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Reports currently under consideration by the

Advisory Committee: Right to food

Preliminary Study on Severe Malnutrition and Childhood Diseases with Children Affected by Noma as an Example

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This preliminary study discusses the intersection between malnutrition, childhood disease and human rights taking children affected by Noma as an example. In 2010, approximately 171 million children globally were stunted and 20 million severely wasted. About 1 million children die directly every year from severe acute malnutrition. Moreover, malnutrition is thought to contribute to one third of the eight million deaths of children under-five every year.

The strong link between malnutrition and childhood diseases is forged by a poor access to sufficient or sufficiently nutritious food, to adequate and timely health care, to safe water and sanitation facilities, to education, to decent work and livelihood opportunities, to adequate shelter and housing and indeed to discrimination of women and the poorest from the rural areas. This lack of access and discrimination is a human rights saga, one depicting the human rights of children and adults that are not being fulfilled.

Malnutrition is the key risk factor of Noma. Noma is a disease that devours the face of children and is fatal in up to 90 per cent of cases if early on a cost-effective treatment consisting of mouth-rinses, antibiotics and nutritious food is not administered. It is a disease last present on a larger scale in Europe in Nazi concentration camps. Today it affects malnourished children between 1-6 living in extreme poverty in Africa, Asia and other parts of the world. Noma is a neglected disease: neglected by the medical community, by governmental authorities, by major private donors and by public opinion. Children surviving this terrible disease face disfigurement, life-long functional impairment in the absence of reconstructive surgery, and social stigma and discrimination.

The persistence of Noma in today's world raises doubts not only about our morality, but it comes to prove that the human rights of children, the most vulnerable members of the international community are being severely ignored and violated. States and international organizations have a duty to act. The preliminary study recommends that the fight against 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 Noma is listed by the WHO as a neglected disease. In the Annex a framework to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by Noma – Principles and guidelines is put forward.

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Annex

A human rights framework to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by Noma – Principles and guidelines

I. Introduction

1. The Advisory Committee of the Human Rights Council identified in the Study on discrimination in the context of the right to food (A/HRC/16/40) children with Noma as victims of *de facto* discrimination in relation to the right to food. Noma is a disease that devours the face of children and is fatal in up to 90 per cent of cases. Malnutrition is the key risk factor of Noma. As a follow up, 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.

2. This preliminary study will take the example of children affected by Noma and exemplify the relation between childhood diseases and malnutrition. Despite being one of the most brutal and tragic faces of malnutrition Noma is largely a neglected child disease. A human rights analysis will help understand why action on combating Noma must be reinforced. The study ultimately aims to open the way for a human rights framework to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by Noma.

3. The drafting group on the right to food, consisting of José Bengoa Cabello, Chinsung Chung, Latif Hüseyinov, Jean Ziegler and Mona Zulficar¹ established by the Advisory Committee at its first session, welcomes the discussion among the Committee members on this preliminary study. Moreover, the drafting group welcomes feedback from all stakeholders, in accordance to the Council's request for the Office of the High Commissioner to collect the views and comments of all Member States, all relevant United Nations special agencies and programmes and all other relevant stakeholders (A/HRC/RES/16/27).

4. The first part of the preliminary study will focus on the intersection between severe malnutrition, childhood disease and human rights. The second part dealing with children at risk of or affected by Noma is based on the background paper of the Advisory Committee A/HRC/AC/3/CRP.3 and on the comments received on that latter study from various stakeholders. In the Annex a framework to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by Noma – Principles and guidelines is put forward.

II. Severe malnutrition, childhood diseases and human rights

5. The intersection between severe malnutrition, childhood diseases and human rights deserves increased 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.² The food crises of the last years

¹ Jean Ziegler thanks Ioana Cismas from the Geneva Academy of International Humanitarian Law and Human Rights for her important contribution during the drafting of the present study.

² 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 malnutrition", 16 March 2011, available at http://www.who.int/nutrition/pressnote_action_on_malnutrition/en/index.html.

characterized by skyrocketing prices for basic foodstuff³, and the very recent famine in the Horn of Africa⁴ add to the urgency of understanding the linkages between severe malnutrition and childhood diseases from a human rights perspective.

6. Second, an identification of the host of human rights which are at stake in the context of severe malnutrition and childhood diseases is necessary in order for the international community to address in its comprehensive reply the symptoms, as well as the root causes of the problem. It is imperative, as the Committee on Economic, Social and Cultural Rights (CESCR) and UN 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.⁵ Surely, children affected by malnutrition are such a vulnerable group, while children affected by or at risk of Noma are among the most vulnerable of the vulnerable. A human rights analysis of severe malnutrition and childhood diseases, including Noma, facilitates the understanding that center stage are 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.

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

7. According to the World Health Organization (WHO), malnutrition essentially means “bad nourishment” and can refer to the quantity as well as the quality of food eaten.⁶ 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.⁷ It includes both undernutrition and overnutrition.⁸ While the latter has become a concern in the past years also for developing countries⁹, the current report will focus on the

³ WHO, Regional Office for Africa, *The Global Food Crisis: Implications for the Health of People in the African Region*, 2008; FAO, *The State of Food Insecurity in the World 2008: High Food Prices and Food Security – Threats and Opportunities* (Rome, 2008); 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* (Rome, 2010).

⁴ Office of the United Nations Resident & Humanitarian Coordinator in Somalia, “The UN Declares Famine in Somalia”, Press Release, 20 July 2011, available at <http://documents.wfp.org/stellent/groups/public/documents/communications/wfp238182.pdf>; UNICEF, *Situation in Horn of Africa set to get worse for millions of children*, Press Release, 17 July 2011, available at http://www.unicef.org/media/media_59241.html; UNICEF, “Amidst regional drought, malnutrition imperils thousands of refugee children in Dadaab, Kenya”, 15 July 2011, available at http://www.unicef.org/infobycountry/kenya_59238.html; “MSF acts on malnutrition and drought in Horn of Africa”, 11 July 2011, available at <http://www.trust.org/alertnet/news/msf-acts-on-malnutrition-and-drought-in-horn-of-africa/>.

⁵ Committee on Economic, Social and Cultural Rights, *supra* note 8, and see for example Report of the Special Rapporteur on the Right to Food, Jean Ziegler, A/HRC/4/30, 19 January 2007; Report of the Special Rapporteur on the Right to Food, Jean Ziegler, A/62/289, 22 August 2007; Report of the Special Rapporteur on the Right to Food, Olivier de Schutter, A/HRC/9/23, 8 September 2008.

⁶ WHO, *Malnutrition*, available at http://www.who.int/water_sanitation_health/diseases/malnutrition/en/.

⁷ M. J. Gibney et al, *Clinical Nutrition*, (Wiley-Blackwell, 2005), pp. 1-2.

⁸ See M. de Onis, M. Blössner, E. Borghi, “Global prevalence and trends of overweight and obesity among preschool children”, *American Journal of Clinical Nutrition* 2010, 92:1257–64; *Population-based prevention strategies for childhood obesity: report of a WHO forum and technical meeting*, Geneva, 15–17 December 2009.

⁹ FAO, *The double burden of malnutrition. Case studies from six developing countries*, FAO

undernutrition aspect of malnutrition in children. As such, malnutrition in children is the consequence of a range 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.¹⁰

8. A classification of malnutrition would include protein-energy malnutrition (deficiency in calories and proteins), as well as micro-nutrient malnutrition (deficiency in vitamins or minerals).¹¹ Malnutrition can take mild, moderate or severe forms; it can be chronic or acute. To measure malnutrition in children anthropometric indices are compared to the WHO child growth standards. The main indices are: height-for-age that portrays performance in terms of linear growth and measures long-term growth faltering, weight-for-height which reflects body proportion, or the harmony of growth, and is particularly sensitive to acute growth disturbances, and weight-for-age which represents a convenient synthesis of both linear growth and body proportion.¹²

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.¹³ In other words, children 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% of children were affected by stunting as of 2010;¹⁴ in Africa stunting has stagnated since 1990 at about 40%.¹⁵

10. Behind the statistics one must understand the tragic consequences of chronic malnutrition on the future of children: adverse cognitive development, reduced learning ability, poor school performance, school drop out and decreased productivity as an adult.¹⁶ “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”.¹⁷ In other words stunted children may become adults incapable of fully assuring by themselves an adequate standard of living; a vicious circle for which they are not responsible and which they cannot escape. The range of human rights which are

Food and Nutrition Paper 84 (Rome, 2006).

¹⁰ This definition is used in M. de Onis, M. Blössner, *WHO Global Database on Child Growth and Malnutrition*, (Geneva, 1997), at 3.

¹¹ Vitamin A deficiency, iron deficiency anaemia and iodine deficiency disorders are the most common forms of micro-nutrient malnutrition. See FAO, *Preventing micronutrient malnutrition: a guide to food-based approaches. Why policy makers should give priority to food-based strategies* (Rome, 1997).

¹² M. de Onis, C. Monteiro, J. Akre and G. Clugston, “The worldwide magnitude of protein-energy malnutrition: an overview from the WHO Global Database on Child Growth”, *Bulletin of the World Health Organization*, 71 (6):703-712, 1993, p. 1.

¹³ See UNICEF, *Tracking Progress on Maternal and Child Undernutrition*, (New York, November 2009), p. 4.

¹⁴ WHO, 10 Facts about nutrition, March 2011, available at <http://www.who.int/features/factfiles/nutrition/en/index.html> and M. de Onis, M. Blössner, E. Borghi, “Prevalence and trends of stunting among pre-school children, 1990-2020”, *Public Health Nutrition*, 2011, available at http://www.who.int/nutgrowthdb/stunting_p1990_2020.pdf.

¹⁵ M. de Onis, M. Blössner, E. Borghi, “Prevalence and trends of stunting among pre-school children, 1990-2020”, *Public Health Nutrition*, 2011.

¹⁶ 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*, 2010, 140(11): 1996-2001.

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

infringed upon during the life cycle of an individual which experienced stunting in childhood is mesmerizing: the right to an adequate standard of living including the rights to food, to health, to 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 puts into perspective the progress on other MDGs, such as child health and education.¹⁸ 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?”¹⁹ 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 those countries that have high rates of stunting in children who without early intervention will probably become unproductive members of their societies.

11. At the global level, 20 million children are estimated to be severely wasted²⁰ and thus suffer of severe acute malnutrition.²¹ The (preventable) tragedy of these children has been described by Nicholas Kristof as 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”.²² The human dignity of these children is being compromised and ultimately their right to life, since about 1 million children die directly every year from severe acute malnutrition.²³

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

[i]nfection 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.²⁴

13. Thus, children become severely malnourished because of acute pediatric diseases such as diarrhoea, pneumonia, measles, malaria, which are not or are inadequately treated

¹⁸ See UN, *The Millennium Development Goals Report 2011* (New York, 2011).

¹⁹ N. Jacobs, “Development goals: celebrating on an empty stomach”, *EUObserver*, 8 July 2011.

²⁰ A child can be moderately wasted (between minus two and minus three standard deviations from the median weight for height) or severely wasted (below minus three standard deviations from the median weight for height). See UNICEF, *Tracking Progress on Maternal and Child Undernutrition*, (New York, November 2009), p. 4.

²¹ *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.

²² N. D. Kristof, “The Hidden Hunger”, *The New York Times*, 23 May 2009, available at <http://www.nytimes.com/2009/05/24/opinion/24kristof.html>.

²³ *Ibid.*

²⁴ K. H. Brown, “Diarrhea and Malnutrition”, *Journal of Nutrition*, Supplement, 2003, 133: 328–332. See also N.S. Scrimshaw, C.E. Taylor & A.J.E. Gordon, *Interactions of Nutrition and Infection*, WHO monograph series no. 57, (WHO, Geneva, 1968).

given poor access to health care in terms of both timing and quality.²⁵ Often a deadly circle ensues. For example, in the last decades applied research has confirmed the deleterious effect of diarrhoeal illness on the nutritional status of children.²⁶ As such, diarrhoea seriously exacerbates malnutrition in children, while at the same time it has been proven that malnourished children are more vulnerable to acute diarrhoea and suffer multiple episodes every year.²⁷ It is important to note in this context that diarrhoea is the second leading cause of death among children under five at the global level, killing about 1.5 million each year.²⁸

14. Equally, chronic child diseases such as HIV, cancer, tuberculosis, sickle-cell anaemia that are not or are inadequately treated may be a reason for severe malnutrition in children.²⁹ As such, in the context of HIV/AIDS, the WHO flags the need for a massive effort “to alleviate the overall burden of malnutrition and to reduce the severity and complexity of the impact that HIV/AIDS and malnutrition have on each other.”³⁰ This complex relation between HIV/AIDS and malnutrition is exemplified by 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.³¹ It remains a cynical fact of today’s world that in developed countries the pursuit of breastfeeding by HIV-infected mothers on antiretroviral treatment constitutes neglect or abuse;³² at the same time, in developing contexts where malnutrition, diarrhoea and pneumonia are rampant and where access to water and sanitation is poor, the same behavior of the mother (even when she is not receiving antiretroviral treatment) represents the better option for HIV-free survival of the child.³³

15. Another facet of the relationship between severe malnutrition and child diseases is that of medical complications with specific aspects or pathogens occurring in malnourished children. Malnutrition is responsible for immuno-compromission and the latter acts as a trigger for severe diseases with unclear etiology and wounds in Kwashiorkor³⁴. Examples of such diseases include Lyell’s syndrome in severely malnourished children, non-infectious wounds in children with severe malnutrition and Myelodysplastic syndromes and Noma.³⁵ The second part of this study will focus extensively on Noma.

²⁵ Communication with Dr. Marie-Claude Bottineau, MSF Pediatrics Working Group Acting Team Leader, 29 June 2011.

²⁶ H. Brown, “Diarrhea and Malnutrition”, *Journal of Nutrition*, Supplement, 2003, 133: 328–332.

²⁷ UNICEF and WHO, *Diarrhoea: Why children are still dying and what can be done*, 2009, p. V and 1.

²⁸ *Ibid.*

²⁹ Communication with Dr. Marie-Claude Bottineau, MSF Pediatrics Working Group Acting Team Leader, 29 June 2011.

³⁰ WHO, *Nutrition and HIV/AIDS*, available at <http://www.who.int/nutrition/topics/hivaids/en/index.html>.

³¹ See WHO, UNAIDS, UNFPA, UNICEF, *Guidelines on HIV and Infant Feeding. Principles and recommendations for infant feeding in the context of HIV and a summary of evidence* (Geneva, 2010).

³² *Ibid.*, p. 18-23

³³ *Ibid.*

³⁴ Communication with Dr. Marie-Claude Bottineau, MSF Paediatrics Working Group Acting Team Leader, 29 June 2011; Kwashiorkor is a form of malnutrition caused by lack of protein-energy and certain micro-nutrients in the diet. Symptoms include a swollen abdomen, severe anemia and ‘oedema’ of the feet, legs and arms. See MSF, *A Beginner’s Guide to Malnutrition*, available at www.msf.or.jp/info/pressreport/pdf/pressMalnutritionE.pdf.

³⁵ Dr. Marie-Claude Bottineau, *Paediatric Intensive Care Unit in MSF ITFCs. Icography 2011*, Médecins Sans Frontières.

16. Infants and young children are the most vulnerable to malnutrition because of their high nutritional requirements for growth and cognitive development.³⁶ Malnutrition as a self-standing 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 eight million deaths of children under-five every year.³⁷

17. The vulnerability of children is strongly connected to the vulnerability of women. Indeed, 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 low-birth-weight baby susceptible to disease and premature death.³⁸ It is contended that “malnourished girls, in particular, risk becoming yet another malnourished mother, thus contributing to the intergenerational cycle of malnutrition”.³⁹ A human rights perspective allows to call into question those cultural practices which place limits on women’s access to nutrition and food, clean water and sanitation and education and expose them as forms of gender discrimination.⁴⁰ 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.⁴¹ Moreover, even in developed contexts breastfeeding mothers face hurdles such as societal pressure not to breastfeed in public or at work and the lack of proper facilities that enable breastfeeding at work.⁴² At the same time, the lack of paid maternity leave or a maternity leave which is not covering the six months exclusive breastfeeding recommended by the WHO is often leaving no choice to young mothers but to return to work.⁴³ Not least non-discriminatory access to resources, including income, land and water and their ownership, as well as equal access to education, science and technology, are as the Human Rights Council itself underlines, vital for women to be able to feed themselves and their families.⁴⁴

18. 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, as the Advisory Committee’s

³⁶ M. Blössner, M. de Onis, *Malnutrition: quantifying the health impact at national and local levels*, WHO Environmental Burden of Disease Series, No. 12 (Geneva, 2005), p.3

³⁷ See J.K. Rajaratnam, “Neonatal, postneonatal, childhood, and under-5 mortality for 187 countries, 1970-2010: a systematic analysis of progress towards Millennium Development Goal 4”, 375 *The Lancet* 9730 (2010), 1988-2008; R.E. Black, “Global, regional, and national causes of child mortality in 2008: a systematic analysis”, 375 *The Lancet* 9730 (2010), 1969 – 1987; MSF, *Fact Sheet: What is Malnutrition?*, p.1, available at www.starvedforattention.org.

³⁸ Ibid, p. 1.

³⁹ Ibid, p. 3.

⁴⁰ See Study of the Human Rights Council Advisory Committee on discrimination in the context of the right to food, UN Doc. A/HRC/16/40, 16 February 2011, para 61 (hereafter, A/HRC/16/40); Report of the Office of the United Nations High Commissioner for Human Rights on preventable maternal mortality and morbidity and human rights, UN Doc. A/HRC/14/39, 16 April 2010, para. 18; I. Rae, *Women and the Right to Food: International Law and State Practice* (FAO, Rome 2008), pp. 12-14.

⁴¹ 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”, 23 *Ethiopian Journal of Health Development* 2, 98-106.

⁴² “Even Part-Time Work Can Have A Negative Effect On Breastfeeding Rates, Says New Study”, *Science Daily*, 29 April 2008; A.R. Cooklin et al, “Maternal employment and breastfeeding: results from the longitudinal study of Australian children”, 97 *Acta paediatrica* 5 (2008) 620-623.

⁴³ Ibid.

⁴⁴ Human Rights Council resolution 16/27 of 25 March 2011, UN Doc. A/HRC/RES/16/27.

Study on Discrimination in the context of the right to food has shown.⁴⁵ The strong link between malnutrition and childhood diseases is forged by poor access to sufficient or sufficiently nutritious food, to adequate and timely health care, to safe water and sanitation facilities, to education, to decent work and livelihood opportunities, to adequate shelter and housing. This lack of access is a human rights saga, one about the human rights of children and adults that are not being fulfilled. A UNICEF publication from 2000 summarizes:

[t]he 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.⁴⁶

The bitter observation remains valid today against the reality of 195 million malnourished children worldwide susceptible to acute and chronic pediatric diseases and medical complications such as Noma.

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

19. The human rights saga is taking place against the background of an international legislative framework that guarantees the host of rights of children and their mothers which are at stake when malnutrition intersects with childhood disease, notably the Convention on the Rights of the Child (CRC), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

20. States parties to these international instruments are legally bound to respect, protect and fulfill human rights. In the context of malnutrition States should assure, in collaboration with international organizations and civil society, the necessary conditions for parents to be able to adequately feed themselves and their children.⁴⁷ 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."⁴⁸ These tools must be used to rectify the current reality which shows "no meaningful improvement" in reducing underweight prevalence among children from poor households as opposed to considerable progress in rich households.⁴⁹ Protecting the rights of the most vulnerable of the vulnerable is a human rights imperative which flows not least from the general prohibition on discrimination under human rights law and the UN Charter.⁵⁰

⁴⁵ Study of the Human Rights Council Advisory Committee on discrimination in the context of the right to food, UN Doc. A/HRC/16/40, 16 February 2011.

⁴⁶ UNICEF, *The Progress of Nations 2000*, (New York, 2000), p. 14.

⁴⁷ See for example International Covenant on Economic, Social and Cultural Rights, adopted 16 December 1966, entered into force 3 January 1976, art. 11.1 (hereafter ICESCR); Committee on Economic, Social and Cultural Rights, General Comment 12: *The right to adequate food (Art.11)* : . 05/12/1999, UN Doc. E/C.12/1999/5.

⁴⁸ FAO Voluntary Guidelines to Support the Progressive Realization of the Right to Adequate Food in the Context of National Food Security, 2004, Guideline 13.

⁴⁹ UN, *The Millennium Development Goals Report 2011* (New York, 2011), p. 14.

⁵⁰ Study of the Human Rights Council Advisory Committee on discrimination in the context of the right to food, UN Doc. A/HRC/16/40, 16 February 2011, paras 9-11.

21. Of great relevance for the intersection of malnutrition and pediatric diseases is article 24 of the CRC, the most widely ratified human rights instrument. It provides that States shall pursue the “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 through the provision of adequate nutritious foods and clean drinking-water.⁵¹ According to the same article States are “[t]o 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”.⁵² Article 12 of the CEDAW requires States Parties to ensure to women appropriate services in relation with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and breastfeeding.⁵³

22. 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 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).⁵⁴

23. The ICESCR enshrines the principle of international assistance and cooperation and thus gives rise to extraterritorial obligations for State parties.⁵⁵ While the width of these obligations has not been tested by jurisprudence given that the communication procedure under the Optional Protocol to the ICESCR did not yet enter into force, it is clear from the interpretation of the CESC that the principle of international assistance and cooperation does carry legal force. In its General Comment 3 the CESC notes that

the phrase to the maximum of its available resources’ [article 2.1.] was intended by the drafters of the Covenant to refer to both the resources existing within a State and those available from the international community through international cooperation and assistance. Moreover, the essential role of such cooperation in facilitating the

⁵¹ Convention on the Rights of the Child, adopted 20 November 1989, entered into force 2 September 1990, article 24.c. (hereafter CRC).

⁵² Ibid, 24.e.

⁵³ Convention on the Elimination of All Forms of Discrimination against Women, adopted 19 December 1979, entered into force 3 September 1981, art. 12.2. (hereafter CEDAW).

⁵⁴ UNICEF, *Progress for Children. Achieving the MDGs with Equity*, No. 9, (New York, September 2010), p. 16.

⁵⁵ See S. Skogly, *Beyond National Borders: States’ Human Rights Obligations in International Cooperation* (Antwerp: Intersentia, 2006); M. Sepulveda, “The obligations of ‘international assistance and cooperation’ under the International Covenant on Economic, Social and Cultural Rights. A possible entry point to a human rights based approach to Millennium Development Goal 8”, 13 *The International Journal of Human Rights* 1 (2009), 86-109; 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”, 11 *Human Rights Law Review* 1 (2011), 1-35.

full realization of the relevant rights is further underlined by the specific provisions contained in articles 11, 15, 22 and 23.⁵⁶

Article 11.2. 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.⁵⁷ A similar stipulation on international cooperation is present in the CRC in relation to the right of the child to health.⁵⁸

24. Articles 22 and 23 of the ICESCR have been considered by the Committee to serve as a framework for the activities of international organizations and UN specialized agencies.⁵⁹ A renewed commitment has been sought from international organizations to respect economic, social and cultural rights while designing and implementing their policies and programs and to assist States in fulfilling their human rights obligations.⁶⁰

25. An analysis by Médecins Sans Frontières (MSF) has however revealed that the aid dedicated by States, international and regional organizations and private actors for nutrition over the period 2004-2007 has stagnated at 350 million USD, the same level since 2000-2004. Taking a World Bank costing exercise⁶¹ as departure point MSF argues that the spending dedicated to nutrition must increase considerably and be specifically earmarked if malnutrition is to be overcome.⁶² Moreover, the organization argues that the money is not being spent on “the right things” and in the most efficient way.⁶³ For example, it emphasizes that if the United States were to renounce their current practice of in-kind food aid – consisting of shipping food produced in the US to the target country – and to adopt a policy of purchasing food locally, about 600 USD could be freed up.⁶⁴ The importance of acquiring locally produced food *inter alia* in the context of the fight against malnutrition has been recognized by other donors and agencies, such as the European Union and the World Food Programme.⁶⁵

26. 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, where states with high rates in malnourished children are accountable to actively removing discrimination patterns (against women, against the poor leaving in the rural areas etc.)⁶⁶, to promoting participation and inclusiveness of the

⁵⁶ General Comment No 3: The nature of States parties obligations (art. 2, para 1), 14 December 1990, E/1991/23;

⁵⁷ ICESCR, art. 11.2.

⁵⁸ CRC, art. 24.4.

⁵⁹ 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”, 11 Human Rights Law Review 1 (2011), 1-35, p. 18.

⁶⁰ Ibid.

⁶¹ See S. Horton et al, *Scaling Up Nutrition: What Will it Costs?* (World Bank: Washington D.C., 2010).

⁶² Médecins Sans Frontières, *Malnutrition: How Much is Being Spent? An Analysis of Nutrition Funding Flows: 2004-2007* (Geneva, November 2009). See also for another analysis The Lancet, “Maternal and Child Undernutrition,” Special Series, January, 2008.

⁶³ Ibid.

⁶⁴ Ibid.

⁶⁵ 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, available at <http://usa.wfp.org/news-release/wfp-launches-strategy-bring-social-security-and-stability-haiti>; Ambassade de France à Port-au-Prince, “De la fourche à fourchette (suite)”, available at <http://www.ambafrance-ht.org/spip.php?article954>.

⁶⁶ See A/HRC/16/40.

most vulnerable, and importantly to systematically eradicate corruption and promote 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.⁶⁷ Moreover, the coherence of international law – as opposed to fragmentation – should be sought by all states, and thus trade and investment regimes should not be allowed to collude with the human rights system: foremost when at stake is the nutritious food⁶⁸ so much needed by malnourished children, or the antiretroviral medicine for their HIV infected mothers.⁶⁹

III. Children at risk of or affected by Noma

27. The first part of this Study has underlined the importance of understanding the intersection of malnutrition and child disease and human rights. Noma is the most brutal face of malnutrition in children and thus gives rise to some of the most atrocious violations of the rights of the child.

28. Noma (*cancrum oris*), which borrows its name from the Greek term “to devour”, is a devastating infectious disease that destroys the soft and hard tissue of the face.⁷⁰ 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 terrible hole in the face.⁷¹ Noma is thought to lead to death in 70-90% of cases.⁷² Most deaths are attributed to complications such as pneumonia, diarrhoea and septicaemia associated with severe malnutrition.⁷³

29. The clinical data available is unanimous: children are the main victims of this debilitating disease. Acute Noma occurs predominantly in malnourished children aged 0 to 6 years,⁷⁴ while sequelae have been observed in adolescents and adults.⁷⁵ Having studied patients with Noma in Nigeria, Phillips et al conclude that Noma is not observable in children of “elite Nigerians residing in affluent sections of the urban areas” and that “[i]t is rather a socioeconomic disease afflicting preferentially the deprived, malnourished children

⁶⁷ See in this respect Special Rapporteur on the right to food, Olivier de Schutter, Draft Guiding Principles on Human Rights Impact Assessments of Trade and Investment Agreements, 1 July 2011.

⁶⁸ In the context of large-scale land acquisitions see Report of the Special Rapporteur on the right to food, Olivier de Schutter, *Large-Scale Land Acquisitions and Leases: A Set of Minimum Principles and Measures to Address the Human Rights Challenge*, UN Doc. A/HRC/13/33/Add.2, 22, December 2009.

⁶⁹ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, UN Doc. A/63/263, 11 August 2008.

⁷⁰ C.O. Enwonwu et al, “Noma (cancrum oris): Seminar”, 386 *The Lancet* (2006), 147-156, p. 147; D. Baratti-Mayer et al, “Noma: an “infectious” disease of unknown aetiology”, 3 *The Lancet Infectious Diseases* 7 (July 2003), 419-431, p. 419.

⁷¹ Ibid; K. Bos, K. Marck, *The Surgical Treatment of Noma*, (Alphen aan den Rijn: Belvedere/Medidac, 2006), pp. 13-14.

⁷² Mark Tsechkovski, Director, WHO Division of Non-Communicable Diseases, “A disease such as Noma should not exist”, *Noma Contact*, (WHO: Geneva, October 1997), p.1.

⁷³ D.E. Barmes et al, “The need for action against oro-facial gangrene (noma)”, 2 *Tropical Medicine and International Health* 12 (1997), 1111-1114, p. 1113.

⁷⁴ Ibid; Mark Tsechkovski, Director, WHO Division of Non-Communicable Diseases, “A disease such as Noma should not exist”, *Noma Contact*, (WHO: Geneva, October 1997), p.1; P.A. Van Damme, “Essay: noma” 368 *The Lancet*, (2006), S61-62.

⁷⁵ C.O. Enwonwu et al, *supra* note 70, p. 147; Facing Africa, “What is noma?”, <http://www.facingafrica.org/FA08/content/site/en/pages/whatisnoma/default.asp>.

in the poor, rural communities”.⁷⁶ 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.⁷⁷

A. History of Noma, incidence and distribution of the disease

30. According to Klaas Marck, who undertook a comprehensive research project on the history of Noma, the disease was already known in classical and medieval Europe.⁷⁸ Already in the 18th century, awareness that Noma is related to poverty, malnutrition and preceding diseases such as measles increased in Northwestern Europe.⁷⁹ Noma remained common in Europe and North America until the beginning of the 20th century. However, it is widely held that before the discovery of penicillin, the disease had almost disappeared from European and North American societies. The economic progress witnessed by these societies is credited with having allowed them to feed their children sufficiently and hence to practically eradicate Noma.⁸⁰ Cases of Noma reappeared in the Nazi concentration camps of Bergen-Belsen and Auschwitz⁸¹ and in some other European countries subjected to extreme food shortages during World War II.⁸² More recently, the disease has been documented in patients with HIV infection or AIDS from developed States.⁸³ A 2006 study reports the recent case of a 68-year old retired man from the United Kingdom who had Noma. The doctors who treated the man conclude that debilitated individuals in the developed world suffering of malnutrition, bad oral hygiene and immunosuppression may also be at risk, despite the predominance of the disease in malnourished children of developing countries.⁸⁴

31. Low- and middle-income countries, particularly in Africa and Asia, are considered to be the most affected by Noma.⁸⁵ Experts, including NGOs, working in the field, describe the area that stretches across parts of West Africa, Central Africa towards Sudan as the “noma belt”.⁸⁶ It is assumed that a large number of individuals affected by Noma live in the sub-Saharan countries of Mauritania, Senegal, Mali, Niger, Nigeria, Chad, Sudan and Ethiopia.⁸⁷ Cases are reported from other countries in Africa, Asia and Latin America⁸⁸, as

⁷⁶ 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)”, 16 *European Cytokine Network* 1 (March 2005), 69-176, p. 70.

⁷⁷ C.O. Enwonwu, “Noma-The Ulcer of Extreme Poverty”, 354 *The New England Journal of Medicine* 3, (January 2006), pp. 221-224; M.L. Srouf et al, “Noma in Laos: Stigma of Severe Poverty in Rural Asia”, 78 *American Journal of Tropical Medicine and Hygiene* 4 (2008), 539-542, p.539.

⁷⁸ K. Marck, “A History of Noma, the “Face of Poverty”, 111 *Plastic and Reconstructive Surgery* 5 (April 2003), 1702-1707.

⁷⁹ *Ibid.*

⁸⁰ R.Voorhoeve, “Review”, 49 *Bulletin of the Netherlands Society of Tropical Medicine and International Health*, 1 (February 2008), p. 13; C.O. Enwonwu, *supra* note 77, p. 222;

⁸¹ C.O. Enwonwu et al, *supra* note 70, p. 148.

⁸² K. Bos, K. Marck, *supra* note 71, p. 11.

⁸³ C.O. Enwonwu et al, *supra* note 70, p. 148

⁸⁴ A. G. Buchanan et al “Necrotizing stomatitis in the developed world”, *Clinical and Experimental Dermatology* 31, 2006, 372-275, p. 372.

⁸⁵ P.E. Petersen, “World Health Organization Global Policy for Improvement of Oral Health – World Health Assembly 2007”, 58 *International Dental Journal* (2008), 115-121, p. 117.

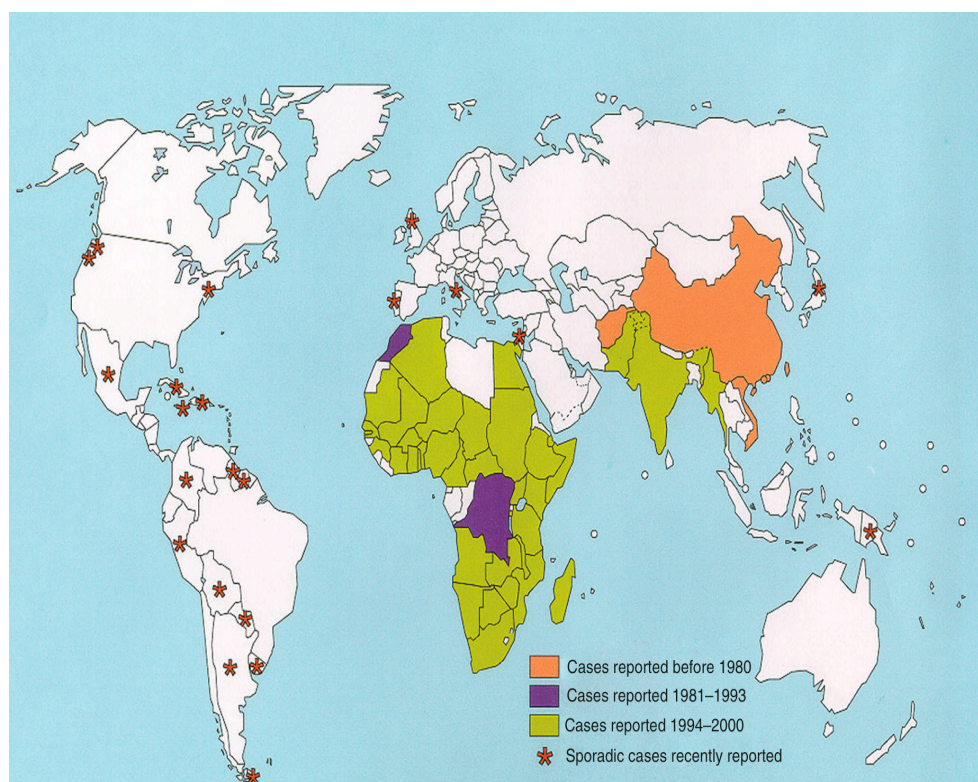
⁸⁶ Consultative Meeting on Management of the Noma Programme in the African region, Harare, Zimbabwe, 19-21 April 2001, Final Report; Facing Africa, “What is noma?”, <http://www.facingafrica.org/FA08/content/site/en/pages/whatisnoma/default.asp>.

⁸⁷ K. Bos, K. Marck, *supra* note 71, p. 12; C.O. Enwonwu et al, *supra* note 70, p. 148.

⁸⁸ K. Bos, K. Marck, *supra* note 71, p. 12.

Figure 1 shows. A recent medical paper on Noma in Laos concludes that “it is likely that it is much more frequent in remote Asian rural communities than is currently appreciated.”⁸⁹

Figure 1 – Global distribution of Noma⁹⁰



32. According to estimates released by WHO in 1998, 140 000 individuals contract Noma on a yearly basis⁹¹, 100 000 of these being children.⁹² The survival rate is between 10 and 30 %, which means that at least 100 000 people, the vast majority of which are children, die every year because of Noma.⁹³ According to the same 1998 WHO report, 770 000 persons survived the disease with heavy sequelae.⁹⁴

⁸⁹ M.L. Srour et al, *supra* note 77, p. 540.

⁹⁰ The source of the map is: P.E. Petersen, “Oral Health”, in K. Heggenhougen and S. Quah (ed), *International Encyclopedia of Public Health*, Vol 4, (San Diego: Academic Press, 2008), 677-685, p.684.

⁹¹ WHO, *The World Health Report 1998 - Life in the 21st Century: A Vision for all* (WHO: Geneva, 1998), p. 45.

⁹² B. Neville et al, *Oral and Maxillofacial Pathology*, 3rd Edition, (Elsevier Health Sciences, 2008), p. 201.

⁹³ The 1998 WHO study puts the number of death at 110000, i.e. 79%. WHO, *The World Health Report 1998 - Life in the 21st Century: A Vision for all* (WHO: Geneva, 1998), p. 45; a 2003 WHO publication mentions the death rate of 90%, 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.

⁹⁴ WHO, *The World Health Report 1998 - Life in the 21st Century: A Vision for all* (Geneva: WHO, 1998), p. 45; A. Fieger et al, “An Estimation of the Incidence of Noma in North-West Nigeria”, 8 *Tropical Medicine and International Health*, 5, May 2003, 402-407, p. 402.

33. 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.⁹⁵ By extrapolating the incidence from Northwestern Nigeria to the countries bordering the Sahara Desert, the research showed an annual incidence of 25 600 cases for that region and a global incidence per year of 30 000 – 40 000.⁹⁶ Experts consider this data to be rather conservative, given that less than 10% of the individuals suffering of Noma seek medical care.⁹⁷ In the suggestive words of Cyril O. Enwonwu, a leading expert on Noma, these cases represent merely “the tip of the iceberg”.⁹⁸

34. More recent data showing the number of cases around the globe is not publically available.⁹⁹ The incidence as well as the distribution of acute Noma worldwide remains uncertain, which in turn leads to the tragic situation that the majority of children and other individuals with Noma are not receiving treatment and are thus neglected.

35. This lack of current information is even more tragic in the context of the recent food and economic crises. The effect of these on the incidence of Noma are 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.¹⁰⁰ 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.¹⁰¹ For example, 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 number of Noma cases is probably explainable by the fact that malnourished babies were born to malnourished mothers, the latter victims of the 2005 food crisis.¹⁰² The importance of accurate and recent information on Noma cannot be understated.

B. Causes, predisposing factors and treatment of Noma

36. Researchers have not identified a specific microorganism responsible for causing Noma.¹⁰³ Despite the lack of certainty in respect to the microbiology and pathophysiology,

⁹⁵ A. Fieger et al, *supra* note 94, p. 403.

⁹⁶ *Ibid*, p. 402.

⁹⁷ C.O. Enwonwu, *supra* note 77, pp. 221-224; D. Baratti-Mayer et al, *supra* note 70, p.421; M.L. Srour et al, *supra* note 77, p.539.

⁹⁸ C.O. Enwonwu, *supra* note 77, pp. 221-224; see also Winds of Hope, WHO/AFRO, *Rapport de la 5ème Table Ronde sur le Noma*, Genève, 9 septembre 2006, available at http://www.nonoma.org/doc_pdf/rapport_table_rond.pdf.

⁹⁹ It has been confirmed that the Regional Office for Africa is finalizing the report of a Noma survey realized in 2007-2008. Communication of Jean Ziegler and Ioana Cismas with Dr. Benoit Varenne, Regional Focal Point on Oral Health at World Health Organization - Regional Office for Africa, 30 May 2011. The results and information on the methodology – whether the survey will be a global one or only focusing on Africa, have not been released as of July 2011.

¹⁰⁰ See UN Doc. A/HRC/AC/3/CRP.3, p. 11-12. A 2008 WHO brief on the consequences of the food crisis in Africa estimates that the number of malnourished children will increase by over 10% for wasting and 40% for stunting. WHO, Regional Office for Africa, *The Global Food Crisis: Implications for the Health of People in the African Region*, 2008.

¹⁰¹ D.E. Barmes et al, *supra* note 73, p. 1112.

¹⁰² P. Joly, Sentinelles, Communication with Jean Ziegler, Feedback on UN. Doc. A/HRC/AC/3/CRP, 27 July 2009.

¹⁰³ R. S. Phillips, C. O. Enwonwu, W. A. Falkler, *supra* note 76, p.70; D. Baratti-Mayer et al, *supra* note 70; B.J. Paster et al, “Bacterial Species and Novel Phylotypes in Advanced Noma Lesions”, 40

there is a wide consensus among experts that Noma results from the interaction between three main elements: malnutrition, compromised immunity and intraoral infections.¹⁰⁴

37. First, malnutrition is considered to be the major predisposing factor for Noma.¹⁰⁵ Experts describe malnutrition as “mandatory” for Noma to appear.¹⁰⁶ 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 the evidence that malnutrition plays a significant role in the development of this disease.¹⁰⁷ In the words of Enwonwu et al: “The global distribution pattern of the disease reflects the worldwide distribution of malnutrition”.¹⁰⁸ Along these lines, protein-energy malnutrition, occurring often in congruence with deficiencies of vitamins (in particular vitamin A and B) and minerals are the most frequently observed in children at risk of Noma.¹⁰⁹

38. Recent research is inquiring into the relevance of pre-natal 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 low-birth-weight baby.¹¹⁰ In early post-natal life, and often extending through adolescence into adulthood, low-birth-weight babies suffer of chronic malnutrition and have a diminished resistance to infections.¹¹¹ These in turn are key contributing elements to the development of Noma. Therefore, also in the context of preventing Noma, tackling malnutrition of babies, as well as mothers, is imperative.

39. Second, the weakening of the immune system due to malnutrition and infections, such as measles, malaria, tuberculosis, HIV, as well as poor oral hygiene can contribute to the development of Noma in children.¹¹²

40. Third, research has shown that a high bacterial load of normal microorganisms from the mouth breaks the resistance of a failing immune system.¹¹³ The present expert consensus is that acute necrotizing gingivitis is the precursor of Noma.¹¹⁴ *Fusobacterium necrophorum* and *Prevotella intermedia* were thought to be key players in this process in which components of the normal oral flora become pathogenic.¹¹⁵ Recent investigations conducted with more advanced technologies could not identify a specific bacteriological agent for Noma.¹¹⁶

Journal of Clinical Microbiology 6 (June 2002), 2187-2191.

¹⁰⁴ A. Fieger et al, *supra* note 94, p. 402; C.O. Enwonwu et al, *supra* note 70, p. 151; C.O. Enwonwu, *supra* note 77; Interview de Bertrand Piccard, «Notre nouveau but : mettre sur pied une Journée mondiale contre le noma», *Tribune Médicale*, 29 septembre 2006.

¹⁰⁵ *Ibid.*

¹⁰⁶ D.E. Barmes et al, *supra* note 73, p. 1111.

¹⁰⁷ C.O. Enwonwu et al, *supra* note 70, p. 151.

¹⁰⁸ *Ibid.*

¹⁰⁹ D.E. Barmes et al, *supra* note 73, pp. 1111-2.

¹¹⁰ C. O. Enwonwu, “Ruminations on the causation of noma”, 104 *Stomatologie* 1 (2007), 43-48, pp. 43-4.

¹¹¹ *Ibid.*

¹¹² K. Bos, K. Marck, *supra* note 71, p. 13.

¹¹³ A. Fieger et al, *supra* note 94, p. 402.

¹¹⁴ D. Baratti-Mayer et al, *supra* note 70, p. 421; P. Moynihan, P. E. Petersen, “Diet, Nutrition and the Prevention of Dental Diseases”, 7 *Public Health Nutrition* 1A (2004), 201-206, p. 203.

¹¹⁵ B. Neville et al, *Oral and Maxillofacial Pathology*, 3rd Edition, (Elsevier Health Sciences, 2008), p. 201; see also M.L. Srouf et al, *supra* note 77, p. 539.

¹¹⁶ B.J. Paster et al, “Bacterial Species and Novel Phylotypes in Advanced Noma Lesions”, 40 *Journal of Clinical Microbiology* 6 (June 2002), 2187-2191; I. Bolivar et al, “Bacterial diversity in oral samples

41. Other important risk factors for the development of Noma are unsafe drinking water and dehydration, poor sanitation and close proximity to unkempt livestock.¹¹⁷

42. It is sobering to note that Noma can reach its terminal phase in the extremely short time span of three weeks.¹¹⁸ The 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, impending Noma can be treated in a manner which is “simple, effective, low-cost”¹¹⁹ with disinfecting mouth-rinses and daily food with vitamins.¹²⁰ During the next phase, involving swelling of the face and fever, mouth-rinses, administration of antibiotics and nutrients supplementation is essential.¹²¹ These have been shown to prevent the progression from the initial ulceration to the extensive gangrene, which presuppose emergency care, and in a late stage costly reconstructive surgery.¹²² 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.¹²³ Without reconstructive surgery, tragically, “[a] child who survives is unlikely ever to be able to speak or eat normally again.”¹²⁴

43. As was noted in a previous section, the death rate associated to Noma is spectacular high. However if recognized early and treated correspondingly with oral hygiene, antibiotics and nutritious feeding, the mortality can drop from 70-90% to approximately 20%.¹²⁵ Hence, early recognition of the clinical signs of this disorder and timely treatment is critical for saving the lives of children affected by Noma.

44. By addressing the predisposing factors of Noma the occurrence of this dreadful disorder can be lowered; a comprehensive perspective is needed. Therefore, addressing chronic and acute malnutrition should be a priority in the fight against Noma. Experts also underline the remarkable overlap between places on the world map with high mortality because of Noma, low vaccination against measles and extreme poverty.¹²⁶ For example, in Northwest Nigeria measles immunization coverage is very low; at the same time this area is considered the epicenter of Noma.¹²⁷ Vaccination against infections such as measles that weaken the immune system would considerably cut the incidence of Noma.¹²⁸ Taking action to improve sanitation, access to clean drinking water and to adequate housing, to provide information on oral hygiene, as well as on the importance of breastfeeding while keeping a focus on the vulnerable children and their mothers from poor rural areas are all essential in the fight against Noma.

of children in Niger with acute Noma, acute necrotizing gingivitis, and healthy controls”, submitted to the *Journal of Clinical Microbiology*.

¹¹⁷ P.E. Petersen, “World Health Organization Global Policy for Improvement of Oral Health – World Health Assembly 2007”, 58 *International Dental Journal* (2008), 115-121, p. 117.

¹¹⁸ WHO, “Acting against Disease, Open the Mouth of Your Children. Acting Against Noma”, Geneva.

¹¹⁹ K. Bos, K. Marck, *supra* note 71, p. 18.

¹²⁰ WHO, “Acting against Disease, Open the Mouth of Your Children. Acting Against Noma”, Geneva.

¹²¹ Ibid; K. Bos, K. Marck, *supra* note 71, p. 18; M.L. Srouf et al, *supra* note 77, p. 539.

¹²² Ibid.

¹²³ D.E. Barmes et al, *supra* note 73, p. 1113.

¹²⁴ Ibid.

¹²⁵ K. Bos, K. Marck, *supra* note 71, p. 18.

¹²⁶ A. Fieger et al, *supra* note 94, p. 406.

¹²⁷ K.W. Marck, “Measles Vaccination Would Cut Noma Deaths”, *Noma Contact*, (WHO: Geneva, October 1997), p. 5.

¹²⁸ Ibid.

C. Discrimination of children affected by Noma and neglect of Noma itself

45. In addition to horrible disfigurement and functional impairment, children who survive Noma are stigmatized, excluded and discriminated. Because of a lack of appropriate information for the population in general and mothers in particular, Noma tends to be perceived as a curse or as shame on the family whose child contracts it. This social stigma attached to Noma pushes families to sometimes hide away or isolate their children with animals, instead of seeking health care.¹²⁹ The chances of these children to be treated early on and to recover are thus further minimized by a lack of accurate information. Given the spectacular death rate, hiding away children with Noma may almost be equated with a death condemnation. It is thus the urgent and imperative human rights obligation of authorities to dispel the myths about Noma and to provide information to health workers and to parents on how to identify Noma and how to treat it. 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. States must act.

46. Survivors of Noma are condemned to a life mired by discrimination. While trying to hide away their mutilated face, they are often condemned to a life in poverty, incapacitated either by the disease or by society to access education, a decent work place or adequate housing. Victims of Noma are, similar as victims of leprosy, shunned and rejected by their communities.¹³⁰ Reconstructive surgery would thus be a rare chance for the survivors to a life without discrimination. International assistance and cooperation – economic and technical – should be pursued with priority in the field of Noma surgery. Yet, active in the field are almost exclusively dedicated individuals and NGOs that often perform reconstructive surgeries without payment during their free time (see next section). Cynically, it has been reported that many of these NGOs and individuals encounter bureaucratic hurdles and corruption while trying to help the most vulnerable.¹³¹ From a human rights perspective such barriers are inqualifiable, since they directly affect the rare chances of the most vulnerable to a decent life and livelihood.

47. The isolation of children, adolescents and adults that survived the acute phases of this disease is also very problematic for establishing the actual incidence and surveillance of the disease.¹³²

48. The neglect of the Noma disease itself has multiple far-reaching consequences. It is a major impediment in the context of determining incidence and assuring the surveillance of Noma.¹³³ To overcome the difficulties of epidemiological surveillance the WHO Regional Office in Africa is planning to work jointly with the Neglected Tropical Diseases WHO programme.¹³⁴ In the view of the authors of this preliminary study, this cooperation

¹²⁹ D.M. Bourgeois, M.H. Leclercq, “The World Health Organization Initiative on Noma”, 5 *Oral Diseases* (1999), 172-174, p. 173; D. Baratti-Mayer et al, *supra* note 70, p. 421; J.E. Tonna et al, “A Case and Review of Noma”, 4 *Neglected Tropical Diseases* 12 (December 2010).

¹³⁰ No Noma International Federation, Winds of Hope Foundation, WHO, World Dental Federation, *Noma: The Face of Poverty, The International Noma Day*, 2008.

¹³¹ Among the incidents reported are the blocking of surgical equipment, materials and needed medicine in the customs for lengthy periods and the request for bribes to facilitate operations. Private communication of NGOs with Jean Ziegler and Ioana Cismas.

¹³² J.E. Tonna et al, “A Case and Review of Noma”, 4 *Neglected Tropical Diseases* 12 (December 2010).

¹³³ D.M. Bourgeois, M.H. Leclercq, “The World Health Organization Initiative on Noma”, 5 *Oral Diseases* (1999), 172-174, pp. 172-3.

¹³⁴ Communication of Jean Ziegler and Ioana Cismas with Dr. Benoit Varenne, Regional Focal Point on Oral Health at World Health Organization - Regional Office for Africa, 30 May 2011.

may indeed be an indication of a wider acknowledgement that Noma is a neglected disease and it should in consequence formally be granted the status of a neglected disease.

49. The neglect of this disease has enormous implication in granting the needed timely treatment to children with acute Noma and later providing reconstructive surgery. For example, Margaret Leila Srour argues that only 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.¹³⁵ Providing information about and training on Noma in Asia and beyond falls into the responsibility of every State, while the leadership must be assured by the WHO. Experts in the field have however reported that Noma is neglected or outright ignored by political authorities, which in turn entertains the vicious circle of neglect of the disease itself and the utter discrimination of those affected by Noma.

50. Despite having an associate mortality rate comparable with diseases such as multiple sclerosis and appendicitis, Noma does not appear in annual global reports of the WHO.¹³⁶ 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 complication of these diseases.¹³⁷ The 2010 report on the global impact of neglected tropical diseases also omits Noma.¹³⁸ According to Alexander Fieger

This reflects the lack of a good monitoring system for noma, and the lack of interest for this affection from the side of public health policy makers both in less privileged countries where noma is prevalent and also of mondial institutions like the WHO and the World Bank.¹³⁹

51. Along these lines, Médecins Sans Frontières has recently undertaken an investigation into the medical humanitarian issues surrounding Noma. It has 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.”¹⁴⁰

D. Initiatives to combat Noma and alleviate the suffering of children affected by the disease

52. Prompted by reports from some governments and several NGOs about the recrudescence of Noma, the WHO organized the first information session on Noma at the World Health Assembly in 1989.¹⁴¹ This was followed, in 1994, by the adoption of a five-point action program 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

¹³⁵ M.L. Srour et al, *supra* note 77, p. 540.

¹³⁶ A. Fieger et al, *supra* note 94, p. 405.

¹³⁷ C. O. Enwonwu, “Ruminations on the causation of noma”, 104 *Stomatologie* 1 (2007), 43-48, p. 43.

¹³⁸ See WHO, Working to Overcome the Global Impact of Neglected Tropical Disease. First WHO Report on Neglected Tropical Disease (WHO: Geneva, 2008).

¹³⁹ A. A. Fieger et al, *supra* note 94, p. 405.

¹⁴⁰ Communication with Jacqueline Tong, charged by Médecins Sans Frontières with writing a review of the challenges and stakes around Noma and Andrej Slavuckij, Deputy Medical Director for Operations, Médecins Sans Frontières.

¹⁴¹ K. Bos, K. Marck, *supra* note 71, p. 15.

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; surgery and rehabilitation.¹⁴²

53. In 1998, the WHO Regional Committee declared the disease a priority on the African continent.¹⁴³ Following a decision of the Regional Consultative Committee in 2000, the Noma Program activities were transferred from the WHO headquarters in Geneva to the WHO Regional Office for Africa.¹⁴⁴ In 2008, Noma has been integrated in the list of diseases targeted for eradication and elimination in the Technical Guidelines for Integrated Disease Surveillance and Response in the African Region (IDSR).¹⁴⁵

54. The current preliminary study cannot fully assess the effect 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 *supra*). 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 program against Noma and Technical Guidelines for Integrated Disease Surveillance and Response in the African Region would thus be intended for application only in relation to Africa; while children in Asia – the other focal point of Noma – 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.

55. In the African region, some progress in the fight against the Noma disease 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.¹⁴⁶

56. For example, the Winds of Hope Foundation – which initiated the International No-Noma Federation gathering over 30 association members¹⁴⁷ – is offering long-term funding to the WHO Regional Office in Africa for the Regional Noma Programme. The Programme consists in developing activities of prevention, early detection and management of Noma in 6 West African countries: Senegal, Mali, Niger, Burkina Faso, Togo and Benin.¹⁴⁸ Other

¹⁴² D.M. Bourgeois, M.H. Leclercq, “The World Health Organization Initiative on Noma”, 5 *Oral Diseases* (1999), 172-174, pp. 153-154.

¹⁴³ “The World Health Organization Action Against Noma – Some Important Landmarks”, *Noma Contact* (WHO: Geneva, July 2006), p. 2.

¹⁴⁴ Consultative Meeting on Management of the Noma Programme in the African region, Final Report, Harare, Zimbabwe, 19-21 April 2001; K. Bos, K. Marck, *supra* note 71, p. 15.

¹⁴⁵ Alongside: Buruli ulcer; Dracunculiasis; Leprosy; Lymphatic filariasis; Neonatal tetanus; Onchocerciasis and Poliomyelitis. WHO Regional Office for Africa, Technical Guidelines for Integrated Disease Surveillance and Response in the African Region, 2nd Edition, (Brazzaville, October 2010).

¹⁴⁶ The paragraphs *infra* should not be interpreted as aiming to provide comprehensive list of all organizations working on Noma.

¹⁴⁷ See <http://www.nonoma.org/index.php>.

¹⁴⁸ In October 2010, the Programme has been reinforced and the work is said to proceed in a more integrated way, with the adoption of results indicators and a focus on training health and community workers. Communication of Jean Ziegler and Ioana Cismas with Dr. Benoit Varenne, Regional Focal

countries in Africa which are part of the so-called “Noma belt” and which have high rates of malnutrition are however not included in the WHO Regional Noma Programme, as of now. Reports show that several other countries in Africa are placing emphasis on “severe oral health problems” including Noma.¹⁴⁹

57. The German foundation Hilfsaktion Noma – an NGO working on prevention and treatment of Noma and aftercare in Niger and Guinea Bissau, including through the setting up vaccination centers, Noma children houses and hospitals¹⁵⁰ – 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.¹⁵¹

58. A number of NGOs and charities are funding reconstructive surgery on survivors of Noma in Africa. These include the British foundation Facing Africa which is supporting financially the multi-annual trips of teams of volunteer surgeons, anaesthetists and nurses to Nigeria and Ethiopia to operate on victims of Noma. Together with AWD Kinderhilfe, the Dutch Noma Foundation and Interplast France, it has further provided for medical material and even infrastructure for the care of patients in their countries of origin.¹⁵² Sentinelles is carrying out awareness raising and prevention work and treatment of Noma and has financially supported surgeries on children affected by Noma in Burkina Faso and Niger. The NGO has also brought children with sequelae of Noma for surgical treatment to Switzerland.¹⁵³

59. An etiological study on Noma is being conducted by the multidisciplinary Geneva Study Group on Noma (GESNOMA) that initiated a large case-control study which includes acute cases in children under 12 years from Niger. This study aims to find out the exact causes of Noma and establish a treatment for it.¹⁵⁴ Over the last decade Cyril O. Enwonwu has led a team of researchers to explore 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 HIV¹⁵⁵ – bacteria, parasites and close residential proximity to livestock, in the genesis of the very destructive disease.¹⁵⁶

Point on Oral Health at World Health Organization - Regional Office for Africa, 30 May 2011; WHO Regional Office for Africa, 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 Décembre 2010, Niamey, Niger.

¹⁴⁹ World Dental Federation, WHO, *Planning Conference for Oral Health in the African Region. Conference Report*, April 14-16, 2004, Nairobi, Kenya available at

http://www.fdiworldental.org/sites/default/files/assets/Activities/Nairobi/Nairobi_Report_en.pdf.

¹⁵⁰ See Hilfsaktion Noma at <http://www.nomahilfe.de/index.php?id=69&L=1>; Feedback on UN Doc. A/HRC/AC/3/CRP from Leo Sibomana, Resident Representative in Niger and Coordinator, Hilfsaktion Noma 1996-2006, 24 July 2009.

¹⁵¹ Communication of Jean Ziegler and Ioana Cismas with Dr. Benoit Varenne, Regional Focal Point on Oral Health at World Health Organization - Regional Office for Africa, 30 May 2011.

¹⁵² The Noma Hospital in Sokoto, Nigeria has been established at the initiative and with the funding of AWD-Kinderhilfe from Germany, the Dutch Noma Foundation and Facing Africa from England with the cooperation of Nigerian authorities. See <http://www.nomahospital.org/00000094b31422c06/00000095750d56b09/index.html>. Facing Africa is developing

¹⁵³ <http://www.sentinelles.org/burkina.htm> and <http://www.sentinelles.org/soinsenfants.htm>.

¹⁵⁴ D. Baratti-Mayer, B. Pittet, D. Montandon, and GESNOMA, “GESNOMA (Geneva Study group on Noma): an aetiological research on noma disease”, 104 *Stomatologie* 1, 1-2. See also <http://www.gesnoma.org/>.

¹⁵⁵ Médecins Sans Frontières. “Noma – what is it, where is it and what to do?”, 1 July 2011, (unpublished study).

¹⁵⁶ http://www.dental.umaryland.edu/dentaldepts/micropath/enwonwu_mission.html

60. Noma is almost ignored by governmental funding and did not benefit of the attention of any major human rights or humanitarian NGO.¹⁵⁷

IV. Conclusions and Recommendations

61. Noma is killing, disfiguring, and destroying the lives of children. The persistence of Noma - the disease of Nazi concentration camps – in today's world raises doubts not only about our morality, but it comes to prove that the human rights of children, the most vulnerable members of the international community are being severely ignored and violated. States and international organizations have a duty to act.

62. Malnutrition is the main predisposing factor of this horrendous childhood disease. Therefore, States – those with high stunting and wasting rates in children, as well as donor states – must reinforce their fight against malnutrition.¹⁵⁸ This is an imperative, which flows from their international legal obligations. Assistance earmarked for nutrition must increase. 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. Vulnerable groups must be targeted with priority. Gender discrimination, discrimination of the poor from the rural areas and corruption must be systematically tackled as a paramount condition for achieving a brighter future for our children.

63. Noma is a disease that affects children worldwide. It thus must be addressed at the global level. This includes worldwide surveillance, prevention, primary health care, surgical and rehabilitation treatment and etiological study. The current focus on Africa, through the WHO Regional Office in Africa, is insufficient. Children in Asia or beyond are also at risk of losing their life to one of the most redoubtable killers, Noma. Governmental and private funding for the fight against Noma in Africa must be increased and funding and WHO coordination for other regions must be urgently provided. States must establish Noma action plans and appoint a Noma focal person.

64. Noma is a neglected disease; neglected by the medical community, by governmental authorities, by major private donors and by public opinion. In spite of that, it is a childhood disease with strikingly high mortality rates and it carries a similar social stigma as leprosy, the latter a neglected disease. Noma needs to be acknowledged as a neglected disease by the WHO, if any change in the current ignorance is to be achieved. States should promote a resolution at the World Health Assembly to list Noma as a neglected disease.

65. This preliminary study has unequivocally shown that malnourished children at risk of Noma are one of the most vulnerable groups from a human rights perspective. Children affected by Noma are facing a life marked by discrimination, similar to individuals affected by leprosy. The parallel to leprosy and the findings of the study has led the authors 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 Advisory Committee (A/HRC/15/30) and of which the Human Rights Council has taken note with appreciation (A/HRC/15/L.18). Therefore the drafting group on the right to food of the Advisory Committee puts forward in the Annex A *human rights framework to improve the protection of children at risk or affected by*

¹⁵⁷ As mentioned above, Médecins Sans Frontières will start work on Noma. See *supra* para 50.

¹⁵⁸ Very relevant in this context is the following strategy document endorsed by a large number of UN agencies and NGOs: *Scaling Up Nutrition: A Framework for Action*, Reprint April 2011, available at <http://siteresources.worldbank.org/NUTRITION/Resources/281846-1131636806329/PolicyBriefNutritionScalingUpApril.pdf>.

malnutrition, specifically at risk of or affected by Noma - Principles and Guidelines. Comments in relation to this human rights framework from all stakeholders, in particular from members of the Advisory Committee, States, the WHO, UNICEF, NGOs and other actors working on Noma and from the human rights and humanitarian fields are strongly encouraged.

Annex

A human rights framework to improve the protection of children at risk or affected by malnutrition, specifically at risk of or affected by Noma – Principles and guidelines

I. Principles

A. The rights of the child

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 fulfillment of the rights of women and of children, including those at risk/affected by malnutrition and Noma.

States have an international obligation to respect, protect and fulfill the rights of the child and of their parents.

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.

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

Every child, including a child at risk/affected by malnutrition and Noma, has the right to water and sanitation. States shall respect, protect and fulfill the right to safe drinking water and sanitation, and thus take steps to realize the physical and economic access to sanitation which is safe, hygienic, secure, socially and culturally acceptable, provides privacy and ensures dignity.

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.

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.

Every child, including a child at risk/affected by malnutrition and Noma, has the right to adequate housing. States shall respect, protect and fulfill the right to housing by ensuring

access to secure, affordable, culturally adequate shelter and characterized by availability of services, materials, facilities and infrastructure essential for health, nutrition and comfort.

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

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

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

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

States shall urgently take all necessarily 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:

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.

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 fulfill 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.

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.

States should promote a resolution at the World Health Assembly to list Noma as a neglected disease.

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.

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:

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.

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.

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 six 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.

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.

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.

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;

Mouth-rinses, antibiotics and nutritional supplements should be made available and free of charge for children with acute necrotizing gingivitis.

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.

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.

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.

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.

States are encouraged to include in their State party reports to the relevant treaty bodies information on the adopted Noma action plans and on the progress as well as problems encountered during implementation.
