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## Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example\* \*\*

The present study discusses the intersection between malnutrition, childhood diseases and human rights, taking children affected by noma as an example. It reiterates the importance of socio-economic conditions in which children are born, grow up and live in influencing their opportunity to be healthy. Malnutrition is the key risk factor of noma, a disease that devours the face of children and is fatal in up to 90 per cent of cases if basic, cost-effective treatment is not administered early on.

The study recommends that the fight against poverty and malnutrition is reinforced and pursued in accordance with human rights principles; that noma is addressed at global level and the efforts to prevent and treat it in Africa are strengthened; and that it is formally listed by the World Health Organization as a neglected disease in an attempt to raise awareness. The annex contains the human rights principles and guidelines to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by noma.

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\* The annex to the present report is circulated as received, in the language of submission only.

\*\* Late submission.

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## I. Introduction

1. The Human Rights Council requested the Advisory Committee in resolution 16/27 of 25 March 2011 to undertake a comprehensive study on the relationship between severe malnutrition and childhood diseases, taking children affected by noma as an example, and on ways to improve the protection of malnourished children. The mandate followed up the Committee's study on discrimination in the context of the right to food (A/HRC/16/40), which identified children with noma as victims of de facto discrimination in relation to the right to food.

2. The drafting group on the right to food, consisting of José Bengoa Cabello, Chinsung Chung, Latif Hüseyinov, Jean Ziegler and Mona Zulficar<sup>1</sup> prepared a preliminary study on severe malnutrition and childhood diseases with children affected by noma as an example (A/HRC/AC/7/CRP.2). At its seventh session, the Committee welcomed the preliminary study and invited the Office of the United Nations High Commissioner for Human Rights to collect the views and comments on the study of all Member States, relevant United Nations special agencies and programmes and other relevant stakeholders.

3. The present study on severe malnutrition and childhood diseases with children affected by noma as an example is the outcome of research and consultations among members of the Advisory Committee and relevant stakeholders, and draws upon previous work of the Committee (A/HRC/16/40 and A/HRC/AC/3/CRP.3). The study benefited from the support, views and comments by Member States, the World Health Organization (WHO), non-governmental organizations and experts in the field of malnutrition and noma.<sup>2</sup> The study was considered and endorsed by the Committee at its eighth session, for submission to the Human Rights Council at its nineteenth session.

4. The first part of the study focuses on the intersection between severe malnutrition, childhood disease and human rights. The second part elaborates on the situation of children at risk of or affected by noma. The annex contains human rights principles and guidelines to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by noma.

## II. Severe malnutrition, childhood diseases and human rights

5. The intersection between severe malnutrition, childhood diseases and human rights deserves greater attention for a number of reasons. First, the timeliness of the mandate entrusted by the Council to the Committee should be seen against statistics that show that malnutrition in children remains strikingly high.<sup>3</sup> The food crises of recent years,

<sup>1</sup> The drafting group on the right to food would like to thank Ioana Cismas from the Geneva Academy of International Humanitarian Law and Human Rights for her important contribution during the drafting of the present study.

<sup>2</sup> The drafting group would like to thank all the stakeholders that provided input on various drafts, including Algeria, Burkina Faso, Canada, Cuba, Ghana, Switzerland, the World Health Organization, CARE International, Dutch Noma Foundation, Ecumenical Advocacy Alliance, Facing Africa, Geneva Study Group on Noma, Hilfsaktion Noma, Label Vert, Medico International, Noma-Hilf-Schweiz, Médecins sans Frontières, Sentinelles, Winds of Hope Foundation, Ruth Dreifuss, Cyril O. Enwonwu, Siv O'Neill and Theophile Mbuguye. Written statements and comments are contained in the files of the Secretariat and Jean Ziegler.

<sup>3</sup> M. de Onis, M. Blössner, E. Borghi, "Prevalence and trends of stunting among pre-school children, 1990-2020", *Public Health Nutrition*, 2011, 1-7; WHO, "WHO, nutrition experts take action on

characterized by skyrocketing prices for basic foodstuffs,<sup>4</sup> and the recent famine in the Horn of Africa<sup>5</sup> add to the urgency of understanding the linkages between severe malnutrition and childhood diseases from a human rights perspective.

6. Second, the host of human rights which are at stake in the context of severe malnutrition and childhood diseases need to be identified in order for the international community to address in a comprehensive reply the symptoms and root causes of the problem. It is imperative, as the Committee on Economic, Social and Cultural Rights and United Nations Special Rapporteurs have emphasized, to pay particular attention to the most vulnerable individuals and groups and their access to food that should satisfy their dietary needs.<sup>6</sup> Surely, children affected by malnutrition are such a vulnerable group, while children affected by or at risk of noma are among the most vulnerable. A human rights analysis of severe malnutrition and childhood diseases, including noma, helps us understand that the rights of children and other individuals – as opposed to privileges which can be given and taken – and obligations of States and international organizations under international law – as opposed to voluntary commitments – are centre stage.

## A. Malnutrition and childhood diseases: vulnerable groups and their human rights

7. According to WHO, malnutrition essentially means “bad nourishment” and can refer to the quantity as well as the quality of food eaten.<sup>7</sup> In medical terms, malnutrition is explained as a state of nutrition in which inadequate intake of calories, proteins, nutrients – including vitamins – causes adverse effects on tissue and/or body functions.<sup>8</sup> It includes both undernutrition and overnutrition.<sup>9</sup> While the latter has also become a concern in recent years for developing countries,<sup>10</sup> the current report will focus on the undernutrition aspect of malnutrition in children. As such, malnutrition in children is the consequence of a range

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malnutrition”, 16 March 2011. Available from [www.who.int/nutrition/pressnote\\_action\\_on\\_malnutrition/en/index.html](http://www.who.int/nutrition/pressnote_action_on_malnutrition/en/index.html).

<sup>4</sup> WHO, “The Global Food Crisis: Implications for the Health of People in the African Region”, 2008; Food and Agricultural Organization (FAO), *The State of Food Insecurity in the World 2008: High Food Prices and Food Security – Threats and Opportunities* (Rome, 2008); United Nations Children’s Fund (UNICEF), *A Matter of Magnitude: The Impact of the Economic Crisis on Women and Children in South Asia* (June 2009); FAO, *The State of Food Insecurity in the World 2010: Addressing food insecurities in protracted crises* (Rome, 2010).

<sup>5</sup> Kun Li, “Amidst regional drought, malnutrition imperils thousands of refugee children in Dadaab, Kenya”, UNICEF, 15 July 2011, available from [www.unicef.org/infobycountry/kenya\\_59238.html](http://www.unicef.org/infobycountry/kenya_59238.html); AlertNet, “MSF acts on malnutrition and drought in Horn of Africa”, 11 July 2011, <http://www.trust.org/alertnet/news/msf-acts-on-malnutrition-and-drought-in-horn-of-africa/>.

<sup>6</sup> Committee on Economic, Social and Cultural Rights, general comment No. 12 on the right to adequate food; reports of the Special Rapporteurs on the right to food, A/HRC/9/23, A/HRC/4/30 and A/62/289.

<sup>7</sup> WHO, “Malnutrition”. Available from [www.who.int/water\\_sanitation\\_health/diseases/malnutrition/en/](http://www.who.int/water_sanitation_health/diseases/malnutrition/en/).

<sup>8</sup> Ed. M. J. Gibney et al., *Clinical Nutrition*, Nutrition Society Textbook Series (Wiley-Blackwell, 2005), pp. 1–2.

<sup>9</sup> See M. de Onis, M. Blössner, E. Borghi, “Global prevalence and trends of overweight and obesity among preschool children”, *American Journal of Clinical Nutrition*, vol. 92, No. 5, 2010, pp. 1257–64.

<sup>10</sup> FAO, *The double burden of malnutrition. Case studies from six developing countries*, FAO Food and Nutrition Paper 84 (Rome, 2006).

of factors that are often related to poor food quality, insufficient food intake, and severe and repeated infectious diseases, or a combination of the above.<sup>11</sup>

8. A classification of malnutrition would include protein-energy malnutrition (deficiency in calories and proteins), as well as micronutrient malnutrition (deficiency in vitamins or minerals).<sup>12</sup> Malnutrition can take mild, moderate or severe forms; it can be chronic or acute.

9. A key indicator of chronic malnutrition is stunting, which is defined as height for age below minus two standard deviations from the median height for age of the standard reference population.<sup>13</sup> In other words, children affected are too short for their age group compared to the WHO Child Growth Standards. In 2010, approximately 171 million children globally were stunted, resulting from not enough food, a diet poor in vitamins and minerals, inadequate child care and disease. In south-central Asia 36 per cent of children were affected by stunting as of 2010;<sup>14</sup> in Africa stunting has stagnated since 1990 at about 40 per cent.<sup>15</sup>

10. In addition to the statistics, the consequences of chronic malnutrition on the future of children must be understood: adverse cognitive development, reduced learning ability, poor school performance, school dropout and decreased productivity as an adult.<sup>16</sup> “Once established, stunting and its effects typically become permanent. Stunted children may never regain the height lost and most will never gain the corresponding weight. And when the window of early childhood is closed, the associated cognitive damage is often irreversible”.<sup>17</sup> In other words, stunted children may be unable to reach their full potential in adulthood, a fate for which they are not responsible and which they cannot escape. A range of human rights are infringed upon during the life cycle of an individual who suffered stunting in childhood: the right to an adequate standard of living including the rights to food, health, water and sanitation, often the right to adequate housing, the right to education, the right to work, non-discrimination and ultimately the right to life. Indeed, the high number of stunted children today cast a shadow over the progress on other Millennium Development Goals (MDGs), such as child health and education. It is legitimate to observe that: “new schools and hospitals are crucial, but how much of a difference can they make if the infants arriving for their lessons and check-ups have already been consigned to debilitating physical and mental limitations by early life nutritional deficiencies?”<sup>18</sup> Yet again the importance of a human rights framework for the MDGs which would stress the interdependence of human rights and move the debate from the arena of voluntarily commitment to that of States’ obligations under human rights law is underscored. In addition, chronic malnutrition puts into question the future of economic development of

<sup>11</sup> M. de Onis and M. Blössner, *WHO Global Database on Child Growth and Malnutrition* (Geneva, WHO, 1997), p. 3.

<sup>12</sup> Vitamin A deficiency, iron deficiency anaemia and iodine deficiency disorders are the most common forms of micronutrient malnutrition.

<sup>13</sup> See UNICEF, *Tracking Progress on Maternal and Child Nutrition. A Survival and Development Priority* (New York, November 2009), p. 4.

<sup>14</sup> WHO, “10 facts on nutrition”, March 2011. Available from [www.who.int/features/factfiles/nutrition/en/index.html](http://www.who.int/features/factfiles/nutrition/en/index.html) and De Onis et al., “Prevalence and trends of stunting”.

<sup>15</sup> De Onis et al., “Prevalence and trends of stunting”.

<sup>16</sup> UNICEF, *The Progress of Nations 2000* (New York, 2000), p. 14; B.T. Crookston et al., “Children who recover from early stunting and children who are not stunted demonstrate similar levels of cognition”, *Journal of Nutrition*, vol. 140, No. 11, 2010, pp. 1996–2001.

<sup>17</sup> Ibid; see also UNICEF, *Progress for Children. Achieving the MDGs with Equity*, No. 9 (New York, September 2010), p. 16.

<sup>18</sup> N. Jacobs, “Development goals: celebrating on an empty stomach”, *EUObserver*, 8 July 2011.

those countries that have high rates of stunting in children who, without early intervention, may be unable to reach their full potential as productive members of society.

11. At the global level, 20 million children are estimated to be severely wasted<sup>19</sup> and thus suffer from severe acute malnutrition.<sup>20</sup> The (preventable) tragic thing about these children has been described by Nicholas Kristof as their equanimity: “They don’t smile. They don’t move. They don’t show a flicker of fear, pain or interest. Tiny, wizened zombies, they shut down all nonessential operations to employ every last calorie to stay alive”.<sup>21</sup> The human dignity of these children is being compromised and ultimately their right to life, since about 1 million children die every year from severe acute malnutrition.<sup>22</sup>

12. As is evident from the above, malnutrition in itself is a serious medical condition that affects children. In addition, there is a two-way relationship between malnutrition and childhood diseases. As medical studies show:

“Infection adversely affects nutritional status through reductions in dietary intake and intestinal absorption, increased catabolism and sequestration of nutrients that are required for tissue synthesis and growth. On the other hand, malnutrition can predispose to infection because of its negative impact on the barrier protection afforded by the skin and mucous membranes and by inducing alterations in host immune function.”<sup>23</sup>

13. Thus, children become severely malnourished because of acute paediatric diseases, such as pneumonia, diarrhoea, malaria and measles, which are not treated or are inadequately treated owing to poor access to health care in terms of both timing and quality.<sup>24</sup> Often a deadly circle ensues. For example, in recent decades, applied research has confirmed the deleterious effect of diarrhoeal illness on the nutritional status of children.<sup>25</sup> Diarrhoea seriously exacerbates malnutrition in children, while at the same malnourished children are more vulnerable to acute diarrhoea and suffer multiple episodes every year.<sup>26</sup> It is important to note in this context that diarrhoea is the second leading cause of death among children under 5 at the global level, killing about 1.5 million each year.<sup>27</sup>

14. Equally, chronic diseases in children, such as HIV, cancer, tuberculosis and sickle-cell anaemia, that are not treated or are inadequately treated may be a reason for severe malnutrition in children.<sup>28</sup> In the context of HIV/AIDS, WHO flags the need for a massive effort “to alleviate the overall burden of malnutrition and to reduce the severity and

<sup>19</sup> For definition, see UNICEF, *Tracking Progress on Maternal and Child Nutrition*, p. 4.

<sup>20</sup> “Community-Based Management of Severe Acute Malnutrition”, A Joint Statement by the World Health Organization, the World Food Programme, the United Nations System Standing Committee on Nutrition and the United Nations Children’s Fund, May 2007, p. 2.

<sup>21</sup> N. D. Kristof, “The Hidden Hunger”, *The New York Times*, 23 May 2009, Available from [www.nytimes.com/2009/05/24/opinion/24kristof.html](http://www.nytimes.com/2009/05/24/opinion/24kristof.html).

<sup>22</sup> “Community-Based Management of Severe Acute Malnutrition”.

<sup>23</sup> K.H. Brown, “Diarrhea and Malnutrition”, *Journal of Nutrition*, vol. 133, No. 1, Supplement (2003), pp. 328–332; N.S. Scrimshaw, C.E. Taylor and A.J.E. Gordon, “Interactions of Nutrition and Infection”, WHO Monograph Series No. 57 (Geneva, 1968).

<sup>24</sup> Communication with Dr. M-C. Bottineau, MSF Paediatrics Working Group Acting Team Leader, 29 June 2011.

<sup>25</sup> Brown, “Diarrhea and Malnutrition”.

<sup>26</sup> UNICEF and WHO, *Diarrhoea: Why children are still dying and what can be done* (2009), pp. V and 1.

<sup>27</sup> *Ibid.*, p. 1.

<sup>28</sup> Communication with Dr. M-C. Bottineau.

complexity of the impact that HIV/AIDS and malnutrition have on each other”.<sup>29</sup> A typical example of this complex relationship between HIV/AIDS and malnutrition is the need to balance the risk of infants acquiring HIV through breast milk with the higher risk among non-breastfed infants, in particular from the developing world, of dying from malnutrition and diarrhoea.<sup>30</sup>

15. Another facet of the relationship between severe malnutrition and childhood diseases is the medical complications ensuing from specific aspects or pathogens occurring in malnourished children. Malnutrition compromises the immune system, which acts as a trigger for severe diseases with unclear aetiology and wounds in kwashiorkor.<sup>31</sup> Examples of such diseases include Lyell’s syndrome in severely malnourished children, non-infectious wounds in children with severe malnutrition, myelodysplastic syndromes and noma. The second part of this study will focus extensively on noma.

16. Infants and young children are the most vulnerable to malnutrition because of their high nutritional requirements for growth and cognitive development and their often vulnerable place in society.<sup>32</sup> Malnutrition as a stand-alone condition and in relation to other childhood diseases – be they chronic, acute or severe complications – contributes significantly to the premature death of children. In fact, malnutrition is thought to contribute to one third of the 8 million deaths of children under 5 every year.<sup>33</sup>

17. It is widely acknowledged that the socioeconomic conditions into which children are born and in which they grow up and live influence their opportunity to be healthy: the lower an individual’s socioeconomic position, the higher their risk of poor health; which applies from country to country, as well as within countries.<sup>34</sup> Poverty is a complex human condition characterized by “sustained or chronic deprivation of the resources, capabilities, choices, security and power necessary for the enjoyment of an adequate standard of living and other civil, economic, cultural, political and social rights” (statement by the Committee on Economic, Social and Cultural Rights, E/C.12/2001/10, para. 8). The Special Rapporteur on extreme poverty and human rights defines the “realities of poverty” as stigmatization, discrimination, penalization, and exclusion (report to the General Assembly, A/66/265, para. 5). In slums and rural areas that have been affected by disinvestment in agriculture in recent decades (see study of the Advisory Committee on discrimination in the context of the right to food, A/HRC/16/40, paras. 18 and 21), poverty and its realities are often responsible for the ignorance of and/or lack of options for parents in respect to food and feeding practices, hygiene and sanitation, healthy child-rearing and child education, and the abyss of child labour and prostitution. The elimination of poverty is an imperative flowing from the human rights obligations of States to realize all human rights for all, while prioritizing the most vulnerable (see chap. II, sect. B.).

<sup>29</sup> WHO, “Nutrition and HIV/AIDS”. Available from [www.who.int/nutrition/topics/hivaids/en/index.html](http://www.who.int/nutrition/topics/hivaids/en/index.html).

<sup>30</sup> See WHO, Joint United Nations Programme on HIV/AIDS (UNAIDS), United Nations Population Fund (UNFPA), UNICEF, *Guidelines on HIV and Infant Feeding 2010. Principles and recommendations for infant feeding in the context of HIV and a summary of evidence* (Geneva, 2010).

<sup>31</sup> Communication with Dr. M-C. Bottineau; MSF, *A Beginner’s Guide to Malnutrition*, [www.msf.or.jp/info/pressreport/pdf/pressMalnutritionE.pdf](http://www.msf.or.jp/info/pressreport/pdf/pressMalnutritionE.pdf).

<sup>32</sup> M. Blössner, M. de Onis, *Malnutrition: quantifying the health impact at national and local levels*, Environmental Burden of Disease Series, No. 12 (Geneva, 2005), p. 3.

<sup>33</sup> See J.K. Rajaratnam et al., “Neonatal, postneonatal, childhood, and under-5 mortality for 187 countries, 1970-2010: a systematic analysis of progress towards Millennium Development Goal 4”, *The Lancet*, vol. 375, No. 9730, 5 June 2010, pp. 1988–2008; R.E. Black, “Global, regional, and national causes of child mortality in 2008: a systematic analysis”, *The Lancet*, vol. 375, No. 9730, 5 June 2010, pp. 1969–1987; [www.starvedforattention.org](http://www.starvedforattention.org).

<sup>34</sup> World Conference on Social Determinants of Health, Rio de Janeiro, 19–21 October 2011.

18. The vulnerability of children is closely connected to the vulnerability of women. Gender plays an important role which cannot be overstated: pregnant women, breastfeeding mothers, girl children are highly vulnerable to malnutrition. A malnourished mother is likely to give birth to a baby of low birthweight susceptible to disease and premature death.<sup>35</sup> It is contended that “malnourished girls, in particular, risk becoming yet another malnourished mother, thus contributing to the intergenerational cycle of malnutrition”.<sup>36</sup> From a human rights perspective, we must question those cultural practices that place limits on women’s access to nutrition and food, clean water and sanitation and education and expose them as forms of gender discrimination.<sup>37</sup> Such discriminatory practices may also be responsible for malnutrition in girl children and later in women, and thus for the propagation of a cycle of malnutrition. Access to nutritious food for a mother and her child is as important as access to information about adequate feeding practices.<sup>38</sup> Even in developed contexts breastfeeding mothers face hurdles, such as societal pressure not to breastfeed in public and the lack of proper facilities that enable breastfeeding at the workplace.<sup>39</sup> At the same time, the lack of paid maternity leave or maternity leave that does not cover the WHO-recommended six months of exclusive breastfeeding often leaves no choice to young mothers but to return to work and to stop/reduce breastfeeding.<sup>40</sup> Furthermore, as the Human Rights Council underlines in its resolution 16/27, non-discriminatory access to resources, including income, land and water and their ownership, and to education, science and technology are vital for women to be able to feed themselves and their families.

19. As the above paragraphs bear witness, the relationship between malnutrition and childhood diseases is one that more often than not rests on poverty; and poverty itself is often traceable to either de jure or de facto discrimination in society and the family itself (see A/HRC/16/40). The strong link between malnutrition and childhood diseases stems from poor access to sufficient or sufficiently nutritious food, adequate and timely health care, safe water and sanitation facilities, education, access to information, decent work and livelihood opportunities, and adequate and sanitary shelter and housing. This lack of access is a saga about the human rights of children and adults that are not being fulfilled. A UNICEF publication from 2000 summarizes:

“The success the world has had in protecting children’s rights and realizing human potential is captured far more eloquently in flesh and bone than in concrete or steel, far more tellingly in the height of children than in that of skyscrapers.”<sup>41</sup>

20. The observation remains valid today against the reality of 195 million malnourished children worldwide susceptible to acute and chronic paediatric diseases and medical complications, such as noma.

<sup>35</sup> Blössner, De Onis, *Malnutrition: quantifying the health impact*, p. 1.

<sup>36</sup> *Ibid.*, p. 3.

<sup>37</sup> A/HRC/16/40, para. 61; report of the OHCHR on preventable maternal mortality and morbidity and human rights, A/HRC/14/39, para. 18; I. Rae, *Women and the Right to Food: International Law and State Practice* (FAO, Rome 2008), pp. 12–14.

<sup>38</sup> B. Teshome et al., “Magnitude and determinants of stunting in children under- five years of age in food surplus region of Ethiopia: The case of West Gojam Zone”, *Ethiopian Journal of Health Development*, vol. 23, No. 2, 2009, pp. 98–106.

<sup>39</sup> *Science Daily*, “Even Part-Time Work Can Have A Negative Effect On Breastfeeding Rates, Says New Study”, 29 April 2008; A.R. Cooklin et al., “Maternal employment and breastfeeding: results from the longitudinal study of Australian children”, *Acta paediatrica*, vol. 97, No. 5, 8 February 2008, pp. 620–623.

<sup>40</sup> *Ibid.*

<sup>41</sup> UNICEF, *The Progress of Nations 2000*, p. 14.



## B. Malnutrition and childhood diseases: binding obligations of States under international law

21. This human rights situation is taking place against the background of an international legislative framework that guarantees the host of rights of children and their mothers that are at stake when malnutrition intersects with childhood disease, notably the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination against Women and the International Covenant on Economic, Social and Cultural Rights.

22. States parties to these international instruments are legally bound to respect, protect and fulfil human rights. In the context of malnutrition, States should ensure, in collaboration with international organizations and civil society, the necessary conditions for parents to be able to adequately feed themselves and their children (Covenant on Economic, Social and Cultural Rights, art. 11, para. 1, and the Committee's, general comment No. 12). Moreover, States have agreed to establish food insecurity and vulnerability maps and to use disaggregated data to identify "any form of discrimination that may manifest itself in greater food insecurity and vulnerability to food insecurity, or in a higher prevalence of malnutrition among specific population groups, or both, with a view to removing and preventing such causes of food insecurity or malnutrition".<sup>42</sup> These tools must be used to rectify the current situation, which has seen "no meaningful improvement" in reducing underweight prevalence among children from poor households as opposed to considerable progress in rich households.<sup>43</sup> Protecting the rights of the most vulnerable is a human rights imperative which flows not least from the general prohibition on discrimination under human rights law and the Charter of the United Nations (A/HRC/16/40, paras 9–11).

23. Of great relevance for the intersection of malnutrition and paediatric diseases is article 24 of the Convention on the Rights of the Child, the most widely ratified human rights instrument. It provides that States shall pursue "full implementation" of the right of the child to the enjoyment of the highest attainable standard of health and shall therefore take appropriate measures to combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and the provision of adequate nutritious foods and clean drinking water. According to the same article, States are "to ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents". Article 12 of the Convention on the Elimination of All Forms of Discrimination against Women requires States parties to ensure to women appropriate services concerning with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and breastfeeding.

24. The 2010 UNICEF report on achieving the MDGs with equity should therefore be read in the key of international legal obligations of States, and not of voluntarily commitments:

"Many countries that have met – or are close to meeting – the MDG 1 target on underweight prevalence must make a serious effort to reduce the prevalence of stunting. A comprehensive approach will address food quality and quantity, water

<sup>42</sup> Voluntary Guidelines to Support the Progressive Realization of the Right to Adequate Food in the Context of National Food Security, guideline 13.

<sup>43</sup> *The Millennium Development Goals Report 2011* (United Nations publication, Sales No. E.11.I.10), p. 14.

and sanitation, health services, and care and feeding practices, as well as key underlying factors such as poverty, inequity and discrimination against women (including low levels of education among girls)”.<sup>44</sup>

25. The International Covenant on Economic, Social and Cultural Rights enshrines the principle of international assistance and cooperation giving rise to extraterritorial obligations for State parties.<sup>45</sup> The legal character of these obligations has been recognized by the International Court of Justice in its advisory opinion on the *Legal Consequences of the Construction of a Wall in the Occupied Palestinian Territory* and the Committee on Economic, Social and Cultural Rights in its general comment No. 3 on the nature of States parties’ obligations (para. 13).<sup>46</sup> Article 11, paragraph 2, of the Covenant is of particular relevance for the current study since it stipulates that State Parties “shall take, individually and through international co-operation, the measures, including specific programmes”, in order for everyone, thus including children, to be free from hunger. A similar stipulation on international cooperation is present in the Convention on the Rights of the Child in relation to the right of the child to health (art. 24, para. 4).

26. Articles 22 and 23 of the Covenant have been considered by the Committee to serve as a framework for the activities of international organizations and United Nations specialized agencies.<sup>47</sup> A renewed commitment has been sought from international organizations to respect economic, social and cultural rights while designing and implementing their policies and programmes and to assist States in fulfilling their human rights obligations.<sup>48</sup>

27. An analysis by Médecins Sans Frontières (MSF) has, however, revealed that the aid dedicated by States, international and regional organizations and private actors to nutrition over the period 2004–2007 has stagnated at 350 million USD, the same level since 2000–2004. Taking a World Bank costing exercise<sup>49</sup> as a starting point, MSF argues that spending dedicated to nutrition must increase considerably and be specifically earmarked if malnutrition is to be overcome.<sup>50</sup> Moreover, MSF argues that the money is not being spent on “the right things” or in the most efficient way.<sup>51</sup> For example, it emphasizes that if the United States of America were to renounce their current practice of in-kind food aid – consisting of shipping food produced in their country to the target country – and to adopt a policy of purchasing food locally, about 600 million USD could be freed up.<sup>52</sup> The importance of acquiring locally produced food inter alia in the context of the fight against

<sup>44</sup> UNICEF, *Progress for Children*, p. 16.

<sup>45</sup> See S.I. Skogly, *Beyond National Borders: States’ Human Rights Obligations in International Cooperation* (Antwerp, Intersentia, 2006); F. Coomans, “The Extraterritorial Scope of the International Covenant on Economic, Social and Cultural Rights in the Work of the United Nations Committee on Economic, Social and Cultural Rights”, *Human Rights Law Review*, vol. 11, No. 1, 29 January 2011, pp. 1–35.

<sup>46</sup> *Advisory Opinion, I.C.J. Reports 2004*, p. 136, paras. 130–134; C. Golay, *The Right to Food and Access to Justice: Examples at the National, Regional and International Levels* (FAO, 2009), pp. 35–36.

<sup>47</sup> F. Coomans, “The Extraterritorial Scope”, p. 18.

<sup>48</sup> Ibid.

<sup>49</sup> See S. Horton et al., *Scaling Up Nutrition: What Will it Cost?* (World Bank, Washington D.C., 2010).

<sup>50</sup> MSF, *Malnutrition: How Much is Being Spent? An Analysis of Nutrition Funding Flows: 2004–2007* (Geneva, 2009). See also *The Lancet*, Maternal and Child Undernutrition Series, January 2008.

<sup>51</sup> Ibid.

<sup>52</sup> Ibid.

malnutrition has been recognized by other donors and agencies, such as the European Union and the World Food Programme.<sup>53</sup>

28. Fighting malnutrition and associated childhood diseases requires accountability and that is precisely what the human rights obligations of States establish. They establish an integrated accountability framework, whereby States with high numbers of malnourished children are accountable for actively removing discrimination patterns (against women, the poor living in the rural areas, etc.; see A/HRC/16/40), promoting participation and inclusiveness of the most vulnerable and, importantly, systematically eradicating corruption and promoting transparency. The human rights framework also requires that the international assistance of wealthier States enables individuals to feed themselves and does not only bring short-term alleviation while stifling the prospects of sustainable agriculture practices.<sup>54</sup> Moreover, coherence – as opposed to fragmentation – of international law should be sought by all States, and trade and investment regimes should thus not be allowed to collude with the human rights system: especially when at stake is the nutritious food so much needed by malnourished children or the antiretroviral medicine for their HIV infected mothers is at stake.

29. In conclusion, as emphasized by the Special Rapporteur on the right to food in his most recent report (A/HRC/19/59), “a transition towards sustainable diets will succeed only by supporting diverse farming systems that ensure that adequate diets are accessible to all, that simultaneously support the livelihoods of poor farmers and that are ecologically sustainable.” Nutrition initiatives should therefore be based upon a human rights approach, defined through accountability, participation and non-discrimination.

### III. Children at risk of or affected by noma

30. The first part of this study has underlined the importance of understanding the intersection of malnutrition, childhood diseases and human rights. Noma is the most brutal face of poverty and malnutrition in children and thus gives rise to some of the worst violations of the rights of the child.

31. Noma (*cancrum oris*), which borrows its name from the Greek term “to devour”, is an infectious yet non-contagious disease that destroys the soft and hard tissue of the face.<sup>55</sup> The lesion is thought to begin as a localized ulceration in the gingiva or the mucosa of the cheek or lip and to spread rapidly through the surrounding tissues. At the same time, there is swelling of the corresponding part of the face. Untreated, the swollen skin will become gangrenous and will perforate, within a week, leaving a hole in the face.<sup>56</sup> Noma is thought to lead to death in 70–90 per cent of cases.<sup>57</sup> Most deaths are attributed to complications such as pneumonia, diarrhoea and septicaemia associated with severe malnutrition.<sup>58</sup>

<sup>53</sup> See Center for Economic and Policy Research, “France Increases Local Rice Procurement for Food Aid; Will the US Follow Suit?”, 18 July 2011; World Food Programme, “WFP Launches Strategy to Bring Social Security and Stability to Haiti”, 30 March 2010; French Embassy in Port-au-Prince, “De la fourche à fourchette (suite)”.

<sup>54</sup> See A/HRC/19/59/Add.5.

<sup>55</sup> C.O. Enwonwu et al., “Noma (*cancrum oris*): Seminar”, *The Lancet*, vol. 386 (2006), p. 147; D. Baratti-Mayer et al., “Noma: an ‘infectious’ disease of unknown aetiology”, *The Lancet Infectious Diseases*, vol. 3, No. 7, July 2003, p. 419.

<sup>56</sup> *Ibid.*; K. Bos, K. Marck, *The Surgical Treatment of Noma* (Alphen aan den Rijn, Belvedere/Medidac, 2006), pp. 13–14.

<sup>57</sup> M. Tschkovski, “A disease such as Noma should not exist”, *Noma Contact*, October 1997, p. 1.

<sup>58</sup> D.E. Barnes et al., “The need for action against oro-facial gangrene (noma)”, *Tropical Medicine and*

32. The clinical data available is unanimous: children are the main victims of this debilitating disease. Acute noma occurs predominantly in malnourished children up to 6 years,<sup>59</sup> while sequelae have been observed in adolescents and adults.<sup>60</sup> Having studied patients with noma in Nigeria, scholars concluded that noma is not observable in children of “elite Nigerians residing in affluent sections of the urban areas” and that “it is rather a socioeconomic disease afflicting preferentially the deprived, malnourished children in the poor, rural communities”.<sup>61</sup> Medical studies concur on the specific population group that is predominantly affected by noma: deprived and severely malnourished young children from communities living in extreme poverty.<sup>62</sup>

#### A. History of noma, incidence and distribution of the disease

33. Known in classical and medieval Europe, noma remained common in Europe and North America until the beginning of the twentieth century.<sup>63</sup> As early as in the eighteenth century, awareness had increased that noma was related to poverty, malnutrition and diseases from which the child suffered previously, such as measles.<sup>64</sup> The economic progress witnessed by European and North American societies is credited with having allowed them to feed their children sufficiently and hence to practically eradicate noma.<sup>65</sup> Cases of noma reappeared in the Nazi concentration camps of Bergen-Belsen and Auschwitz<sup>66</sup> and in some other European countries subjected to extreme food shortages during the Second World War.<sup>67</sup> More recently, the disease has been documented in patients with HIV or AIDS from developed States, suffering of malnutrition, bad oral hygiene and immunosuppression.<sup>68</sup>

34. Low- and middle-income countries, particularly in Africa and Asia, are considered to be the most affected by noma.<sup>69</sup> Experts, including from non-governmental organizations (NGOs), working in the field describe the area that stretches across parts of West Africa and Central Africa towards Sudan as the “noma belt”.<sup>70</sup> It is assumed that a large number of

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*International Health*, vol. 2, No. 12, 1997, p. 1113.

<sup>59</sup> Ibid; Tsechkovski, “A disease such as Noma should not exist”, p. 1; P.A. Van Damme, “Essay: noma” *The Lancet*, vol. 368, December 2006, pp. S61–62.

<sup>60</sup> Facing Africa, “What is noma?”. Available from [www.facingafrica.org/FA08/content/site/en/pages/whatisnoma/default.asp](http://www.facingafrica.org/FA08/content/site/en/pages/whatisnoma/default.asp).

<sup>61</sup> R. S. Phillips, C. O. Enwonwu, W. A. Falkler, “Pro- *versus* anti-inflammatory cytokine profile in African children with acute oro-facial noma (*cancrum oris*, noma)”, *European Cytokine Network*, vol. 16, No. 1, March 2005, p. 70.

<sup>62</sup> C.O. Enwonwu, “Noma – The Ulcer of Extreme Poverty”, *The New England Journal of Medicine*, vol. 354, No. 3, January 2006, pp. 221–224; M.L. Srour et al., “Noma in Laos: Stigma of Severe Poverty in Rural Asia”, *American Journal of Tropical Medicine and Hygiene*, vol. 78, No. 4, April 2008 p. 539.

<sup>63</sup> K. Marck, “A History of Noma, the “Face of Poverty”, *Plastic and Reconstructive Surgery*, vol. 111, No. 5, April 2003, pp. 1702–1707.

<sup>64</sup> Ibid.

<sup>65</sup> R. Voorhoeve, “Review”, *Bulletin of the Netherlands Society of Tropical Medicine and International Health*, vol. 49, No. 1, February 2008, p. 13; Enwonwu, “Noma – The Ulcer”, p. 222.

<sup>66</sup> Enwonwu, “Noma (*cancrum oris*)”, p. 148.

<sup>67</sup> Bos, *Surgical Treatment*, p. 11.

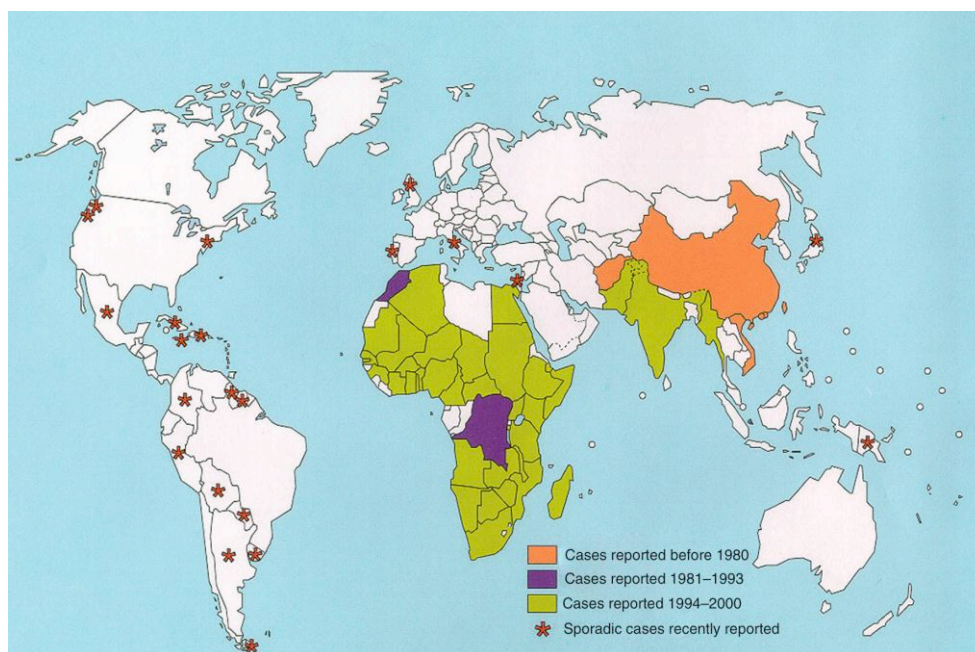
<sup>68</sup> Enwonwu, “Noma (*cancrum oris*)”, p. 148; A. G. Buchanan et al., “Necrotizing stomatitis in the developed world”, *Clinical and Experimental Dermatology*, vol. 31, 2006, p. 372.

<sup>69</sup> P.E. Petersen, “World Health Organization Global Policy for Improvement of Oral Health – World Health Assembly 2007”, *International Dental Journal*, vol. 58, 2008, p. 117.

<sup>70</sup> Consultative Meeting on Management of the Noma Programme in the African region, Harare, 19-21 April 2001, Final Report; Facing Africa, “What is noma?”.

individuals affected by noma live in the sub-Saharan countries of Chad, Ethiopia, Mali, Mauritania, Niger, Nigeria, Senegal and Sudan.<sup>71</sup> Cases are reported from other countries in Africa, Asia and Latin America,<sup>72</sup> as figure 1 shows. A medical paper on noma in the Lao People's Democratic Republic concludes that "it is likely that it is much more frequent in remote Asian rural communities than is currently appreciated".<sup>73</sup>

Figure 1  
Global distribution of noma<sup>74</sup>



35. According to estimates released by WHO in 1998, 140,000 individuals contract noma on a yearly basis;<sup>75</sup> 100,000 of these are children.<sup>76</sup> The survival rate is between 10 and 20 per cent, which means that at least 110,000 people, the vast majority of which are children, die every year because of noma.<sup>77</sup> According to the WHO *World Health Report 1998*, 770,000 persons survived the disease with heavy sequelae.<sup>78</sup>

36. In 2003 data on the incidence of noma have been calculated based on information from patients which have been admitted with the disease in two hospitals in Sokoto, Nigeria.<sup>79</sup> By extrapolating the incidence from north-western Nigeria to the countries bordering the Sahara Desert, the research showed an annual incidence of 25,600 cases for

<sup>71</sup> Bos, *Surgical Treatment*, p. 12; Enwonwu, "Noma (cancerum oris)", p. 148.

<sup>72</sup> Bos, *Surgical Treatment*, p. 12.

<sup>73</sup> Srour, "Noma in Laos", p. 540.

<sup>74</sup> From P.E. Petersen, "Oral Health", in K. Heggenhougen and S. Quah (ed.), *International Encyclopedia of Public Health*, vol. 4, (San Diego, Academic Press, 2008), p.684.

<sup>75</sup> WHO, *The World Health Report 1998 - Life in the 21st Century: A Vision for all* (Geneva, 1998), p. 45.

<sup>76</sup> B. Neville et al., *Oral and Maxillofacial Pathology*, 3rd ed., (Elsevier Health Sciences, 2008), p. 201.

<sup>77</sup> WHO, *World Health Report 1998*, p. 45; P.E. Petersen, *The World Oral Health Report 2003: Continuous Improvement of Oral Health in the 21st Century – the Approach of the WHO Global Oral Health Programme* (Geneva: WHO, 2003), pp.7- 8.

<sup>78</sup> Also A. Fieger et al., "An Estimation of the Incidence of Noma in North-West Nigeria", *Tropical Medicine and International Health*, vol. 8, No. 5, May 2003, p. 402.

<sup>79</sup> *Ibid.*, p. 403.

that region and a global incidence per year of 30,000–40,000.<sup>80</sup> Experts consider this data to be rather conservative, given that less than 10 per cent of the individuals suffering from noma seek medical care.<sup>81</sup> In the evocative words of Dr. Enwonwu, a leading expert on noma, these cases represent merely “the tip of the iceberg”.<sup>82</sup>

37. This need for recent data is more pressing in the context of the recent food and economic crises. The effect of the latter on the incidence of noma is believed to be important given that, as a consequence of the crises, the number of individuals, including children, suffering of hunger and malnutrition has skyrocketed.<sup>83</sup> Previous medical studies have pointed to the link between economic crisis, shortages in food and the incidence of noma. Some specifically identify the declining food supplies in the 1980s in sub-Saharan Africa and the subsequent severe chronic malnutrition as one of the explaining factors of the reported increase of noma.<sup>84</sup> The effects of the food crisis in Niger in 2005 were registered by the NGO Sentinelles three years later when the number of small children with noma doubled. This increase in noma cases is probably explainable by the fact that malnourished babies were born to malnourished mothers, the latter victims of the 2005 food crisis.<sup>85</sup> The importance of accurate and up-to-date information on noma cannot be understated.

38. On an institutional level, attempts to focus on noma have been discouraged by the lack of recent data.<sup>86</sup> In turn, the lack of focus on noma is precisely what determines the low interest in gathering information on the incidence and distribution of acute noma worldwide. This vicious circle leads to the situation that the majority of children and other individuals with noma are not receiving treatment and are thus neglected.

## B. Causes, predisposing factors and treatment of noma

39. Researchers have not identified a specific micro-organism responsible for causing noma.<sup>87</sup> Despite the lack of certainty in respect to the microbiology and pathophysiology, there is a wide consensus among experts that noma results from the interaction between several main elements: malnutrition, poor oral hygiene – itself a consequence of extreme poverty, compromised immunity and intraoral infections.<sup>88</sup>

<sup>80</sup> Ibid., p. 402.

<sup>81</sup> Enwonwu, “Noma – The Ulcer”, pp. 221–224; Baratti-Mayer, “Noma: an ‘infectious’ disease”, p. 421; M.L. Srour, “Noma in Laos”, p. 539.

<sup>82</sup> Enwonwu, “Noma – The Ulcer”, pp. 221–224; see also Winds of Hope, WHO/AFRO, *Rapport de la 5ème Table Ronde sur le Noma*, Geneva, 9 September 2006. Available from [www.nonoma.org/doc\\_pdf/rapport\\_table\\_rond.pdf](http://www.nonoma.org/doc_pdf/rapport_table_rond.pdf).

<sup>83</sup> A/HRC/AC/3/CRP.3, pp. 11–12; WHO, “The Global Food Crisis: Implications for the Health of People in the African Region”, 2008.

<sup>84</sup> Barmes, “The need for action”, p. 1112.

<sup>85</sup> P. Joly, Sentinelles, Communication with Jean Ziegler, 27 July 2009.

<sup>86</sup> The Regional Office for Africa is said to be finalizing the report of a noma survey realized in 2007–2008 in Africa.

<sup>87</sup> Phillips, “Pro- *versus* anti-inflammatory cytokine profile”, p. 70; Baratti-Mayer, “Noma: an ‘infectious’ disease”; B.J. Paster et al., “Prevalent Bacterial Species and Novel Phylotypes in Advanced Noma Lesions”, *Journal of Clinical Microbiology*, vol. 40, No. 6, June 2002, pp. 2187–2191.

<sup>88</sup> Fieger, “An estimation”, p. 402; Enwonwu, “Noma (cancrum oris)”, p. 151; Enwonwu, “Noma – The Ulcer”; interview by Bertrand Piccard, «Notre nouveau but: mettre sur pied une Journée mondiale contre le noma», *Tribune Médicale*, 29 September 2006.

40. First, malnutrition is considered to be the major predisposing factor for noma.<sup>89</sup> Experts describe malnutrition as “mandatory” for noma to appear.<sup>90</sup> The absence of noma cases in well-nourished African children associated with the occurrence of the illness in Nazi concentration camps where malnourishment was rampant strongly supports other evidence that malnutrition plays a significant role in the development of this disease.<sup>91</sup> In the words of Dr. Enwonwu et al, “the global distribution pattern of the disease reflects the worldwide distribution of malnutrition”.<sup>92</sup>

41. Recent research is inquiring into the relevance of prenatal malnutrition for the contraction of noma by children. In several countries where noma has been documented, malnutrition is said to commence in utero as a consequence of the poor nutrition of the mother, which then results in intrauterine growth retardation and a baby with a low birthweight.<sup>93</sup> In early postnatal life, and often extending through adolescence into adulthood, babies with a low birthweight suffer of chronic malnutrition and have a diminished resistance to infections.<sup>94</sup> These in turn are key contributing elements to the development of noma. Therefore, in the context of preventing noma, tackling malnutrition of babies, as well as mothers, is imperative.

42. Second, poor oral hygiene is necessary for noma to develop. Experts consider that noma is less likely to occur in malnourished children provided that oral care is undertaken regularly and thoroughly.<sup>95</sup> Preventive oral examinations and providing education to parents on good practices in respect to oral hygiene are key interventions to preventing noma in malnourished children.

43. Third, the weakening of the immune system due to malnutrition and infections, such as measles, malaria, tuberculosis and HIV, can contribute to the development of noma in children.<sup>96</sup>

44. Fourth, research has shown that a high bacterial load of normal micro-organisms from the mouth breaks the resistance of a failing immune system.<sup>97</sup> The present expert consensus is that acute necrotizing gingivitis is a precursor of noma.<sup>98</sup> Previously *Fusobacterium necrophorum* and *Prevotella intermedia* were thought to be key players in this process in which components of the normal oral flora become pathogenic,<sup>99</sup> but recent investigations conducted with more advanced technologies could not identify a specific bacteriological agent for noma.<sup>100</sup>

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<sup>89</sup> Ibid.

<sup>90</sup> Barmes, “The need for action”, p. 1111.

<sup>91</sup> Enwonwul, “Noma (cancrum oris)”, p. 151.

<sup>92</sup> Ibid.

<sup>93</sup> C.O. Enwonwu, “Ruminations on the causation of noma”, *Stomatologie*, vol. 104, No. 1, 2007 pp. 43–44.

<sup>94</sup> Ibid.

<sup>95</sup> Submission by MSF, November 2011.

<sup>96</sup> Bos, *Surgical Treatment*, p. 13.

<sup>97</sup> Fieger, “An estimation”, p. 402.

<sup>98</sup> Baratti-Mayer, “Noma: an ‘infectious’ disease”, p. 421; P. Moynihan, P.E. Petersen, “Diet, Nutrition and the Prevention of Dental Diseases”, *Public Health Nutrition*, vol. 7, No. 1A, February 2004, p. 203.

<sup>99</sup> Neville, *Oral and Maxillofacial Pathology*, p. 201; see also Srour, “Noma in Laos”, p. 539.

<sup>100</sup> Paster, “Prevalent Bacterial Species”, pp. 2187–2191; I. Bolivar et al., “Bacterial diversity in oral samples of children in Niger with acute Noma, acute necrotizing gingivitis, and healthy controls”, submitted to the *Journal of Clinical Microbiology*.

45. Other important risk factors for the development of noma are unsafe drinking water and dehydration, poor sanitation including due to unsanitary housing conditions and close proximity to unkempt livestock.<sup>101</sup>

46. Noma can reach its terminal phase in the extremely short timespan of three weeks.<sup>102</sup> WHO identifies four stages of the disease and the treatment of noma differs accordingly. In the early stage, when the gingiva is bleeding and has lesions, the onset of noma can be treated in a manner which is “simple, effective, low-cost”<sup>103</sup> with disinfecting mouth rinses and daily food with vitamins.<sup>104</sup> During the next phase, involving swelling of the face and fever, mouth rinses, administration of antibiotics and nutrients supplementation is essential.<sup>105</sup> These have been shown to prevent progression from the initial ulceration to the extensive gangrene, which require emergency care and, in the latter stage, costly reconstructive surgery.<sup>106</sup> Survivors suffer disfigurement and functional impairment. Doctors describe the restriction of the jaw movement and the loss of part of the maxilla, mandible or other facial bones as the usual consequences of noma.<sup>107</sup> Without reconstructive surgery “[a] child who survives is unlikely ever to be able to speak or eat normally again.”<sup>108</sup>

47. As was noted in a previous section, the death rate associated with noma is very high. However, if recognized early and treated correspondingly with oral hygiene, antibiotics and nutritious feeding, mortality can drop from 70–90 per cent to approximately 20 per cent.<sup>109</sup> Hence, early recognition of the clinical signs of this disorder and timely treatment is critical for saving the lives of children affected by noma.

48. By addressing the predisposing factors to noma, the occurrence of this disorder can be lowered; a comprehensive perspective is needed. Therefore, addressing oral hygiene as well as chronic and acute malnutrition should be a priority in the fight against noma. Vaccination against infections such as measles that weaken the immune system would considerably cut the incidence of noma.<sup>110</sup> Taking decisive action to improve sanitation and access to clean drinking water and adequate housing, and to provide information on oral hygiene and on the importance of breastfeeding, while keeping a focus on the vulnerable children and their mothers from poor rural areas and slums, are all essential in the fight against noma. Overall, the fight against extreme poverty is certainly also a fight against noma.

### C. Initiatives to combat noma and alleviate the suffering of children affected by the disease

49. Prompted by reports from several NGOs and some Governments about the recrudescence of noma, WHO organized the first information session on noma at the World Health Assembly in 1989.<sup>111</sup> This was followed, in 1994, by the adoption of a five-point

<sup>101</sup> P.E. Petersen, “World Health Organization global policy for improvement of oral health – World Health Assembly 2007”, *International Dental Journal*, vol. 58, 2008, p. 117.

<sup>102</sup> WHO campaign “Acting against Disease, Open the Mouth of Your Children. Acting Against Noma”.

<sup>103</sup> Bos, *Surgical Treatment*, p. 18.

<sup>104</sup> WHO campaign “Acting against Disease”.

<sup>105</sup> Ibid; Bos, *Surgical Treatment*, p. 18; Srour, “Noma in Laos”, p. 539.

<sup>106</sup> Ibid.

<sup>107</sup> Barmes, “The need for action”, p. 1113.

<sup>108</sup> Ibid.

<sup>109</sup> Bos, *Surgical Treatment*, p. 18.

<sup>110</sup> Fieger, “An estimation”, p. 406.

<sup>111</sup> Bos, *Surgical Treatment*, p. 15; see, for the important input of Edmond Kaiser,



action programme against noma, which comprised: prevention – ensuring training and awareness on early diagnosis and treatment for each public health structure and raising awareness and informing populations, especially mothers; epidemiology and surveillance – finding out the incidence and incorporating noma surveillance into existing epidemiological surveillance systems; etiological research – establishing the causes of noma and why it develops in some children but not in others; primary health care – including making sure that the necessary antiseptics, drugs and nutritional supplements are available; and surgery and rehabilitation.<sup>112</sup>

50. In 1998, the WHO Regional Committee for Africa declared the disease a priority on the continent.<sup>113</sup> Following a decision of the Regional Consultative Committee in 2000, the noma programme activities were transferred from the WHO headquarters in Geneva to the WHO Regional Office for Africa.<sup>114</sup> In 2008, noma was integrated into the list of diseases targeted for eradication and elimination in the Technical Guidelines for Integrated Disease Surveillance and Response in the African Region.<sup>115</sup>

51. This study cannot fully assess the effects of the transfer of responsibilities from the WHO Geneva headquarters to the WHO Regional Office for Africa on the fight against noma in Africa (see above). What can be clearly ascertained, however, is that, as a consequence of the transfer, there is no longer a global overview of the situation of noma. The fight against noma is coordinated by the WHO Regional Office for Africa exclusively on the African continent. The 1994 five-point action programme against noma and the technical guidelines are thus intended for application only in Africa, while children in Asia and in other regions are excluded from surveillance, health care, surgery and rehabilitation. From a public health perspective, the neglect of Asia and other parts of the world where malnutrition rates are disturbingly high and children may be exposed to noma is highly problematic. From a human rights point of view, it may amount to a violation of the rights of the children at risk or affected by noma.

52. In the African region, some progress in the fight against noma has been achieved. In this context, it is fundamental to note the crucial importance of the activity developed by NGOs, charities and private individuals based in Africa or abroad. These have been the driving force of the fight against noma, offering financial, logistical, medical, surgical and post-operative support and assistance, and undertaking etiological research.<sup>116</sup>

53. The Regional Noma Programme of the WHO Regional Office in Africa receives long-term funding from the Winds of Hope Foundation – which initiated the No-Noma International Noma Federation gathering over 30 members.<sup>117</sup> The programme develops noma prevention, early detection and management activities in six West African countries: Benin, Burkina Faso, Mali, the Niger, Senegal and Togo.<sup>118</sup> Other countries in Africa which

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[www.medecine.unige.ch/enseignement/apprentissage/module4/immersion/archives/2006\\_2007/travaux/07\\_r\\_noma.pdf](http://www.medecine.unige.ch/enseignement/apprentissage/module4/immersion/archives/2006_2007/travaux/07_r_noma.pdf).

<sup>112</sup> D.M. Bourgeois, M.H. Leclercq, “The World Health Organization initiative on noma”, *Oral Diseases*, vol. 5, 1999, pp. 153–154.

<sup>113</sup> WHO, “The World Health Organization Action Against Noma – Some Important Landmarks”, *Noma Contact*, July 2006, p. 2.

<sup>114</sup> Consultative Meeting on Management of the Noma Programme in the African region, final report; Bos, *Surgical Treatment*, p. 15.

<sup>115</sup> WHO Regional Office for Africa, *Technical Guidelines for Integrated Disease Surveillance and Response in the African Region*, 2nd ed., (Brazzaville, 2010).

<sup>116</sup> It goes beyond the capacity of the present study to provide a comprehensive list of all non-governmental actors working on noma.

<sup>117</sup> See <http://www.nonoma.org/index.php>.

<sup>118</sup> Communication of J. Ziegler and I. Cismas with Dr. B. Varenne; WHO Regional Office for Africa,

are part of the so-called “noma belt” and which have high rates of malnutrition are now not included in the WHO regional noma programme, however. Reports show that several other countries in Africa are placing emphasis on “severe oral health problems”, including noma.<sup>119</sup>

54. The German foundation Hilfsaktion Noma – a non-governmental organization that works on prevention and treatment of noma and aftercare in the Niger and Guinea-Bissau – inter alia through setting up vaccination centres, noma children houses and hospitals<sup>120</sup> – is supporting the WHO Regional Office for Africa in the development of a manual on the integrated prevention and the management of main oral diseases, including noma, in the African region.<sup>121</sup>

55. A number of NGOs and charities are funding reconstructive surgery on survivors of noma in Africa and are increasingly investing in the aftercare of patients in their home countries. These include the British foundation Facing Africa which has been financially supporting the multiannual trips of teams of volunteer surgeons, anaesthetists and nurses to Nigeria and Ethiopia to operate on victims of noma.<sup>122</sup> AWD-Stiftung Kinderhilfe from Germany and Noma-Hilfe-Schweiz are active in Nigeria and Guinea-Bissau, respectively.<sup>123</sup> Among others, the Dutch Noma Foundation, Interplast France and PhysioNoma are involved.<sup>124</sup> Sentinelles is carrying out awareness raising and prevention work and treatment and has financially supported surgery on children affected by noma in Burkina Faso and Niger.<sup>125</sup>

56. The multidisciplinary Geneva Study Group on Noma initiated a large case-control study that includes acute cases in children under 12 years from Niger, aiming to identify the exact causes of noma and establish a treatment for it.<sup>126</sup> Over the last decade, Dr. Enwonwu explored the etiopathogenesis of noma and has contributed to a better understanding of the potential roles of viruses (noma is seen now as a co-infection with HIV),<sup>127</sup> bacteria, parasites and close residential proximity to livestock in the genesis of the very destructive disease.<sup>128</sup>

#### D. Discrimination of children affected by noma and neglect of noma itself

57. Children who survive noma are stigmatized, excluded and discriminated against, in addition to suffering from disfigurement and functional impairment. Given the lack of appropriate information for the population in general and mothers in particular, noma tends

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Health Ministry of Niger, Winds of Hope, Programme régionale de lutte contre le noma, “Rapport de l’atelier conjointement organisé par le Bureau Régional de l’OMS pour l’Afrique et le Ministère de la santé publique du Niger”, 7–9 December 2010, Niamey.

<sup>119</sup> World Dental Federation, WHO, *Planning Conference for Oral Health in the African Region. Conference Report*, 14–16 April 2004, Nairobi.

<sup>120</sup> [www.nomahilfe.de/index.php?id=69&L=1](http://www.nomahilfe.de/index.php?id=69&L=1); submission from Leo Sibomana, Resident Representative in Niger and Coordinator, Hilfsaktion Noma 1996–2006, 24 July 2009.

<sup>121</sup> Communication of J. Ziegler and I. Cismas with Dr. B. Varenne.

<sup>122</sup> See [www.facingafrica.org](http://www.facingafrica.org).

<sup>123</sup> See [www.awd-stiftung-kinderhilfe.de/kinderhilfe/en/home/Our\\_projects/sokoto\\_noma\\_project.html](http://www.awd-stiftung-kinderhilfe.de/kinderhilfe/en/home/Our_projects/sokoto_noma_project.html) and [www.noma-hilfe.ch/](http://www.noma-hilfe.ch/).

<sup>124</sup> See [www.noma.nl](http://www.noma.nl), <http://missions-interplast.blogspot.com> and <http://www.physionoma.fr>.

<sup>125</sup> [www.sentinelles.org/soinsenfants.htm](http://www.sentinelles.org/soinsenfants.htm).

<sup>126</sup> D. Baratti-Mayer et al., “GESNOMA (Geneva Study group on Noma): an aetiological research on noma disease”, *Stomatologie*, vol. 104, No. 1, pp. 1–2. See also [www.gesnoma.org](http://www.gesnoma.org).

<sup>127</sup> MSF, “Noma – what is it, where is it and what to do?”, 1 July 2011 (unpublished study).

<sup>128</sup> See [www.dental.umaryland.edu/dentaldepts/micropath/enwonwu\\_mission.html](http://www.dental.umaryland.edu/dentaldepts/micropath/enwonwu_mission.html).

to be perceived as a curse, “coming from the devil” and, ultimately, shame on the family. The social stigma attached to noma pushes families to sometimes hide away or isolate their children with animals, instead of seeking health care.<sup>129</sup> The chances of these children being treated early on and recovering are thus further minimized. Given the high death rate, hiding children with noma away virtually gives them a death sentence. If they survive, hidden children with noma are also left out from any statistics on the disease. It is thus the urgent and imperative human rights obligation of authorities to dispel the myths about noma and provide information to health workers and parents on how to identify and treat noma. Foremost, the right to life of these children must be protected, in addition to the right to adequate and timely health care and to non-discrimination.

58. Survivors of noma are condemned to a life marred by discrimination. While trying to hide away their mutilated face, they are often condemned to a life in poverty, unable – either because of the disease or society – to access education, a decent work place or adequate housing. Victims of noma are similar to victims of leprosy, shunned and rejected by their communities.<sup>130</sup> Reconstructive surgery would thus be a rare chance for the survivors to live without discrimination. Dedicated individuals and NGOs are almost the only actors in that field and often perform reconstructive surgery without payment during their free time (see next section). Yet many NGOs reported encountering bureaucratic hurdles and corruption, which are thus affecting the already poor chances of the most vulnerable to a decent life and livelihood.

59. The neglect of the noma disease itself has far-reaching consequences. It is a major impediment in the context of determining incidence and assuring the surveillance of noma.<sup>131</sup> To overcome the difficulties of epidemiological surveillance, the WHO Regional Office in Africa is planning to work jointly with the WHO Neglected Tropical Diseases Programme.<sup>132</sup> This cooperation may indeed be an indication of a wider acknowledgement that noma is a neglected disease and it should, as a consequence, formally be granted the status of a neglected disease.

60. The neglect of this disease has enormous implications for the needed timely treatment to children with acute noma and later reconstructive surgery. For example, Dr. Srour argues that only a few doctors in Asia are aware of noma and that probably they would not recognize it because it has rarely been described as a disease present on the Asian continent.<sup>133</sup> Providing information about and training on noma in Asia and beyond falls to the responsibility of every State, while the leadership must be assured by WHO. Experts in the field have, however, reported that noma is neglected or outright ignored by political authorities, which perpetuates the vicious circle of neglect of the disease itself and the discrimination of those affected by noma. It would thus not be far-fetched to describe children with noma as representing a group of neglected victims.

61. Despite having an associate mortality rate comparable to diseases such as multiple sclerosis and appendicitis, noma does not appear in the annual WHO global reports.<sup>134</sup> Moreover, noma is not listed among the major killers like malaria, diarrheal diseases, HIV-infection/AIDS, measles, tuberculosis, and severe chronic malnutrition; however it is a

<sup>129</sup> Bourgeois, “WHO initiative on noma”, p. 173; Baratti-Mayer, “Noma: an ‘infectious’ disease”, p. 421; J.E. Tonna et al., “A Case and Review of Noma”, *Neglected Tropical Diseases*, vol. 4, No. 12, December 2010.

<sup>130</sup> *Noma: The Face of Poverty, The International Noma Day*, 2008. Available from [www.nonoma.org/doc\\_pdf/world\\_noma\\_day\\_anglais.pdf](http://www.nonoma.org/doc_pdf/world_noma_day_anglais.pdf).

<sup>131</sup> Bourgeois, “WHO initiative on noma”, pp. 172–173.

<sup>132</sup> Communication of J. Ziegler and I. Cismas with Dr. B. Varenne.

<sup>133</sup> Srour, “Noma in Laos”, p. 540.

<sup>134</sup> Fieger, “An estimation”, p. 405.

complication of these diseases.<sup>135</sup> The 2010 *First WHO Report on Neglected Tropical Disease* “*Working to Overcome the Global Impact of Neglected Tropical Disease*” also omits noma.<sup>136</sup> According to Alexander Fieger, this reflects the lack of a good monitoring system for noma, and the lack of interest for this affliction from public health policymakers both in less privileged countries where noma is prevalent and world institutions like WHO and the World Bank.<sup>137</sup>

62. MSF has recently undertaken an investigation into the medical humanitarian issues surrounding noma. It concluded that this disease is “more than neglected, it is ignored and is concerned by the low level of awareness, funding and the lack of global oversight. Besides ensuring that there is an ongoing high level expertise for the detection and treatment of noma in its malnutrition projects, MSF is planning to examine how it can work towards the goal that noma gets more recognition as a neglected disease by WHO and other global health actors.”<sup>138</sup>

63. Noma is ignored by Government funding and has escaped the interest of major human rights or humanitarian NGOs. Across the board, the actors consulted during the drafting process agreed that more needs to be done in the fight against noma – starting with policies aimed at eliminating poverty and reducing malnutrition – and that States and relevant specialized agencies ought to assume responsibility.

64. In its statement on the Advisory Committee’s preliminary study, the Winds of Hope Foundation, the main funder of the WHO Regional Noma Programme in Africa, declares:

“A clear statement from the United Nations Human Rights Council would be a powerful catalyst to raise awareness among political authorities and other international organisations about the fight against this neglected and deadly disease of poverty. This would encourage Governments to implement the practical measures that could really make a difference.”<sup>139</sup>

65. In its submission on the preliminary study, WHO expresses its “hopes that the study may help generate increased interest and support from Member States to WHO to address noma and to strengthen its mandate in this regard. Such support could help ensure, as is recommended in the study, that the program has a global mandate, independent of the geographical location it is led from”.<sup>140</sup>

#### IV. Conclusions and recommendations

66. The present study has reiterated the importance of socioeconomic conditions into which children are born and in which they grow up and live in influencing their opportunity to be healthy. The reduction of malnutrition and childhood diseases cannot be dissociated from the elimination of extreme poverty and its direct consequences: stigmatization, discrimination and exclusion. As imperatives flowing from human rights law obligations:

<sup>135</sup> Enwonwu, “Ruminations”, p. 43.

<sup>136</sup> WHO, Geneva, 2008.

<sup>137</sup> Fieger, “An estimation”, p. 405.

<sup>138</sup> Communication with J. Tong, MSF, A. Slavuckij, Deputy Medical Director for Operations, MSF.

<sup>139</sup> Statement of Winds of Hope Foundation, 8 December 2011.

<sup>140</sup> Submission by the WHO, 25 November 2011.

(a) States – those with high stunting and wasting rates in children, as well as donor States – should step up their fight against malnutrition;<sup>141</sup>

(b) International assistance earmarked for nutrition should be increased. Such aid should be spent more efficiently and with a human rights framework in mind, by enabling individuals to feed themselves not by fuelling a dependency cycle;

(c) Policies for the reduction of poverty and malnutrition should prioritize the most vulnerable groups. Gender discrimination, discrimination of the poor from the rural areas and slums, exclusion and corruption must be systematically tackled as a paramount condition for achieving a brighter future for children.

67. As the present study has revealed, noma is a neglected disease killing, disfiguring, and destroying the lives of children worldwide. It is a disease of extreme poverty, the main predisposing factor of which is malnutrition. The persistence of noma - the disease of Nazi concentration camps – **in today's world raises doubts not** only about our morality, but proves that the human rights of children, the most vulnerable members of the international community are being severely ignored and violated. States and international organizations should assume responsibility for the neglected victims of noma. The following is therefore recommended:

(a) The exclusive focus on noma in Africa through the WHO Regional Office in Africa is insufficient; therefore noma should be addressed at the global level. This includes worldwide surveillance, prevention, primary health care, surgical and rehabilitation treatment and etiological study.

(b) Government and private funding for the fight against noma in Africa should be increased and funding and WHO coordination for other regions urgently provided.

(c) Affected States must establish noma action plans and appoint a noma focal person.

(d) Modalities to raise awareness about noma among the medical community, Government authorities, private donors and public opinion should be explored. As a means to reach this aim, noma could be formally acknowledged as a WHO neglected disease. States should promote a resolution at the World Health Assembly to list noma as a neglected disease.

(e) The Advisory Committee invites the Human Rights Council to encourage States to implement the Human rights principles and guidelines to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by noma.

<sup>141</sup> See

<http://siteresources.worldbank.org/NUTRITION/Resources/2818461131636806329/PolicyBriefNutritionScalingUpApril.pdf>.

## Annex

### Human rights principles and guidelines to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by noma<sup>142</sup>

#### I. Principles

##### A. The rights of the child

1. Children at risk or affected by malnutrition and noma are entitled on an equal basis to other individuals to the rights proclaimed by the Universal Declaration of Human Rights, enshrined in international human rights instruments to which their respective States are parties, including in the Convention on the Rights of the Child, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights, as well as to the rights stipulated by customary international law. The well-being and human rights of children are intrinsically linked to the right of their mothers. The full realization of the rights stipulated by Convention on the Elimination of All Forms of Discrimination against Women is thus paramount for the fulfilment of the rights of women and of children, including those at risk/affected by malnutrition and noma.

2. States have an international obligation to respect, protect and fulfil the rights of the child and of their parents. Authorities at local, regional and national level are bound by these obligations. State decisions regarding children should be guided by the principles of non-discrimination, adherence to the best interests of the child, the right of children to life, survival and development, and the right of children to participate in matters that affect them.

3. Every child, including a child at risk/affected by malnutrition and noma, has the inherent right to life. States Parties shall ensure to the maximum extent possible the survival and development of the child.

4. Every child, including a child at risk/affected by malnutrition and noma, has the right to food. States shall respect, protect and fulfil the right of the child to have regular and permanent access to quantitatively and qualitatively adequate and sufficient food that ensures a physical and mental dignified life free of hunger and malnutrition.

5. Every child, including a child at risk/affected by malnutrition and noma, has the right to water and sanitation. States shall respect, protect and fulfil the right to safe drinking water and sanitation, and thus take steps to realize the physical and economic access to

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<sup>142</sup> The parallel to leprosy and the findings of the study on severe malnutrition and childhood diseases with children affected by Noma as an example has led the Committee to consider as a model for further action the *Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members* prepared by Shigeki Sakamoto, adopted by the Committee (A/HRC/15/30) and of which the Human Rights Council has taken note with appreciation (A/HRC/15/L.18). Special thanks for the input on the earlier draft of the principles and guidelines aimed at improving the protection of children at risk or affected by malnutrition, specifically at risk of or affected by noma are due to the Government of Canada (submission on A/HRC/AC/7/CRP.2, not dated).

sanitation which is safe, hygienic, secure, socially and culturally acceptable, provides privacy and ensures dignity.

6. Every child, including a child at risk/affected by malnutrition and noma, has the right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. The health of the mother is vital in preventing malnutrition in children and hence preventing noma. Therefore particular attention must be given to the health and nutrition of women, in particular during the pre- and post-natal period.

7. A mentally or physically disabled child, including as a result of malnutrition and/or noma, has the right to enjoy a full and decent life, in conditions, which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

8. Every child, including a child at risk/affected by malnutrition and noma, has the right to adequate housing. States shall respect, protect and fulfil the right to housing by ensuring access to secure, affordable, sanitary, culturally adequate shelter and characterized by availability of services, materials, facilities and infrastructure essential for health, nutrition and comfort.

9. Every child, including a child at risk/affected by malnutrition and noma, has the right to education. States shall respect, protect and fulfil the right of children to education, which is available, accessible, acceptable and adaptable.

10. Every child, including a child at risk/affected by malnutrition and noma, and her/his parents have the right to seek, receive and impart information.

## B. Equality and non-discrimination

11. Every child, including a child at risk/affected by malnutrition and noma, and her/his parents have the right to exercise their rights and freedoms without de jure or de facto discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, disability or other status. The prohibition on discrimination gives rise to both positive and negative obligations of States. In particular, States shall ensure that a child or an adult with sequelae is not discriminated against based on her/him being affected by noma.

## C. International cooperation and assistance

12. States have undertaken to cooperate internationally and to promote and encourage international assistance with a view to achieving progressively the full realization of economic, social and cultural rights and the rights of the child. This commitment is equally to be upheld for the full realization of the rights of children at risk or affected by malnutrition or noma.

## II. Guidelines

13. Acknowledging that the worsening of the world food crisis, which seriously undermines the realization of the right to food for all, including mothers and children, and threatens to further undermine the achievement of the Millennium Development Goals, States shall urgently take all necessary measures to diminish child morbidity and mortality ensuing from the intersection of malnutrition and childhood diseases, which threaten the development and survival of the child. To this end:

(a) States should prioritize the budgetary spending on the prevention and treatment of malnutrition in children and women. Donor States should sharply increase earmarked international assistance for nutrition which respects and promotes human rights and does not increase the vulnerability of children and their parents on long-term;

(b) States should establish national strategies for the prevention and treatment of chronic and acute malnutrition in children and women. The national strategies should apply a human rights framework and thus respect, protect and fulfil the right to food, the right to water and sanitation, the right to health, the right to housing, the right to education and the right to information of the child and her/his parents and eliminate discrimination patterns in particular in relation to women or the poor living in the rural area;

(c) States should establish food insecurity and vulnerability maps and use disaggregated data to identify any form of discrimination that may manifest itself in greater food insecurity and vulnerability to food insecurity, or in a higher prevalence of malnutrition among specific population groups, in particular children, with a view to removing and preventing such causes of food insecurity or malnutrition. They should use this food insecurity and vulnerability maps in implementing the national strategies for the prevention and treatment of chronic and acute malnutrition in children and women;

(d) States should promote a resolution at the World Health Assembly to list noma as a neglected disease;

(e) States, in collaboration with the World Health Organization, should take all necessary steps to establish the incidence of noma at the global level and assure the surveillance of the disease in all affected States by incorporating it into existing epidemiological surveillance systems;

(f) All affected States should adopt a noma action plan focusing on the elimination of discrimination in all spheres of life of children affected by noma and adults with sequelae, on awareness raising and prevention of noma, on primary health care, surgery and rehabilitation of children at risk/affected by noma. Inter alia, the following priorities should be set:

- (i) States should ensure that de jure and de facto discrimination of children affected by noma and adults with sequelae is eliminated. Particular attention should be given that children with noma are not isolated or hidden away by their families or communities, that they have access to sufficient nutritious food, to timely and qualitative health care, to education, and that they have adequate housing, clean drinking water and sanitary conditions of life;
- (ii) States should raise awareness about noma through all means, including by using media and health workers to inform communities, in particular mothers, social and religious leaders with the view to remove the social stigma attached to this disease and the discrimination of children affected by noma and adults with sequelae;
- (iii) States should undertake targeted information campaigns through media and health workers for mothers, comprising information on breastfeeding, on complementary feeding of infants after the age of 6 months, and on improved hygiene practices including washing of hands. States should ensure access to specific educational information to help to ensure the health and well-being of women, including information and advice on family planning;
- (iv) States should systematically provide information and tackle administratively and legislatively cultural food practices, which amount to discrimination against women and are detrimental to the nutrition and health of mothers and their children;



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- (v) States should ensure training and education for each public health structure on early diagnosis and treatment of noma, including in respect to the crucial relevance of malnutrition as a risk factor of noma;
  - (vi) Oral checks during health investigation of infants and children should be mandatory in order to identify the first signs of noma, usually acute necrotizing gingivitis;
  - (vii) Mouth-rinses, antibiotics and nutritional supplements should be made available and free of charge for children with acute necrotizing gingivitis;
  - (viii) States should to the maximum of their available resources ensure access to reconstructive surgeries for children and adults with sequelae from noma and to rehabilitation and should seek international cooperation and assistance to that end;
  - (ix) States should ensure that no bureaucratic barriers or hurdles stemming from corruption are preventing the activity of international organizations and NGOs related to awareness raising, prevention, primary health surgery and rehabilitation in relation to noma;
  - (x) States should promote collaborative programmes involving the Government, NGOs and private institutions to raise funds and develop programmes to improve the standard of living of children affected by noma and adults with sequelae;
  - (xi) States should appoint a noma focal person to liaise with the World Health Organization, the United Nations Children's Fund, NGOs and other actors working on noma.

14. States are encouraged to include in their State party reports to the relevant treaty bodies, specifically, the Committee on the Rights of the Child, information on the adopted noma action plans and on the progress as well as problems encountered during implementation.

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