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

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## V. REGIONAL INTERPRETATIONS OF THE RIGHT TO HEALTH OF THE CHILD: A FOCUS ON EUROPE

### 5.1. INTRODUCTION

The Vienna Declaration on Human Rights provides that all human rights are universal, indivisible, interdependent and interrelated. Kinney argues that ‘the right to health must be the same for all nations and people, to have meaning’.<sup>823</sup> However, this seems to be an unrealistic requirement, because the actual implementation of the right to health is dependent upon resources, budget allocation, cultural values and health policies in individual countries and communities. This vision is mirrored by the Committee on Economic, Social and Cultural Rights, which recognizes the relevance of the local context by stating that the precise application of the elements identified in General Comment 14 to the ICESCR, ‘will depend on the conditions prevailing in a particular State party thereby demonstrating a high level of local context sensitivity’.<sup>824</sup> Similarly, the vision of the European Association for Children in Hospital that the right to health in countries must be evaluated in the context of the health care services available to them in their home country, better reflects the actual reality of implementing children’s right to health in the daily lives of children.<sup>825</sup>

This chapter seeks to investigate what the States priorities are in realizing the highest attainable standard of health of children in Europe. In this region, many developments are taking place that guide the interpretation of the concept of ‘the highest attainable standard of health’ of the child. Therefore, the analysis of the key elements of child-friendly healthcare as elaborated in European legislation may give additional insight into the key research question ‘what the key elements of the right to the highest attainable standard of health of the child are and whether there are different, progressive standards to realize this right’.

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<sup>823</sup> E.D. Kinney, ‘International Human Right to health: what does it mean for our nation and the world?’, *Indiana Law Review* 2001, p. 1457. Accessed on 16 May 2012 at: <http://heinonline.org/HOL/Page?handle=hein.journals/indilr34&collection=journals>.

<sup>824</sup> General Comment No. 14 (2000) The right to the highest attainable standard of health: 11/08/2000. E/C.12/2000/4. CESCR, § 12.

<sup>825</sup> ‘A Guide to General Comment 7: Implementing Child Rights in Early Childhood’, produced by Bernard van Leer Foundation and UNICEF, 2006, p. 74.

After providing an introduction into the debate on universalism versus local interpretations of children's rights, the interpretation of the highest attainable standard of health of the child in Europe will be looked at by analysing the European Social Charter, the relevant law of the European Union and the recent guidelines on child-friendly health care as adopted by the Council of Europe as a point of reference. In this way, the developments within the European region illustrate that the interpretation of the right to health of the child in one particular region of the world. This region has been chosen, because considerable developments have taken place between 2010–2015 in elaborating guidelines on child-friendly healthcare. However, it must be taken into account that these guidelines are strongly oriented towards the right to health of the child in the medical sector itself, whereas the realization of this right strongly depends on social, biological and environmental factors. More research is required on interpretations in other regions.

## 5.2. UNIVERSALISM IN A LOCAL CONTEXT

The formal discussion on the universality of human rights arose in the period of the adoption of the Universal Declaration of Human Rights by the United Nations in 1948. Based on the belief in a universal human nature, several fundamental rights were laid down, applicable to every human being, notwithstanding their age, sex, sexual orientation, ethnic, religious or political background.<sup>826</sup> The guiding idea of universalists is that every person has equal human rights based on his inherent humanity, even if there are cultural differences between people. In that view, similarity must prevail over cultural differences with respect to ensuring human rights.<sup>827</sup> Critics on the other hand put forward that this perspective is 'lacking empirical validity, and is historically and culturally imperialistic'.<sup>828</sup> Relativists put forward that western values have been masqueraded as universal values.<sup>829</sup> These criticisms have also been made with respect to the Convention on the Rights of the Child.<sup>830</sup> The debate between universalists and relativists thus arises from the translation of human rights values into different cultures, more particularly in this case, on translating the meaning of the right to health of the child into different local contexts.

Criticism on the universal applicability of children's rights has been fierce. Some scholars have even stated that international human rights norms and

<sup>826</sup> E. Brems, 'Universele grondrechten', *NJB* 2010, no. 6, pp. 19–21.

<sup>827</sup> L.S. Bell, 'Introduction: Culture and human rights', in: L.S. Bell, L.S. (a.o.), *Negotiating culture and human rights*, New York: Columbia University Press 2001, pp. 1–15.

<sup>828</sup> *Ibidem* supra note 825.

<sup>829</sup> *Ibidem* supra note 825.

<sup>830</sup> S. Goonesekere, 'Introduction', in: *Protecting the World's Children, Impact of the Convention on the Rights of the Child in Diverse Legal Systems*, UNICEF 2007, Cambridge University Press, p. 1.

children's rights in particular do not acknowledge traditional values and conceptions of human rights.<sup>831</sup> Arts on the other hand, provides several arguments for the statement that the Children's Rights Convention gives opportunity for a culturally sensitive interpretation of (several of) its provisions. She argues that the Children's Rights Convention was particularly designed to be implemented in the variable circumstances of different countries, cultures, legal, economic and political systems and that the involvement of countries from all continents in the negotiation process<sup>832</sup> and the wide support for the Convention proves the success in achieving this purpose.<sup>833</sup> She furthermore points to the possible advantages of a flexible interpretation technique, including the potential for a more realistic implementation of children's rights and therefore for wider support for the Convention. On the other hand, she points to the potential for abuse, misinterpretation and withdrawal of obligations.<sup>834</sup> However, her statement that the advantages seem to outnumber the disadvantages is not supported with practical examples.

Kaime thoroughly delves into the issue of the cultural legitimacy of the CRC.<sup>835</sup> He identifies that there is a tension between the merits of adopting a universal legal framework and the wish to protect cultural diversity.<sup>836</sup> However, he affirms that culture is not a static, unchangeable concept, but that it is shaped and transformed by the actions and perceptions of individual actors.<sup>837</sup> Therefore, he establishes that if the principles enshrined in the CRC are to be implemented in different cultures and local practices, this requires the acceptance of these principles across the communities in which children live.<sup>838</sup> This is also necessary for societies where people from multiple cultures live together. Further investigation into the interaction between the CRC principles and the involvement of children, family members, medical professionals and other actors for the realization of the right to health of the child will be presented in chapter 6.

<sup>831</sup> A.P. Preis, 'Human rights as cultural practice: an anthropological critique', *Human Rights Quarterly* 1995, Volume 18, p. 286. Reproduced in: T. Kaime, *The African Charter on the Rights and Welfare of the Child; A socio-legal perspective*, Cape Town: Pretoria University Press 2009, p. 3.

<sup>832</sup> Countries participating in the negotiation process included 19 western, 6 eastern-European, 15 Asian, 9 African and 8 Latin-American Countries. See: D. Johnson, 'Cultural and Regional Pluralism in the drafting of the UN Convention on the Rights of the Child', in: M. Freeman & P. Veerman (red.), *The ideologies of Children's Rights*, Dordrecht: Martinus Nijhoff Publishers 1992, p. 96. Retrieved from Arts, supra note 827.

<sup>833</sup> K. Arts, Inaugural lecture: 'Coming of Age in a world of diversity? An assessment of the UN Convention on the Rights of the Child', 18 November 2011, p. 13. See also: K. Arts, '21 Jaar VN-Verdrag voor de Rechten van het Kind: Een volwassen bijdrage aan kinderrechten in de wereld?', *International Spectator* 2011, year 65, no. 6, June, p. 336.

<sup>834</sup> Ibidem supra note 832, p. 339.

<sup>835</sup> T. Kaime, *The Convention on the Rights of the Child: A Cultural Legitimacy Critique*, Europa Law Publishing 2011.

<sup>836</sup> Ibidem supra note 834, p. 29.

<sup>837</sup> Ibidem supra note 834, p. 41.

<sup>838</sup> Ibidem supra note 834, p. 48.

### 5.2.1. UNIVERSALISM AND THE RIGHT TO HEALTH OF THE CHILD

Two different dimensions for interpretation of the highest attainable standard of health of the child can be identified in translating human rights across cultures, namely variations deriving from thematic and variations deriving from regional differences. Whereas the ideal of equality was intended to benefit every individual person, the UDHR was predominantly constituted by white, heterosexual, Christian males.<sup>839</sup> Therefore, the needs of particular subgroups, such as women, children and people from minority cultural or religious groups have not been fully taken into consideration in formulating ‘universal principles’ of human rights in general.<sup>840</sup> For example, infants are fully dependent on others to survive. Their need for care and protection, e.g. in the family context, in armed conflicts or in humanitarian situations is different from that of adults. Also, children do not regularly participate in democratic processes. The inclusion of their interests in mainstream policy decisions therefore requires special measures and representation by others.

Universal claims are thus primarily based on the opinions of one dominant subgroup of the international community in that period.<sup>841</sup> In later years, several subgroups have asked for attention for the specific protection needed of their particular human rights, which may differ from the core content as determined in the initial discussions. This has resulted in the adoption of separate conventions, such as the Convention on the Rights of the Child (CRC) and the Convention on the Elimination of Discrimination Against Women (CEDAW) specifying the particular human rights violations of the groups involved and in the renewed interpretation of traditional human rights provisions.<sup>842</sup> Brems has further demonstrated that the inclusion of the protection of minority groups under human rights law has broadened the reach and protection level of human rights, but at the same time complicated their interdependence and explanatory value. She gives the example that a national judge deciding upon a case involving a foreign refugee girl, has to combine insights from the domain of children’s, women’s and minority rights. This is further complicated by the different levels of (sometimes conflicting) national, regional and international legislation applicable, increasingly developing at regional and international levels. Similarly, with respect to achieving the highest attainable standard of health of this girl, considerations deriving from international health law and medical ethics must also be taken into account. Also, the existence of the regional treaties itself reemphasizes the question whether the original universal human rights have universal value.

<sup>839</sup> Ibidem supra note 825, Brems.

<sup>840</sup> Ibidem supra note 825, Brems.

<sup>841</sup> Ibidem supra note 825, Brems.

<sup>842</sup> Ibidem supra note 825, Brems.

In addition to these identified thematic restraints to a universal application of human rights, other problems may arise from local differences in applying children's right to health. For example, when discussing the role of parents or the family in ensuring the right of the child to the highest attainable standard of health, the composition of a family strongly affects the influence of parents on their children's health. In the European Union for example, most children live in nuclear families, whereas this picture is changing due to increased levels of divorces in some areas and the influx of broken families and unaccompanied asylum seeking children in others.<sup>843, 844</sup> In other continents, such as Africa, children live in extended families where different family members are de facto considered responsible for realizing children's health and well-being.<sup>845, 846</sup> Heavily influenced by the large-scale HIV/AIDS epidemic, children are cared for by different family members by migrating across the country from family to family.<sup>847</sup> This influences their opportunities to see the same doctor and have access to qualitative health care facilities over time. Also, increasing migration streams between different continents influence the way in which children's health is viewed upon. For example, when children from non-Dutch origin are present at the school doctor with mental health problems, explanations range from a biomedical cause to the influence of spirits or ancestors. These differences must be taken into account when considering medical treatments.

Differences in interpretations of the right to health of the child demonstrate the influence of the (absent) family structures in which children live on the ways in which the right to health is interpreted and implemented. However, Freeman warns against focusing too much on the family by commenting that: 'Children suffer from ideological idealization of the family that assumes that parents love and nurture their children. The case for children's rights is based on the fact that many children do not live in such conditions'.<sup>848</sup> Freeman thus highlights that not all children live in a loving family. Although not explicated, this can be explained as referring to children who are not living in a family at all and of children who are living in a family in which children's best interests are not fully taken into account. The hesitance to approach the realization of children's right to health predominantly from a focus on the family, also becomes apparent in the analysis

<sup>843</sup> Heywood, Colin, *A History of Childhood: Children and Childhood in the West from Medieval to Modern Times*, Cambridge, UK: Polity Press 2001.

<sup>844</sup> M. Daly, 'Changing family life in Europe: Significance for state and society', *European Societies* 2005, Volume 7, Issue 3, pp. 379–398.

<sup>845</sup> L. Blerk & N. Ansell, 'Children's experiences of migration: moving in the wake of AIDS in southern Africa', *Environment and Planning D: Society and Space* 2006, volume 24, pp. 449–471.

<sup>846</sup> G. Foster, 'The capacity of the extended family safety net for orphans in Africa', *Psychology, Health & Medicine* 2000, Volume 5, Issue 1, pp. 55–62.

<sup>847</sup> L. Young & N. Ansell, 'Fluid Households, Complex Families: The Impacts of Children's Migration as a Response to HIV/AIDS in Southern Africa', *The Professional Geographer* 2003, Volume 55, Issue 4, November, pp. 464–476.

<sup>848</sup> M. Freeman, *Human rights, an interdisciplinary approach*, Polity Press 2011, p. 152.

made by Nolan, who argues that the particular inclusion of children's right to health offers a more far reaching protection of this right than when the right to health of the child is strongly related to the rights of the parents and the family.<sup>849</sup> Therefore, the child should be considered as a subject of the right to health in its own right. With respect to the interpretation of the role of the family as clarified in the CRC, Nolan identifies that although there is a strong emphasis on the role of the family in ensuring children's rights, 'it sets out a wide range of rights for children, and makes clear that the best interests of the child are to be accorded priority in all actions concerning them'. On the basis of the rights in the CRC, the rights of the child are thus centrally important, while being grounded in the broader context of the family.

Other differences in interpretations of children's right to health across the world result from different visions on childhood and vulnerability. Whereas in many western countries there is a strict (age) limit between childhood and adulthood, for example by protecting children against child labour, in other cultures taking responsibilities and participating in daily work activities is part of the upbringing process and often a necessary requirement to survive. Instead of a clear-cut age limit there is thus a more fluent transition phase for delineating childhood from adulthood.

Brems concludes that universality does not require uniformity. This implies that whereas children's right to health has to be applied universally in every country of the world, the way in which this right is put into practice can be adjusted to the requirements of the local circumstances. Whereas it is desirable to find the common denominators of human rights across cultures, flexibility and inter-cultural awareness are required in establishing the highest attainable standard of health that can be attained in the local context.<sup>850</sup>

The question then rises, what the margin of appreciation of countries is in setting priorities in the implementation of the right to the highest attainable standard of health in the local context. No clear guidelines exist yet in international law on this issue.<sup>851</sup> In any case, there should be a continuous dialogue on the different possible interpretations within and between different cultures and countries, so that mutual understanding can be enhanced and existing international legal norms developed. This requires an open attitude to listen to people with different visions on children's health upbringing and the willingness to adapt normative frameworks and usual behaviours. Such will necessarily require the input of children, parents, medical professionals and other caretakers, as is becoming

<sup>849</sup> A. Nolan, 'The child's rights to health and the courts', in: J. Harrington. M. Stuttaford (a.o.), *Global Health and human rights, legal and philosophical perspectives*, London: Routledge 2010, p. 146.

<sup>850</sup> M. Obemeyer, 'A cross-cultural perspective on reproductive rights' in: *Human Rights Quarterly* 1995, Issue 17, pp. 366–368. Reproduced in T. Kaime, *The African Charter on the Rights and Welfare of the Child; A socio-legal perspective*, Cape Town: Pretoria University Press 2009, p. 18.

<sup>851</sup> E. Brems, 'Universele grondrechten', *NJB* 2010, no. 6.



clear by the inclusion of the principles of accountability and participation into the basic AAAQ scheme as elaborated in chapter 4. Furthermore, current legal developments in the European region increasingly take into account the explicit role that (individual) children and their families can play in realizing the highest attainable standard of health of the child.

### 5.3. CHILDREN'S RIGHT TO HEALTH IN EUROPE

In Europe, children's right to health has been extensively elaborated. Both within the European Union and in the Council of Europe, developments have taken place that ground the right to health of all citizens and those of children in particular in different legal documents. Most far-reaching, though non-binding are the recently adopted Guidelines on Child-Friendly Health Care of the Council of Europe as adopted by the Committee of Health Ministers on 21 September 2011 in Lisbon. In this chapter it will be investigated what priorities are set in the elaboration of the right to the highest attainable standard of health of the child in the European region by looking at the relevant legal documents in the European Union and the Council of Europe, including relevant case law of the European Court on Human Rights (ECHR)<sup>852</sup> and interpretative legal instruments such as the Conclusions of the European Committee on Economic and Social Rights.<sup>853</sup>

#### 5.3.1. THE RIGHT TO HEALTH OF THE CHILD IN THE EUROPEAN UNION

The right to health in the EU is laid down in article 35 of the Charter on the Fundamental Rights in the European Union, stating that: 'Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities'.<sup>854</sup> In the phrasing of this provision, the importance attached to prevention and protection is clear. Furthermore, access to both preventive health care and to medical treatments is prioritized. However, the provision of access is not oriented towards basic health services, such as in the CRC or in the European Social Charter, but towards medical treatments 'under

<sup>852</sup> Cases of the ECHR relevant to children were retrieved through using the Theseus Database: [www.coe.int/t/dg3/children/caselaw/CaseLawChild\\_en.asp](http://www.coe.int/t/dg3/children/caselaw/CaseLawChild_en.asp).

<sup>853</sup> The European Committee of Social Rights (ECSR) was set up to judge the conformity of national law and practice with the Charter. It is composed of independent members elected by the Committee of Ministers for a period of six years.

<sup>854</sup> Charter of fundamental rights of the European Union, Doc. 2000/C 364/01. available at: [www.europarl.europa.eu/charter/pdf/text\\_en.pdf](http://www.europarl.europa.eu/charter/pdf/text_en.pdf).

the conditions established by national laws and practices'. This provision thus gives room for individual European Countries to take measures to achieve the highest attainable standard of health of children by referring to their national laws and practices. Examples of elaborated health care standards of individual countries can thus be indicative of the highest attainable standard of health within the European Union.<sup>855</sup>

The opportunity for individual countries to elaborate its own health policy is further elaborated in the very extensive article 168 Treaty on the Functioning of the European Union (TFEU), replacing the previous article 152 of the EC Treaty. Under this new article 168, a strong focus is placed on preventing health problems by stating in paragraph 1 that 'A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.' In doing so, paragraph 168(7) provides that the Union 'shall respect the responsibilities of the Member States for the definition of their health policy and for the organization and delivery of health services and medical care. The responsibilities of the Member States shall include the management of health services and medical care and the allocation of the resources assigned to them.' The primary responsibility for ensuring health care thus lies with the Member States. In addition, Union actions shall 'complement national policies' and cooperation between Member States is encouraged 'to improve the complementarity of their health services in cross-border areas'. The key phrase 'a high level of human health protection' in article 35 of the European Charter particularly indicates the intention to go beyond ensuring basic or even intermediate levels of health care. The same phrase is also the starting point of article 168 of the TFEU. Paragraph 5 further expands the phrase by not only referring to 'protect human health' but by also referring to 'improve human health'. The provision thus seems to entail not only an obligation to protect, but also an obligation to actively fulfil. In addition, paragraph 5 not only phrases to protect 'human health' but also to protect 'public health'. The difference lies in a distinctive focus on individual health on the one hand and collective or public health on the other.

In the remainder of article 168 TFEU, several measures are specified that guide the interpretation of the highest level of 'human health protection'. Paragraph 1 provides that all Union actions 'shall be directed towards improving public health, preventing physical and mental illness and diseases, and obviating sources of danger to physical and mental health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their

<sup>855</sup> See for an actual overview of health systems the European Observatory on Health systems and policies, available at: [www.euro.who.int/en/who-we-are/partners/observatory/health-systems-in-transition-hit-series/countries](http://www.euro.who.int/en/who-we-are/partners/observatory/health-systems-in-transition-hit-series/countries). See also Joint Report on Health systems, prepared by the European Commission and the Economic Policy Committee, 2010. Available at: [http://ec.europa.eu/economy\\_finance/publications/occasional\\_paper/2010/pdf/ocp74\\_en.pdf](http://ec.europa.eu/economy_finance/publications/occasional_paper/2010/pdf/ocp74_en.pdf) and Working paper on Health systems in the European Union: a comparative study by the European Parliament, 1998. Available at: [www.europarl.europa.eu/workingpapers/saco/pdf/101\\_en.pdf](http://www.europarl.europa.eu/workingpapers/saco/pdf/101_en.pdf).

transmission and their prevention, as well as health information and education, and monitoring, early warning of and combating serious cross-border threats to health.’ From this enumeration, it appears that again a strong focus is placed on preventive measures. On this basis, it seems logical to assume that prioritizing children’s right to health is a legitimate focus for realizing the right to health of the general public. This vision is shared by the WHO Regional Office for Europe, which acknowledges that ‘The period between birth and 5–6 years of age is critical.’<sup>856</sup> The report elaborates that:

‘Childhood is the best period in which to act. This is when action is most effective in both promoting good health and preventing ill health in childhood and later life. Health in childhood determines health over the total lifespan and into the next generation. The first years of life lay the foundations for people’s achievement of their health potential. How the brain develops in early life determines whether people have the skills to cope with disease risk in later life. Problems in early childhood development have a strong relationship to NCDs in adult life. Health promotion is most effective in the early years of life. Further, disease prevention and control should counter the negative influences on health as early as possible in life, to keep problems from passing into later stages of development. To a large extent, each stage in the development of a child prepares the way for the next. That is why it is important to anticipate risks as and when they are likely to emerge. This means that the wisest policies on children’s health focus on early and well-targeted interventions.’<sup>857</sup>

Article 24 of the Charter of Fundamental Rights of the EU focuses on the rights of children. In the phrasing of this article, the connection between this article and the CRC is identifiable:

1. Children shall have the right to such protection and care as is necessary for their well-being. They may express their views freely. Such views shall be taken into consideration on matters which concern them in accordance with their age and maturity.
2. In all actions relating to children, whether taken by public authorities or private institutions, the child’s best interests must be a primary consideration.
3. Every child shall have the right to maintain on a regular basis a personal relationship and direct contact with both his or her parents, unless that is contrary to his or her interests.

The vision of the child as an individual in need of protection is visible in the words ‘the right to such protection and care as is necessary for their well-being’ is balanced in paragraph 1 with the view of the child as a capable individual in ‘they

<sup>856</sup> WHO Regional Office for Europe, *The European Health Report 2005, Public health action for healthier children and populations*, Copenhagen 2005, p. IX.

<sup>857</sup> *Ibidem* supra note 855, p. 47.

may express their views freely'. The concepts of 'developing capacities' (§ 1) and of the 'best interests of the child' (§ 2) are primary considerations in all actions relating to children. Aasen comments that these elements are relevant for the medical sector as well as for 'a wide range of measures and services to protect children's health in a broad sense'.<sup>858</sup> For example, children's health is at stake in the youth protection sector, in schools and in institutions for juvenile justice. Aasen argues that ministries of health could play a leadership role in order to streamline activities to protect children's health in these different sectors.<sup>859</sup> On an organizational level this is true, although empowering children and parents also means that they take ownership of their own health.

Following the Treaty of Lisbon, the European Union is under a legal obligation to accede to the European Convention on Human Rights.<sup>860</sup> The Treaty introduces the protection of children's rights among the EU's objectives and internal and external policies. However, as will be elaborated further below, the ECHR does not contain a provision on the right to health. Its accession thus has a limited value for ensuring children's right to health in the EU. All in all, there is a need to investigate other channels to clarify the interpretation of the highest attainable standard of health of the child in the European Union. In the following, the EU strategies, ESC, EACH and Guidelines on Child-Friendly Healthcare will be analysed.

### 5.3.2. THE EU STRATEGY ON THE RIGHTS OF THE CHILD IN EUROPE

In 2008, the European Parliament adopted a Resolution on a EU strategy on the rights of the child.<sup>861</sup> In this Resolution, subparagraphs 157–170 directly address the right to health of the child and 171–177 are indirectly relevant, such as the paragraph on children's right to be registered at birth. The EU Resolution ensures that pregnant and lactating mothers have the right to access to 'quality pre- and postnatal health care in the public sector to reduce maternal and infant mortality and to prevent transmission of diseases from mother to child.' (no. 159). The principle of non-discrimination is highlighted in the provisions (nos. 166 and 174)

<sup>858</sup> H.S. Aasen, 'Children and the right to health protection' in: Toebes, Hartlev, Hendriks & Herrman, *Health and Human Rights in Europe*, Groningen: Intersentia 2012, pp. 227–247, p. 243.

<sup>859</sup> *Ibidem supra* note 857.

<sup>860</sup> The European Union's accession to the European Convention on Human Rights is required under Article 6 of the Lisbon Treaty and foreseen by Article 59 of the ECHR as amended by Protocol 14, whose aim is to guarantee the long-term efficiency of the Court by optimizing the filtering and processing of applications entered into force on 1 June 2010.

<sup>861</sup> OJ 2009 C41E/24 OJ 2009 C41E/24, Towards an EU strategy on the rights of the child – European Parliament resolution of 16 January 2008. Available at: [www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P6-TA-2008-0012&language=EN](http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P6-TA-2008-0012&language=EN).

stating that the access to health care must be equal for children of both genders and that particular attention must be given to disadvantaged children and to children of ethnic and social minorities. In order to achieve this equal access for all children, conditions must be created that 'enable every child to have access to all kinds and levels of health services and where necessary to take positive measures to enable disadvantaged groups to benefit from healthcare service options from which they would otherwise remain excluded' (no. 168). Also, the fact is highlighted that invisibility of unregistered children increases their vulnerability and the likelihood that violations of their rights will go unnoticed (no. 171) and more particularly that the absence of a birth certificate may prevent children from gaining access to healthcare services and material assistance from the State (no. 175). Therefore, every child must be legally recognized by being registered at birth (nos. 171 and 173) by 'establishing permanent registration systems operating from the national to village level, available free of charge to the entire population including those living in remote areas, through the provision of, inter alia, mobile registration units where appropriate, adequate training for civil registrars and the allocation of sufficient resources to finance these initiatives (no. 176). For as long as (groups of) children do not have a birth certificate and legal recognition, measures must be taken to ensure that health services are universally provided to all children until the official registration process has been established (no. 175) to prevent children from being excluded from necessary medical care.

The recommendations in the Strategy that are focused on children's health pay extensive attention to sex education, reproduction (pregnancy and lactating) and the prevention of sexually transmitted diseases (nos. 161–165, 167, 169). Reflective of the high living standards and the concomitant welfare diseases in the European Union Member States, is the inclusion of recommendations to address the problems of obesity (no. 157), alcohol-related health problems in children and (pregnant) mothers (no. 167) environmental health and pollution (nos. 158 and 170).

The provisions in the EU Resolution on an EU strategy on the rights of the child thus establish several important benefits to children additional to the existing framework on public health in the TFEU. Most specifically it elaborates upon the region specific health challenges, such as obesity, alcohol, drug and tobacco abuse. However, it must be noted that the identified provisions only constitute an obligation of effort and not of result by phrasing that 'measures must be taken'. In line with article 35 in the EU Charter, in which access for everyone is highlighted, the principle of non-discrimination is elaborated extensively in the EU Resolution on a strategy on the rights of the child, thereby ensuring access to all vulnerable groups of children, notwithstanding their official status.

### 5.3.3. THE WHO STRATEGY ON THE RIGHTS OF THE CHILD IN EUROPE

The WHO Office for Europe has elaborated on the concept of ‘access to people-centred health care’. This approach renews the focus on primary health care as laid down in the Declaration of Alma-Ata (1978).<sup>862</sup> This approach goes beyond the narrow medical care concept and takes a holistic view on health as a starting point.<sup>863</sup> It implies a fundamental change in service delivery to enable people-centred care, being characterized as ‘coordinated, integrated, comprehensive and continuous and accessible to all’.<sup>864</sup> This approach attaches great importance to the continuity of care. This concept has several dimensions, namely practically, the follow-up from one visit to another,<sup>865</sup> informational continuity, meaning the routine keeping of medical records for each child and visit over the entire time-span and across all different sectors involved in the health care of the child, longitudinal continuity in the place where the health care is provided and last but not least interpersonal continuity, being defined as ‘a continuing personal relationship between the patient and the care provider characterized by personal trust and respect’.<sup>866</sup> This continuous relation between patient and medical professional can go as far as integrating preventive, curative, rehabilitative and palliative care activities all with one primary health care provider that is close to the child and its family.<sup>867</sup> Such an approach could be highly beneficial for children because it increases the transparency and the personal attention of the medical trajectory.

The WHO Office for Europe has furthermore developed a strategy for child and adolescent health in 2005.<sup>868</sup> This strategy is not binding, but it offers support to countries in providing best practices and measures to realize children’s right to health. The strategy takes four principles as a starting point: 1. taking a life-course approach from prenatal life to adolescence; 2. it recognizes the need for equity and policies to address it; 3. it promotes intersectoral action and addressing the

<sup>862</sup> See chapter I.

<sup>863</sup> The WHO renewed its commitment to this holistic approach to health in The World health report 2008. *The world health report 2008, Primary health care – Now more than ever*, Geneva, World Health Organization, 2008, Available at: [www.searo.who.int/LinkFiles/Reports\\_whr08\\_en.pdf](http://www.searo.who.int/LinkFiles/Reports_whr08_en.pdf).

<sup>864</sup> *The world health report 2008, Primary health care – Now more than ever*, Geneva, World Health Organization, 2008, Available at: [www.searo.who.int/LinkFiles/Reports\\_whr08\\_en.pdf](http://www.searo.who.int/LinkFiles/Reports_whr08_en.pdf).

<sup>865</sup> Starfield (a.o.), ‘Continuity and coordination in primary care: their achievement and utility’, *Medical Care* 1976, Issue 14, pp. 625–636.

<sup>866</sup> J.W. Saultz, ‘Defining and measuring interpersonal continuity of care’, *Annals of Family Medicine* 2003, Issue 1, pp. 134–143. Available at: [www.annfammed.org/cgi/content/full/1/3/134](http://www.annfammed.org/cgi/content/full/1/3/134).

<sup>867</sup> WHO Office for Europe, European Health Report 2009 Health and Health systems, p. 122. Available at: [www.euro.who.int/\\_\\_data/assets/pdf\\_file/0009/82386/E93103.pdf](http://www.euro.who.int/__data/assets/pdf_file/0009/82386/E93103.pdf).

<sup>868</sup> U.N. Doc. EUR/05/5048378, WHO Regional Office for Europe, *European strategy for child and adolescent health and development. From resolution to action*, Copenhagen 2005. Available at: [www.euro.who.int/\\_\\_data/assets/pdf\\_file/0020/79400/E87710.pdf](http://www.euro.who.int/__data/assets/pdf_file/0020/79400/E87710.pdf).

fundamental determinants of health; 4. it promotes participation and the need to involve young people in decisions about their own services. Paragraph 14 sets out the overall goal, which is ‘to enable children and adolescents in the European Region to realize their full potential for health and development and to reduce the burden of avoidable disease and mortality.’ This goal is to be achieved by taking a life-course approach which sets out in detail the different provisions required during the different phases of a child’s life, starting with the pre-conception period, pregnancy, during delivery. During the first four weeks of life, during the first year of life, early childhood, late childhood and adolescence.<sup>869</sup> In addition to outlining the possible activities that can be undertaken by different sectors,<sup>870</sup> the Report elaborates on the role that children can play themselves in ensuring their right to health by stating that ‘Experience has shown that the participation of children and adolescents is crucial to the successful development and implementation of strategies, policies and services focused on this population group. Participation needs to be more than lip service; it requires the genuine engagement of young people.’<sup>871</sup> With respect to the participation of young children, the report elaborates that ‘younger children may not have the skills to be directly involved in policy-making and planning, it is, nevertheless, still possible to include advocates on their behalf, such as adults with particular expertise in and understanding of young children’s needs.’ It even appears that life-style interventions are more effective if they have been developed with the involvement of children and young children.<sup>872</sup>

#### 5.3.4. THE ROLE OF CHILDREN IN ENSURING THE HIGHEST ATTAINABLE STANDARD OF HEALTH OF THE CHILD IN THE EUROPEAN UNION

The opportunity of individuals to become involved in realizing the highest attainable standard of health of children in the European Union can only indirectly be derived from article 168 TFEU, which speaks of ‘health information and education’. Still, it is not formulated as a separate right or duty of individuals, but as a general measure that should be taken by States. Several EU Documents offer additional insight into the potential role of individuals in realizing the highest attainable standard of health of children in the European Union.

The Council’s conclusions on early detection and treatment of communication disorders, such as an impairment in hearing, vision and speech, in children

<sup>869</sup> Ibidem supra note 825, pp. 7–12.

<sup>870</sup> See for a further elaboration chapter 6 on the responsibilities of the different actors in involved in realizing the right to health of the child.

<sup>871</sup> Ibidem supra note 861, p. 17, § 83.

<sup>872</sup> Ibidem supra note 861, p. 17, § 84. See also Chapter II on General Comments 7 and 12 to the CRC.

establishes the link between children's health and their opportunities in life by stating in paragraph 2 that 'each EU citizen, and children in particular, should have equal opportunities to develop.'<sup>873</sup> This should be done by making accessible the appropriate tools and procedures to prevent, detect, treat and to monitor health problems'. Paragraph 7 furthermore establishes the importance of children's health for their future life and development by stating that 'children's good health is fundamental for their proper development and influences their quality of life and social and economical situation in the future'.<sup>874</sup> Thereto, *particularly crucial for children* is that 'prevention, early detection, monitoring and active surveillance play a significant role in warding off the development of diseases and disorders.' The prevention of health problems at the earliest possible stage, during childhood, is thus set as a priority.

This focus on early intervention for preventing future health problems is also found in the Council's conclusions on preventing chronic respiratory diseases in children.<sup>875</sup> Paragraph 15 emphasizes that 'conditions before birth and in early childhood influence health in adult life.' Thereto, both 'children and pregnant women must be protected against negative influences of environmental factors.' The role of pregnant women in ensuring their children's future health is thereby explicitly recognized. Similarly, the role of pregnant women and young mothers in influencing the health of their children by choosing the nutrition of their newborn children is acknowledged in the Guideline on infant formulae, elaborating that Member States must take appropriate measures to provide information that ensures adequate use of artificial nutrition, meanwhile promoting the use of breast feeding.<sup>876</sup>

The central role for children in managing their own health status is expressly highlighted in several instances. For example, in the Council's conclusions on preventing chronic respiratory diseases in children, it is recognized that there are several 'important elements for the prevention and treatment of respiratory diseases in children', namely children's ability for 'self-management, their participation in decisions affecting them, taking into account their age and

<sup>873</sup> EU Document 2011/C 361/4, Council conclusions of 2 December 2011 on early detection and treatment of communication disorders in children, including the use of e-Health tools and innovative solutions. Published in the Official Journal of the European Union on 10<sup>th</sup> December 2011. Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2011:361:009:0010:EN:PDF>. Article 8 defines a communication disorder as an impairment in hearing, vision or speech that influences the ability to comprehend and receive information.

<sup>874</sup> Ibidem supra note 872.

<sup>875</sup> EU Document 2011/C 361/5, Council conclusions of 2 December 2011 on prevention, early diagnosis and treatment of chronic respiratory diseases in children. Published in the Official Journal of the European Union on 10 December 2011. Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2011:361:0009:0010:EN:PDF>.

<sup>876</sup> EU Document Commission directive 2006/141/EC of 22 December 2006 on infant formulae and follow-on formulae and amending Directive 1999/21/EC, § 28. Published in the Official Journal of the European Union on 31 December 2006, L 401/1. Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2006:401:0001:0001:EN:PDF>.



maturity, as well as the active involvement of the parents and family.<sup>877</sup> Both the active involvement of children themselves and of their parents is thus expressly required. According to paragraphs 16 and 19, this active involvement is to be achieved by ‘continuous health education of children, parents, teachers and training of health professionals’ in preventing and responding to chronic respiratory diseases.<sup>878</sup> Furthermore, paragraph 20 requires that ‘health professionals’ and patients’ organizations are engaged to work towards more patient empowerment in the process of prevention, early diagnosis and treatment of chronic respiratory diseases.’ Children and parents thus do not stand alone in the process of empowerment in health. They must be enabled and supported by professionals that are active in the health care field.

Similarly, the need to actively involve children and their family in managing children’s mental health status is highlighted by the European Parliament, stating that ‘any future proposal by the Commission should involve partnership and consultation with and the participation of those who have experienced or are experiencing mental health problems, their families and carers and advocacy NGOs, associations of family members and other interested parties, so as to make decision-making processes more representative and inclusive, and should promote networking among members of the families of psychiatric patients.’<sup>879</sup> The role of children themselves in managing their own health status is reinforced in paragraph 55, stating that it is essential to apply ‘individualised methods of promoting mental health, taking into account the particular needs of individuals and target groups’. With regard to improving adolescents’ health, possible measures to stimulate adolescents to take responsibility for their own health are communicated in the Council’s conclusions on the health and well-being of young people.<sup>880</sup> These include the involvement of young people ‘in the development and implementation of health-related initiatives, particularly by peer learning’, ‘in all areas’ as well as by ‘strengthening the partnership with young people and their organizations’ and by ‘promoting the ‘youth’ dimension in health-related initiatives and the implementation of measures for the health of

<sup>877</sup> EU Document 2011/C 361/5, Council conclusions of 2 December 2011 on prevention, early diagnosis and treatment of chronic respiratory diseases in children. Published in the Official Journal of the European Union on 10<sup>th</sup> December 2012. Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2011:361:0009:0010:EN:PDF>.

<sup>878</sup> The issue of health education of all actors involved, including vulnerable groups of children, health professionals and others is also mentioned in the Council’s Conclusion on the prevention of injury and the promotion of safety. EU Document 2007/C 164/01, p. 3. Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2007:164:0001:0002:EN:PDF>.

<sup>879</sup> EU Document 2006/C 305 E/148. Resolution of the European Parliament on improving the mental health of the population. Towards a strategy on mental health for the European Union (2006/2058(INI)). Published in the Official Journal of the European Union on 14 December 2006. Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:305E:0148:0155:EN:PDF>.

<sup>880</sup> EU Document 2008/C 319/01, Resolution of the Council and the Representatives of the Governments of the Member States, meeting within the Council of 20 November 2008 on the health and well-being of young people.

young people'. In doing so, it is believed, that not only will young people be better able to take responsibility over their own health, but this will also raise their self-esteem and increase their autonomy, in particular by raising young people's awareness of the positive effects of a healthy lifestyle and of the risks related to their health'. The notion that children should be involved in the design of health services and strategies is also put forward in the European Health Report, stating that 'Implementation strategies are most successful when they are based on comprehensive national planning that involves children themselves, utilizes the contributions of families and communities, schools, the mass media, the health system and governments'.<sup>881</sup>

In the discussion on children and the right to health protection in the European context, Aasen focuses on the need to tackle inequalities in health. It has been established that socio-economic living conditions have a strong linkage to the increasing numbers of obesity in school children, alcohol and drug abuse, mental health problems and chronic respiratory conditions or allergies. Aasen comments that strategies at the individual level are not sufficient and that public health initiatives are urgently required.<sup>882</sup> Although this is a legitimate claim, caution must be taken by approaching children as one or several groups of vulnerable children that are reached by many gross-scale standardized measures. In developing and applying such measures, the view of the child as an independent holder of human rights must be kept at the forefront and also as a person in its own right must be respected. Different children have different experiences, views and needs which must be taken into account in determining the highest attainable standard of health and the health measures that are required to achieve this standard of health.

### 5.3.5. THE ROLE OF FAMILIES IN ENSURING THE HIGHEST ATTAINABLE STANDARD OF HEALTH OF THE CHILD

The Guideline on early detection and treatment of communication disorders in children, stipulates that 'Awareness of the problem, integrated and coordinated multidisciplinary approaches, which must be accompanied by active parental involvement during the whole process of child development and across healthcare and educational settings, are of significant importance'.<sup>883</sup> Both in the context

<sup>881</sup> WHO Regional Office for Europe, *The European Health Report 2005, Public health action for healthier children and populations*, Copenhagen 2005, p. 80.

<sup>882</sup> H.S. Aasen, 'Children and the right to health protection', in: Toebes, Hartlev, Hendriks & Herrman, *Health and Human Rights in Europe*, Groningen: Intersentia 2012, pp. 227–247, particularly p. 230.

<sup>883</sup> EU Document 2011/C 361/4, § 11, Council conclusions of 2 December 2011 on early detection and treatment of communication disorders in children, including the use of e-Health tools and innovative solutions. Published in the Official Journal of the European Union on 10 December

of ensuring the health of adolescents<sup>884</sup> and in improving the mental health of the population<sup>885</sup> the significant influence of family members for preventing, mitigating and responding to mental health problems is signalled in different life stages, such as early childhood (§ 18, 19 and 22), childhood, adolescence (§ 20) generally (§ 56) by acknowledging that ‘whereas the precondition for good mental health is an upbringing in a healthy family environment providing both material and psychological security and parental love’ (§ 18) and that ‘mental health problems commonly have their roots in early childhood’, (§ 22), urged is for ‘support for mothers during the prenatal and postnatal periods in order to prevent depression’ (§ 19), because good mental health of mothers and parents helps children to develop without hindrance and grow into healthy adults’. In this phrasing, the future health of children is directly linked to the (mental) health of their parents or caretakers during the upbringing of their children.

### 5.3.6. THE ROLE OF MEDICAL PROFESSIONALS

The role of professionals in responding to health problems in children is also addressed. Particularly with respect to children, a multidisciplinary and multi-agency approach is propagated for supporting children or adolescents with developmental or behavioural problems or eating disorders.<sup>886</sup> Thereto, continuous training for intermediaries and family practitioners is required,<sup>887</sup> as well as a critical reflection over the appropriate treatments for children, which extend to medicines that are particularly suitable for children, although the term treatment should extend to influencing psychosocial and environmental factors, because ‘particularly in the case of children and young people, the growing medicalisation and pathologisation of life stages, without a comprehensive search for causes is criticized’.<sup>888</sup> Therefore, factors such as personal experiences, family, social support and living and working conditions must be taken into account in determining the causes of mental health problems, whereas an appropriate social

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2012. Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2011:361:0009:0010:EN:PDF>.

<sup>884</sup> EU Document 2008/C 319/01, Resolution of the Council and the Representatives of the Governments of the Member States, meeting within the Council of 20 November 2008 on the health and well-being of young people. In point 6 is noted that ‘parents play a vital role in the well-being and healthy environment of young people and further measures should therefore be taken to support them.’

<sup>885</sup> EU Document 2006/C 305 E/148. Resolution of the European Parliament on improving the mental health of the population. Towards a strategy on mental health for the European Union (2006/2058(INI)). Published in the Official Journal of the European Union on 14 December 2006. Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:305E:0148:0155:EN:PDF>.

<sup>886</sup> *Ibidem supra* note 883, § 20.

<sup>887</sup> *Ibidem supra* note 883, § 23 and 39.

<sup>888</sup> *Ibidem supra* note 883, § 48.

and work environment as well as family and community support is required to provide support to people with mental health problems.<sup>889</sup>

## 5.4. THE INTERPRETATION OF THE RIGHT TO HEALTH OF THE CHILD BY THE COUNCIL OF EUROPE

This paragraph will discuss the relevant treaties and recommendations of the Council of Europe on the right to health of the child. The next paragraph will address the Guidelines on child-friendly health care separately, because these constitute a significant step forward in the elaboration of the concept of the highest attainable standard of health of the child.

### 5.4.1. INTERPRETATION OF THE RIGHT TO HEALTH OF THE CHILD IN THE EUROPEAN SOCIAL CHARTER

The European Social Charter<sup>890</sup> is central in ensuring children's rights in Europe through two channels: firstly, it addresses social rights directly relevant for children, such as article 8 ESC, (special protection for employed pregnant women), article 16 (the right of the family to social, legal and economic protection), article 11 (the right to protection of health) and article 13 (the right to adequate assistance, in particular by benefits under a social security system, in case of sickness for all nationals and people on the territory). Article 19 furthermore ensures that services for health, medical attention and good hygienic conditions must be provided for migrant workers and their families. In these articles, children's rights are intrinsically related to the rights of their families. A dual focus is found on providing protection on the one hand and on providing health services and adequate assistance on the other hand.

Secondly, the European Social Charter contains specific rights relating exclusively to children, such as article 7 (the right of children and young persons to protection) and article 17 (the right of children and young persons to social, legal and economic protection).<sup>891</sup> Articles 7–9 of the ESH, persons under 18 years of age and pregnant women are provided with protection rights in their working environment. Particularly relevant to the right to health of the child, article 8

<sup>889</sup> Ibidem supra note 883, § 47–48.

<sup>890</sup> The European Social Charter ensures economic and social human rights, such as the right to housing, health, social protection and non-discrimination. It was adopted in 1961 and revised in 1996, being signed by 47 member states of the Council and ratified by 39.

<sup>891</sup> Children's rights under the European Social Charter, Information document prepared by the secretariat of the ESC, March 2009, p. 1 and 2. See also the revised European Social Charter ETS 163, 3.V.1996.

of the European Social Charter provides protection to pregnant women, thus also affecting their unborn children. This protection includes the right of the mother to paid maternity leave of at least 14 weeks, the right to maternity pay, the prohibition of dismissal during pregnancy, the provision of sufficient time and regulations for nursing and healthy working conditions. Article 11 provides for an elaborated framework of measures required to ensure the right to health, namely the removal of the causes of ill-health, the establishment of advisory and educational facilities for the promotion of health and for the encouragement of individual responsibility and the prevention of accidents, epidemic, endemic and other diseases. Although both the family-related rights as well as the child-specific rights have a strong focus on children's right to protection (of their health), there is also explicit attention for the role of individuals in taking responsibility over their own health, being supported by the provision of educational facilities for health promotion to enable them to take the individual responsibility for their own health.

Under the European Social Charter States have the duty to ensure 'the best possible state of health for the population according to existing knowledge'.<sup>892</sup> This implies that existing knowledge is determinative in establishing the 'best possible state of health'. Furthermore, as explained in the information materials of the Secretariat of the European Social Council, this phrase means that avoidable health risks must be prevented as indicated by important health indicators such as life expectancy and principal causes of death, as compared to the European averages. Infant and maternal mortality must be reduced to rates as close to zero as possible.<sup>893</sup> Health measures to achieve these targets can generally be divided in health promotion and health provision initiatives.<sup>894</sup> Health promotion includes preventive measures (environmental health, immunisation, prevention of accidents), education (personal and public behaviour and health education at school) and the implementation of health regulations (occupational health, children's, women's and elderly persons' health). Mikkola asserts that health education for children is only sufficient if this is part of the school curricula and continued throughout basic education.<sup>895</sup>

The section on health provision most specifically implies the right to have adequate access to health for the entire population. Furthermore, health care must be available to all children without discrimination, including refugee children

<sup>892</sup> The right to health and the European Social Charter, Information document prepared by the secretariat of the ESC, March 2009, p. 9. Conclusions XV-2, Denmark, pp. 126–129 and United Kingdom, p. 599.

<sup>893</sup> Conclusions 2003, Romania, p. 390.

45 Conclusions XV-2, Belgium, pp. 93–96; Conclusions 2003, France, p. 146.

<sup>894</sup> The right to health and the European Social Charter, Information document prepared by the secretariat of the ESC, March 2009, pp. 2–10.

<sup>895</sup> M. Mikkola, *Social Human Rights of Europe*, Karelactio 2010, p. 485.

and undocumented children.<sup>896</sup> Also, vaccination programmes must be widely accessible and there must be high vaccination coverage rates.<sup>897</sup> This right to have access to health care has four central implications:<sup>898</sup>

- 1) the cost of health care should be borne, at least in part, by the community as a whole;<sup>899</sup>
- 2) health costs should not place an excessive burden on individuals; hereto measures must be taken so that medical costs are not only carried by people from disadvantaged populations;<sup>900</sup>
- 3) access to treatment must be based on transparent criteria, not causing unnecessary delay while assessing a patient's need for medical help. These criteria should address the risk of deterioration of the health status in both clinical (immediate) and quality of life terms;<sup>901</sup>
- 4) there must be an adequate number of health care professionals and equipment (at least 3 beds per thousand population).<sup>902</sup>

It appears from these implications, that whereas the total costs should be borne by the entire community, 'no excessive burden' should be placed on individuals. The particular position of individuals is thus taken into account in a protective sense. Furthermore, preventive and primary health care measures are prioritized for achieving health for all. This should give all individuals the opportunity to realize a basic level of health care. Involvement of individuals in ensuring their own level of health is stimulated by organizing health education.

The broadly elaborated article 17 ESC, lastly, provides that States Parties take all necessary measures to ensure that children 'have the care, the assistance, the education and the training they need' (§ 1a) and that states undertake 'to protect children against negligence, violence or exploitation' (§ 1b) and 'provide protection and special aid for children temporarily or definitively deprived of their family's support' (§ 1c). The phrasing in § 1a obliges States to protect children against the detrimental (health) consequences of negligence and violence against children. This is important, because medical professionals are often the first to

<sup>896</sup> See International Federation of Human Rights Leagues (FIDH) v. France, Complaint No. 14/2003.

<sup>897</sup> See Belgium and Turkey, where the situation was found to be in breach of Article 11§ 3 owing to insufficient coverage rates for certain diseases (ECSR, Conclusions XV-2). Reproduced in the Factsheet on the right to health and the European Social Charter, Information document prepared by the secretariat of the ESC, March 2009, p. 5.

<sup>898</sup> The right to health and the European Social Charter, Information document prepared by the secretariat of the ESC, March 2009, pp. 9–10.

<sup>899</sup> Conclusions I, pp. 59–60, Statement of Interpretation on Article 11; Conclusions XV-2, Addendum, Cyprus, pp. 26–28.

<sup>900</sup> Conclusions XVII-2, Portugal, pp. 680–683.

<sup>901</sup> Conclusions XV-2, United Kingdom, p. 599.

<sup>902</sup> Conclusions XV-2, Addendum, Turkey, p. 257.

signal instances of child abuse and neglect, because they are allowed to conduct physical examinations on children.

#### 5.4.2. THE BIOMEDICAL CONVENTION

The ESC takes a broader approach by focusing on both health care and underlying determinants of health than the other health-related convention of the Council of Europe, the Biomedical Convention.<sup>903</sup> The Biomedical Convention focuses more narrowly on the protection of human dignity in the field of biology and medicine.<sup>904</sup> As such, it focuses on the provisions of health care access by stipulating in article 3 that ‘Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.’ In doing so, article 2 stipulates that ‘the primacy of the human being shall prevail over the sole interest of society or science’. With respect to children, it is furthermore elaborated in article 6, 17 and 20 BC respectively that whereas authorization for a medical treatment, for inclusion in medical research or for organ donation may be given by the representative of a minor, ‘the opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.’ With respect to medical research, this must further be beneficial for the health of the child and the child must not object, whereas organ donation by children is forbidden unless several strict conditions are met.<sup>905</sup>

The Explanatory Memorandum to the Biomedicine Convention elaborates that healthcare must be of a fitting standard and that it must be subject to continuous quality assessment.<sup>906</sup> Aassen argues that this must be viewed in relation to children’s particular vulnerabilities and needs.<sup>907</sup>

<sup>903</sup> The Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine CETS No. 164 entered into force on 1 December 1999.

<sup>904</sup> H.S. Aasen, ‘Children and the right to health protection’, in: Toebes, Hartlev, Hendriks & Herrman (a.o.), *Health and Human Rights in Europe*, Groningen: Intersentia 2012, p. 233.

<sup>905</sup> Article 20 Biomedicine Convention sets several conditions which must be met before organ donation by a minor is allowed. These include 1. there is no compatible donor available who has the capacity to consent; 2. the recipient is a brother or sister of the donor; 3. the donation must have the potential to be life-saving for the recipient; 4. the potential donor does not object.

<sup>906</sup> Explanatory Memorandum to the Biomedicine Convention, § 24–25, Council of Europe 1996.

<sup>907</sup> H.S. Aasen, ‘Children and the right to health protection’, in: Toebes, Hartlev, Hendriks & Herrman (a.o.), *Health and Human Rights in Europe*, Groningen: Intersentia 2012, p. 233.

### 5.4.3. KEY HEALTH ISSUES IN THE RECOMMENDATIONS OF THE COUNCIL OF EUROPE

The Council of Ministers and the Parliamentary Assembly of the Council of Europe have also adopted several non-binding recommendations on the health of children and adolescents. A broad range of topics have dealt with the interaction between children, their family and the state in ensuring the (right to) health of children. Relevant health issues addressed include the safeguarding of children and young people against obesity and diabetes II,<sup>908</sup> the health issues of teenagers in distress,<sup>909</sup> the safeguarding of the health of children living in single parent families,<sup>910</sup> the treatment of children with ADHD<sup>911</sup> and the care of children from birth until age eight.<sup>912</sup>

In the contents of the recommendations of the Council of Europe, a development can be discerned in which the role of the child is strengthened over the years. Whereas the child was already regarded as an individual in his own right in 1981, its active involvement in determining his own lifestyle is becoming increasingly dominant. For example, in the recommendation of the Parliamentary Assembly on controlling the diagnosis and treatment of hyperactive children in Europe (2002),<sup>913</sup> most elements address the responsibilities of the ‘medical, scientific and pharmaceutical industry’ in (§ 7) as well as the international organizations and member states involved (§ 8). Only in the last paragraph (§ 8-3-c) is mentioned that ‘the Committee of Ministers is recommended...to invite the governments of the member states...to produce information material designed for *parents* of hyperactive children explaining what possibilities exist for improving their condition’. No mention is made of the role of children or teenagers themselves in managing their own hyperactivity, although they are the first who suffer from its existence and who may benefit from any improvements.

In more recent recommendations, the Council of Europe has acknowledged that ‘there is a greater awareness than before of children as individuals with their

<sup>908</sup> Recommendation of the Council of Ministers of the Council of Europe. ‘Safeguarding children and young people against obesity and diabetes II’, (1966) 2011. See also Resolution 1804 (2011) of the Parliamentary Assembly on Safeguarding children and young people from obesity and type 2 diabetes.

<sup>909</sup> Recommendation of the Parliamentary Assembly of the Council of Europe. ‘Teenagers in distress: a social and health-based approach to youth malaise’, REC (1632) 2003.

<sup>910</sup> Recommendation of the Council of Ministers of the Council of Europe. ‘On securing and promoting the health of single-parent families’, REC (4) 1997.

<sup>911</sup> Recommendation of the Parliamentary Assembly of the Council of Europe. ‘Controlling the diagnosis and treatment of hyperactive children in Europe, REC (1562) 2002.

<sup>912</sup> Recommendation of the Council of Ministers of the Council of Europe. ‘Concerning the care and education of children from birth to the age of eight, REC (3) 1981. See also the Recommendation of the Council of Ministers of the Council of Europe. ‘On child day-care’, REC (8) 2002.

<sup>913</sup> Resolution 1804 (2011) of the Parliamentary Assembly on Safeguarding children and young people from obesity and type 2 diabetes.



own rights'.<sup>914</sup> Thereto, it is elaborated that 'children need to be able to grow up and develop according to their own capacities and to receive acknowledgement for that, the need for security, stability and confidence in their environment and their relationships, and the need for unconditional love and acceptance; the need to create possibilities for children to make their opinions heard on matters concerning them, and to ensure that their views are taken into account in decision-making processes, respecting parents as the first educators of the child'.<sup>915</sup> In this vision on children, both the direct involvement of children and the primary responsibility of parents in caring for their children is apparent.

The important role of the family was already acknowledged in 1981 by stating that 'the child will normally depend primarily on his family to recognize and secure these rights. It also becomes evident from the health-related recommendations for children growing up in single-parent families. The recommendation on securing health in single-parent families qualifies living in a single parent family as 'a major public health problem', because the heavy burden goes hand in hand with psychological and physical stress. Therefore, many measures are suggested for preventing and mitigating the negative health impacts on children by growing up in a single parent family, such as the early identification of specific health problems, strengthening of personal skills, the provision of self-help groups and counselling services and day centres that are adjusted to the working hours of single-parents and that can respond to the needs of single parents when their children are sick. In doing so, it is furthermore recommended that in establishing such services, single parent families must be consulted and involved in the design of services so that these will best respond to their needs. To counter the risk of stigma, the Council of Europe stipulates in part I.2 that 'The health policy should respect the current diversity of family structures, make efforts to integrate them, accept the changing quality and content of family life and afford equal treatment to different types of family.'

The family thus operates within a wider social framework from which it should be able to obtain the support it needs to fulfil its obligations. In providing such support, care should be taken not to undermine parental responsibilities towards the child.<sup>916</sup> With respect to the functioning of the health sector, it is established that 'health services should work with, and through, the family to provide continuity of experience for the child'.<sup>917</sup> In addition, the state is charged with the responsibility 'to assist parents and others responsible for the child to secure the conditions necessary for the child's development' and to ensure that

<sup>914</sup> Ibidem supra note 911.

<sup>915</sup> Ibidem supra note 911.

<sup>916</sup> Recommendation of the Council of Ministers of the Council of Europe. 'Concerning the care and education of children from birth to the age of eight, REC (3) 1981, § I.A.

<sup>917</sup> Ibidem supra note 915.

‘services responsible for the care and protection of children conform to standards established by competent authorities, particularly in the area of health’.<sup>918</sup>

In the 2003 recommendation that deals with the issues of teenagers in distress,<sup>919</sup> more attention is paid to the role of the individual youngsters themselves, by stating in § 9 that ‘to strengthen the ability of young people to cope with the uncertainty and unpredictability of their future, programs to foster resilience should be made an integral part of general youth policies’. At the same time, the necessity to establish a supporting social network is clearly established by indicating ‘the supportive role of the family’ (§ 5), the need to ensure ‘access to advice and counseling in a friendly and supportive environment’ (§ 8) and ‘to devise health education programs’ (§ 10-4-b), giving evidence of a balance between strengthening the role of teenagers and establishing a strong and supporting social network.

In a more recent recommendation, it appears that the Parliamentary Assembly aims to empower the child to take responsibility over the realization of its own right to health. For example, resolution 1804 on safeguarding children against obesity and diabetes II, contains several provisions that call for educational measures to inform children and young people (and their parents) about (5.4) ‘the benefits of healthy eating habits, as well as the dangers and the long-term consequences of nutritionally unbalanced fast-food consumption and the risks of poor health due to induced obesity;’ Furthermore, measures are propagated to (6.2) promote active behaviour and provide for opportunities to become active and to (6.1) raise awareness among children about the nutritional value of food instead of regarding it as a way of comforting themselves when they experience negative emotions. Full participation of children is furthermore stimulated in active behaviour (6.6) as well as in (10) the design of public health programs.

The last step in the increasing recognition of children’s right to involvement by the Council of Europe is the adoption of the Recommendation on Promoting the participation by children in decisions affecting them.<sup>920</sup> Paragraph 3 mentions that children should be involved, ranging from dialogues with decision-makers at all levels to individual decisions that concern children. It particularly mentions health, medical care and family policy (§ 3) as well as in programs for violence prevention (§ 8).

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<sup>918</sup> Ibidem supra note 909.

<sup>919</sup> Recommendation of the Parliamentary Assembly of the Council of Europe. ‘Teenagers in distress: a social and health-based approach to youth malaise’, REC (1632) 2003.

<sup>920</sup> EU Doc. 12080, Recommendation 1864, on Promoting the participation by children in decisions affecting them, adopted at the 1069<sup>th</sup> meeting of the Ministers’ Deputies, 4 November 2009.

#### 5.4.4. THE EUROPEAN CONVENTION ON HUMAN RIGHTS

The right to health as such is not incorporated in the European Convention on Human Rights. However, ‘the protection of health’ is mentioned in article 8-2 as a possible justification for interfering with the right to respect for family life as laid down in article 8-1 ECHR. This means that the protection of health, under circumstances, can be prioritized over the protection of the family life.

Although the right to health is not included in the European Convention on Human Rights, the right to health for children has been explained by the European Committee on Social Rights (ECSR): it has been established that medical services must exist at schools and periodical medical examinations must be carried out throughout schooling.<sup>921</sup> Examples include health education in nurseries and infant schools on ‘respect for the body’ and training in high school on ways to decrease high risk behaviour among adolescents. However, the Committee identified that some of the programs were not integrated in the regular curriculum and dependent on the initiative of individual teachers.

The European Court of Human Rights has considered children’s right to health in a limited number of cases. All cases dealt with procedural issues related to medical care around childbirth.<sup>922</sup> The European Court on Human Rights applies the doctrine of the ‘margin of appreciation’ to take into account differences in cultural interpretations of the provisions in the ECHR and the ESC.<sup>923</sup> The margin of appreciation is applied to distinguish between matters that are left to national discretion and matters that are of such importance that similar conditions are required for countries with different cultural or ideological standpoints.<sup>924</sup> Although case law is not particularly consistent on the determination of the

<sup>921</sup> Belgium and France, European Committee on Social Rights, Conclusions XV-2 (2001), pp. 96–97 and 208–209.

<sup>922</sup> For cases involving children’s right to health see:

- *Tysic v. Poland*, 20 March 2007: “Lawful therapeutic abortion in Poland”;
- *Byrzykowski v. Poland*, 27 June 2006: “Death of a woman during childbirth and her child’s ensuing health problems”;
- *Yardimci v. Turkey*, 5 January 2010: “Child suffering infirmity attributable, according to its parents, to inappropriate medical treatment during childbirth, in Turkey”;
- *Oyal v. Turkey*, 23 March 2010: “Child contaminated by HIV when given blood transfusions immediately after his birth, in Turkey”.

<sup>923</sup> The doctrine of the margin of appreciation was first addressed in the *Belgian Linguistics Case* – ‘In the case “relating to certain aspects of the laws on the use of languages in education in Belgium” v Belgium’, Application no 1474/62; 1677/62; 1691/62; 1769/63; 1994/63; 2126/64 and further elaborated in *Handyside v. United Kingdom*, Application no. 5493/72, 7 December 1976. In this second case the Court judged that it had limited competence to control the Treaty Parties to ECHR and judged that article 10 ECHR had not been violated. Following this judgement, the doctrine of the margin of appreciation of countries was then applied to other provisions.

<sup>924</sup> F. Mahony, ‘Marvellous richness of Diversity or Individious Cultural Relativism’, *Human Rights Law Journal* 1998, Issue 19, p. 1.

margin of appreciation,<sup>925</sup> several elements have been identified to influence the decisions of the Court on this matter,<sup>926</sup> namely the level of consensus on the matter between European countries, the nature of the protected objective and thirdly, the interests of the complainant. Last but not least the socio-economic policy of the State Party is taken into account.<sup>927</sup> Especially from the last element, it appears that there is room to take the interests of the complainant into account in interpreting their right to health. Furthermore, it appears from the cases that have been dealt with by the Court, that prevention of health problems is prioritized by making medical services and regular examinations particularly available for children.

## 5.5. CHILD-FRIENDLY HEALTH CARE: A STEP FORWARD?

### 5.5.1. THE GUIDELINES ON CHILD-FRIENDLY HEALTHCARE: A FOCUS ON CHILDREN AND THEIR FAMILIES

Holistic interpretation of the different CRC provisions implies a more far reaching standard for achieving children's right to health than the isolated application of article 24 CRC. For European countries this more far reaching standard has recently been concretized in the Guidelines of the Committee of Ministers of the Council of Europe on child-friendly health care.<sup>928</sup> As such, it establishes an explicit legal framework for determining the peculiarities of child-friendly health care in the European context.

These Guidelines provide for a comprehensive framework on children's rights in health care. The Guidelines have been developed in the context of the Council of Europe Program 'Building a Europe for and with children',<sup>929</sup> the 2009–2011

<sup>925</sup> J. van de Lanotte & Y. Haeck, *Handboek EVRM. Deel 1 Algemene beginselen*, Antwerpen-Oxford: Intersentia 2005, p. 220.

<sup>926</sup> J. Gerards, 'Methoden en beginselen van interpretatie en toetsing, inclusief de margin of appreciation-doctrine', in: J.H. Gerards, H.J. Janssen & J. van der Velde (red.), *EVRM Rechtspraak en Commentaar*, Den Haag: SDU 2010, aanv. 88 (part 2.1), pp. 56–87. See also: J.H. Gerards, 'Pluralism, Deference and the Margin of Appreciation Doctrine', *European Law Journal* 2011, Volume 17, no. 1, pp. 80–120.

<sup>927</sup> Ibidem supra note 911.

<sup>928</sup> The Guidelines on child-friendly health care were adopted in Lisbon on 28<sup>st</sup> September 2011 in the context of the Strategy 'Building a Europe for and with children' 2009–2011.

<sup>929</sup> The program 'Building a Europe for and with children' was implemented in 2005 after the 3<sup>rd</sup> Summit of Heads of State and Government of the Council of Europe I Warsaw and comprises two strands: the promotion of children's rights and the protection of children against violence. See for more information: [www.coe.int/t/dg3/children](http://www.coe.int/t/dg3/children). The Program contains several projects including child-friendly social services, children's participation, child-friendly justice and child-friendly health care. See also [www.coe.int/t/dg3/children/participation/Newdefault\\_.en.asp](http://www.coe.int/t/dg3/children/participation/Newdefault_.en.asp) and [www.coe.int/t/dghl/standardsetting/childjustice](http://www.coe.int/t/dghl/standardsetting/childjustice).

Strategy for the Rights of the Child<sup>930</sup> and the current 2012–2015 Strategy for the Rights of the Child. They build on previously existing Recommendations of the Council of Europe, the previously adopted Guidelines on child friendly justice,<sup>931</sup> as well as on the CRC and relevant documents issued by the health sector itself. In addition to basic provisions on children's right to health, protection and social security, progress has been made in developing a legal framework to achieving not only regular health care, but also to child-friendly health care.

Some argue that the term 'child-friendly' health care should be replaced by the term 'child-oriented' or child-appropriate health care, because these expressions would better reflect the necessary character of integrating the different aspects of children's rights in health care. Defining health care as 'child-friendly' is perceived to be too voluntarily, whereas a specific orientation of health care towards children is claimed to be essential for ensuring adequate health care. In this thesis I opt for the term 'child-friendly' health care, being in line with the applied terminology in the Guidelines of the Council of Europe on children's rights in justice and in health care, although I do support the idea that ensuring children's rights in health care is more than a luxury and that it is crucial in establishing health care that is truly beneficial for children's health.

The Guidelines of the Council of Europe define child-friendly health care as 'Health care policy and practice that are centered on children's rights, needs, characteristics, assets and evolving capacities, taking into account their own opinion'.<sup>932, 933</sup> Also, the concept of child-friendly health care includes the notion of family-friendly health care, defined as 'facilitating bonding between newborn babies and their mothers/parents, facilitating contacts between the child and his or her family and preventing the separation of the child from his or her family unless it is in the best interests of the child'.<sup>934</sup> In establishing a relation with children, medical professionals thus have to intrinsically take into account the influence and role of parents in guiding their children through the health care system, although the best interests of the child should remain a priority.

Within the European region, the guidelines on child-friendly health care pose an interesting example of a legal framework that is developed to reach the highest attainable standard of health within the health sector. The guidelines are extensive and in the drafting process medical professionals were intensively involved. Furthermore, information was obtained of more than 2200 children and

<sup>930</sup> The 2009–2011 Strategy prioritized vulnerable children, focusing on children without parents, children with disabilities and children in or at risk of poverty and social exclusion. See: [www.coe.int/t/dg3/children/news/200911Strategy\\_en.asp](http://www.coe.int/t/dg3/children/news/200911Strategy_en.asp).

<sup>931</sup> Guidelines of the Council of Europe on child-friendly justice, adopted on 17 November 2010. See for example § 3 of the Guidelines on child-friendly healthcare.

<sup>933</sup> Elsewhere, namely in footnote 19 of the Explanatory Memorandum, the child friendly health care approach is defined as 'integrating the principles of participation, promotion, protection and prevention into a practical framework of provision based on pathways to guide the planning, delivery and improvement of children's services.'

<sup>934</sup> § 21 of the Guidelines on child-friendly healthcare.

adolescents from a large online survey in several member states of the Council of Europe.<sup>935</sup>

Child-friendly health care is required for several reasons. In the first place, it aims to protect sick children, because they have plural vulnerabilities: in the first place for being dependent on adults in their quality of being a child and in the second place for being dependent on medical professionals who are better informed and experienced on the (highly technical) medical treatments that they may undergo.<sup>936</sup> Thirdly, children are in development, which means that any infections, diseases, treatments and possible complications not only impact upon them at present, but possibly also in the future. Fourthly, since children are sick, they have less energy and resilience they have less energy to stand up for their rights in the course of their medical treatments. Aasen furthermore acknowledges that ‘children are not only vulnerable due to their physical and mental conditions, but also because of their physical and social environments’.<sup>937</sup> Fifthly, medical treatments can make enormous infringements on the physical integrity of the child, thereby potentially causing a lot of harm if this happens against the will or best interests of the child or if it does not respect medical professional standards. In the society at large and specifically from the part of the medical professionals, there is increasing awareness and call for guidance on applying children’s rights in health care.<sup>938</sup> Last but not least, the common principle in international health law to ‘progressively realize the right to health’ (of children) as found both in the Convention on the Rights of the Child and in the International Covenant on Economic, Social and Cultural Rights offers a strong argument for further developing the right to health of the child. It must be noted that the guidelines on child-friendly healthcare focus on children’s rights within the health care sector, indicating the strong medical orientation of looking at children’s health in contrast to the focus on basic health measures and underlying determinants of health in article 24 CRC and 12 ICESCR.

<sup>935</sup> It is questionable to what extent the views are representative of the particular vulnerable youth population. Unclear is whether children within the hospital, undergoing medical treatments or marginalized children, such as refugee children or others who do not have internet at their disposal, were able to have access to the survey. It appears from the report that only a small percentage of children under 10 were involved in the research. As part of the study, the Irish National Ombudsman for children did conduct qualitative research with children, but the results of this study can not be simply transposed to children under 10 in other countries, because health systems differ widely, as well as underlying presumptions on children, health and health care.

<sup>936</sup> G. Bricher, ‘Children in the Hospital: Issues of Power and Vulnerability’, *Pediatric Nursing* 2000, May, available at: [http://findarticles.com/p/articles/mi\\_m0FSZ/is\\_3\\_26/ai\\_n18610056/](http://findarticles.com/p/articles/mi_m0FSZ/is_3_26/ai_n18610056/).

<sup>937</sup> H.S. Aasen, ‘Children and the right to health protection’, in: Toebe, Hartlev, Hendriks & Herrman, *Health and Human Rights in Europe*, Groningen: Intersentia 2012, p. 230.

<sup>938</sup> The Guidelines of the Council of Europe were developed in close cooperation with pediatricians from a variety of member States. In the Netherlands, the 33<sup>rd</sup> Yearly Conference of Pediatricians organized two symposia on children’s rights in health care in November 2011.

### 5.5.2. KEY ELEMENTS OF CHILD-FRIENDLY HEALTH CARE

The question now is what encompasses the notion of child-friendly health care. How is it elaborated in the newly established Guidelines of the Council of Europe and what role is attributed to children and their families in realizing the right to the highest attainable standard of health of the child?

The central aim of the Guidelines on child-friendly practice is to improve the quality of child health care by focusing on effectiveness, efficiency, equity, patient safety and satisfaction.<sup>939</sup> The Preamble of the Guidelines on child-friendly health care reiterates relevant international legal treaties<sup>940</sup> and relevant texts adopted by the Committee of Ministers on children and<sup>941</sup> on health care.<sup>942</sup> By adhering to the basic principles in international law, the guidelines integrate the concepts of non-discrimination, dignity, participation, equitable access and the best interests of the child,<sup>943</sup> concomitantly constituting ‘an integrated conceptual and operational framework<sup>944</sup> which fully respects children’s rights, health needs and resources.’<sup>945</sup>

<sup>939</sup> See § 29 of the Guidelines on child-friendly healthcare.

<sup>940</sup> – The United Nations Covenant on Economic, Social and Cultural Rights (1966), and in particular its Article 12 on the right to the highest attainable standard of health;  
– the United Nations Convention on the Rights of the Child (1989);  
– the United Nations Convention on the Rights of Persons with Disabilities (2006);  
– the Convention for the Protection of Human Rights and Fundamental Freedoms (1950, ETS No. 5);  
– the European Social Charter (1961, ETS No. 35) and the revised European Social Charter (1996, ETS No. 163);  
– the European Convention on the Exercise of Children’s Rights (1996, ETS No. 160);  
– the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1987, ETS No. 126);  
– the Council of Europe Convention on the Protection of Children against Sexual Exploitation and Sexual Abuse (2007, CETS No. 201);  
– the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (1997, ETS No. 164), in particular Article 6.

<sup>941</sup> – Guidelines on Child-friendly Justice, adopted on 17 November 2010;  
– Recommendation CM/Rec(2010)2 on deinstitutionalisation and community living of children with disabilities;  
– Recommendation CM/Rec(2009)10 on integrated national strategies for the protection of children from violence;  
– Recommendation Rec(98)8 on children’s participation in family and social life.

<sup>942</sup> – Recommendation Rec(2006)7 on management of patient safety and prevention of adverse events in health care;  
– Recommendation Rec(2006)5 on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006–2015;  
– Recommendation Rec(2000)5 on the development of structures for citizen and patient participation in the decision-making process affecting health care.

<sup>943</sup> See § 6–16 of the Guidelines on child-friendly healthcare.

<sup>944</sup> The Guidelines are intended to provide a practical framework that drives cultural change in the medical domain. See § 20 of the Guidelines on child-friendly healthcare.

<sup>945</sup> See § 17 of the Guidelines on child-friendly healthcare.

It takes into account the changing epidemiology of childhood,<sup>946</sup> the rising costs of health care and unacceptable variations in the quality of health care services for children and their families and it aims to achieve a continuum of care between the primary, secondary and tertiary health care organizations consequently and simultaneously involving health, education, social care and justice systems in public, private and voluntary sectors.<sup>947</sup> All in all, the child-friendly health care approach must be designed around children and their families.<sup>948</sup>

The scope of child-friendly health care as laid down in the guidelines is thus very broad, including both different levels of health care as different disciplines relevant to children's health status. This can be confusing and non-transparent for children. Therefore, it would be helpful for children to be guided by a 'child health advocate', an independent professional who guides the child through the health care process by explaining the role of the different doctors and organizations the child encounters in the process. Furthermore, the child health advocate can help to ensure that the child's interests are put central during the entire process and support the child in balancing its rights and the rights of the parents and support the child in balancing its rights *vis-à-vis* its parents and medical professionals.<sup>949</sup>

Although the large plurality of legal treaties and conventions relevant to the right to health of the child offers a starting point for understanding the highest attainable standard of health of the child, the guidelines have an additional value. This added value is created by elaborating its basic principles to be applied in the medical practice. The involvement of a wide range of experts, including paediatricians has undoubtedly added to this practical applicability.<sup>950</sup> As argued above, a good start has been made to involving children in the development of the guidelines, but more in-depth research is required to get further insights into the interaction between the realization of children's rights in health care and the visions of children upon these rights. The underlying principle of satisfaction in

<sup>946</sup> See for example U.N. Doc. WHO (2010), Millennium Development Goals in the WHO European Region: A situational analysis at the eve of the 5-year countdown. Copenhagen, WHO Regional Office for Europe.

<sup>947</sup> Examples of services involved that are enumerated in the Explanatory Memorandum, range from screening and immunization programs to neonatal intensive care and heart-lung transplantations to other interventions such as anti-bullying campaigns, health promoting schools, social care support organizations in cases of child maltreatment and the voluntary sector supporting children with disabilities or chronic diseases and access to housing, safe drinking water and sanitation.

<sup>948</sup> Explanatory Memorandum to the Guidelines on child-friendly health care, § 17 and 21.5.

<sup>949</sup> According to the Guidelines on child-friendly health care, the health care domain is divided into several pathways. These will be further discussed in the remainder of this paragraph.

<sup>950</sup> The Committee of Experts was composed of 15 independent specialists who were selected by the European Health Committee. The request was to prepare guidelines on child-friendly healthcare, proposing a practical approach to assist member states to improve their health care systems. In addition, a wide range of observers, including representatives of leading intergovernmental and non-governmental organizations such as UNICEF, the WHO, the European Youth Forum, the European Patient Forum, the European Pediatric Association, the European Public Health Alliance, Schools for Health in Europe, the Royal College of Nursing and the European Network of Ombudspersons for Children also contributed.



the guidelines offers a legal basis for grounding such research because satisfaction can only be established by taking into account the views and experiences of children themselves. Such an approach allows for a full evaluation of the health care provided, because it integrates the experiences of children in health care assessments with more solid criteria such as medical outcome statistics, costs and other measurable criteria. In that way, the views and opinions of children are integrated in the elaboration of the highest attainable standard of health of the child.

### 5.5.3. PRACTICAL RELEVANCE OF THE GUIDELINES

The practical orientation of the guidelines is reflected by its distinction of the different pathways that exist within the health care system. In addition to the individual journey in health care, defined as ‘the individual experience of the health services’, a group of similar journeys constitutes a ‘pathway’ of which individual parts are delivered by a team of professionals. Three pathways are distinguished, each consisting of the four components Prevention, Identification, Assessment and Interventions.<sup>951</sup>

- initial pathway: The development, identification, initial assessment and management of the medical condition of the child.
- cyclical pathway: The regular review of the medical condition of the child with a focus on the best management of the condition and prevention of complications or other morbidities.
- transition pathway: The transition to the normal situation if the condition is cured, to adult health care or to palliative care if there is further deterioration likely to result in death.

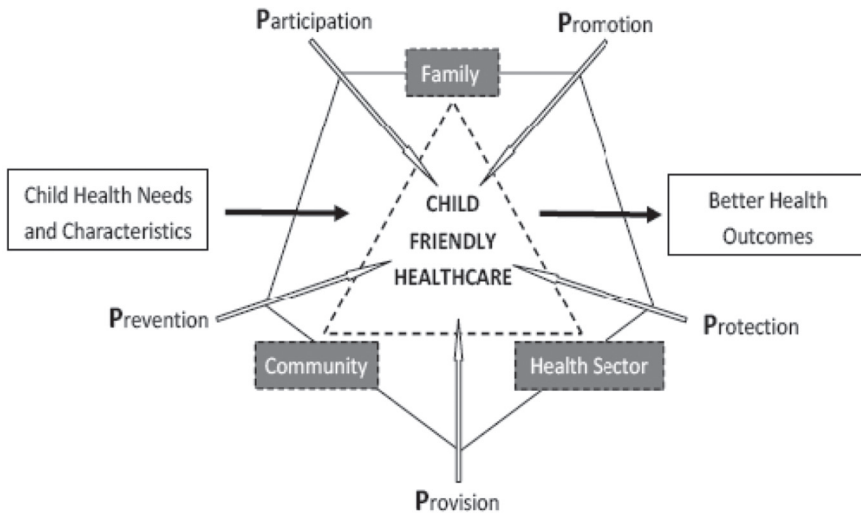
Multidisciplinary collaboration within and between these pathways must create synergy and alignment between the policy level, the service level and the individual level, so that an integrated health system is established that takes into account the various actors and factors involved.<sup>952</sup> As set out in figure 1 below, this integrated health system, the child-friendly health care approach, is characterized

<sup>951</sup> See § 30–31 of the Guidelines on child-friendly healthcare. See also the Explanatory Memorandum, § 49–59.

<sup>952</sup> See § 33 and 37 of the Guidelines on child-friendly healthcare. See also *supra* note 58.

by the '5 P's':<sup>953</sup> Participation,<sup>954</sup> Promotion,<sup>955</sup> Protection,<sup>956</sup> Prevention<sup>957</sup> and Provision.<sup>958</sup> The 5 P's concomitantly place the needs of children and their families at the heart.

Figure 1. Overview by the Committee of Experts on child-friendly health care, 2011<sup>959</sup>



<sup>953</sup> The 5 P's are laid down in § 23–28 of the Guidelines and further explained in § 41–54 and in the Explanatory Memorandum, pp. 16–17.

<sup>954</sup> Participation in the health field is divided between giving free and informed consent on the one hand and taking part in social decision-making processes on health care issues, including the assessment, planning and improvement of health care services, on the other hand. Children are recognized as active stakeholders and rights bearers and the level of participation depends on their age, evolving capacities, maturity and on the importance of the decision being taken. See § 11, 12, 23 and 24 of the Guidelines on child-friendly healthcare.

<sup>955</sup> Promotion is defined in § 25 of the Guidelines as 'The process of enabling people to increase control over their health and its determinants and thereby improve their health'. This definition is drawn from the WHO Health Promotion Glossary, 1998. The Guidelines further explain promotion as 'including all actions that allow children to become more involved in their own health and increase their exposure to positive determinants of health. It involves activities at family and community level and factors in health care services and settings.

<sup>956</sup> Protection is defined in § 26 of the Guidelines on child-friendly healthcare as 'all actions that either limit or avoid children's exposure to hazards in families, communities or health services'.

<sup>957</sup> Prevention is defined in § 27 of the Guidelines on child-friendly healthcare and 'refers to any service which contributes to the health and well-being of children and families and therefore includes more than just the traditional health services'.

<sup>958</sup> Provision is defined in § 28 of the Guidelines on child-friendly healthcare and 'refers to any service which contributes to the health and well-being of children and families and therefore includes more than just the traditional health services.

<sup>959</sup> The model was taken from the preparatory document on child-friendly health care for and with children in Europe by J.A. Diaz Huertas and A.I.F. Guerreiro, Council of Europe Document No. MSN (2011) 4E.

The concept of Promotion as a central element to children’s health care is additional to the ‘4 P’s’ that are central in the Convention on the Rights of the Child, although health promotional activities are inexplicitly mentioned in article 24 CRC and in the Guidelines on Reporting<sup>960</sup> on article 24 CRC as well.

Overall, the child-friendly health care approach is characterized by the so-called 5-4-3-2-1 approach: there are 5 basic principles (the 5 P’s), 4 components of the different pathways of the principle P-rovision (prevention, identification, assessment and interventions), 3 pathways (initial, cyclical and transitional), 2 driving forces (alignment between services and coupling measures, feedback and action) and one central aim (improvement in outcomes and impact).<sup>961</sup> This system appears to be somewhat artificial. Furthermore, because the guidelines and explanatory memorandum are complementary, addressing different elements of the 5 P’s in the child-friendly health care approach, the resulting schedule of the guidelines is somewhat chaotic. Therefore, figure 3 integrates all elements in one scheme. Figure 3 demonstrates the integrated health system<sup>962</sup> based on the different pathways and elements of the child-friendly health care approach discerned.

Figure 2. Key concepts of child-friendly health care based on the 5-P-rinciples

1. PARTICIPATION in:
a. <i>individual decision-making</i> (consultation, informed consent and confidentiality)
b. <i>feedback</i> on children’s experiences in the services provided;
c. involvement and priority setting in service <i>planning and policy</i> .
d. research
2. PROMOTION by:
a. general support directed towards <i>all children</i> : health promotion programmes, such as child-friendly healthcare, schools and sporting facilities and financial arrangements;
b. additional targeted support directed towards (socially, emotionally or financially) <i>vulnerable children</i> ;
c. <i>children</i> (repeatedly) <i>using health services</i> : chronically ill, recovering from trauma
3. PROTECTION of:
a. general protection for all children against environmental hazards, physical, social, emotional or financial harm, racism. E.g. improving parental skills and support for families with low incomes, legislation on equal access and child protection measures).
b. special protection for vulnerable children, such as refugee and minority children, disabled children or children with rare chronic diseases.
c. children using health services, e.g. by ensuring a patient-safety policy framework and feedback mechanisms.
4. PREVENTION levels:

<sup>960</sup> U.N. Doc. HRI/GEN/2/Rev.6, 3 June 2009.

<sup>961</sup> See Appendix II to the Explanatory Memorandum.

<sup>962</sup> The WHO defines health systems as ‘all organizations, people and actions whose primary intent is to promote, restore or maintain health’. See: [www.who.int/alliance-hpsr/resources/9789241563895/en/index.html](http://www.who.int/alliance-hpsr/resources/9789241563895/en/index.html).

<ul style="list-style-type: none"> <li>a. primary: population-based interventions (vaccinations, water fluoridation).</li> <li>b. secondary: early detection (neonatal screening for health problems).</li> <li>c. tertiary: prevent secondary disabilities or deficiencies (use of asthma inhalers).</li> <li>d. quaternary: avoid harm through the contact with the health system itself (e.g. by separation of parents, disruption of social network, unnecessary medical treatments and lack of information).</li> </ul>
<p>5 PROVISION of health care through:</p> <ul style="list-style-type: none"> <li>a. individual journeys and collective pathways, provided by networks of medical professionals and consisting of prevention-identification-assessment-intervention.</li> <li>b. evidence-based, user-friendly, readily accessible, competent practitioners, appropriate care environment, timely</li> <li>c. measurement, feedback, continuous learning</li> </ul>

#### 5.5.4. THE CHARTER OF THE EUROPEAN ASSOCIATION ON CHILDREN'S RIGHTS

Before adoption of the Guidelines on child-friendly health care, the European Association for Children in Hospitals (EACH), an umbrella organization for non-governmental and non-profit associations from 18 European member states that are involved in the welfare of children in hospital, had already established an ethical foundation for the care of children in hospital.<sup>963</sup>

The EACH Association was founded by 12 European voluntary organizations to address the needs of children in hospital, who were found to suffer from the detrimental effects of health care in hospitals, largely because of the (long-term) separation from their families resulting in long-lasting emotional disturbances. The EACH Charter was adopted in Leiden in 1988, preceding corresponding and binding rights in the UN Convention on the Rights of the Child and addressing all sick children between 0–18 years.

The Charter applies to all sick children, 'regardless of their illness or age or disability, their origin or their social or cultural background, or of any possible reason for treatment or forms or places of treatment, whether as in-patients or out-patients.'<sup>964</sup> The principle of non-discrimination is thus specifically highlighted in implementing the right to health of children in the EACH Charter. On the other hand, the focus selectively on 'sick children' is narrower than that of the Guidelines on child-friendly health care. Therein, three categories of children are distinguished for targeting health related activities, namely 'children in general', 'sick children' and other groups of 'vulnerable children'.

The EACH Charter contains 10 fundamental principles. Furthermore, the Association identifies 16 (sub-) rights of the UN Children's Rights Convention that are relevant to implementing children's right to health, namely article 8, 24,

<sup>963</sup> See the website of EACH: [www.actionforsickchildren.org/index.asp?ID=186](http://www.actionforsickchildren.org/index.asp?ID=186).

<sup>964</sup> See the EACH website: [www.each-for-sick-children.org/each-charter](http://www.each-for-sick-children.org/each-charter). Last accessed on 25 July 2011.

3-1 and 3-3, 5, 9-1, 12-1, 16, 17, 18, 19, 23-3 and 23-4, 25, 28, 29-1a and c, 30 and 31.<sup>965</sup>

Despite the fact that the EACH Charter has not been adopted by a formal legislative organ, the specificity of the provisions relevant to children's right to health is helpful in elaborating upon children's right to health as laid down in other international legal documents, especially in the European context. Its direct relevance is justified by the close involvement of medical professionals in its elaboration, giving it practical relevance. Furthermore, the relevance of the EACH Charter has been reconfirmed in the Preamble of the Guidelines of the Committee of Ministers of the Council of Europe on child-friendly health care.<sup>966</sup> The rights enshrined in the EACH Charter are generally divided into three categories:<sup>967</sup>

- Rights to resources and care – good hospital care, food, warmth, safety, parents' loving care;
- Rights to protection from harm – from neglect and abuse, from fear, pain and loneliness, from too many medical interventions or the neglect of being denied necessary treatment;
- Rights to self determination, dignity, respect, integrity, non-interference, the right to make informed personal decisions.

Especially the third category is often criticized by adults, arguing that children would refuse all treatments if they are allowed to decide for themselves. However, such a point of view is heavily prejudicial towards the understanding and capacities of (young) children. Alderson identifies several age-assumptions that have been proven wrong about children undergoing medical care, including 'children under 3 years old do not understand explanations' and 'young children do not mind that their privacy is being disregarded', 'children of 5/6 years are too young to participate in complex medical decisions' and 'adolescents do not want close mothering care'.<sup>968</sup> These examples demonstrate that seeking children's views is essential in interpreting the type of health care they wish to receive and the standard of health they wish to attain. Even when children are not capable of expressing their own views, parents or other representatives may be able to provide additional insights into their particular point of view and medical

<sup>965</sup> Presumably the drafters of the EACH Charter were informed about the drafting process of the Convention on the Rights of the Child, as they did already refer to the contents of this Convention before it was officially adopted.

<sup>966</sup> Guidelines of the Committee of Ministers of the Council of Europe on child-friendly health care, adopted by the Committee of Ministers on 21<sup>st</sup> September 2011 at the 1121<sup>st</sup> meeting of the Ministers' Deputies explicitly refer to the relevance of the EACH Charter in its Preamble.

<sup>967</sup> P. Alderson, 'European Charter of Children's Rights', *Bulletin of Medical Ethics*, October 1993, p. 13–15.

<sup>968</sup> P. Alderson, 'European Charter of Children's Rights', *Bulletin of Medical Ethics*, October 1993, p. 13–15.

situation, which are indispensable to providing the highest attainable standard of health.<sup>969</sup>

In order to allow parents and children to be involved in the medical treatment, medical professionals must be able to clearly explain and motivate the choices made in treating children. This requirement not only involves the question what is the least invasive treatment available, but also the question whether it is really necessary to perform a medical intervention and if so, whether it is really necessary to admit the child to hospital. The right to health of children thus also encompasses the right *not* to be treated. Especially in high-tech hospitals, with highly educated and sometimes intimidating doctors, it is important to give children and their families the opportunity to question and criticize the possible benefits of medical interventions.<sup>970</sup> Evidence has even been found about the paradox that ‘the more professionals believe they have provided a safe haven for children in hospital, the bigger the risk is that questions will be seen as negative and ungrateful, so that their right to make informed choices is threatened.’<sup>971</sup> Also, history has shown that many children have resided much longer than required in medical institutions (far) away from their homes and families.<sup>972</sup> This residential staying disturbs their daily eating, sleeping and relaxing routines more than necessary, hinders the contacts with family and friends and also places an additional burden on family members having to travel for hours a day to see their child.

On the website of the European Association for Children in Hospital additional explanations of the 10 fundamental principles is provided.<sup>973</sup> The central idea of the principles is to reduce the negative psychological impact of medical treatments on children as much as possible. In the first place (article 1), this must be achieved by minimizing the hospitalization of children as much as possible by enabling their parents to take care of their children themselves -if possible at home- by providing them all necessary information, assistance and support and by regularly reviewing the type of care that is provided to the child to prevent unnecessary hospital stays. In the second place (article 2), if hospitalization of the child is absolutely necessary and unavoidable, all efforts must be made to keep the child and its parents together during all possible phases, such as during the night, during treatments and examinations, during periods of coma and immediately after recovery. To achieve this (article 3), parents must be provided with, explicitly invited to and supported by the staff to reside close to their children in free accommodation with – at a minimum – a bed, the availability of a bathroom,

<sup>969</sup> U.N. Doc. CRC/C/GC/7/Rev.1, General Comment 7 on Child rights in early childhood, 20 September 2006, § 27.

<sup>970</sup> P. Alderson, ‘European Charter of Children’s Rights’, *Bulletin of Medical Ethics*, October 1993, pp. 13–15.

<sup>971</sup> B. Mayall, ‘Learning from well children’, in: P. Alderson (ed.), *Children’s decisions in health care and research*, In press, London: Institute of Education. Reproduced in: P. Alderson, ‘European Charter of Children’s Rights’, *Bulletin of Medical Ethics*, October 1993, pp. 13–15.

<sup>972</sup> M. Bonn, ‘The effects of hospitalization on children: a review’, *Curationis* 1994, Jun; 17(2): 20-4.

<sup>973</sup> <http://each-for-sick-children.org/each-charter/charter-and-annotations?showall=1>.

sitting and dining facilities and a storage space for personal belongings.<sup>974</sup> Parents and children must also be provided the opportunity for private and undisturbed communication and association (article 10).

Furthermore, according to EACH Charter, parents may not be charged financially for staying overnight and eating in the hospital, they should be given the opportunity to have paid leave from work during the illness of their child and they should be financially compensated for loss of income due to the fulltime care of their child or the supervision over healthy siblings by others. Whereas it remains unclear in the Charter how these targets must be achieved, it may be possible to achieve this through specialized medical legislation for extraordinary medical costs. In the Netherlands, for example, special medical costs for long-term hospitalization and professional support at home are covered by the AWBZ (Algemene Wet Bijzondere Ziektekosten – General Law Special Health Costs). However, this law does not cover all the entitlements found in the EACH Charter. Also, given the current economic crisis and the steadily increasing costs of health care, it seems unlikely to become a priority in the health care policy of the near future.<sup>975</sup> On the other hand, prevention of hospitalization of children would significantly improve children's well-being and be cost-effective in the long-term.<sup>976, 977, 978</sup> An example of reduction of hospital stays in the United States with only half a day was estimated to account for a reduction in costs of \$725 (per half a day).<sup>979</sup> It has been estimated that the average hospital rate in the Netherlands is significantly higher than in other OECD and EU countries and than the United States.<sup>980</sup> Considerable cost reductions should therefore be possible. The reductions

<sup>974</sup> Recent developments in the Netherlands demonstrate that such measures are successful in improving the health care provided to children. To assess the progress made by hospitals in establishing such child-friendly health care units, the foundation Child & Hospital (Kind & Ziekenhuis), member of the European Association on Children in Hospital has established a system of 'smileys' that are granted to hospitals that are qualified as child-friendly. A distinction is made between the requirements of the departments of neonatal care, daycare and the children's department.

<sup>975</sup> See for the Netherlands a notification by the Central Bureau on Statistics on the increasing costs in health care as a percentage of the GDP, 20 May 2010. ([www.cbs.nl/nl-NL/menu/themas/gezondheid-welzijn/publicaties/artikelen/archief/2010/2010-039-pb.htm](http://www.cbs.nl/nl-NL/menu/themas/gezondheid-welzijn/publicaties/artikelen/archief/2010/2010-039-pb.htm).) See for an overview of measures on reducing health care costs: [www.lvg.org/digi/2011/24/euro.htm](http://www.lvg.org/digi/2011/24/euro.htm).

<sup>976</sup> S.C. Schimpff, *The Future of Medicine: Megatrends in Medicine that Will Improve Your Health Care & Your Quality of Life*, Nashville: Thomas Nelson Publishers 2007. Schimpff argues that 'Prevention is the key to both better health and lower healthcare costs over the long haul.'

<sup>977</sup> R. Keren, 'Direct Medical Cost of Influenza-Related Hospitalizations in Children', *Pediatrics* 2006, Volume 118, no. 5, November 1, pp. e1321–132.

<sup>978</sup> V. Sazonov Kozevar, 'Variations in Pediatric Asthma Hospitalization Rates and Costs Between and Within Nordic Countries', *Chest* 2004, 125, pp. 1680–1684.

<sup>979</sup> M. Raut (et al.), 'Estimating the economic impact of a half-day reduction in length of hospital stay among patients with community-acquired pneumonia in the US', *Current Medical Research and Opinion* 2009, 25 (9), p. 2151–2157, Available at: [www.ncbi.nlm.nih.gov/pubmed/19601711](http://www.ncbi.nlm.nih.gov/pubmed/19601711).

<sup>980</sup> I. Borghmans (et al.), 'Benchmarking and reducing length of stay in Dutch hospitals', *BMC Health Services Research* 2008, Volume 8, p. 220. Available at: [www.biomedcentral.com/1472-6963/8/220/](http://www.biomedcentral.com/1472-6963/8/220/).

possible are dependent on the type of disease and the actual benchmark of length of hospital stay, which varies considerably.

When hospitalization of the child can not be prevented, all efforts must be made to ensure that the environment in which children reside is child-friendly. This means that enough possibilities must exist for play, recreation and education suited for the different age groups, developmental stages, gender and possible medical limitations. This applies to the decoration and furnishing in all areas where children reside and are treated, for the time available and the staff supporting the children (article 7). Also, children must be cared for along with children with similar developmental and medical needs (article 6.1) and no age restrictions must be put in place to receive friends, siblings or other visitors (article 6.2).

Within the category of protection of children against (medical) harm and in order to reduce the invasiveness of medical treatments, children must be protected against unnecessary treatments (article 5.2), for example when no beneficial effects can be expected. Furthermore, steps must be taken to mitigate physical and emotional stress (article 4.2) by granting sufficient periods of rest between treatments, by avoiding isolation and the use of restraints, by providing psychological support to children and their parents, by supporting parents whose children are receiving palliative care (article 4.2) and by deploying staff (article 8) that is well-trained and sensitive to respond to the physical, emotional and developmental needs of children and families. In all medical interventions, specifically trained staff must be involved and there must be continuity in the staff caring for the child (article 9). This requires good team work and communication by a limited number of professionals, extending to those caring for the child when it returns home.

To allow children and their parents to be genuinely involved in their medical treatment, good communication with both parents and their children is essential, meaning that all information must be continuously and openly shared in a confidential atmosphere and without time pressure, to enable parents to care for their children (article 3.3), to make informed medical decisions extending to their medical situation, possible treatments, side-effects, risks and outcomes and to integrate this knowledge in the existing knowledge (article 5.1) and while respecting the autonomy and privacy of the child also *vis-à-vis* his parents (article 10). The information must be child-friendly and at the same time understandable for the parents, considerate of the cultural and religious backgrounds and both the child and its parents must be encouraged to ask questions and given the opportunity to express their views. This open and well-informed communication and decision-making process requires that medical professionals are given enough time and training for communicating with their patients.



### 5.5.5. RELATION BETWEEN THE EACH CHARTER AND THE GUIDELINES ON CHILD-FRIENDLY HEALTH CARE

Whereas the EACH Charter is referred to in the Guidelines on child-friendly healthcare, both sets of principles codifying children's rights in health care show some overlaps and distinctions. In the first place, it is remarkable that both sets of principles are practically oriented while simultaneously suffering from a considerable degree of inconsistency. The EACH Charter, being much less elaborate than the Guidelines, contains 10 principles that are categorized in a somewhat non-logical and random order. For example, principles 3.3, 4.1, 5.1 and 10 all address issues of communication that could have been better dealt with in comprehension. Similarly, principles 4.2 and 5.2 aim to mitigate emotional and physical stress and prevent unnecessary medical treatments and principles 8 and 9 both refer to the role and training of medical staff. A better structure would have been beneficial to the clarity of the principles. The same is true to an even larger extent for the Guidelines of the EU Committee on child-friendly health care. Several different ways of structuring the basic principles are elaborated in the '5-4-3-2-1' structure,<sup>981</sup> as appears from Annex II to the Guidelines. However, this ordering does not appear very clearly from the Guidelines themselves and seems to be somewhat artificial. Furthermore, the Explanatory Memorandum to the Guidelines does not follow the order in which the Guidelines are structured: the three pathways and the elaboration of the 5 P-principles are reversed, further complicating the already limited transparency of the prioritization of the different ordering structures. Furthermore, whereas 4 P-principles are divided in 3 different categories, P-revision is organized in 3 × 3 different categories, without clearly explaining this difference and the relation to the 3 pathways and the 4 stages therein. It can be deduced by carefully considering the pictograms in the Explanatory Memorandum, but many questions (e.g. how do primary, secondary and tertiary prevention relate to the transitional pathway? How do the stages of prevention, identification, assessment and intervention relate to protective or promotional activities?) remain unclear. Notwithstanding the importance of the issues addressed, better streamlining of the different values and structuring systems would have definitely benefited the transparency of the Guidelines and thereby also the practical applicability.

A difference between the two sets of principles lays in the scope. Whereas the Guidelines are enormously broad,<sup>982</sup> covering not only medical, but also socio-economic, schooling and housing aspects of children's right to child-friendly health care, the EACH Charter is more particularly focused on ensuring children's rights in the strict medical domain. The main focus of the EACH Charter is

<sup>981</sup> See supra § 5.2.3 and figure 2.

<sup>982</sup> See supra § 5.2.3 for a further discussion of all parties and organizations involved.

thereby oriented towards prevention of harm resulting from medical treatments and possible hospital stays during those treatments, whereas the Guidelines also cover preventive, promotional and provisional aspects of health care policy. Both sets of principles emphasize the importance of providing information on and ensuring participation of children in medical treatment, but these concepts are elaborated more extensively in the Guidelines.

Last but not least, the documents have a different focus *vis-à-vis* the children that are primarily targeted. In line with the broad, both medically and society-oriented approach of the Guidelines, the focus distinguishes children as a general group, sick children and vulnerable groups of children, whereas the EACH Charter focuses only on sick children.<sup>983</sup>

The additional value of the EACH Charter for the Guidelines on child-friendly health care is that the annotations are particularly concrete, making the 10 basic principles practically applicable and demonstrating a thorough insight in the daily reality of children's lives in medical care. This can be of additional value to interpreting and implementing the Guidelines on service and individual levels.

## 5.6. CONCLUSION

### 5.6.1. THE MARGIN OF APPRECIATION ON CHILDREN'S RIGHT TO HEALTH IN EUROPE

Two distinct concepts are discerned in determining the margin of discretion of European States in implementing the right to health of the child. Within the European Union, the CFREU provides that access to preventive health care and medical treatments must be established under the conditions established by national laws and practices. Member States thus have the room to define the health measures that they deem appropriate in their national legislation. On the basis of article 168 TFEU, Member States retain their primary responsibility for defining their health policy and for the organization and delivery of medical services. Both the management and the allocation of resources fall under the responsibility of the Member States. However, 168 TFEU instigates that both the Union actions and the activities of individual member States in cross-border areas complement national policies. In that way, European countries can support each other to raise their health standards.

Under the European Social Charter States have the duty to ensure 'the best possible state of health for the population according to existing knowledge'. In addition to measures established by national law, existing knowledge is

<sup>983</sup> See supra § 5.2.3 for the division of targeted children: general measures targeted towards all children in society, special measures for vulnerable children and special measures for children in medical care.

determinative for establishing the ‘best possible state of health’. This phrasing gives room for more flexible interpretation of existing legal provisions, since medical knowledge is in constant motion.

Several areas of particular concern to the European region are identified, including sexual and reproductive health, maternal and child healthcare, obesity, diabetes II, teenagers in distress, mental health problems (ADHD), alcohol, drug and tobacco abuse and children in their early childhood (0–8). The margin of discretion enables countries to prioritize health measures on the basis of the specific health indicators in the country. This practice is in line with the requirement as established by the UN Committee on the Rights of the Child that national health policies must be based on disaggregated health data. In addition, the priorities mentioned in the following paragraphs derive from European human rights law.

#### 5.6.2. FOCUS ON PREVENTION OF HEALTH PROBLEMS

Both from the perspective of the EU and from the Council of Europe, a clear focus is visible on the need to prevent health problems from the very beginning: before conception, during pregnancy, birth and in the earliest years of life going on in school years and through adolescence. Measures must be directed both at individual and public health (art. 35 CFREU) so that a high level of human health protection is achieved. Preventive measures include the following (art. 168 TFEU):

- Promote research into the causes of disease;
- Prevent transmission of disease;
- Provide health information and education;
- Ensure monitoring and early warning;
- Combat serious cross-border threats;
- Ensure non-discriminatory access to health services. The EU strategy specifies measures to ensure that all children receive birth certificates:
  1. Birth registration must be free of charge;
  2. Civil servants must be well-trained;
  3. Permanent and if necessary mobile birth registration units must be available;
  4. Sufficient resources must be allocated.

Article 24 of the Charter of the Fundamental Freedoms specifically focuses on the need to prevent health problems in children. Immunizations, healthy lifestyles, prevention of injuries and prevention of violence against children are all crucial components of the comprehensive approach to reach the highest attainable standard of health of the child.

### 5.6.3. CHILD-CENTRED HEALTH CARE

The Guidelines on child friendly healthcare of the Council of Europe establish that health care must be centred around the rights, needs and characteristics of children. The identification of these elements requires taking into account their own opinion as well as the role and influence of their parents/family.

Both the Guidelines on child friendly healthcare and the WHO strategy establish that child-centred healthcare requires a coordinated, integrated, comprehensive and continuous approach. The Guidelines speak of child friendly healthcare and the WHO of people-centred health care. The Guidelines specify that such an approach should address:

- The changing epidemiology of childhood.
- Resources and rising costs of health care.
- Variations in the quality of care.
- Multidisciplinary cooperation.
- Continuity of care between primary, secondary and tertiary health services *or* continuity of care in the initial, cyclical and transitional pathway. The WHO strategy for Europe offers additional insight into the concept of continuity by elaborating that continuity of care consists of four elements:
  - i. Follow-up between subsequent visits (life course approach).
  - ii. Informational continuity.
  - iii. Longitudinal continuity.
  - iv. Interpersonal continuity: the WHO suggests that preventive, curative, rehabilitative and palliative care should be provided as much as possible by one provider, so that transparency and personal attention are maximized.

### 5.6.4. FAMILY FRIENDLY HEALTH CARE

Creating a healthy family environment in which children can grow up safely is crucial to ensuring both the health of children and the health of adults in the future. Therefore, many of the identified interventions can and should be taken at the level of the family (art. 8, 13, 16, 17, 19 ESC and the Guidelines on Child Friendly Healthcare). The Guidelines not only speak about child-friendly but also about family-friendly health care. These Guidelines establish that healthcare must be designed around children and their families. The idea is that when health services work through families, this creates continuity of experience for the child. Three central aims are specified:

- Facilitate bonding between new-borns and their parents.
- Facilitate bonding between children and their family members.
- Prevent separation of children from their parents.

Although this child and family-centred approach can have many benefits for realizing the right to health of the child, caution must be taken not to submerge the interests of the child in the broader set of family-oriented rights and interests.

#### 5.6.5. EMPOWERMENT

The Council of Europe and the WHO emphasize that health measures must be taken to enable children to reach their full potential for health and development and reduce the burden of disease and mortality. Hereto, individuals must be stimulated to take responsibility over their own health.

The central role of children in managing their own health status is expressly highlighted in several instances. Children's ability for self-management and their participation in decisions affecting them, taking into account their age and maturity, as well as the active involvement of the parents and family' must be stimulated. In order to increase this ability of children to ensure their own health, continuous health education of children through incorporation of health education in school curricula, parents, teachers and training of health professionals' is required (ESC Conclusions). To ensure that children have access to regular medical check-ups, the ESC provides that medical services must exist at schools so that children can receive periodical examinations. Furthermore, health professionals' and patients' organizations must be involved in the empowerment of children and parents in the health care field.

The importance of approaching children as individual holders of human rights is central in the Guidelines on Child-Friendly Healthcare of the Council of Europe. Children need to grow up and develop according to their capacities and receive acknowledgement for that. In the design of the health care process, both in individual health decisions and in an abstract sense, children and their families must be directly consulted. Hereto, more research into the interaction between the realization of children's rights in health care and the visions of children upon these rights is necessary. The underlying principle of satisfaction in the Guidelines on Child-Friendly Health care, offers a basis for grounding such research, because satisfaction necessarily requires taking into account the views and experiences of children themselves. In such a way, interventions aimed at realizing the highest attainable standard of health will not only be more effective, but they give children and their families the opportunity to raise the highest attainable standard of health to a level that they value and personally contribute to.

#### 5.6.6. DISCUSSION

The body of law in the children's rights domain and in international health and human rights law takes very basic health measures as a starting point, including the provision of basic health services. This chapter illustrates that the legal frameworks in the European region focus more on the way in which the different levels of health services are organized. Also, many are more oriented towards specific subthemes, so-called welfare diseases, which are relevant in the European region, including obesity, mental health problems and alcohol and drug abuse.

More in-depth analyses can be made for other regions, such as the Americas, Africa, the Middle-East and Asia. The next chapter will take a closer look at the interaction between the legal provision on the right to health of the child and the role of the different actors involved in its implementation. Investigated is how this interaction influences the way in which the right to health of the child is interpreted in different communities.