdschrift voor de Geneeskunde* 1999, July 24; Volume 143, Number 30, p. 1569–72.

²² K. Mink & J.P. Kleijburg, *Jaarbericht Kinderrechten* 2008, Voorburg/Amsterdam: Unicef Nederland and Defence for Children International Nederland 2008.

²³ K.C. Braat, *Ik ben er wel, maar ze zien me niet*, Amsterdam: Defence for Children International Nederland 2004.

²⁴ A. Eide & W.B. Eide, *A Commentary on the UN CRC Article 24: The right to health*, Leiden: Martinus Nijhoff Publishers 2006, p. 16.

establishes the right of children to opportunities to survive, grow and develop to their full potential as the basic presumption.²⁵

1.2. PROBLEM STATEMENT AND RESEARCH QUESTIONS

Large numbers of children all over the world face significant health risks, such as infectious and chronic diseases, injuries and the consequences of natural disasters, protracted armed conflicts and poverty.²⁶ Every year, 4 million babies die within the first month of their life and almost 8 million children under the age of five die from preventable diseases such as malaria, pneumonia, measles and diarrhoea.²⁷

These general statistics do not reveal the underlying inequalities in health between and within countries. For example, the under-five mortality ratio in 2008 ranged from 257/1000 in Afghanistan to 2/1000 in Liechtenstein.²⁸ Whereas developing countries face basic health risks such as infectious diseases, malnutrition and birth complications, developed countries predominantly face health problems such as cancer, asthma, diabetes, coronary and heart diseases, eating disorders, problems resulting from smoking, alcohol and drugs abuse and mental health problems.

One of the causes of the inequalities is that, in many countries, vulnerable groups of children have no or only limited access to adequate health care facilities,^{29, 30, 31} consequently running larger health risks than other groups of children in the mainstream society. For example, refugee children in developed countries, especially the ones that have come from tropical areas and the ones who have resided in refugee camps, suffer from the basic health risks that usually occur in developing countries.³²

²⁵ CRC/C/GC/15, 17 April 2013, § 1. General Comment 15 on the right to the highest attainable standard of health of the child.

²⁶ UNICEF report 'The State of the World's children 2010', Statistical Table on Basic Indicators.

²⁷ Ibidem supra note 26.

²⁸ Ibid, Statistical table on under-five mortality ratios. The under-five mortality ratio is defined as the probability of dying between birth and exactly five years of age, expressed per 1000 live births.

²⁹ See for example the Concluding Observations of the Committee on Argentina (2010), § 31 en § 58, Australia (2006), § 72 en § 88, Uganda (2006), § 242c, § 258, § 267, § 276, Lebanon (2006), § 409b, § 432, § 433–437, Bulgaria (2008), § 45–46, the Netherlands (2009), § 51–52. Reports can be found through the website: www.unhcr.org/refworld/publisher/CRC/CONCOBSERVATIONS/ARG/4c32dae02,0.html.

³⁰ Davidson et al., 'An issue of access: Delivering equitable health care for newly arrived refugee children in Australia', *Journal of Paediatrics* 2004, 40, p. 569–575.

³¹ F.S. Mendoza, 'The Health of Latino Children in the United States', *Critical Health Issues for Children and Youth* 1994, 4 (3), p. 43–72.

³² A. Tjon, W.E. Ten & T.W. Schulpfen, 'Medical care of underage refugees', *Nederlands Tijdschrift voor de Geneeskunde* 1999, 143 (30), p. 1569–72.

As a result of the financial hardship due to the current economic crisis, children face additional risks to deprivation of basic health care requirements. In the Netherlands for example, children are disproportionately represented in the poorest households, predominantly by being part of one-parent families.³³ This financial situation has impact on their (financial) access to health care, social insurances, healthy food, water and gas supply, access to information (e.g. through internet, newspapers and television) and other housing conditions.³⁴ Numerous studies come to similar conclusions that children living in poverty face larger health risks than their wealthier peers, such as higher infant and child mortality rates, lower birth weight, higher risks to suffer from neglect and abuse, general disabilities and severe chronic illnesses.³⁵ Generally speaking, the health related quality of life of children and youth is worse for those living in less advantaged socioeconomic conditions.³⁶

The relevance of investigating the international right to health is also related to its international dimension. The highest attainable standard of health is not a right of which the implementation should be limited to the territory of the State.³⁷ Increasingly, discussion arises as to the external influence of the right to health.^{38, 39, 40} This is exemplified by the increasing inclusion of international health arrangements in national health policies and the harmonisation of health policies across foreign and regional policies.⁴¹ Similarly, Nolan and others argue

³³ 'Armoedesignalement 2010, Sociaal en Cultureel Planbureau/Centraal Bureau voor de Statistiek, Den Haag, december 2010'. In the Netherlands in 2009, 7% of the general population was categorized as a low-income household, whereas 10% of the minors was categorized as such.

³⁴ Ibidem supra note 33.

³⁵ B. Zuckerman & S. Parker, 'Preventive pediatrics: New models of providing needed health services', *Pediatrics* 1995, 95(5), p. 758–762.

³⁶ A.E. Simon, K.S. Chan & C.B. Forrest, 'Assessment of children's quality of life in the United States with a multidimensional index', *Pediatrics* 2008, 121(1), e118–e126.

³⁷ General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 38–42.

³⁸ See for example: 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 Volume 3, 2009, Ruffer & Rub, p. 100–108.

³⁹ See also: J.W. Owen & O. Roberts, 'Globalisation, health and foreign policy: emerging linkages and interests', *Global Health* 2005, Volume 1, Number 12. (Published online 2005 July 29, available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC1188066/).

⁴⁰ H. Feldbaum, K. Lee & J. Michaud, 'Global health and foreign policy', *Epidemiologic reviews* 2010, Volume 32, Issue 1, p. 82–92.

⁴¹ See for example the Dutch policy document 'Responsibility for Freedom', April 2011, p. 10, specifically addressing the Dutch commitment to help to realize access to pre- and postnatal health care, sexual and reproductive health rights and family planning. Available at: www.rijksoverheid.nl/documenten-en-publicaties/rapporten/2011/04/05/notitie-verantwoordelijk-voor-vrijheid.html. For more information on health diplomacy see: www.who.int/trade/diplomacy/en/.

that extra-territorial obligations of States to realize children's right to health contain at least the duty to protect and respect the right to health.⁴²

At least three central objectives are discerned in adopting a border-crossing approach to ensuring children's right to health: i) the combat of infectious diseases, ii) the construction of shared health policies and health indicators and iii) the provision of humanitarian aid in case of humanitarian crises. Another issue that impacts upon the right to health of children in other countries is the role of the private sector in realizing the right to health of children, such as the role of pharmaceutical companies in testing (new) medicines and ensuring availability and affordability to everyone.

With regard to the first point, recent upsurges of infectious diseases such as Ebola, SARS and MERS, avian influenza and the Mexican flu, demonstrate the epidemiological interrelatedness and its potential impact on the realisation of human rights, on public health and on trade within and between nations.^{43, 44} Ensuring good health for people in other countries in the entire world is therefore an essential requirement for ensuring the right to health of people within states.

Secondly, the enormous numbers of people travelling over the world for business, immigration, refugee or tourism purposes, have increased global awareness of the impact of aid, trade, conflicts and travelling itself on health and living circumstances across different countries and regions of the world, resulting in moral, ethical, political and economic demands to further investigate and address health policies across the different countries in the world. The right to health is a logical first pretext to start developing and implementing such policies, given its widely accepted legal recognition in both the WHO Constitution and the ICESCR and the internationally oriented interpretation of the provisions incorporated therein, for example in the Concluding Observations of the ECOSOC Committee on the individual Country Reports submitted to it.⁴⁵ Some countries have even integrated a human rights approach in their foreign policy,⁴⁶ so that national governments do not only serve their national interests but also aim to advance the right to health (among other human rights) around the world. However, in order to effectively cooperate with other developing and donating countries, a common human rights framework for improving the public

⁴² A. Nolan, A.E. Yamin & B.M. Meier, Submission on the Content of a Future General Comment on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (art. 24).

⁴³ D.P. Fidler, & N. Drager, 'Health and foreign policy', *Bulletin of the World Health Organization* 2006, September, Issue 86, Number 9, p. 687. Available at: www.who.int/bulletin/volumes/84/9/06-035469.pdf.

⁴⁴ In 2008, a WHO conference was organized in Geneva, addressing the issue of foreign policy and global health.

⁴⁵ See Concluding Observations of the Committee on Economic, Social and Cultural Rights. Available at: www.ishr.ch/treaty-body-monitor/cescr.

⁴⁶ Ibidem supra note 41.

health system is necessary.⁴⁷ Furthermore, it is required to develop shared and internationally applicable health indicators.⁴⁸

NGOs and intergovernmental organizations such as the WHO, UNICEF and the World Bank are specifically addressed to contribute to the realization of the right to health. In the Concluding Observations on Country Reports of the Committee on the Rights of the Child, States are repeatedly stimulated to seek assistance from organizations such as UNICEF and the WHO to find ways to realize children's right to health.⁴⁹ Article 2 of the WHO Constitution makes the WHO responsible for playing a leading role in setting the health research agenda, norms and standards of global health policy, providing technical support to countries and monitoring and assessing health trends.⁵⁰ However, the process of priority setting by the World Health Organization does not seem to be guided by the right to health, nor have NGOs been systematically involved.⁵¹

Thirdly, in the case of sudden crisis situations, States have a strong obligation to provide emergency care to affected regions and populations, especially if local authorities have been affected and are therefore not able to promptly respond to the need of its population, as was for example the case in the aftermath of the Haitian earthquake in January 2010. An assessment of the relief provided after the tsunami in South-East Asia led to the division of responsibilities between different UN organizations and other international organizations involved in emergency relief.⁵²

⁴⁷ 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 Volume 3, 2009, Ruffer & Rub p. 104.

⁴⁸ Kinney and Clark convincingly demonstrated that incorporation of the right to health in the national constitution does not relate to the actual commitment of states to realize this right. They even found that countries with the most ambitious provision ensuring the right to health were often to the highest degree violating or neglecting this right (e.g. Haïti previous to the 2010 earthquake). It may be assumed that a similar conclusion may be drawn with respect to the commitment to respond to international commitments, especially given the disputed justiciability of economic and social rights. See: E.D. Kinney & B.A. Clark, 'Provisions for Health and Health Care in the Constitutions of the Countries of the World', *Cornell International Law Journal* 2004, Volume 37, p. 287.

⁴⁹ General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 63–65.

⁵⁰ The WHO Department on Ethics, Trade, Human Rights and Health Law aims to integrate a human rights based approach to health. WHO Factsheet No.31 on the Right to Health, prepared by the Office of the United Nations High Commissioner for Human Rights, p. 29.

⁵¹ Submission of Nord-Sud XXI to the UN Committee on the Rights of the Child for the preparation of General Comment 14 to the CRC on the right to health: www2.ohchr.org/english/bodies/crc/calls/submissionsCRC_received.htm.

⁵² During a meeting with Mrs. A. Golaz at UNICEF Geneva, May 2012, I was informed that a division of tasks was made in responding to the consequences of natural disasters. For example, the WHO is responsible for the provision of health care, UNHCR and the International Organization on Migration are responsible for camp coordination and management, UNICEF and Save the Children take the lead on education and UNCHR and IFRC take the lead in ensuring shelter for affected people.

1.2.1. RESEARCH QUESTION

The scope of the right to the highest attainable standard of health has been subject to much debate, ranging from a narrow interpretation of a right to health as a right limited to health services to a broad interpretation incorporating other human rights such as the right to adequate nutrition, water, sanitation, housing, privacy and education.⁵³ In a variety of international legal documents,⁵⁴ the right to health is defined as ‘the highest attainable standard of health in view of the available financial resources’. The right to health of the child is thus dependent upon the available resources. The approach taken in this research is predominantly legal. The additional value of a legal approach is that it sets objective standards for the right to health of the child instead of formulating subjective ambitions that can change easily. Such an approach is important, because many countries, especially in the current economic crisis situation, are faced with cutbacks in financial budgets on health expenditure. Therefore, the question is which aspects of the right to health of the child must be prioritized within these challenging circumstances. These priorities should ensure a minimum standard of health for all children that can not be derogated off. Furthermore, a legal approach creates the opportunity for legal remedies that help to improve children’s health, although it must be noted that the justiciability of the right to health of children as a social rights disputed.

According to international law standards, the right to the highest attainable standard of health of children as laid down in article 24 CRC is insufficiently realized in both low-income and in high-income countries. As a result, large numbers of children suffer and even die from easily preventable diseases. Also, it has been established that poor health care access leads to higher rates of hospitalization for chronic diseases.⁵⁵

A central problem in the realization of the right to health of the child is the interpretation of ‘the highest attainable standard of health’ of children. The vagueness of the concept of ‘the highest attainable standard of health’ makes it difficult to identify the elements of the right to health that must be prioritized for implementation in a country’s health policy. Secondly, the realization of the right to the highest attainable standard of health is dependent upon the (limited) financial resources available. Thirdly, the realization of children’s right to the highest attainable standard of health depends on both situational circumstances and individual characteristics such as the genetic predisposition and lifestyle of both the parents and the child. Unclear is therefore what elements of the right

⁵³ See General Comment of the Committee on Economic Social and Cultural Rights on the right to the highest attainable standard of health, U.N. Doc. E/C.12/2000/4, 11 August 2000, § 4.

⁵⁴ See for example the Preamble of the WHO Constitution, art. 12 of the International Covenant on Economic Social and Cultural Rights (ICESCR) and art. 24 of the UN Convention on the Rights of the Child.

⁵⁵ A.B. Bindman, ‘Preventable hospitalizations and access to health care’, *Journal of the American Medical Association* 1995; 274, Volume 4, p. 305–311.

to the highest attainable standard of health fall under the responsibility of the State and what the responsibilities are of medical professionals, the parents and the child itself. Fourthly, the qualification of the right to the highest attainable standard of health as a social human right means that there is on-going debate over its legal effect. Unclear is whether the right to health of the child can be enforced as an obligation of effort or as an obligation of result and what the scope is of this obligation. If so, how far does this obligation extend?

This research aims to identify the standards in international law for realizing the right to the highest attainable standard of health. Can we speak of progressive standards and if so, how can they be enforced?

The central questions that will be analysed in this thesis are:

- (a) what priorities derive from the concept of the highest attainable standard of health of the child, its definition and the interpretation of the key constituent elements on the basis of international human rights law?*
- (b) how should this concept be implemented in the light of the international human rights standards?*

Consequently, the following sub questions will be answered in the subsequent chapters:

- I. What priorities relating to the right to the highest attainable standard of health of the child can be derived from the interpretations of this right found in the international children's right domain?
- II. How are the priorities relating to the international children's rights domain with respect to the interpretation of the highest attainable standard of health of the child explained in the Concluding Observations of the CRC Committee on Country Reports for countries with different levels of development?
- III. What priorities related to the right to the highest attainable standard of health of the child can be derived from the interpretation found in the international health and human rights law? What is the additional value of this body of law for the interpretation of the right to the highest attainable standard of health in the children's rights domain?
- IV. What priorities relating to the right to the highest attainable standard of health of the child are found in the interpretation found in the human rights law in Europe?

- V. How does the process of realization influence the interpretation of the highest attainable standard of health of the child and which actors are responsible in the process of implementation?

1.3. METHODOLOGY

1.3.1. THEORETICAL FRAMEWORK: THE CAPABILITY APPROACH

This research builds on the capability approach of Amartya Sen.⁵⁶ The focus of this approach is on people's capabilities, on their abilities to effectively do and become what lies within them. As such, the capability approach differs from philosophical theories that take people's happiness or basic needs as a starting point. It also differs from utilitarian theories that focus on the benefit to society that can be derived from developing individuals.

The capability approach focuses on the intrinsic (or innate) opportunities that people have. It assumes that people have the freedom to choose the capabilities that they wish to realize in order to live a life which they find valuable. Examples of capabilities are the capability to be healthy, the capability to be a successful athlete or the capability to become a medical doctor. As such, the capability approach takes into account the heterogeneity of people, as is exemplified in relation to the human physic by the different health needs of children based on their age, gender, health status, bodily weight, climate or social environment. For example, a very tall and sporty adolescent boy needs different quantities and types of nutrition than an infant girl to be healthy. According to Sen 'Human diversity is no secondary complication (to be ignored, or to be introduced 'later on'); it is a fundamental aspect of our interest in equality'.⁵⁷

It is important to distinguish between capacities and capabilities. A capacity is the realized ability to perform a certain act, such as walking, talking, dancing or reproducing. It is clear that very young children have limited capacities, since they haven't had the time to (fully) develop yet. A capability, on the other hand, refers to the *potential* to develop. Young children do have the potential to develop a wide variety of functionings. In identifying potential capabilities that can be realized, debate is ongoing on the possible level of determination that should be achieved. Nussbaum, for example, has compiled a list of ten central human capabilities that can be achieved, including physical health. She uses her elaboration of the capability approach as a 'justification of the central constitutional principles

⁵⁶ A.K. Sen, *Equality of What?* Stanford University: Tanner Lectures on Human Values 1979.
A.K. Sen, *Commodities and Capabilities*, North-Holland 1985.

⁵⁷ A.K. Sen, *Inequality Reexamined*, Oxford: Oxford University Press 1992, p. xi.

that citizens can demand from their governments'.⁵⁸ Sen, on the other hand, explicitly rejects the compilation of such a list, although he does introduce the notion of basic capabilities, capabilities that are necessary for physical survival.⁵⁹ Sen argues that an exhaustive list limits the opportunity to be open to the wide diversity of individual capabilities. As such, the adoption of an exhaustive list of capabilities would limit the possibilities to take into account all possible best interests of individual children.

In addition to the concept of capabilities, Sen introduces the concept of functionings. The distinction between capabilities and functionings is that capabilities are freedoms or *possible* achievements of people in the future, whereas functionings are *effectively realized* achievements. As phrased by Sen 'Functionings are the "beings and doings" of a person, whereas a person's capability is "the various combinations of functionings that a person can achieve."⁶⁰ For example, children have the capability to be healthy. Related functionings could be 'birth weight', 'lung capacity', 'height', 'life expectancy' and 'child and mortality ration'. Robeyn describes the difference as 'Achieved functionings are (at least indirectly) measurable, whereas the person's capability would also include all the opportunities this person had but chose not to take.' Furthermore, functionings are measurable and comparable.

Freedom of choice is thus a central notion in the capability approach. Two children (e.g. twins) with exactly the same characteristics, may have exactly the same capabilities, but achieve completely different functionings, because they have or develop fundamentally different opinions upon what it means to lead a good life. Furthermore, the transformation of capabilities into (a set of) functionings, is influenced by individual (sex, intelligence, age, metabolism, physical condition, reading skills), social (power relations and social and religious norms, discriminatory practices and gender roles) and environmental (climate, infrastructure, availability of underlying determinants of health) conversion factors. Both by assuming different individual capabilities and by taking into account the different choices that individuals can make to achieve a set of functionings, the capability approach thus accounts for interpersonal variations. With a view to realizing the highest attainable standard of children's health, it is therefore essential to identify the capabilities of individual children, being dependent on their innate genetic predispositions, the circumstances in which they are brought up, including the support provided by their caretakers, the underlying determinants, such as quality of food, medicines or drinking water, that they have at their disposal and also the influence of the choices that they and

⁵⁸ M. Nussbaum, 'Capabilities as fundamental entitlements: Sen and social justice', *Feminist Economics* 2003, 9(2/3), p. 33–59.

⁵⁹ A.K. Sen, 'Capabilities, Lists, and Public Reason: Continuing the Conversation', *Feminist Economics* 2004, 10, no. 3, p. 77–80. (A frequently cited interview with Amartya (A.K.) Sen in which he elaborates on his rejection of a fixed list of capabilities).

⁶⁰ A.K. Sen, *Inequality Reexamined*, Oxford: Oxford University Press 1992.

their parents make with regard to the capabilities that they wish to realize, the health choices that they make.

The capability approach of Amartya Sen has four fundamental elements:

- I. Having the same amount and quality of resources, individuals can differ greatly in the functionings they wish and the functionings they are able to achieve. For example, a pregnant woman having a certain amount of food will realize other functionings (namely becoming a mother) than a woman who has that same amount of food not being pregnant. Therefore, an approach that only focuses on resources available to a person is insufficient because it does not take into account the agency of the person in transforming those resources.
- II. People can take the circumstances in which they live for granted. For example, someone living with a chronic disease can state that he feels very healthy and thereby influence the overall perception of his quality of life. An approach that only takes people's subjective experience into account thus misses the evaluation of the objective circumstances in which people live.
- III. Notwithstanding the functionings that people achieve, it makes a great difference whether those functionings were opted for or forced into. For example, someone who becomes very sick because he did not have access to vaccination has not opted for becoming sick. On the other hand, someone who refuses a vaccination has deliberately taken the risk to become sick. Therefore, both the resultant functionings and the freedom of choice must be taken into account.
- IV. Reality is complicated and individuals have their own variable truths. Therefore, an open-mind is essential to integrating the many different choices made on the sets of functionings that people wish or are able to achieve.

1.3.2. RELATING THE CAPABILITY APPROACH TO THE HIGHEST ATTAINABLE STANDARD OF HEALTH

Sen's capability approach offers a lens through which normative frameworks, such as the international legal framework on children's right to health, can be assessed. As identified by Robeyn, 'The capability approach to well-being and development evaluates policies – or in the case of this research – according to their impact

on people's capabilities.⁶¹ It asks whether people are being healthy, and whether the resources necessary for this capability, such as clean water, access to medical doctors, protection from infections and diseases, and basic knowledge on health issues, are present.'

Translated to the field of children's health, the capability approach thus looks at the capability of children to be or to become healthy. It relates to the legal question of what is the highest attainable standard of health of children. The achievement of the highest attainable standard of health is necessarily dependent on the individual choices, characteristics and living circumstances of each child and its family and the choices they make. Subdivided into separate legal domains; the children's rights domain, other sources of international health and human rights and human rights in the European region, the international legal framework on children's right to health will be assessed for their impact on realizing the highest attainable standard of health of the child, i.e. the capability of the child to be healthy.

Applying the capability approach to the children's rights domain, offers a way to take into account both the child's present and the child's future needs and rights. Peleg has taken this approach with respect to the child's right to development. He argues that the approach taken by the Committee on the Rights of the Child primarily approaches children as 'human becomings' instead of 'human beings', thereby 'focusing on the child as a future adult, without respecting its present agency and voice'.⁶²

The capability approach offers room to approach children as individual human beings in their own right and holding their own (children's) rights, because they are assumed to have the freedom to choose between the capabilities that they wish to realize. As such, they can exercise agency, shape their own life and take an active role in realizing their own right to health.⁶³ In that way, they have the freedom to express their unique individuality. According to Peleg, it is the duty bearers, being the primary caretakers and the government, that are to enable children to exercise their agency and capabilities.⁶⁴ Peleg contests the standpoint taken by critics that children lack the competency to self-determination, stating that 'debates on children's capabilities and capacities do not relate to children's ability to choose, but rather to the space that society, adults and the law give to children and the tolerance that they have towards presumed mistakes'.⁶⁵ This point is very important, since it is only by enabling children to express themselves and their opinions, for example with respect to medical consent, that their abilities to do

⁶¹ I. Robeyn, *The Capability Approach: a theoretical survey*, Journal of Human Development, Volume 6, Number 1, March 2005. Available at: www2.dse.unibo.it/ardeni/ESCA_2012/Robeyns.pdf.

⁶² N. Peleg, *Reconceptualising the Child's Right to Development: Children and the Capability Approach*, in: International Journal on Children's Rights, 2013, Volume 21, Issue, pp. 523–542.

⁶³ Ibidem supra note 62, p. 527.

⁶⁴ Ibidem supra note 62, p. 531.

⁶⁵ Ibidem supra note 62, p. 533–534.

so become visible. I would even argue that taking children seriously in their own right and giving them the space, support and information necessary to make their own decisions concerning their health, contributes significantly to developing their abilities to choose between the capabilities that they wish to realize.

With respect to the linkage between human rights and capabilities, Sen claims that human rights law can establish the framework to impose obligations on states to provide for the capabilities necessary to achieve human development. At the same time, ensuring human rights can provide for a safe space to achieve the functionings that individuals opt for. With respect to realizing the rights of (vulnerable) children, a balance must therefore be struck between creating a safe space for children to flourish, while at the same time preserving the room to develop, make mistakes, fall and stand-up again.

Sen does not presume that capabilities, in terms of opportunities of people to be healthy, can only be corrected by the government. Indeed, it seems logical to assume that other actors, including children and their families themselves, but also private companies, non-governmental organizations, fellow citizens as well as life events and natural disasters, can have a significant impact or even play a central role in increasing the capability of children to be healthy and thus in increasing their opportunity to realize the right to health of the child. Therefore, the presumption underlying this research is that the responsibility to realize the highest attainable standard of health of the child is shared between the child itself, its parents, the government and other actors that influence upon the realization of the right to the highest attainable standard of health of the child.

1.3.3. RESEARCH METHODOLOGY

The research methodology will consist of a literature research of the relevant international legal documents, the *travaux préparatoires*, General Comments, the Concluding Observations of the Committee on the Rights of the Child on the Country Reports, UN documents, EU documents and relevant scientific literature. In the following paragraphs, the basic concepts of this study, namely the concept of health (paragraph 4), health as a right (paragraph 5), primary health care (paragraph 6), vulnerable children (paragraph 7) and responsible actors (paragraph 8) will be elaborated. This research covers the period between January 2010 and January 2014. Literature after this date has not been included. Given the focus of the capability approach on the unique development of individual children and the role of different actors in realizing the right to health of the child, three key elements are structurally taken into account in the analysis of the relevant legal documents. The identification of priorities of the right to health of the child is done on the basis of these elements. The elements are:

- Measures that relate to the role of children and parents themselves in ensuring the right to health of children.
- Measures that clarify the attribution of responsibilities to different actors involved in realizing the right to health of children.
- Measures required to ensure that children grow up in healthy circumstances, including access to necessary health services.

The research looks at the international legal framework on the right to health of the child. As an example of a regional interpretation of the right to health of the child, chapter 5 takes a closer look into the legal framework in Europe, since there have been considerable developments in interpreting the right to health of the child. Further research in other regions on the right to health of the child is highly relevant. However, it would be too extensive to include all regions in this research. Furthermore, although this research does not aim to clarify the applicable international legal framework on the right to health of the child for the Netherlands, it does use some examples of national laws and implementation measures of this country.

1.4. DEFINITION OF HEALTH

1.4.1. RELEVANCE OF A DEFINITION OF HEALTH

Defining the concept of health has been subject to debate across all cultures and throughout all periods of time, being a highly subjective experience.⁶⁶ Identifying the content of the concept of health for exploring the right to health of children has both theoretical and practical relevance.⁶⁷ Theoretically, it forms the basis for understanding the phenomena of health and disease and practically it influences people to determine what they should individually and socially do to advance health. A clear and acceptable definition of health is also necessary to allow for comparisons.⁶⁸ Furthermore, in understanding the right to health, the question of what health is, determines what steps are required to realize the right to health.

Ruger argued that in order to provide a workable operationalization of the right to health, a shared standard of health must be identified.⁶⁹ She refers to the Aristotelian capability view to argue that ‘social justice and the right to

⁶⁶ B.C.A. Toebes, *The Right to Health as a Human Right in International Law*, Antwerp: Intersentia 1999, p. 20.

⁶⁷ L. Breslow, ‘A Quantitative approach to the World Health Organization Definition of Health: Physical, Mental and Social Well-being’, *International Journal of Epidemiology* 1972, Volume 1, Number 4, p. 349.

⁶⁸ J.P. Ruger, ‘Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements’, *Yale Journal of Law & the Humanities* 2006, Volume 18, p. 312.

⁶⁹ J.P. Ruger, ‘Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements’, *Yale Journal of Law & the Humanities* 2006, Volume 18, p. 279.

health require a universally shared norm of health to establish a framework for interpersonal health comparisons' and 'the prioritization of health dimensions when resources are scarce'. The central idea of the Aristotelian capability view as identified by Ruger, is that the right to health must be treated as an ethical demand and that this involves both legal instruments for enforcement as internalization by individuals, states and non-state actors of this public ethical norm in their daily functioning to enhance implementation and compliance with the right to health in international human rights policy and law. She argues that the progressive realization of the right to health is more likely to occur 'when individuals within a given society take ownership of the public moral norm as a guiding principle for their individual and collective efforts, as evidenced by their domestic social, political and economic activity'.⁷⁰ This will be more likely when they can identify with the moral norm on the basis of their own notion of health and duties and obligation to achieve that state of health. The difficult question now is what would be a workable definition of health throughout different countries and cultures in the world in order to further clarify the content and scope of the right to health.

1.4.2. IN SEARCH OF A DEFINITION OF HEALTH

Throughout European history, the concept of health has varied from physical to mental and even spiritual well-being. The ancient Greek notion, exemplified by a statement by Aristotle, focused on the physical well-being: 'In the case of the body, excellence is health in the form of making use of the body without illness...'.⁷¹ Hippocrates considered health as a harmonious mixture of the humours of the body; blood, phlegm, black bile and yellow bile deriving from four organs; the heart, brain, liver and spleen. Sickness, in his theory, was caused by any imbalance of the system and health could be restored by nature, special diets and special medicines.⁷² It has also been noted by Sigerist that the concept of health was mainly 'aristocratic' in character, being directed only to a few individuals, rather than on improving the public health of many.⁷³

During the earlier part of the Roman period, the physically oriented notion of health from the Greek changed to a balance between body and mind: 'ut sit mens sana in corpore sano'.⁷⁴ Parallel to the increasing familiarity with Greek

⁷⁰ J.P. Ruger, 'Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements', *Yale Journal of Law & the Humanities* 2006, Volume 18, p. 278.

⁷¹ Aristotle, *On Rhetoric*, New York/Oxford: Oxford University Press, 1991 (G.A. Kennedy Translation).

⁷² J.S. Larson, 'Conceptualization of health', *Medical Care Research & Review* 1999, Issue 56, p. 124.

⁷³ H.E. Sigerist, *Medicine and Human Welfare*, New Haven/London: Yale University Press/Oxford University Press 1941, p. 53–104.

⁷⁴ Your prayer must be for a sound mind in a sound body (Juvenal, *Satires*, x, 356).

philosophical ideas in the later Roman era, the concept changed again to a predominant physical approach.

During the Christian era, the physical orientation of the meaning of health was completely reversed to a more spiritual interpretation of health: 'It is the soul that counts. Everybody is sick without Christ. No diets nor exercise are needed, but baptism is the bath that gives health.'⁷⁵ The second difference with the classical definitions of health was that health was not intended for the lucky few, but for all. This was reflected by the increasing attention for collective hygiene.⁷⁶ These examples show that the clarification of the definition of health is determinative for the question what people, in particular children, need to achieve or maintain that level of health, and thus what entitlements they should have on the basis of their right to health.

To provide a further basis on which the right to health in an international context will be established, several examples of interpretations of health from different parts of the world will now be identified.

Across different cultures in the world, the modern definition of 'health' is broadly diversified, reflecting the core themes of the underlying cultures. For example, the Han people, numerically and politically dominant in China, define health as 'a harmonious relationship between humans and the cosmos and among humans'.⁷⁷ A healthy body is a body in which Qi, an energy flow that runs through the universe, and blood, vital essence, body fluid and nutrients are in careful balance. Any imbalance in this system results in illness. Another example of an understanding of health is found in the ancient Egyptian doctrine, wherein health (*senb*) is seen as 'the action that establishes harmony within duality'. The definition of healing in ancient Egyptian natural medicine is the establishment of harmony in this life and beyond, by developing the inner resources of the patient.⁷⁸ According to the Egyptian natural medicine, we must have good eating habits, a good exercise system for the nine bodies and a good system for conducting our emotions. If we manage to establish harmony between our nine bodies and between these systems, health will be ours for our lifetime and for eternity.⁷⁹ Other examples of health include the concept of health found in the Amazon base of Venezuela and Brazil, where the Yanomamo Indians believe that illnesses are caused by spirits, ghosts or ancestors and the interpretation of health

⁷⁵ H.E. Sigerist, *Medicine and Human Welfare*, New Haven/London: Yale University Press/Oxford University Press 1941, p. 53–104.

⁷⁶ H.E. Sigerist, *Medicine and Human Welfare*, New Haven/London: Yale University Press/Oxford University Press 1941, p. 53–104.

⁷⁷ M. Singer & H. Baer, *Introducing medical anthropology*, Lanham: AltaMira Press 2007, p. 69.

⁷⁸ In the Egyptian doctrine, our nine bodies consist of *Ren* (the sound body), *Eb* (the heart body), *Khat* (the physical body), *Sekhem* (the electromagnetic body), *Ka* (the desire body), *Kihibit* (the astral body), *Ba* (the soul body), *Saah* (the spiritual body) and *Khu* (the universal spirit of God within every atom). See www.siaacademy.com/html/Monthly.html.

⁷⁹ www.siaacademy.com/html/Monthly.html.

of the !Kung San of the Kalahari Desert in south-western Africa: the ability to sweat is regarded as good health since it is regarded as a life-giving substance.⁸⁰

In the current western literature on health, the focus is on individual determinants of health. Health care is focused on subparts of the human body, the medical organizational system being subdivided into separate compartments, such as cardiology, gynaecology, dermatology, neurology and psychiatry. This approach is exemplified by the definition of health in the Oxford Dictionary: 'Soundness of body; that condition in which its functions are duly and efficiently discharged'. Both the physical and the functional aspect are predominant in this definition. Furthermore, the concept and measurement of health in the current western medical domain has generally focused on ill health.⁸¹ Doctors approach patients from their pathology and medical textbooks bundling an enormous collection of diseases.⁸² The presence of a disease in this interpretation can be identified through various bodily signs, such as a high or low temperature, blood pressure, or heart rate.⁸³ As such, it can be established by a professional such as a biomedical physician or another formally recognized medical practitioner. Applied to the broader context, public health is measured by determining infant and child mortality and morbidity. A population is said to be healthy when these rates are low.⁸⁴

Over time and across cultures, the different concepts of health thus varied from an emphasis on physical, mental, social or spiritual health to a combination of these three approaches.⁸⁵ Another distinctive feature shifted between the more 'negative' description, such as 'the absence of disease or infirmity' to a more positive formulation, such as 'health is well-being' or 'health is the capacity to work and love'.⁸⁶ Over time, when the so-called 'positive idea of health' emerged, the holistic and positive definition of the WHO has been adopted as an international

⁸⁰ M. Singer & H. Baer, *Introducing medical anthropology*, Plymouth: Altamira Press 2007, p. 69.

⁸¹ L. Breslow, 'A Quantitative Approach to the World Health Organization Definition of Health: Physical, Mental and Social Well-being', *International Journal of Epidemiology* 1972, Volume 1, No. 4, Oxford University Press, p. 1.

⁸² The insight that western medicine is heavily oriented towards a negative formulation of health was acquired from Richard Smith in his blog for the British Medical Journal, entitled 'The end of disease and the beginning of health', 8th July 2008. Available at: <http://blogs.bmj.com/bmj/2008/07/08/richard-smith-the-end-of-disease-and-the-beginning-of-health/>.

⁸³ M. Singer & H. Baer, *Introducing medical anthropology*, Lanham: AltaMira Press 2007, p. 64–66.

⁸⁴ L. Breslow, 'A Quantitative approach to the World Health Organization Definition of Health: Physical, Mental and Social Well-being', *International Journal of Epidemiology* 1972, Volume 1, Number 4, Oxford University Press, p. 347.

⁸⁵ H.E. Sigerist, *Medicine and Human Welfare*, New Haven/London: Yale University Press/Oxford University Press 1941, p. 53–104.

⁸⁶ This formula was cited by Erik Erikson, but it is not to be found in Freud's works, although the sentiment is sometimes implied. During his long engagement Freud stated that his own ambition in life was to have Martha as his wife and to be able to work (e.g. "Couldn't I for once have you and the work at the same time?" Freud-Martha Bernays 21 October 1885). Freud also referred to Eros and Ananke [Love and Necessity] as the foundations of society. In 'Civilization and Its Discontents' (1930) he wrote: "The communal life of human beings had, therefore, a

standard. The World Health Organization defines health as ‘a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity’.⁸⁷ This means that the health concept is positively formulated, not dependent on the concepts of disease and illness. This is a remarkable approach to health, as we have seen that most modern doctors focus on diseases, not on health and thus apply a negatively formulated definition of health.

However, the holistic WHO definition of health has been heavily criticized. Whereas it was acknowledged that the widening of the concept of health was a major advance including the underlying determinants of health, the concept is said to be so broad that it has no operational value and that it ‘ensures that hardly anybody is truly healthy’.⁸⁸ Huber righteously argued that due to highly sensitive modern diagnostic tools, it is fairly impossible to reach a state of complete health.⁸⁹ As a result of the far-reaching technological possibilities for genetic testing, blood tests and MRI scanning, it is even stated that health is an illusion, as there always is a (genetic) predisposition encountered for the existence of latent diseases.⁹⁰ The result is that the concept of health as adopted by the WHO has often been said to be too vague and not subject to scientific application.⁹¹ Huber righteously points to the risk that the ever further reaching search for medical treatments significantly increases the risk of medicalization of society and people.⁹² She eloquently poses that the WHO definition becomes counterproductive, because ‘it minimizes the role of human capacity to cope with life’s ever changing physical, social and emotional challenges’. One could even argue that the increased medicalization of society significantly reduces people’s inclination to take responsibility for their own health and possibly also for the health of their children. However, the parallel development in which people have better access to health information runs against this development, because people are better able to question doctors

two-fold foundation: the compulsion to work, which was created by external necessity, and the power of love...”. (S.E. XXI.101). See for more information: www.freud.org.uk/about/faq/.

⁸⁷ 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.

⁸⁸ R. Saracci, ‘The world health organization needs to reconsider its definition of health’, *British Medical Journal* 1997, Volume 314, Number 1409. Available at: www.bmj.com/content/314/7091/1409.

⁸⁹ M. Huber e.a., ‘How should we define health?’, *British Medical Journal* 2011, Volume 343, number b4163. Available at: www.bmj.com/content/343/bmj.d4163.

⁹⁰ This insight was acquired from Richard Smith in his blog for the British Medical Journal, entitled ‘The end of disease and the beginning of health.’ 8th July 2008. Available at: <http://blogs.bmj.com/bmj/2008/07/08/richard-smith-the-end-of-disease-and-the-beginning-of-health/>.

⁹¹ L. Breslow, ‘A Quantitative approach to the World Health Organization Definition of Health: Physical, Mental and Social Well-being’, *International Journal of Epidemiology* 1972, Volume 1, Number 4, Oxford University Press, p. 348.

⁹² M. Huber e.a., ‘How should we define health?’, *British Medical Journal* 2011, Volume 343, number b4163. Available at: www.bmj.com/content/343/bmj.d4163.

on the proposed treatments and stand up for their own and their children's right to the highest attainable standard of health.

A further elaboration of the concept of health was promoted at the Alma-Ata conference in 1978, wherein health was no longer seen as a technically complex medical matter, but as a daily concern which individuals can and must face themselves. It is thus much broader than the sporadic encounters with medical professionals.

Following from this the concept of primary health care was officially launched (see discussion in paragraph 5), aiming to reach the entire population.

Two contributors to the *British Medical Journal* have tried to overcome the problem of the limited practical value of the WHO definition and did an extensive search for further information on the concept. As this produced little information, an online invitation by the *British Medical Journal* was posted to revise the current definition, amounting to a vast amount of suggestions, ranging from, 'Health is the state of the organism when it functions optimally without evidence of disease' to 'Health is inner peace'.⁹³ Interesting is the question whether the increasing expectations of health due to changes in diagnostic abilities lead to a broader conceptualization of the right to health.

More recent work on the concept of health in the context of enforcing it as a right has been done by Ruger. The definition proposed by Ruger is the following:

'(1) The state of the organism when it functions optimally without evidence of disease or abnormality. (2) A state of dynamic balance in which an individual's or a group's capacity to cope with all circumstances of living is at an optimum level. (3) A state characterized by anatomic, physiologic, and psychologic integrity, ability to perform personally valued family, work and community roles, ability to deal with physical, biologic, psychologic, and social stress; a feeling of well-being; and freedom from the risk of disease and untimely death.'⁹⁴

Ruger claimed that this model is useful because it includes physical, mental and social aspects of humans.⁹⁵ It is also valued for including both potential as well as actual health status and because it respects the freedom of individuals to pursue their health capabilities through the health functions that are available to them.⁹⁶ The definition contains several elements worth noticing: the element of dynamicity is reflected in the second sentence by the phrase 'a state of dynamic balance'. As can be seen in the third sentence, this dynamic balance requires the ability to perform in societal roles and to deal with a variety of stress factors.

⁹³ A.R. Jadad & L. O'Grady, 'How should health be defined?', *British Medical Journal* 2008, Volume 337, no. a2900. See also: www.bmj.com/content/337/bmj.a2900.full?rss=1.

⁹⁴ J.P. Ruger, 'Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements', *Yale Journal of Law & the Humanities* 2006, Volume 18, p. 316.

⁹⁵ Ibidem supra note 94.

⁹⁶ Ibidem supra note 94, p. 317.

By incorporation of this element it is acknowledged that health is not a static situation, but that it requires continuous effort and adjustment to ever changing circumstances to attain and to maintain a state of health. This state of health, as can be seen in sentence 1 and 2, should function ‘at an optimum level’. Sentence one particularly refers to the functioning of the organism, whereas sentence 2 emphasizes (external) circumstances of living in assessing the potential optimal level of functioning. This element, ‘optimal functioning’ reflects the notion that the ‘highest attainable level of health’ may differ according to personal and situational circumstances (within and between different countries and populations). That same idea of a different standard of health is also found in the general definition of health of the WHO, which states that individuals have a right to ‘*the highest attainable standard*’ of health, leaving space for differentiation between distinct living circumstances in prioritization and goal-setting. The question is what this variable concept of the highest attainable standard of health means for the enforcement of health as a right, as will be discussed in the following paragraph and beyond.⁹⁷

Another element in Ruger’s definition of health is the particular mentioning of ‘the individuals and the groups capacity’ to cope with differing circumstances. This accounts for the differing requirements for ensuring an individual’s (right to) health and the requirements for developing public health policies. This notion gives room for discussing whether social determinants, such as the availability of clean water and the establishment of hygienic sanitary conditions should receive a higher prioritization than ensuring high-tech medical care for individuals. It has been acknowledged that social determinants have a greater impact on health than access to medical services.⁹⁸ On the other hand, it must be acknowledged that the illness of an individual may spread through the entire society through schools, work environments, clubs, religious institutions etcetera, thereby impacting upon the health of both the individual and large numbers of others.⁹⁹ More importantly, the rights of an individual should not in principle be subordinated to the rights of the majority.

Whereas the whole of Ruger’s suggested definition of health seems to be more practical than the definition of the WHO, the phrase in the last sentence ‘freedom from the risk of disease and untimely death’ seems somewhat utopian again, as it is impossible to be completely free of the *risk* to disease or untimely death. (Unknown) risks are always present and can (and should) not be completely ruled

⁹⁷ In Chapter 3 the different interpretations of children’s right to health in countries with different levels of human development will be discussed on the basis of the Concluding Observations of the UN Committee on the Rights of the Child.

⁹⁸ G. Greenivasan, ‘Opportunity is not the Key’, in: B. Steinbock, A.D. Arras & A.J. London, *Ethical Issues in Modern Medicine*, New York: McGraw-Hill 2009, p. 235.

⁹⁹ W.M. Sage, ‘Solidarity: Unfashionable, But Still American’, *Connecting American Values with Health Reform* 2009, The Hastings Centre, p. 10.

out. Such a definition would lead to a level of risk-aversion that does not seem desirable for a flourishing life.

Key elements in Ruger's definition of health match well with the recently introduced definition of health by Huber. Criticizing the static nature of the WHO definition of health 'a complete *state* of physical, mental and social well-being' as well as the inability to ever reach a state of *complete* state health, she introduces the definition that health is the 'ability to adapt and self-manage in the face of social, physical and emotional challenges'.¹⁰⁰ This definition takes adaptability of the human being to life's changing circumstances as well as resilience as a starting point.¹⁰¹ Not only does this definition better take into account the continuously changing nature of people's living circumstances, but it also enhances opportunities for operationalization. The requirement to augment people's resilience requires the development of so-called 'health-literacy', people's capacities for engaging in healthy behaviour and for developing the capacities of individuals to take responsibility for their own health and the health of their children. Not only does this increase the overall capacity of people involved in realizing the highest attainable standard of health of children, but it also improves people's sense of self-reliance and well-being.¹⁰² This focus on the freedom and responsibility of individuals to realize their own right to health and to make choices in favour of or against healthy behaviour (of their children) and thereby achieve certain functionings, is in line with Amartya Sen's capability approach. The implications of this new vision on health for the interpretation and realization of health as a right are discussed in the following section.

1.5. HEALTH AS A RIGHT

The acknowledgement of the State's co-responsibility to ensure health for its citizens goes back to old times, when ancient civilisations, including Egypt, India, Troy, the Roman Empire and the Inca society established water supply and drainage systems, aiming to prevent community infections.¹⁰³ The Greek philosopher Aristotle supports such ancient State practices with theory, by stating that the end that all political activity should strive for is human flourishing.¹⁰⁴ He recognizes that there are natural and social impediments to human flourishing. According to Ruger, 'this justifies health as a primary objective of health policy, having both an intrinsic and an instrumental value.'¹⁰⁵ Also, whereas the right

¹⁰⁰ Ibidem supra note 92 Huber.

¹⁰¹ Ibidem supra note 92 Huber.

¹⁰² Ibidem supra note 92 Huber.

¹⁰³ G. Rosen, *A History of Public Health*, Baltimore/London: The John Hopkins University Press 1993, p. 47, 55, 106, 111, 244.

¹⁰⁴ J.P. Ruger, 'Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements', *Yale Journal of Law & the Humanities* 2006, Volume 18, p. 288.

¹⁰⁵ Ibidem supra note 104, p. 290.

to health may be qualified as a basic civil or political right, it may be an essential precondition for the realization of those rights.¹⁰⁶

The modern development of health as a right was only instigated following the age of enlightenment and the establishment of universal human rights in the 18th century. In this period, the importance of health and its social effects were recognized, leading to the establishment of a 'medical police' in the larger cities of Europe and the United States, aimed at improving the public sanitation and hygiene.¹⁰⁷ One of its instigators, Johann Peter Frank, emphasized the link between poverty and health and called for the need to exchange health information on an international level in his 'Letter of Invitation to Scholars'.¹⁰⁸ More influential to the development of the right to health was the Industrial Revolution in the 19th century, creating unhealthy living and working conditions for large amounts of workers and their families.¹⁰⁹ In his 'Report on an Inquiry into the Sanitary Conditions of the Labouring Population of Great Britain', Chadwick promoted the need to guarantee health based on the utilitarian belief that a healthy working class benefits the entire society. This led to the passage of the Public Health Act in 1848, leading to the establishment of sewage systems, water supply and Medical Officers of Health.¹¹⁰

Other approaches included the need to protect health as a property right of the working man by Neumann,¹¹¹ as he claimed that this was the only right of those who have no other property than the labour they deliver. However, this foundation of health as a right does not provide for a strong entitlement for children, as they could not be qualified as formal workers yet, nor did they have the duty to provide for their families' living. Others saw health as a social and political value in its own right.¹¹²

Later in the 19th century, a series of International Sanitary Conferences were organized. The purpose of the conferences seemed to be the protection of Europe

¹⁰⁶ See: F.I. Michelman, 'Foreword: On Protecting the Poor Through the Fourteenth Amendment', *Harvard Law Review* 1969, Issue 7, p. 7. See also: A.E. Buchanan, 'The Right to a Decent Minimum of Health Care', *Philosophy and Public Affairs* 1984, Volume 13, no. 1, p. 61. [According to Rawls, certain social goods can be qualified as 'primary goods', meaning that virtually all individuals value them despite interpersonal differences in desires and life goals. Rawls concludes that at least some forms of health care seem to bear the earmarks of Rawlsian primary goods: they facilitate the effective pursuit of ends in general and may also enhance our ability to criticize and revise our conceptions of the good.] found in: R. Korobkin, 'Determining health care rights behind a veil of ignorance', *University of Illinois Law Review* 1998, no. 3, p. 806.

¹⁰⁷ A. de Swaan, *In Care of the State*, Oxford/Cambridge: Basil Blackwell/Polity Press 1988, p. 126.

¹⁰⁸ *Epistola Invitoria ad Eruditos*, 1776, Rosen 1993, p. 267.

¹⁰⁹ C.F. Brockington, *Public Health in the Nineteenth Century*, London, England: Livingston 1965.

¹¹⁰ G. Rosen, *A History of Public Health*, Baltimore/London: The Johns Hopkins University Press 1993, p. 196.

¹¹¹ S. Neumann, *Die öffentliche Gesundheitspflege und das Eigentum [Public Health Care and Property]*, Berlin: Adolf Riek 1847.

¹¹² M. Susser, 'Ethical components in the definition of health', *International Journal of Health Services* 1974, volume 4, pp. 539–548.

against alien diseases, being a hindrance to international trade.¹¹³ It was not until the 11th edition in 1907, that the Rome Agreement was signed to establish an international office of public health in Paris. This Office was linked to the League of Nations until the creation of the United Nations.¹¹⁴

Following the atrocities of World War II, the United Nations Charter in article 1 affirmed the dignity and worth of the human person as the cornerstone of human rights. In 1946, the Constitution of the World Health Organization was signed,¹¹⁵ being the first international human rights document to formulate the individual's right to health, without distinction of race, religion, political belief, economic or social condition.¹¹⁶ Particular mention is made of the basic importance of the healthy development of the child: the ability to live harmoniously in a changing total environment is essential to such development. The adopted definition of health reflects the notion that the right to health is broader than only the provision to ensure health care facilities, referring to the responsibility of the government to provide for adequate health and social measures.

This broad formulation of health as a human right was reaffirmed in 1948, when the United Nations adopted the Universal Declaration on Human Rights encompassing article 25, which reads: '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, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.' The Committee on Economic Social and Cultural Rights elaborated upon this provision in article 12 of its International Covenant. This article is in line with the WHO Constitution, as it refers both to a right to health care as to a broader range of public health measures to ensure the underlying determinants of health (or 'healthy conditions') to be taken by States. It provides for key provisions to progressively realize the right to health, including the provision for the reduction of the stillbirth rate, infant mortality and the healthy development of the child (12-2-a) and the creation of conditions which assure to all medical services and medical attention in the event of sickness. The right to health as laid down in article 12 ICESCR (1966) was further elaborated upon in General Comment 14 of the Committee on Economic Social and Cultural Rights (2000). The distinctive features of this general right to health are further discussed in chapter 5. The right to health in international health law is used as a shorthand expression for a

¹¹³ H.D.C. Roscam Abbing, 'Recht op gezondheidszorg: een beschouwing over grenzen aan het stellen van grenzen (liber amicorum voor Prof. Dr. H.J.J. Leenen)', in: J.K.M. Gevers & J.H. Hubben, *Grenzen aan de Zorg: Zorgen aan de Grens*, Alphen aan de Rijn: Samsom/H.D. Tjeenk Willink 1990, p. 91. See also, WHO, *The First Ten Years of the World Health Organization*, 1958, pp. 1–15.

¹¹⁴ WHO, *The First Ten Years of the World Health Organization*, 1958, p. 22–24.

¹¹⁵ The WHO Constitution was signed during the International Health Conference in New York on 22 July 1946 and entered into force on 7 April 1948.

¹¹⁶ Preamble of the WHO Constitution (see also note 95).

broad range of entitlements, including health care and underlying determinants of health. Other terms used include the right to health care, the right to health protection or the right to health maintenance. Neither of these covers the range of entitlements as defined in the WHO Constitution, namely the right to health care and the right to have the underlying determinants of health fulfilled. However, it does not go so far as to implicate a right to be healthy because this can not be guaranteed solely by the efforts of States. Health also depends on individual (biological) characteristics and behaviour. Furthermore, the right to 'the highest attainable standard of health' depends on the available resources of a State.

It has been acknowledged that the indeterminacy of the right to health is a central point of weakness in realizing the right to health.¹¹⁷ In the modern debate, several aspects have been central. In determining the contents of the right to health, the focus has shifted between solely ensuring medical services to also ensuring the underlying determinants of health. Furthermore, shifts have been made between a focus on the individual and a focus on a collectively oriented appeal. This shift in focus has been attributed to the distinctive influence of the clinical sector, focusing primarily on the health status of individuals. In addition, the influence of the public health sector played a part, focusing on the health of populations and the need to ensure conditions under which people can be healthy.¹¹⁸ The third dimension analysed is that the formulation of the right to health has shifted between a negative formulation, such as 'health is the absence of disease' to a positive formulation of health, such as the holistic interpretation of health by the WHO.

In the newly introduced definition of health by Huber the focus shifts from an external orientation with regard to entitlements to health services and underlying determinants to an internal orientation, in which people's capacities to self-manage their health status and to adapt to changing circumstances become key to ensuring the right to the highest attainable standard of health. From this perspective, the obligations of the State in realizing the right to the highest attainable standard of health have to enable and stimulate people to take responsibility over their own health. In that way, they regain their opportunity to choose the different functionings they wish to realize. What this approach means for the way in which the right to the highest attainable standard of health of the child is realized is investigated in this research.

¹¹⁷ D.P. Fidler, 'Geographical morality' Revisited International Relations, International law and the controversy over placebo – controlled HIV Clinical trials', *Harvard International Law Journal* 2001, Volume 42, no. 2, Issue 299, p. 348.

¹¹⁸ J. Asher, *The right to health, A resource manual for NGOs*, London: Commonwealth Medical Trust 2004, p. 18.

1.6. FOCUS ON THE PROVISION OF PRIMARY HEALTH CARE

Article 24(2)(b) CRC demands priority for ensuring the provision of necessary medical assistance and health care to all children with an emphasis on the development of primary health care. Thus the question arises what is meant with the phrase primary health care and how it can contribute to realizing the highest attainable standard of health of the child.

The content of primary health care was elaborated in the 1978 Declaration of Alma Ata on Primary Health Care, during a conference that was sponsored by UNICEF and the WHO. The UN General Assembly endorsed the Declaration by resolution 34/43 of 19 November 1979.¹¹⁹

The declaration contains an elaborate definition of primary health care, characterized by several key elements. First of all, primary health care is essential health care that is universally accessible and affordable for all individuals in the community.¹²⁰ Stated is that it is the first level of contact for individuals and families with the national health system and that it constitutes a central function and main focus of the country's health system. It aims to bring health care as close as possible to where people live and work. Thereto, primary health care envisages small, but widely accessible institutions and should be distinguished from more complex types of health care such as hospitals.¹²¹

The role and functioning of primary health care in society is further elaborated as being dependent on and therefore reflective of the economic, social, cultural and political rights in a country. The Declaration of Alma-Ata underlines that relevant research results and public health experiences must be applied in primary health care. It states that the key issues in primary health care require an integrated approach by all sectors of society to ensure a basic level of nutritious food, water, sanitation, mother and child health care, immunization against the major infectious diseases, adequate treatment of the most common diseases and injuries and the provision of essential drugs. The propagated approaches to achieve these targets include (education on) the promotion, prevention, curation and rehabilitation of the main health problems in a country. Because the health system relies on a wide variety of properly trained health workers, including traditional practitioners, individuals and communities they must be educated to take a proactive, participative and self-reliant role in the planning, organization and control of primary health care.¹²² This is deemed necessary to make the fullest use of all available resources, in addition to internal resources of the country and external resources from other countries. Last but not least, the Declaration

¹¹⁹ International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978.

¹²⁰ See § VI-VIII of the Declaration International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978.

¹²¹ A. Eide & W.B. Eide, *A Commentary on the UN CRC Article 24: The Right to Health*, Leiden: Martinus Nijhoff Publishers 2006, p. 21.

¹²² Ibidem supra note 120.

states that priority must be given to those most in need. Given the significant vulnerability of young children and the particular mention made of children's health in the Declaration of Alma-Ata, this irrefutably includes children aged 0–5, who by nature of their age have a relatively high level of vulnerability in comparison to older children.

The Declaration of Alma-Ata was revolutionary in the approach to health care, as earlier health campaigns in the 20th century were exclusively targeted at the eradication of specific diseases, such as smallpox. Successful community based health programs in China and several other countries led to the new approach of health care, which was characterized by a holistic approach to health, including not only the prevention of specific diseases, but also the principles of equity, health promotion, community involvement, recognition of multiple determinants of health and intersectoral collaboration. The initial enthusiasm over this approach led to the incorporation of Primary Health Care principles in national health programs.¹²³ However, economic constraints in the 1980s impeded effective implementation.¹²⁴ More importantly, when actual efforts were made to involve local communities in health programs, this appeared to be a serious threat to the elites, (central) governments and also the medical elites, who had maintained a powerful control over the practice and knowledge of healing.¹²⁵ This combination of governmental bureaucracy and lack of will by the medical community to relinquish its autonomy in the medical sector placed great obstacles in achieving the targets of the Primary Health Care Approach.¹²⁶ Under the banner of the Primary Health Care approach, high-tech government-run medical initiatives were launched in remote areas, replacing the locally-based initiatives by communities. This has led to conclusions that the Primary Health Care approach failed, but also to conclusions that the approach was never actually tried.¹²⁷ Scarce examples of comprehensive health programs very much in line with the Alma-Ata principles, suggest that the PHC approach can be very successful if three basic conditions are present: 1) political will to meet citizens' basic needs, 2) active popular participation to realize this goal and 3) social and economic equity.¹²⁸

Following the objections of several governments and medical professionals, the Primary Health Care approach was reduced to several key elements, described

¹²³ D. Sanders & D. Werner, 'The Politics of Primary Health Care and Child Survival', *HealthWrights*, 1997, p. 19.

¹²⁴ J. Walsh & K. Warren, 'Selective Primary Health Care: An interim Strategy for Disease Control in Developing Countries', *New England Journal of Medicine* 1979, 301, number 18, p. 967–974.

¹²⁵ D. Sanders & D. Werner, 'The Politics of Primary Health Care and Child Survival', *HealthWrights*, 1997, p. 19.

¹²⁶ D. Sanders & D. Werner, 'The Politics of Primary Health Care and Child Survival', *HealthWrights*, 1997, p. 20.

¹²⁷ See for example: B. Wisner, *Power and Need in Africa*, Trenton, New Jersey: Africa World Press 1989, p. 53–86. See also: D. Werner, 'The Life and Death of Primary Health Care or The McDonaldisation of Alma Ata', *HealthWrights*, 1997.

¹²⁸ D. Sanders & D. Werner, 'The Politics of Primary Health Care and Child Survival', *HealthWrights*, 1997, p. 21.

as the Selective Primary Health Care approach. One of its presumptions was the targeting of high risk groups that were carefully selected. Community participation, social and economic equity and intersectoral collaboration were excluded on the basis of recommendations by international health experts and it was widely stated that the goal to realize 'a complete state of physical, mental and social well-being' was unrealistic.

Focus was again placed on immunization against a selection of childhood diseases and outreach activities were organized to provide for a minimum healthcare package for families.¹²⁹ In line with this Selective Primary Health Care approach, UNICEF launched the IMCI, the integrated management of childhood illnesses in 1990, encompassing growth monitoring, oral rehydration, breastfeeding and immunization (GOBI). This campaign was expanded to GOBI-FFF (Family Planning, Food supplies and Female education), though never received as enthusiastically as the narrower GOBI-program. Some countries even narrowed their health policy to 'the engines of the child survival revolution', namely immunization and/or oral rehydration.¹³⁰ In 2002, the ACSD, the accelerated child survival and development program, directed at decreasing the high rates of infant mortality in 11 countries, was initiated. Critics said that these programs avoided discussing political and social causes of poor health, keeping health interventions under medical control.

It has thus become clear that the actual content of the concept of 'Primary Health Care' is strongly influenced by policy decisions of national governments. Given the relatively scarce resources available for improving (children's) health, it should be recognized that allocation of resources to tertiary health care (hospitals and more specialized methods of health care) benefits only a small number of people, limiting the possibility to reach everyone, both in rural as in urban areas, coming from all different subsections of the society, by primary health care.¹³¹ Article 24(2)(b) emphasizes the need to prioritize resource allocation to primary health care.¹³² This implicates a major challenge to stimulate commitment amongst all parties involved to establish a widely accessible primary health care system. In analysing the health systems in different countries, it must be kept in mind that the way in which primary health care is made accessible strongly differs. For example in the Netherlands, primary health care, or 'first line health care' is characterized by a first encounter with the family doctor who decides whether a referral to a specialized doctor, such as a gynaecologist, a paediatrician or a psychiatrist is required.¹³³ In other countries, in which this system of gatekeeping does not exist,

¹²⁹ Ibid supra note 128.

¹³⁰ Ibid supra note 128.

¹³¹ C. Sepúlveda, 'The right to child health: the development of primary health services in Chile and Thailand', *Innocenti Occasional Research Papers Child Rights Series*, number 7.

¹³² A. Eide & W.B. Eide, *A Commentary on the UN CRC Article 24: The right to health*, Leiden: Martinus Nijhoff Publishers 2006, p. 21.

¹³³ For a discussion on the gatekeeping role of the family doctor in the Netherlands and several other developed countries, see B. Meyboom-de Jong, 'De huisarts als poortwachter', *Arts en*

the hospital is the first step in the health care process. This difference unavoidably has consequences for the ways in which the key elements of primary health care can be realized.

1.7. CHILDREN AND VULNERABILITY

1.7.1. DEFINITION OF THE CHILD

Article 1 of the Children's Rights Convention defines children as 'every human being below the age of 18 years, unless under the law applicable to the child, majority is attained earlier.' The age of majority is recognized in law as being the threshold for ending minority and entering into adulthood. The minor ceases to be legally considered as a child and therefore assumes to have control over its own actions and decisions, thereby terminating the legal control over and the responsibilities of the parents or legal guardian. The age of legal majority is legally fixed, but it may differ depending on the jurisdiction of a particular country or on a particular subtheme. For example, in some countries the age of majority is determined at 18 years, whereas the legal threshold for being allowed to consume alcoholic beverages is 21 and whereas the legal age for consent to medical decisions is determined at 12 or 16 years of age. The concept of minority does not necessarily correspond to the actual physical or mental maturity of an individual. Provisions that could lead to an earlier ending of childhood include marriage before the age of eighteen,¹³⁴ having a baby¹³⁵ or the passage of certain rituals,¹³⁶ depending on the country and region of the world. Deviations from the international standard for the age of adulthood include Iran (15 years),¹³⁷ Scotland (16 years),¹³⁸ Indonesia (15 for girls and 18 for boys)¹³⁹ and Japan (20 years).¹⁴⁰

Remarkable is that the beginning of childhood is not mentioned in article 1 CRC, so that this must be determined by regional treaties or domestic legislation

samenleving in: *Nederlands Tijdschrift voor de Geneeskunde*, 31 December 1994, 138(53), pp. 2668–2673. In the Netherlands, 6 key functions of the family doctor are mentioned, including accessibility for all patients, continuity in diagnosis, treatment and care, the permanent relationship with the patient, involvement in the family and living circumstances of the patient, prevention, triage and epidemiology in patient population.

¹³⁴ See for example article 1:233 of the Dutch Civil Law Code (art. 1:233 BW).

¹³⁵ See for example article 1:253ha of the Dutch Civil Law Code (art. 1:253ha BW).

¹³⁶ In Jewish traditions, the age of adulthood is reached at the age of Bar Mitzvah (usually 13 for Jewish boys), when they have to learn the Torah and other Jewish principles.

¹³⁷ See world law direct: www.worldlawdirect.com/forum/law-wiki/27181-age-majority.html.

¹³⁸ Age of Legal Capacity (Scotland) Act 1991, article 1.

¹³⁹ See world law direct: www.worldlawdirect.com/forum/law-wiki/27181-age-majority.html.

¹⁴⁰ The age(s) of adulthood, The Japan Times Online, Sunday, February 24th 2008. <http://search.japantimes.co.jp/cgi-bin/ed20080224a1.html>. See also, World Law Direct: www.worldlawdirect.com/forum/law-wiki/27181-age-majority.html.

of states.¹⁴¹ A legal determination of minority ages does not appear in the European Convention on Human Rights nor in the International Covenant on Civil and Political Rights. Some individual states define the conception as the starting point of childhood,¹⁴² thereby prohibiting abortion if not for saving the life of the mother.¹⁴³ Others set a specific moment during pregnancy, for example the moment of viability of the foetus as the legal standard or the date of birth.¹⁴⁴

The European Court on Human Rights has considered the question whether individual children are entitled to benefit from a specific right only on a case-by-case basis.¹⁴⁵ The question on the beginning of life has been considered in the context of the right to life in article 2, paragraph 1 of the European Convention on Human Rights.¹⁴⁶ The determination of the beginning of childhood (or life) is essential in answering the question whether abortion is permitted or prohibited under the European Convention.¹⁴⁷ This determination also has implications for neonatal testing or the admittance of medical drugs to pregnant women. A limited number of cases have been considered by the European Court, addressing the question

¹⁴¹ For a discussion on the issues raised during the drafting process of the CRC see: Leblanc, *The Convention on the Rights of the Child: United Nations Law Making on Human Rights*, Lincoln: University of Nebraska Press, pp. 66–73. See also the declarations of France (UN Doc. CRC/C/11/Add.1, p. 112) and the UK (UN Doc CRC/C/3/Add.15, p. 11).

¹⁴² Examples include Poland, Malta, Chili, Nicaragua, Saudi-Arabia. See: Abortion Policies, a global review, United Nations.; www.un.org/esa/population/publications/abortion/profiles.htm.

¹⁴³ For a discussion on balancing the right to life of the mother and the unborn baby see M. Cornock & H. Montgomery, 'Children's rights in and out of the womb', *International Journal on Children's Rights* 2011, Issue 19, pp. 3–19.

¹⁴⁴ For example, in the Dutch Penal Law (article 82a Sr.) the legal term until which abortion is admitted is 24 weeks.

¹⁴⁵ G. Van Bueren, *Child Rights in Europe*, Council of Europe Publishing 2007, p. 51.

¹⁴⁶ See for example *Paton v. the United Kingdom*, ECHR, 3. See also *Vo v. France*, European Court on Human Rights, 8 July 2004. In *Vo v. France*, no violation of the right to life in article 2 ECHR was found in a case where a pregnant woman who had been mistaken with another woman had to undergo a therapeutic abortion as a result of the mistake. The rationale was that no unintended homicide had been committed, since the fetus was not considered as a human being yet.

¹⁴⁷ Hogan, 'The right to life and the abortion question under the European Convention on Human Rights', in: Heffernan (ed.), *Human Rights: A European Perspective*, 1994, p. 104.

of the beginning of childhood and the protection of (unborn) life,^{148, 149, 150, 151} concomitantly leading to the conclusion that the child is protected under the European Convention on Human Rights from birth. European states have the discriminative authority to extend this protection to the prenatal period, although possible health risks for the mother can justify an abortion.¹⁵² In deciding upon this highly sensitive issue, State Parties are left a great margin of appreciation.¹⁵³

From the side of the medical profession, voices have been raised that notwithstanding the legal definition of the beginning of life of the child, it is especially the first term of the pregnancy that is crucial in ensuring the right to health of the child once it is born, because this is the period in which the

¹⁴⁸ In the case of *Paton*, No 8416/78 *Paton v. UK*, Dec 13.05.80, 19 DR, p. 244, 3 EHHR 408, the Commission considered that the right to life as laid down in article 2 ECHR can be interpreted in three ways: 1) article 2 ECHR applies after birth, 2) the unborn child is entitled to protection subject to limitations and 3) article 2 recognizes the right to life of the unborn child as absolute. This last interpretation was rejected, because the right to life of the fetus would be deemed of higher value than the right to life of the pregnant woman. No choice was made between the two remaining interpretations and the question whether the right to life of the child is enjoyed by the unborn child thus remains unresolved. See also Harris, O'Boyle & Warbrick, *Law of the European Convention on Human Rights*, Oxford University Press 2009, p. 53–55.

¹⁴⁹ In the case *H v. Norway*, No 17004/90 *hudoc* (1992) it was held that an abortion of a 14-week-old fetus can be lawful, if 'pregnancy, birth or care for the child may place the woman in a difficult situation of life'. However, the Commission did state that 'in certain circumstances' article 2 may protect the right to life of a fetus younger than 12 weeks. However, these circumstances were not specified. The case of *A.B.C. v. Ireland* No 25579/05 (2010) involved three pregnant women who all had different reasons for requiring an abortion; A) having a baby while other children had been placed under custody would hinder reunion, B) a single parent would suffer from stigma and humiliation and C) a woman who was recovering from cancer, so that the check-ups could damage the child. The ECHR decided that Ireland's failure to implement the existing constitutional right to abortion when a woman's life is at risk (case C), constituted a violation of the right to a private and family life under article 8 ECHR. All other claims were dismissed.

¹⁵⁰ In the case of *Boso v. Italy*, No 50490/99 *hudoc* (2002) DA the Commission held that if an abortion is performed under Italian law within the first 12 weeks of the pregnancy because of the risk for woman's physical or mental health, was not a breach of article 2 ECHR.

¹⁵¹ In the case of *R.R. v. Poland*, No 27617/04 (2004), a woman was not allowed prenatal diagnostic support nor an abortion, although defects had been seen on the echo. The ECHR judged that Poland had violated article 3 (degrading treatment) and 8 (private and family life) of the ECHR. In the case of *Tysiac v. Poland*, No 5410/03 (2007), the ECHR concluded that Polish law, applied to the applicant's case, did not contain any effective mechanism to determine whether the conditions for obtaining a lawful abortion were met. Therefore, Ms Tysiac had suffered severe distress about the possible negative consequences of her pregnancy for her health, namely deterioration of her sight. Therefore, the Court concluded that her right to a private life as laid down in article 8 ECHR had been breached.

¹⁵² Bueren, van, G., *'Child rights in Europe'*, Council of Europe Publishing, 2007, p. 57.

¹⁵³ As is commented by Harris, O'Boyle & Warbrick, see *supra* note 100, p. 54, generally, 'the limitations upon any right to life that the unborn child may have are capable of covering most cases in which voluntary abortion is sought.' Also, they identified that 'The Court state that 'given the absence of a European legal, medical, ethical, or religious consensus as to when life begins, a margin of appreciation applies, even to the point where the Court doubted whether it was desirable or even possible as matters stand, to answer the abstract question whether the unborn child is a person for the purposes of article 2 CRC.' See p. 55.

fundamental structures of the future body are formed.^{154, 155} Therefore, protecting the right to health of the child after birth, is intrinsically linked to the health behaviour of the mother during (the first term of) her pregnancy, and thus also to the balancing of her rights against the right to life of the foetus.

In addition to static age limits, article 5 CRC refers to ‘the evolving capacities’ of the child, recognizing the increasing independency of children. This concept also gives space for a flexible level of protection, participation and autonomy, depending on the capacities of the individual child, the context and type of decision.¹⁵⁶

1.7.2. DEFINITION OF VULNERABILITY

In essence, children are both vulnerable and resilient. The CRC Preamble highlights the need for special consideration for children who live in exceptionally difficult conditions. Sen’s capability approach, takes children’s capability or their potential for development as a starting point. This paragraph investigates the conceptualization of vulnerability of children in the international children’s rights domain. It does so to identify in the following chapters the priorities required ensuring that all children, including those characterized by a high level of vulnerability can thrive in the best possible circumstances.

The CRC emphasizes the need for special protection and care for children who are vulnerable and at risk. In achieving this, the role of the family is very important, with the support of the state (article 18 CRC). Deriving from the CRC, several groups of particularly vulnerable children can be discerned; orphaned children and children who are separated from their family (article 9 and 20), adopted children (article 21), refugee children (article 22), mentally or physically handicapped children (article 23), children in need of medical care (article 24), children placed out-of-home (article 25), children belonging to minorities, including ethnic, religious, indigenous minorities and girls (article 2 and 30), children who are confronted with drugs (article 33), children who are vulnerable to (sexual) exploitation, abuse, trafficking and hazardous labour (articles 33–36), children in armed conflict (article 38) and children in conflict with the law (article 40). Although no particular provision is found in the CRC on special measures required for infants and toddlers, interpretative tools, such as General

¹⁵⁴ H.J.J. Leenen, ‘Leven in wording, prenatale diagnostiek en behandeling van de foetus’, in: H.J.J. Leenen & J.K.M. Gevers redacteuren, *Handboek Gezondheidsrecht. Deel 1: Rechten van Mensen in de Gezondheidszorg*, Houten: Bohn Stafleu Van Loghum 2000, p. 152–4.

¹⁵⁵ In a case in the Netherlands, a 30-year-old pregnant woman was put under custody because she was addicted to cocaine. Medical professionals pledged for a stricter application of the Convention of the Rights of the Child in order to protect the future life of the unborn baby. See: Hondius, Stikker, Wenink en Honig, ‘Wet BOPZ toegepast bij vroege zwangerschap van verslaafde’, *Nederlands Tijdschrift voor de Geneeskunde* 2012, 156, A3818.

¹⁵⁶ S. Meuwese, *Handboek Internationaal Jeugdrecht*, Nijmegen: Ars Aequi Libri 2005, p. 70.

Comment 7 to the CRC on Implementing Child Rights in early Childhood, offer strong argumentation for providing special care for the health and well-being of the youngest.

Generally, vulnerability is associated with the potential realization of an adverse outcome.¹⁵⁷ Taking the capability approach as a starting point, it becomes clear that young children have limited opportunities for choosing between the different functionings they wish to realize due to their large dependence on others.

Landsdown makes a distinction between inherent vulnerability of the child, exemplified by factors such as age, physical weakness, immaturity and lack of knowledge and lack of experience, versus structural vulnerability, meaning a lack of economic and political power, access to money, opportunities to express feelings and have their rights taken seriously.¹⁵⁸ This distinction is useful for identifying what aspects of vulnerability can be addressed through policy and legislation and what aspects can only be accepted as a matter of fact. Landsdown claims that there is a tendency to rely heavily on ‘the presumption of innocence and vulnerability of children’ in developing law and policy. Drawing a parallel with the emancipation of women and the establishment of their rights, she poses that inherent vulnerability is used as an excuse for their structural vulnerability, but that in fact it is the structures in which children live that make them vulnerable to abuse, exploitation, neglect and disregard for their views in situations of poverty, discrimination, conflict or disaster. This means that children’s vulnerability is only partially dependent on their vulnerability as being a child, and partially based on circumstances being subject to policy and legal developments. Therefore, Landsdown stated that the adoption of the CRC has been a major achievement in promoting a rights-based approach to addressing the needs of vulnerable groups of children. As such, it has created plural opportunities for children to stand up for their own rights. This does not only lead to an urgent call for attention for vulnerable children, but it provides them with a legal basis to claim their right to the provision of basic determinants of health and a life in dignity to change the circumstances in which they live and diminish the level of structural vulnerability.¹⁵⁹ Furthermore, it specifically acknowledges children’s right to be involved in decisions affecting them as a basic principle, so that they or their legal representatives can make a claim to actually influence their structural vulnerability.

Other factors identified that may lead to inherent vulnerability include dependency on adults, (traumatic) experiences in the past, a lack of future perspectives, cultural differences, language, health and developmental

¹⁵⁷ G. Landsdown, *Taking Part: Children’s Participation in Decision Making*, p. 35.

¹⁵⁸ Ibidem supra note 157.

¹⁵⁹ The additional value of the third Optional Protocol on a communications procedure for children for making (individual) claims will be discussed in chapter 7.

problems.¹⁶⁰ Factors identified as leading to structural vulnerability include living with caretakers with serious problems like poverty, illness (HIV/AIDS or chronic diseases), disabilities, trauma, substance addiction or abusive habits, living on the street, being forced into an early marriage, being accused of witchcraft or displaying certain physical traits such as being an albino or being part of a twin. Structural vulnerability can be further divided into permanent and temporal vulnerability.¹⁶¹ In this distinction, permanent vulnerability results from long-term living conditions, such as a general lack of infrastructure or legal protection, whereas temporal vulnerability is the result of sudden, mostly unforeseen events, such as natural disasters. Vulnerability of the second category requires measures and action plans of a different nature, focused on mitigating the harmful consequences of a particular event.

Helpful in assessing children's vulnerability is also the Best Interests of the Child Model.¹⁶² This model provides for 14 preconditions for the healthy development of the child.¹⁶³ Absence of these preconditions may be indicative of vulnerability.

Landsdown asserts that the degree of vulnerability of children decreases rapidly as they grow and develop.¹⁶⁴ Skinner, Tsheko et al. even qualify children as vulnerable on the basis of their limited access to basic needs, such as education, health and social services.¹⁶⁵ This identification recognizes that children can be vulnerable on the basis of material, emotional or social deprivation in itself.

The concept of children's vulnerability with respect to their right to health has been constructed by a myriad of factors, including their increased susceptibility to violations of their right to health, as they, especially the youngest ones, are less able to physically and verbally protect themselves, and as they are less capable

¹⁶⁰ C. van Os & S. de Jong, 'The Dutch Report on 'Enhancing Vulnerable Asylum Seekers Protection' 2010, Defence for Children International-ECPAT The Netherlands, pp. 18–21.

¹⁶¹ Ibidem supra note 157.

¹⁶² M.E. Klaverboer & A.E. Zijlstra, *Het Belang van het Kind in het Vreemdelingenrecht, Kinderen uit Asielzoekersgezinnen. Ontwikkeling, Perspectief en Juridische Positie*, Rijksuniversiteit Groningen: 2008.

¹⁶³ The preconditions are divided into four categories; (A) Present Family Conditions, (B) Past and Future Family Conditions, (C) Present Societal Conditions and (D) Past and Future Societal Conditions.

A.I. (physical care) includes (1) adequate physical care and (2) a safe physical direct environment.

A.II. (care and upbringing) includes (3) an affective atmosphere, (4) a supporting, flexible upbringing structure, (5) adequate examples by parents and (6) interest.

B. includes (7) continuity and stability in upbringing conditions and a future perspective.

C. includes (8) safe wider physical environment, (9) respect, (10) social network, (11) education, (12) contact with peers or friends, (13) adequate examples in society.

D. includes (14) stability in life circumstances and a future perspective.

¹⁶⁴ G. Landsdown, *Taking Part: Children's Participation in Decision Making*, p. 36.

¹⁶⁵ D. Skinner, N. Tsheko, S. Mtero-Munyati, M. Segwabe, P. Chibatamoto, S. Mfecane, B. Chandiwana, N. Nkomo, S. Tlou, *Definition of orphaned and vulnerable children*, Cape Town: HSRC Press 2004.

to benefit from available protection and provision mechanisms.¹⁶⁶ Also, it has been identified that young children are less likely to have the necessary skills to participate in the democratic decision-making process to ensure that their rights (to health) are being taken into consideration and that sufficient resources are allocated to ensure adequate access to health care facilities.¹⁶⁷ Violations of children's right to health have therefore been identified as a result of 'deeply-rooted systemic inequality'.¹⁶⁸ Furthermore, the Office of the High Commissioner on Human Rights has identified that both the short-term and the long-term physical and psychological effects on children of violations of their right to health will usually be more intrusive than they are on adults, as they are not fully developed yet.¹⁶⁹

The deprivation of continuous health care is especially pressing for 'mobile children', children who do not live in the same place for a considerable period of time and who risk discontinuous health care or even a loss of access to health care resulting from their mobility. This is particularly the case for refugee and immigrant children,^{170, 171} children living on the street,^{172, 173, 174} children in conflict and crisis situations,¹⁷⁵ Roma children¹⁷⁶ and also for children confronted with domestic violence.¹⁷⁷ In this last subgroup, it has occurred that parents maltreating their children often move around the country to avoid facing the

¹⁶⁶ A. Nolan, 'The child's right to health and the courts', in: *Global Health and Human Rights: Legal and Philosophical Perspectives*, edited by J. Harrington & M. Stuttaford, London: Routledge, p. 137.

¹⁶⁷ Ibidem supra note 166, pp. 137–139.

¹⁶⁸ Ibidem supra note 166, p. 138.

¹⁶⁹ Office of the High Commissioner on Human Rights, 2001.

¹⁷⁰ A. Hjern & P. Bouvier, 'Migrant children – a challenge for European paediatricians', *Acta Paediatrica* 2004, Issue 95, pp. 1535–1539.

¹⁷¹ B. Gushulak & D. Macpherson, 'The basic principles of migration health: Population mobility and gaps in disease prevalence', in: *Emerging themes in Epidemiology*, May 2006, p. 3. Accessed through: www.biomedcentral.com/content/pdf/1742-7622-3-3.pdf.

¹⁷² K. Panter-Brick, 'Street children, human rights and public health: A Critique and Future Directions', *Annual Review of Anthropology* 2002, Vol. 31, pp. 147–171.

¹⁷³ L. Nodjadjim & K. Wyss, 'Access to health care by street children in the urban context of N'Djamena, Chad.', *International workshop paper*, Geneva, Palais des Nations – 3–6 May 2000.

¹⁷⁴ *Making Health Care Accessible to Street Children: The 'Hospital on Wheels' Project (2000–2006)*, published by SNEHA, 2008, p. 13. Accessible through www.snehamumbai.org/download/hospital_on_wheels_report.pdf.

¹⁷⁵ UNICEF, news report, New York, 28 December 2004. Available at: www.unicef.org/emerg/disasterinasia/index_24659.html.

¹⁷⁶ Rechel, Boika and Blackburn, Clare, 'Access to health care for Roma children in Central and Eastern Europe: findings from a qualitative study in Bulgaria', *International Journal for Equity in Health*, Volume 8 (Article 24), 2009.

¹⁷⁷ Moving frequently is one of the family characteristics identified as a risk factor for child maltreatment: See for example: *KNMG-Meldcode en Stappenplan Artsen en Kindermishandeling*, Utrecht, September 2008, page 36. See also: W. Ghent, 'Family violence: guidelines for recognition and management', *Canadian Medical Association Journal* 1985, 1 March, Volume 132, pp. 541–553. See also: F. Buffing, & R. v.d. Zanden, 'Signalen en signaleren van kindermishandeling', in: H. Baartman, H. & A. Montfoort (Red.), *Kindermishandeling. Resultaten van multidisciplinair onderzoek*, Utrecht: Bruna 1992.

same professionals, such as medical practitioners, thereby prohibiting the opportunity to develop a reliable and coherent analysis of the health status of children and the health situation they are living in.¹⁷⁸ Examples have even been noted of families moving to other countries to avoid confronting youth protection measures in their country of origin.¹⁷⁹ Continuity in health care is important to enhance the development of a stronger knowledge base and even to prevent future hospitalizations.¹⁸⁰

Practical obstacles for different groups of vulnerable children to have access to primary health care facilities may range from inappropriate resource allocation to organizational and sociocultural circumstances,¹⁸¹ resulting in discrimination of certain groups of children from having access to primary health care facilities.

1.7.3. EMPOWERMENT

In the Convention on the Rights of the Child, two visions of the child are discerned; children as vulnerable creatures in need of protection and children as autonomous, self-reliant persons. The concept of the ‘evolving capacities of the child’ as laid down in article 5 CRC is the line along which the focus shifts from protection to participation. Whereas age does influence a child’s evolving capacities, other criteria such as experience, level of comprehension and the availability of health information all contribute to the determination of the evolving capacities of the individual child. Furthermore, although children aged 0–12 are to a large extent dependent on adults for the realization of their right to health, they do have innate capabilities that can be realized in the course of their future lives. Health choices made by the parents during pregnancy and after the birth of the child, directly influence the future health choices of children and their opportunities to realize the highest attainable standard of health. Taking children’s capabilities as a starting point, this research investigates how the right to the highest attainable standard of health of the child can be realized and what the role is of the different actors involved in the realization process.

The shift of the child as a vulnerable individual in need of protection to a self-reliant individual that can take increasing responsibility for its own health evokes the question what minimum requirements must be met to enable children to realize their right to health. What elements fall under the responsibility of the State, the parents, the child and other actors and what level of flexibility is

¹⁷⁸ Ibidem supra note 177.

¹⁷⁹ A Dutch Documentary of ‘Netwerk’ revealed that Dutch families flee to Belgium to avoid a confrontation with youth care.

¹⁸⁰ L.J. Weiss & J. Bluestein, ‘Faithful patients: the effect of long-term physician-patient relationships on the costs and use of health care by older Americans’, *American Journal of Public Health* 1996, Issue 86, pp. 1742–1747.

¹⁸¹ A. Eide & W.B. Eide, *A Commentary on the UN CRC Article 24: The right to health*, Leiden: Martinus Nijhoff Publishers 2006, p. 19.

required to leave room for the specific requirements and characteristics of the individual child.

1.8. OUTLINE OF THE PHD STUDY

In this introductory chapter of the study, the problem statement, research questions and key concepts in the study have been elucidated. In the following part, I will analyse, what opportunities, lacunae, contradictions and overlaps exist between the different bodies of law that have reference to the right to the highest attainable standard of health of the child. Hereto, chapter 2 and 3 will concomitantly present the analysis of the interpretation of the right to the highest attainable standard of health of the child in the international children's rights domain. Chapter 2 will address the sub question 'What priorities in the interpretation of the right to the highest attainable standard of health of the child can be derived from the international children's rights domain (CRC)?' Chapter 3 will focus on the question 'How are the priorities deriving from the international children's rights domain with respect to the interpretation of the highest attainable standard of health of the child explained in the Concluding Observations of the CRC Committee on Country Reports for countries with different levels of development?'. Focus will be placed on the right of the child to have access to health as a way to achieve the highest attainable standard of health in a selection of the Concluding Observations of the CRC Committee on individual Country Reports. Chapter 4 will answer the questions 'What priorities in the interpretation of the right to the highest attainable standard of health of the child can be derived from international health and human rights law (WHO, ICESCR, UDHR)?' and 'What is the additional value of this body of law for the interpretation of the right to the highest attainable standard of health in the children's rights domain?' Hereto, the analysis of the Constitution of the World Health Organization, the International Covenant on Economic Social and Cultural Rights and General Comment 14 of the Committee on Economic, Social and Cultural Rights will be presented and compared to the highest attainable standard of health of the child in the international children's rights domain. Chapter 5 will answer the question 'What priorities in the interpretation of the right to the highest attainable standard of health of the child are found in human rights law in Europe?'. Chapter 6 will analyse who are the responsible actors for realizing the identified priorities of children's right to the highest attainable standard of health and how the process of realization influences the interpretation of the right to the highest attainable standard of health. In this part, the legal value of the right to health of children as a social human right is investigated. The question is answered 'How does the process of realization influence the interpretation of the highest attainable standard of health of the child and which actors are responsible in this process?'

Finally, the central question will be answered in the concluding chapter 7 ‘What elements does the right to the highest attainable standard of health entail and how should this concept be further implemented in light of the international human rights standards?’