NOMA & HUMAN RIGHTS LAW – A DOCTRINAL LEGAL ANALYSIS WITH FOCUS ON BURKINA FASO, NIGER AND LAOS

Background Study, 2020

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INTRODUCTION

This background study has been prepared in the framework of the research project Noma: The Neglected Disease. An Interdisciplinary Exploration of Its Realities, Burden, and Framing (hereafter, the Noma Project). It has a twofold aim. First, it seeks to complement and update the legal analysis provided in the 2012 Study of the Human Rights Council Advisory Committee (HRCAC) on severe malnutrition and childhood diseases with children affected by noma as an example (hereafter, the 2012 HRCAC Study).² That report was the first iteration of noma's framing from a human rights perspective and sought to identify the human rights of individuals at risk of or with noma that are at stake and pinpoint some of the states' obligations that arise in the context of this disease. As it was restricted to 10,700 words,³ the study was not able to provide a deep grounding of noma in international and regional human rights law. The current study aims to address this shortcoming though as systematic legal analysis, whilst taking stock of the normative developments relevant to this disease and the legal and medical literature published in the past eight years. Second, the study aims to serve as background research for an article on the human rights framing of noma, as well as for policy papers developed for organisations working on the monitoring and prevention of noma which seek to integrate a human rights framework in their work.

Methodologically, the document utilises doctrinal legal analysis to map the international and regional human rights framework relevant to the experiences of children at risk of noma, as well as children and adult survivors of the disease. It draws on some early findings on risk factors and social determinants in Burkina Faso, Niger and Laos, which are being produced as part of the Noma Project's research package 3 'Realities and Lived Experiences of Noma'. The study is intended as a working document and will be updated to integrate findings as the data analysis of research package 3 progresses.

Structurally, the paper's first part identifies the international human rights treaties to which the project's three case study countries, Burkina Faso, Niger and Laos are party. Following a section that seeks to clarify the use of some key human rights concepts, it identifies the legal basis and definitional contours of selected rights, and examines the normative descriptors of rights, and the correlative obligations of states. The second part focuses on the regional human rights treaties, identifying legal provisions of particular relevance in the context of our inquiry on noma. The third part briefly outlines the transposition of international and regional obligations relating to noma into domestic law.

¹ We gratefully acknowledge the research grant awarded by the Swiss Network for International Studies (SNIS) which has made this research possible.

² I Cismas, 'Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example' (24 February 2012) UN Doc. A/HRC/19/73.

³ The word count is standard in UN reports of this type.

⁴ See https://thenomaproject.org/realities.

1. INTERNATIONAL HUMAN RIGHTS TREATIES

Central to determining sources of law are states' consent to be bound by international legal norms.⁵ Burkina Faso, Niger and Laos's human rights obligations find legal basis in the international treaties to which they are party. Table A depicts the three states' ratification history of five of the nine core international human rights instruments, the principal treaties which enshrine the rights identified by the 2012 HRCAC Study. The following economic, social and cultural (ESC) and civil and political (CP) rights were emphasised:

- the right to food;
- the right to water and sanitation;
- the right to health;
- the right to adequate housing;
- the right to education;
- the right to life;
- the right to freedom of expression;
- the right of children with disabilities to a full and decent life;
- the right to equality and non-discrimination.

As will be systematically shown in this research, for children at risk of noma, as well as children and adult survivors, these rights are particularly vulnerable to pervasive violation across the intersections of structural antecedents, clinical development, and medico-social effects of the disease.

Table A - Ratification of International Human Rights Treaties⁶

Treaty	Burkina Faso	Niger	Laos
International Covenant on Civil and Political Rights (ICCPR)	04 Jan 1999 (a)	07 Mar 1986 (a)	25 Sep 2009
International Covenant on Economic, Social and Cultural Rights (ICESCR)	04 Jan 1999 (a)	07 Mar 1986 (a)	13 Feb 2007
Convention on the Elimination of All Forms of Discrimination against Woman (CEDAW)	14 Oct 1987 (a)	08 Oct 1999 (a)	14 Aug 1981
Convention on the Rights of the Child (CRC)	31 Aug 1990	30 Sep 1990	08 May 1991 (a)
Convention on the Rights of Persons with Disabilities (CRPD)	23 Jul 2009	26 Oct 2004	25 Sep 2009

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⁵ C Chinkin, 'Sources' in D Moeckli, S Shah & S Sivakumaran (eds), *International Human Rights Law* (2nd edn, OUP 2014), 77-78.

⁶ The source of the ratification history is available here: https://indicators.ohchr.org.

1.1. CONCEPTUAL PRELIMINARIES

In the past three decades, we have witnessed a normative re-positioning of ESC rights on the same value plane as CP rights.⁷ This has been achieved, *inter alia*, through the normative clarification work undertaken by international treaty bodies, in particular the Committee on Economic, Social and Cultural Rights (CESCR)⁸ and UN Special Procedures,⁹ the increased adjudication of ESC rights by national and regional courts and under the Optional Protocol to the ICESCR,¹⁰ and as a result of efforts by scholars, feminist and social movements, and nongovernmental organisations.

At the same time, the development of positive obligations – or obligations to protect and fulfil – CP rights, through the interpretative practice of treaty bodies, principally the Human Rights Committee (CCPR) and adjudication by regional courts should be noted. ¹¹ This development has contributed to de-mystifying the notion that CP rights are negative rights, which in order to be realised require that states merely refrain from interferences. ¹² Much rather today an (increasingly) shared understanding among human rights scholars and practitioners exists which recognises that both CP and ESC rights attach positive *and* negative obligations and that *all* of their realisation requires states to undertake legislative, administrative, judicial, educational and other measures.

It is in the above-outlined context that the present study places noma; in this section, thus, we presents some key concepts for understanding how states' CP and ESC rights obligations are interpreted, monitored and assessed by relevant international and regional supervision mechanisms.

⁷ For a discussion see I Cismas, 'The Intersection of Economic, Social, and Cultural rights and Civil and Political rights', in E Riedel *et al.*, *Economic, Social, and Cultural Rights in International Law. Contemporary Issues and Challenges* (OUP, 2014), 448-472.

⁸ See M Sepúlveda, *The Nature of the Obligations under the International Covenant on Economic, Social and Cultural Rights* (Antwerp, Oxford, New York: Intersentia, 2003), 73-112.

⁹ C Golay, C Mahon, and I Cismas, 'The Impact of the UN Special Procedures on the Development and Implementation of Economic, Social and Cultural rights' (2011) 15(2) *The International Journal of Human Rights* 299-318.

¹⁰ See for example: C Golay, *Droit à l'alimentation et accès à la justice* (Bruxelles: Bruylant, forthcoming in 2011); M Langford (ed.), *Social Rights Jurisprudence: Emerging Trends in Comparative and International law* (New York: Cambridge University Press, 2008); F Coomans (ed.), *Justiciability of Economic and Social rights: Experiences from Domestic Systems* (Antwerp: Intersentia, 2006); C de Albuquerque *et al.*, *The Optional Protocol to the International Covenant on Economic, Social and Cultural Rights: A Commentary* (1st edn PULP, 2016).

¹¹ See for example: I Cismas, 'The Intersection of Economic, Social, and Cultural rights and Civil and Political rights', in E Riedel *et al.*, *Economic, Social, and Cultural Rights in International Law. Contemporary Issues and Challenges* (OUP, 2014), 448-472; M Nowak, *UN Covenant on Civil and Political Rights. CCPR Commentary* (2nd edn., Kehl: N.P Engel, 2005), at XXI; D Xenos, *The Positive Obligations of the State under the European Convention of Human Rights* (Routledge, 2012).

¹² See I Cismas, 'The Right to Food Beyond De-Mythification: Time to Shed the Inferiority Complex of Socio-Economic Rights' (2014) 5(4) *Global Policy* 474–476.

1.1.1. Progressive realisation and non-retrogression¹³

Article 2(1), ICESCR entails a progressive realisation clause, which acknowledges the different levels of development of state parties and the resource constraints these may face. It reads:

"Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures." ¹⁴

Art. 4, CRC equally entails a progressive realisation provision:

"States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation." ¹⁵

In interpreting Article 2(1), the CESCR has sought to strike a balance between the reality of varying resource constraints and the object and purpose of the ICESCR, which is the full realisation of socio-economic rights. As such, both the ICESCR and the CRC gives rise to some immediate obligations. The obligations "to take steps" and "undertake all appropriate measures" are obligation of immediate effect, which can be discharged through the adoption of legislation, judicial or other remedies, administrative, financial, educational, and social measures.¹⁶ According to the CESCR, states must directly, constantly and concretely move towards the full realization of rights, "using all appropriate means, including particularly but not only the adoption of legislative measures".¹⁷

In General Comment 3, the Committee introduces the notion of "deliberately retrogressive measures", yet provides no specification on the concept — retrogression is generally understood to refer to an "erosion of progress" or "step back" in the protection of socioeconomic rights.

¹³ This section draws on background research undertaken by I Cismas and partly reproduced in International Law Association, Committee on Human Rights in Times of Emergency, Interim Report: Developments in Standard Setting and Practice (1990-2020), Kyoto, 2020.

¹⁴ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 2(1).

¹⁵ Convention on the Rights of the Child (entered into force 2 September 1990) 1577 UNTS 3 (CRC), Article 4.

¹⁶ OHCHR, 'CESCR General Comment 3, The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant), (Contained in Document E/1991/23), 14 December 1990, paras. 1-7.

¹⁷ *ibid*, para. 16.

¹⁸ B Warwick, 'Unwinding Retrogression: Examining the Practice of the Committee on Economic, Social and Cultural Rights' (2019) 19(3) Human Rights Law Review 467, 468.

¹⁹ M Sepúlveda, *The Nature of the Obligations under the International Covenant on Economic, Social and Cultural Rights* (Intersentia nv, 2003), 323.

The interpretative practice post-1998 evidences a general presumption for the impermissibility of deliberately retrogressive measures, ²⁰ which holds true, in the Committee's view, also in times of emergency, such an armed conflict situation. The presumption's rationale maps onto the logic of limitations to rights – often referred to in relation to CP rights – which envisages that "the relation between right and restriction and between norm and exception must not be reversed", as this would empty the right or the norm of its meaning.²¹

The non-retrogression doctrine has had several iterations in the work of CESCR. To start with, in General Comment 3 of 1990, the Committee stipulates three conditions in respect to deliberately retrogressive measures; they:

"[1] would require the most careful consideration and [2] would need to be fully justified by reference to the totality of the rights provided for in the Covenant and [3] in the context of the full use of the maximum available resources."²²

Put differently, the obligation not to take deliberately retrogressive measures is not absolute – except in respect to the core content of rights. Yet, the permissibility of such measures depends on the ability of the state party to provide evidence that it meets the above outlined conditions.

Eighteen years later, in General Comment 19 on the right to social security, the CESCR provides the fullest iteration of factors which it would consider in assessing whether deliberately retrogressive measures are permissible.²³

The reason for resource scarcity appears to play a significant role in the assessment of justification of the retrogressive measures.²⁴ An unwilling v unable scenario – or rather a

²⁰ See: OHCHR, 'CESCR, General Comment No. 13, The Right to Education (Art. 13)', E/C.12/1999/10, 8 December 1999, para. 45; OHCHR, 'CESCR, General Comment No. 14: The right to highest attainable standard of health (article 12 of the ICESCR)' E/C.12/2000/4, 11 August 2000, para. 42; OHCHR, 'CESCR General Comment No. 18, The right to work', 6 February 2006, E/C.12/GC/18, para. 34; OHCHR, 'CESCR General Comment 19, The right to social security (art. 9)', E/C.12/GC/19, 4 February 2008, para. 19. Sepúlveda notes that the CESCR's monitoring of retrogressive measures has received an impetus after the adoption of the Maastricht Guidelines in 1998. See M Sepúlveda, *The Nature of the Obligations under the International Covenant on Economic, Social and Cultural Right* (Intersentia nv, 2003), 326.

²¹ Human Rights Council, General Comment No. 34: Freedoms of opinion and expression, 12 September 2011, UN Doc. CCPR/C/GC/34, para. 21.

²² OHCHR, 'CESCR, General Comment No. 3', para. 9.

²³ The assessment would consider whether: The justification for the measure was reasonable; Alternatives were comprehensively explored; Genuine participation of affected groups in examining the proposed measure and alternatives had taken place; The measures were directly or indirectly discriminatory; The measures will have a "sustained impact" or "unreasonable impact" on the right or whether "an individual or group is deprived of access to the minimum essential level", i.e. whether the measure affects the core content of the right; Domestic independent review exists. See also B Warwick, "Unwinding Retrogression: Examining the Practice of the Committee on Economic, Social and Cultural Rights" (2019) 19(3) Human Rights Law Review, 467; A Nolan, NJ Lousiani and C Courtis, "Two Steps Forward, No Steps Back? Evolving Criteria on the Prohibition of Retrogression in Economic and Social Rights" in A Nolan (ed.), *Economic and Social Rights after the Global Financial Crisis* (Cambridge University Press, 2014), 133-135.

²⁴ See discussion in A Mueller, *The Relationship between Economic, Social and Cultural Rights and International Humanitarian Law* (1st edn Nottingham Studies on Human Rights, 2013), 131-132.

spectrum with the two extremes – can be discerned from the "objective criteria" which the CESCR outlines in a Statement occasioned by the drafting of the Optional Protocol.²⁵ As such, a certain discretion appears to be afforded to states facing situations of emergency, such as armed conflict or natural disaster, or economic recession. However, mere reliance on the emergency situation to justify retrogression would appear to be insufficient – the assessment would need to engage with the other criteria and factors identified above.²⁶

Notably, the CESCR underscores the importance of the phrase "through international assistance and cooperation" in progressive realization, which is understood to be essential in facilitating full realization through economic and technical resources and responsibilities.²⁷ Not asking or accepting international assistance would be a clear example of unwillingness to undertake all possible measures towards the realisation of ESC rights.

1.1.2. Core content of ESC rights and corresponding obligations

In General Comment 3, the CESCR proclaimed "a minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights is incumbent upon every State party"²⁸. The concepts of minimum core content of rights (or essential minimum levels) and corresponding obligations, whilst not explicit in the ICESCR or the CRC, are grounded simultaneously in the subsistence nature of many ESC rights and the object and purpose of these treaties. As such, the CESCR notes:

A State party in which any significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or of the most basic forms of education is, prima facie, failing to discharge its obligations under the Covenant.²⁹

Starting with General Comment 12 on the right to food in 1999,³⁰ the CESCR has consistently identified core content obligations. These comprise variations of the following obligations:

• to ensure access to minimum levels of a right;

²⁵ The identified factors are: "(a) The country's level of development; (b) The severity of the alleged breach, in particular whether the situation concerned the enjoyment of the minimum core content of the Covenant; (c) The country's current economic situation, in particular whether the country was undergoing a period of economic recession; (d) The existence of other serious claims on the State party's limited resources; for example, resulting from a recent natural disaster or from recent internal or international armed conflict; (e) Whether the State party had sought to identify low-cost options; and (f) Whether the State party had sought cooperation and assistance or rejected offers of resources from the international community for the purposes of implementing the provisions of the Covenant without sufficient reason." Committee on Economic, Social and Cultural Rights, An evaluation of the obligation to take steps to the "maximum of available resources under an Optional Protocol to the Covenant – Statement, 10 May 2007, E/C.12/2007/1, para. 10.

²⁶ See, for example: OHCHR, 'CESCR Concluding Observations on the Democratic Republic of Congo, E/C.12/COD/CO/4, 16 December 2009, para. 16.

²⁷ OHCHR, 'CESCR General Comment No. 3: The Nature of States Parties' Obligations (Art. 2. Para. 1, of the Covenant)' (14 December 1990) UN Doc. E/1991/23, para. 13.

²⁸ OHCHR, 'CESCR General Comment 3', para. 10.

²⁹ Ibid.

³⁰ OHCHR, 'CESCR General Comment No. 12: The Right to Adequate Food (Art. 11)', E/C.12/1999/5, 12 May 1999.

- non-discriminatory access, "especially for disadvantaged and marginalized individuals and groups";
- to respect and protect from third party interferences the existing access to a right;
- to adopt and implement national strategies and action plans;
- to monitor the extent of realisation of a right.³¹

The CRC Committee has employed the notion of "core obligations" in some of its general comments on socio-economic rights,³² but not in others, an ambiguity, which has been suggested, may reflect some of the remaining uncertainties relating to this concept.³³ In particular, the uncertainty remains concerning whether universal minimum levels of a right must be ensured or a national minimum. A too expansive understanding of universal core content obligations may lead to the practical impossibility for many developing states or those facing emergency situations to meet their obligations; a too modest approach will provide developed states with insufficient incentives to advance socio-economic rights.³⁴

1.1.3. Limiting CPR rights

Very few human rights are absolute rights. One such example is the right to life, yet even this right — often presented as the archetype human right — provides certain restricted circumstances when deprivation of life may not be considered arbitrary. As noted earlier, although a CP right, the right to life attaches positive obligations. General Comment 36 of the CCPR makes this point abundantly clear: "The right to life is a right that should not be interpreted narrowly. It concerns the entitlement of individuals to be free from acts and omissions that are intended or may be expected to cause their unnatural or premature death, as well as to enjoy a life with dignity." As noted in the analysis below, the positive obligations relating to the right to life or of outmost importance for individuals at risk of or those who have developed noma.

The majority of rights – and indeed this is the case for the right to freedom of expression, which is of particular relevance to the context of noma – are qualified rights. This means that they can be subjected to limitations provided that the interference resulting from these restrictions fulfil a set of strict conditions: they are prescribed by law, pursue a legitimate aim

³¹ See for example: OHCHR, 'CESCR, General Comment 19' para. 59.

³² Committee on the Rights of the Child, General comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health (art. 24), 17 April 2013, CRC/C/GC/15, para. 73.

³³ See C Courtis and J Tobin, "Article 28: The Right to Education" in J Tobin (ed), *The UN Convention on the Rights of the Child. A Commentary* (OUP 2019), 1056-1115.

³⁵ "Paragraphs 2, 4, 5 and 6 of article 6 of the [ICCPR] set out specific safeguards to ensure that in States parties that have not yet abolished the death penalty, death sentences are not applied except for the most serious crimes, and then only in the most exceptional cases and under the strictest limits... The prohibition on arbitrary deprivation of life contained in article 6 (1) further limits the ability of States parties to apply the death penalty. The provisions in paragraph 3 regulate specifically the relationship between article 6 of the Covenant and the Convention on the Prevention and Punishment of the Crime of Genocide." Committee on Civil and Political Rights, General Comment 36: Article 6: right to life, CCPR/C/GC/36, 3 September 2019, para. 5.

³⁶ Ibid., para. 3.

(usually exhaustively detailed in treaty provisions), and are necessary and proportional to the sought aim.³⁷

1.1.4. The tripartite obligation to respect, protect and fulfil

The tripartite typology of "how human rights obligations should be secured", observes Mégret, has been widely adopted and implemented by UN treaty bodies – as well as regional courts and UN Special Procedures –, imposing upon States parties correlative obligations to *respect*, to *protect* and to *fulfil* human rights.³⁸ Conveyed through a wide variety of UN mechanisms, these obligations can be broadly defined as

- meaning that "States must refrain from interfering with or curtailing the enjoyment of human rights" (respect),
- requiring "States to protect individuals and groups against human rights abuses" (protect), and
- meaning that "States must take positive action to facilitate the enjoyment of basic human rights" (fulfil).³⁹

1.2. DEFINING THE RIGHTS

As referenced earlier, the 2012 HRCAC study discusses a range of human rights at risk of violation in the context of noma. This section of the background study identifies the legal basis of each right, the core content and the dimensions subject to the principle of progressive realisation (if applicable), or the limitations which may be placed on the right in certain conditions.

1.2.1. The right to food

Legal basis

Article 11(1) ICESCR: "The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The States Parties will take appropriate steps to ensure the realization of this right, recognizing to this effect the essential importance of international co-operation based on free consent". 40

³⁷ See generally: F Mégret, 'Nature of Obligations' in D Moeckli, S Shah & S Sivakumaran (eds), *International Human Rights Law* (2nd edn, OUP 2014), 110-112.

³⁸ F Mégret, 'Nature of Obligations' in D Moeckli, S Shah & S Sivakumaran (eds), *International Human Rights Law* (2nd edn, OUP 2014), 101.

³⁹ 'International Human Rights Law' (OHCHR n.d.)

https://www.ohchr.org/en/professionalinterest/pages/internationallaw.aspx accessed 3 February 2020.

⁴⁰ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 11(1).

Article 11(2) "The States Parties to the present Covenant, recognizing the fundamental right of everyone to be free from hunger, shall take, individually and through international cooperation, the measures, including specific programmes...".⁴¹

Core Content

According to the CESCR, States parties have "a core obligation to take the necessary action to mitigate and alleviate hunger as provided for in paragraph 2 of article 11, even in times of natural or other disasters", ensuring "the availability of food in a quantity and quality sufficient to satisfy the dietary needs of individuals, free from adverse substances, and acceptable within a given culture [and] the accessibility of such food in ways that are sustainable and that do not interfere with the enjoyment of other human rights".⁴²

Progressive Realization

The interrelated dimensions of the right to food subject to the principle of progressive realization are outlined by the Food and Agriculture Organization's 2005 'Voluntary Guidelines to support the progressive realization of the right to adequate in the context of national food security'.⁴³ Listed below are some of the nineteen comprehensive guidelines identified by the FAO, which thematically map the progressive realization of the right to food:

- "Democracy, good governance, human rights and the rule of law;
- Promotion of broad-based, sustainable economic development, with a focus on sustainable agriculture and improving resource-access in situations of rural poverty;
- Building and implementation of national human rights strategies that include monitoring mechanisms. Prioritisation of basic services, broad based consultation with stakeholders, develop policies specifically for small-scale rural farmers to increase productivity;
- Facilitation of sustainable and non-discriminatory access and utilization of resources, promote and protect access of vulnerable groups to economic opportunities and resources. Implement gender-sensitive legislation around inheritance and possession of land and property;
- Provide education around healthy diets. Implement, manage and monitor programmes for the production and consumption of healthy foods, promote breastfeeding, disseminate information;
- Educative and infrastructure measures to improve housing conditions and means of food production, particularly in rural households;
- Transparent use of national resources;
- With regards to vulnerable groups, systematic undertaking of disaggregated analysis on food insecurity, vulnerability and nutritional status of different groups in society;

⁴¹ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 11(2).

⁴² OHCHR, 'CESCR, General Comment No. 12: The Right to Adequate Food (Art. 11)' (12 May 1999) UN Doc. E/C.12/1999/5, paras. 6-8.

⁴³ Food and Agriculture Organization, 'Voluntary Guidelines to support the progressive realization of the right to adequate food in the context of national food security' (adopted by 127th Session of the FAO Council, November 2004).

- International food aid policies to support the national efforts of recipient States to achieve food security;
- Monitoring, indicators and benchmarks. States may wish to establish mechanisms to monitor and evaluate the implementation of these guidelines towards progressive realization, may wish to consider conducting 'Right to Food Impact Assessments', develop a set of process, impact and outcome indicators [evaluation process]".⁴⁴

1.2.2. The right to water and sanitation

Core Content

The right to water is provided for within the category of guarantees constituting the right to an adequate standard of living (article 11(1) ICESCR).⁴⁵ The CESCR details a number of core obligations of immediate effect in relation to the right to water:

- "To ensure access to the minimum essential amount of water, that is sufficient and safe for personal and domestic uses to prevent disease;
- To ensure the right of access to water and water facilities and services on a nondiscriminatory basis, especially for disadvantaged or marginalized groups;
- To ensure physical access to water facilities or services that provide sufficient, safe and regular water; that have a sufficient number of water outlets to avoid prohibitive waiting times; and that are at a reasonable distance from the household;
- To ensure personal security is not threatened when having to physically access to water:
- To ensure equitable distribution of all available water facilities and services;
- To adopt and implement a national water strategy and plan of action addressing the
 whole population; the strategy and plan of action should be devised, and periodically
 reviewed, on the basis of a participatory and transparent process; it should include
 methods, such as right to water indicators and benchmarks, by which progress can be
 closely monitored; the process by which the strategy and plan of action are devised,
 as well as their content, shall give particular attention to all disadvantaged or
 marginalized groups;
- To monitor the extent of the realization, or the non-realization, of the right to water;
- To adopt relatively low-cost targeted water programmes to protect vulnerable and marginalized groups;
- To take measures to prevent, treat and control diseases linked to water, in particular ensuring access to adequate sanitation".⁴⁶

Progressive Realization

⁴⁴ Food and Agriculture Organization, 'Voluntary Guidelines to support the progressive realization of the right to adequate food in the context of national food security' (adopted by 127th Session of the FAO Council, November 2004).

⁴⁵ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 11(1).

⁴⁶ OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 37.

The CESCR states that, in accordance with the rights to health and adequate housing, "States parties have an obligation to progressively extend safe sanitation services, particularly to rural and deprived urban areas, taking into account the needs of women and children".⁴⁷ Additionally, the CESCR identifies the requirement to monitor progress towards the realization of the right to water (para. 37(f)), in particular identifying "the factors and difficulties affecting implementation of their obligations".⁴⁸

1.2.3. The right to health

Core Content

Article 12(1) ICESCR: "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health".⁴⁹

For the right to health, the CESCR expansively details the following core obligations incurred by States Parties:

- a. "To ensure the right of access to health facilities, goods and services on a nondiscriminatory basis, especially for vulnerable or marginalized groups;
- b. To ensure access to the minimum essential food which is nutritionally adequate and safe, to ensure freedom from hunger to everyone;
- c. To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;
- d. To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;
- e. To ensure equitable distribution of all health facilities, goods and services;
- f. To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups".

The CESCR also confirms the following as obligations of comparable priority:

- a. "To ensure reproductive, maternal (prenatal as well as post-natal) and child health care:
- b. To provide immunization against the major infectious diseases occurring in the community;

⁴⁷ OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 29.

⁴⁸ OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 52.

⁴⁹ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 12(1).

- c. To take measures to prevent, treat and control epidemic and endemic diseases;
- d. To provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them;
- e. To provide appropriate training for health personnel, including education on health and human rights". 50

Progressive Realization

As the most appropriate measures for the implementation of this right will vary from the economic, social and political circumstances of individual states, there are no fixed prescriptions elucidated in international treaties.⁵¹ However, article 12 (2) of the ICESCR states, "the steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

- a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
- b) The improvement of all aspects of environmental and industrial hygiene;
- c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
- d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness".⁵²

1.2.4. The right to adequate housing

Core Content

Article 11(1) ICESCR: "The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The States Parties will take appropriate steps to ensure the realization of this right, recognizing to this effect the essential importance of international co-operation based on free consent". 53

The CESCR further delineates a number of obligations of immediate effect in the context of the right to adequate housing:

- a. "States parties must give due priority to those social groups living in unfavourable conditions by giving them particular consideration" (para. 11).
- b. "...the Covenant clearly requires that each State party take whatever steps are necessary for [achieving the full realization of the right]" (para. 12).
- c. "Effective monitoring of the situation with respect to housing", providing in particular detailed information about vulnerable and disadvantaged groups, including

⁵⁰ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, paras. 44.

⁵¹ OHCHR, 'The Right to Health: Fact Sheet No. 31' (Office of the United Nations High Commissioner for Human Rights, 2008), 24.

⁵² International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 12(2).

⁵³ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 11(1).

- "homeless persons and families, those inadequately housed and without ready access to basic amenities..." (para. 13).
- d. States must demonstrate, "that, in aggregate, the measures being taken are sufficient to realize the right for every individual in the shortest possible time in accordance with the maximum of available resources" (para. 15).⁵⁴

Progressive Realization

According to OHCHR, "some components of the right to adequate housing are... deemed subject to progressive realization". The CESCR observed the following, in relation to the Dominican Republic:

- "In order to achieve progressively the right to housing, the Government is requested to undertake, to the maximum of available resources, the provision of basic services (water, electricity, drainage, sanitation, refuse disposal, etc.) to dwellings and ensure that public housing is provided to those groups of society with the greatest need".
- "It should also seek to ensure that such measures are undertaken with full respect for the law. In order to overcome existing problems recognized by the Government in its dialogue with the Committee, the Government is urged to give consideration to initiatives designed to promote the participation of those affected in the design and implementation of housing policies".
- "Such initiatives could include: (a) a formal commitment to facilitating popular participation in the urban development process; (b) legal recognition of community-based organizations; (c) the establishment of a system of community housing finance designed to open more lines of credit for poorer social sectors; (d) enhancing the role of municipal authorities in the housing sector; (e) improving coordination between the various governmental institutions responsible for housing and considering the creation of a single governmental housing agency".⁵⁵

1.2.5. The right to education

Core Content

Article 13(1) ICESCR: "The States Parties to the present Covenant recognize the right of everyone to education. They agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms...".⁵⁶

Article 13(2)(a): "Primary education shall be compulsory and available free to all".57

⁵⁴ OHCHR, 'CESCR General Comment No. 4: The Right to Adequate Housing (Art. 11 (1) of the Covenant)' (13 December 1991) UN Doc. E/1992/23, paras. 11-15.

⁵⁵ OHCHR, 'The Right to Adequate Housing: Fact Sheet No. 21 (rev. 1)' (Office of the United Nations High Commissioner for Human Rights, 2009), 31.

⁵⁶ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 13(1).

⁵⁷ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 13(2)(a).

The CESCR identifies the minimum core obligation of the right to education as the obligations of State Parties to ensure:

- "the right of access to public educational institutions and programmes on a nondiscriminatory basis;
- that education conforms to the objectives set out in article 13(1);
- to provide primary education for all in accordance with article 13(2)(a);
- to adopt and implement a national educational strategy which includes provision for secondary, higher and fundamental education...".⁵⁸

Progressive Realization

The following obligations are qualified by the principle of progressive realization in the CESCR's general comment on the right to education: "...[w]hereas primary education shall be available "free to all", States parties are required to progressively introduce free secondary and higher education". ⁵⁹

1.2.6. The right to life

Legal basis

Article 6(1) ICCPR: "Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life".⁶⁰

Article 6 CRC: "1. States Parties recognize that every child has the inherent right to life. 2. States Parties shall ensure to the maximum extent possible the survival and development of the child".⁶¹

Normative content

As noted in a previous section, the right to life needs to be interpreted broadly as it "concerns the entitlement of individuals to be free from acts and omissions that are intended or may be expected to cause their unnatural or premature death, as well as to enjoy a life with dignity." The CCPR notes the interdependence of the right to life with other human rights, and that its "content can be informed" by these other rights. 63

In General Comment 36, the CCPR provides a serious of specific elaborations which are relevant in the context of noma. As such:

 "States parties should take appropriate measures to address the general conditions in society that may give rise to direct threats to life or prevent individuals from enjoying

⁵⁸ OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, para. 57.

⁵⁹ OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, para. 6(b, iii).

⁶⁰ International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (ICCPR), Article 6.

⁶¹ Convention on the Rights of the Child (entered into force 2 September 1990) 1577 UNTS 3 (CRC), Article 6(1)(2).

⁶² OHCHR, 'CCPR General Comment 36: Article 6: right to life', CCPR/C/GC/36, 3 September 2019, para. 5.

⁶³ Ibid., para. 2.

their right to life with dignity. These general conditions may include ... the prevalence of life-threatening diseases, such as AIDS, tuberculosis and malaria, ... widespread hunger and malnutrition and extreme poverty and homelessness." ⁶⁴

- The Committee goes on to note that the "measures called for to address adequate conditions for protecting the right to life include, where necessary, measures designed to ensure access without delay by individuals to essential goods and services such as food, water, shelter, health care, electricity and sanitation, and other measures designed to promote and facilitate adequate general conditions, such as the bolstering of effective emergency health services, ... and social housing programmes."65
- Moreover, States parties are called upon to "develop strategic plans for advancing the
 enjoyment of the right to life, which may comprise measures to fight the
 stigmatization associated with disabilities and diseases, ... which hamper access to
 medical care; ... and for improving access to medical examinations and treatments
 designed to reduce maternal and infant mortality."66
- "When taking special measures of protection, States parties should be guided by the best interests of the child, and by the need to ensure all children's survival, development and well-being." ⁶⁷

It should be noted that noma is a disease with a staggering high mortality rate among children (estimated at 90%),⁶⁸ hence the above normative interpretations are of particularly relevance and pressing.

1.2.7. The right to freedom of expression

Core Content

Article 19(2) ICCPR: "Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice".

Article 13(1) CRC: "The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice". 69

Article 7(3) CRPD "States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in

⁶⁴ Ibid., para. 26.

⁶⁵ Ibid.

⁶⁶ Ibid.

⁶⁷ Ibid.

⁶⁸ WHO, 'Promoting Oral Health in Africa: Prevention and control of oral diseases and noma as part of essential noncommunicable disease interventions' (Brazzaville, WHO Regional Office for Africa 2016).

⁶⁹ Convention on the Rights of the Child (entered into force 2 September 1990) 1577 UNTS 3 (CRC), Article 13(1).

accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right."

In the context of noma, the aspects of freedom of expression which are particularly relevant for children, parents, guardians, and carers as well as their communities relate to receiving health-related information about the disease, as well as information which seeks to dispel myths and reduce stigmatisation relating to its occurrence.

Limitation Clauses

Article 19(3) ICCPR (and near-equivalent in article 13, CRC): "The exercise of the rights provided for in paragraph 2 of this article carries with it special duties and responsibilities. It may therefore be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:

- a. For respect of the rights or reputations of others;
- b. For the protection of national security or of public order (ordre public), or of public health or morals".⁷⁰

Note that the CCRP in its General Comment explains the restrictions on freedom of expression may not empty the right of its content.⁷¹

1.2.8. The rights of children with disabilities to a full and decent life

Core Content

Article 23(1) CRC: "States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community".⁷²

Article (1) CRPD: "States shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children".⁷³

Progressive Realization

The CESCR's general comment No. 5 on persons with disabilities states: "the obligation of States parties to the Covenant to promote progressive realization of the relevant rights to the maximum of their available resources clearly requires Governments to do much more than merely abstain from taking measures which might have a negative impact on persons with disabilities. The obligation in the case of such a vulnerable and disadvantaged group is to take positive action to reduce structural disadvantages and to give appropriate preferential

⁷⁰ International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (ICCPR), Article 19.

⁷¹ OHCHR, 'CCPR General Comment 34: Article 19: Freedom of opinion and expression, CCPR/C/GC/34, 12 September 2011, para. 21

⁷² Convention on the Rights of the Child (entered into force 2 September 1990) 1577 UNTS 3 (CRC), Article 23(1).

⁷³ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) A/RES/61/106 (CRPD), Article (1).

treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities. This almost invariably means that additional resources will need to be made available for this purpose and that a wide range of specially tailored measures will be required".⁷⁴

1.2.9 The overarching right to equality and non-discrimination

The right to equality and non-discrimination is guaranteed by all of the principal human rights treaties, as Moeckli observes, "international human rights law prohibits discrimination in treatment (direct discrimination) as well as in outcome (indirect discrimination), regardless of whether it is intended or unintended".⁷⁵

Legal basis

Article 2(2) ICESCR: "The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status". ⁷⁶

Similar provisions can be found in Article 2(1), ICCPR and 2(1), CRC. The CEDAW and CRPD are treaties which seek precisely to eliminate discrimination against groups of individuals, specifically women and persons with disabilities. Article 6, CRPD provides for specific protections to women with disabilities recognising that they often suffer from intersectional discrimination. In the context of neglected tropical diseases – which the Noma Project argues noma is one –, intersectional discrimination is has been observed: "Research on stigma and tropical diseases reveals that women may experience more social disadvantages than men from physically disfiguring conditions, such as lymphatic filariasis".⁷⁷

Correlative Obligations

The CESCR states in its General Comment 20 that, "[n]on-discrimination is an immediate and cross-cutting obligation in the Covenant... requir[ing] States parties to guarantee non-discrimination in the exercise of each of the economic, social and cultural rights enshrined in the Covenant". 78

It should be noted that the tripartite obligation to respect, protect *and* fulfil applies to non-discrimination. In particular, "it is now well established in international human rights law that it is not sufficient for states to have anti-discrimination legislation in place. Instead they also

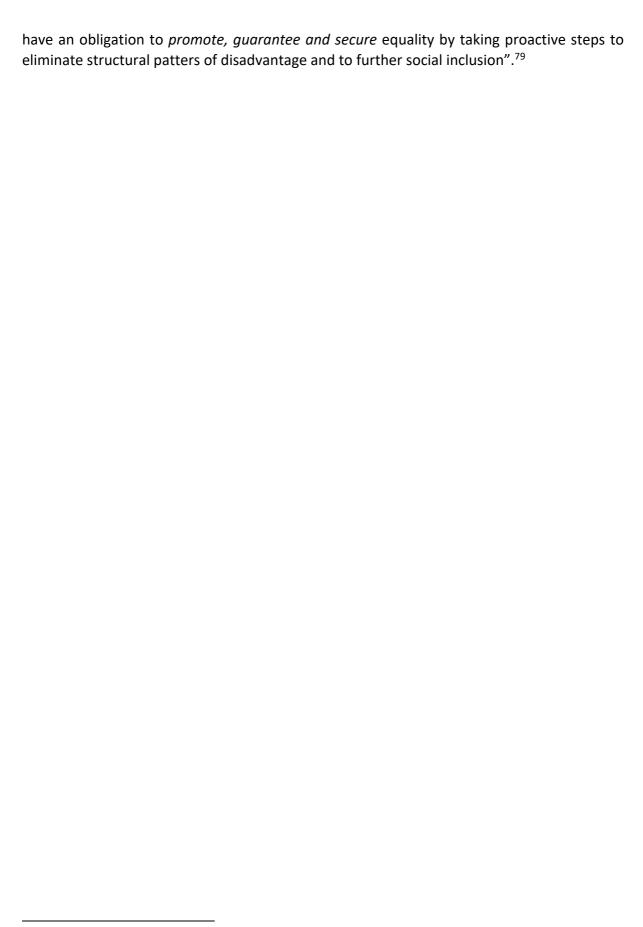
⁷⁴ OHCHR, 'CESCR General Comment No. 5: Persons with Disabilities' (9 December 1994) UN Doc. E/1995/22, para. 9.

⁷⁵ D Moeckli, 'Equality and Non-Discrimination' in D Moeckli, S Shah & S Sivakumaran (eds), *International Human Rights Law* (2nd edn, OUP 2014), 157.

⁷⁶ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 2(2).

⁷⁷ Coreil *et al.*, as cited in P Hunt *et al.*, 'Neglected diseases: A human rights analysis' (2007) WHO Special Topics No. 6 Social, Economic and Behavioural Research, 25.

⁷⁸ OHCHR, 'CESCR General Comment No. 20: Non-discrimination in economic, social and cultural rights (art. 2, para. 2, of the International Covenant on Economic, Social and Cultural Rights)' (2 July 2009) UN Doc. E/C.12/GC/20, para. 7.



⁷⁹ D Moeckli, 'Equality and Non-Discrimination' in D Moeckli, S Shah & S Sivakumaran (eds), *International Human Rights Law* (2nd edn, OUP 2014), 170.

1.3. NORMATIVE DESCRIPTORS OF ESC RIGHTS

Normative standards of availability, accessibility, adequacy and acceptability have been developed through the work of UN treaty bodies and UN Special Procedures. These describe elements that States are required to meet in the context of fully realizing their obligations owed towards all rights-holders. In this section, the standards are presented alongside analytical examples drawn from existing clinical and socio-legal work on noma, as well as from material pertaining to the project's case study contexts.

1.3.1. Availability of...

<u>Adequate Food:</u> "...of food in a quantity and quality sufficient to satisfy the dietary needs of individuals, free from adverse substances, and acceptable within a given culture".⁸⁰

- The CESCR clarifies the terms dietary needs as implying that "the diet as a whole contains a mix of nutrients for physical and mental growth, development and maintenance, and physical activity that are in compliance... at all stages throughout the life cycle".⁸¹
- The importance of the availability of an adequately nutritious diet for children at risk of noma has been affirmed by Srour *et al.* (2017), who state that "malnutrition is an ever present factor" in the etiology of the disease.⁸² Indeed, the CESCR's 2016 concluding observations on the report of Burkina Faso express concern at "the alarming persistence of acute malnutrition among children under the age of 5 years and at the prevalence of the noma disease".⁸³
- Availability, determines the CESCR, also refers to "the possibilities either for feeding oneself directly from productive land... or for well-functioning distribution, processing and market systems",⁸⁴ a dimension of the right to food refracted through structural complexity and precarity in all case study contexts.

<u>Water:</u> "...the water supply for each person must be sufficient and continuous for personal and domestic uses. These uses ordinarily include drinking, personal sanitation, washing of clothes, food preparation, personal and household hygiene".⁸⁵

• Improvements in oral hygiene and safe drinking water are recognised as effective ways to manage and treat noma in its early stages.⁸⁶

⁸⁰ OHCHR, 'CESCR General Comment No. 12: The Right to Adequate Food (Art. 11)' (12 May 1999) UN Doc. E/C.12/1999/5, paras. 8.

⁸¹ OHCHR, 'CESCR General Comment No. 12: The Right to Adequate Food (Art. 11)' (12 May 1999) UN Doc. E/C.12/1999/5, para. 9.

⁸² ML Srour *et al.*, 'Noma: Overview of a Neglected Disease and Human Rights Violation' (2017) 96(2) American Journal of Tropical Medicine and Hygiene, 268.

⁸³ OHCHR, 'CESCR Concluding observations on the initial report of Burkina Faso' (12 July 2016) UN Doc E/C.12/BFA/CO/1, para. 34.

⁸⁴ OHCHR, 'CESCR General Comment No. 12: The Right to Adequate Food (Art. 11)' (12 May 1999) UN Doc. E/C.12/1999/5, para. 12.

⁸⁵ OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 12(a).

⁸⁶ M Ahlgren *et al.*, 'Management of noma: practice competence and knowledge among healthcare workers in a rural district of Zambia' (2017) 10 Global Health Action, 1.

• Therefore, water must be available on a sufficiently regular basis in order to promote structured routines of oral hygiene.

<u>Highest Attainable Standard of Health:</u> "...functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party... They will include, however, the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs".⁸⁷

• The availability of medical care in rural communities is known to influence the decision-making processes of noma patients and their families. Often, their first point of contact with the healthcare pyramid is with community-based traditional healers. Farley *et al.* investigate the use of traditional healers by noma patients, decisions shaped by availability, affordability and expediency of this form of healthcare. This is further supported by an initial analysis of the findings from research package 3, as per the SNIS Intermediate Narrative Report.

<u>Education:</u> "...functioning educational institutions and programmes have to be available in sufficient quantity within the jurisdiction of the State party".⁸⁹

- The availability of education in rural areas of the case study countries is a key concern in the context of noma, as the disease is thought to affect severely malnourished children living in rural communities predominantly.
- Oluwatobi and Olurinola suggest that two principal issues limit the educative opportunities of people living in rural Africa: the often prohibitive cost of education, and the lack of proximity to schools.⁹⁰

Adequate Housing: refers to the adequacy of "services, materials, facilities and infrastructure. An adequate house must contain certain facilities essential for health, security, comfort and nutrition. All beneficiaries of the right to adequate housing should have sustainable access to natural and common resources, safe drinking water, energy for cooking, heating and lighting, sanitation and washing facilities, means of food storage, refuse disposal, site drainage and emergency services". 91

⁸⁷ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 12(a).

⁸⁸ E Farley *et al.*, "I treat it but I don't know what this disease is: a qualitative study on noma (cancrum oris) and traditional healing in northwest Nigeria' (2012) International Health 12(1), 31.

⁸⁹ OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, 6(a).

⁹⁰ S Oluwatobi & I Olurinola, 'Mobile Learning in Africa: Strategy for educating the poor' (2015) SSRN Electronic Journal, 1.

⁹¹ OHCHR, 'CESCR General Comment No. 4: The Right to Adequate Housing (Art. 11 (1) of the Covenant)' (13 December 1991) UN Doc. E/1992/23, para. 8(b).

- According to scholars, "[h]ousing and clustering can be seen as an important intermediary social determinant for many of the NTDs, having direct causal links to poverty as a structural social determinant".⁹²
- As such, the first recommended action in the context of NTD management is to address water, sanitation and household-related factors, i.e. the "preventive package". This "should be introduced in populations where data have shown a particularly heavy burden of several relevant NTDs (as well as non-NTDs)... The intervention will be a combination of preventive measures regarding water supply, sanitation, house improvement, cleaning of the peri-domestic area and clustering of people within confined areas".⁹³

1.3.2. Accessibility of...

Adequate Food: "...encompass[ing] both economic and physical accessibility. Economic accessibility implies that personal or household financial costs associated with the acquisition of food for an adequate diet should be at a level such that the attainment and satisfaction of other basic needs are not threatened or compromised... Physical accessibility implies that adequate food must be accessible to everyone, including physically vulnerable individuals". 94

- Srour et al. examine wider issues of accessibility in their socio-medical discussion of noma, identifying food security as a key prevention factor for noma in the face of "rising economic disparities [and] higher food prices" driving up etiological risk factors.⁹⁵
- Within the case study contexts of Burkina Faso and Niger, the economic and physical accessibility of food as delineated by the CESCR remains a critical concern.
- As reported by the World Food Programme (WFP), Niger is "facing a food deficit", with almost one fifth of the population unable to meet food needs due to factors such as inadequate agricultural production, whilst Burkina Faso has long experienced "chronically high rates of food insecurity".⁹⁶
- Corina et al. observe in Niger factors such as growing populations, recurrent climatic shocks, increased reliance on food imports, seasonality and stagnation in food prices combining to complicate and often curtail food accessibility, increasing malnutrition annually during "the hunger months of May-September", which occur prior to annual harvests.⁹⁷ Recent periods of armed violence in central and northern regions of

⁹² J Aagaard-Hansen & C Chaignat, 'Neglected tropical diseases: equity and social determinants' in E Blas and AS Kurup (eds), *Equity, social determinants and public health programmes* (1st edn, WHO 2010), 141.

⁹³ J Aagaard-Hansen & C Chaignat, 'Neglected tropical diseases: equity and social determinants' in E Blas and AS Kurup (eds), *Equity, social determinants and public health programmes* (1st edn, WHO 2010), 147.

⁹⁴ OHCHR, 'CESCR General Comment No. 12: The Right to Adequate Food (Art. 11)' (12 May 1999) UN Doc. E/C.12/1999/5, para. 13.

⁹⁵ ML Srour *et al.*, 'Noma: Overview of a Neglected Disease and Human Rights Violation' (2017) 96(2) American Journal of Tropical Medicine and Hygiene, 268.

⁹⁶ 'Niger' (World Food Programme n.d.). < https://www.wfp.org/countries/niger accessed 26 January 2020; 'Burkina Faso' (World Food Programme n.d.). < https://www.wfp.org/countries/burkina-faso accessed 26 January 2020.

⁹⁷ GA Cornia, L Deotti & M Sassi, 'Food Price Volatility over the Last Decade in Niger and Malawi: Extent, Sources and Impact on Child Malnutrition' (2012) WP-002 United Nations Development Programme, 9.

Burkina Faso have also been linked with the food insecurity of millions of people, caused by chronic food shortages, soaring prices and displacement.⁹⁸

<u>Highest Attainable Standard of Health:</u> "Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party. Accessibility has four overlapping dimensions:

- [1] Non-discrimination: ...must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds;
- [2] Physical accessibility: ...must be within safe physical reach for all sections of the population... Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach;
- [3] Economic accessibility (affordability): ...must be affordable for all. Payment for health-care services, as well as services related to the underlying determinants of health, has to be based on the principle of equity;
- [4] Information accessibility: ...includes the right to seek, receive and impart information and ideas concerning health issues."99
 - The normative standard of accessibility in the right to health is directly applied to the
 context of people living with neglected diseases by Special Rapporteur Paul Hunt in
 2007. Hunt considers the stigma often associated with diseases such as leprosy and
 tuberculosis directly in relation to the provisions of the CESCR's general comment on
 health, remarking:
 - "[t]he realization of the right to access to treatment can constitute an effective way of combating stigma arising from neglected diseases. (CESCR, General Comment No. 14: para. 12(b))".¹⁰⁰
 - The 2012 HRCAC study notes the successes of early recognition and timely correspondence of treatment of noma, which is achieved through relatively inexpensive methods of oral hygiene, antibiotics and nutritious feeding.¹⁰¹

<u>Water:</u> "Water and water facilities and services have to be accessible to *everyone* without discrimination, within the jurisdiction of the State party. Accessibility has four overlapping dimensions:

⁹⁸ 'Displacement and Hunger: An Unprecedented Crisis in Burkina Faso, 20 May 2019' (Action Against Hunger 2019). < https://www.actionagainsthunger.org.uk/blog/displacement-and-hunger-an-unprecedented-crisis-in-burkina-faso accessed 26 January 2019.

⁹⁹ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 12(b).

¹⁰⁰ P Hunt *et al*, 'Neglected diseases: A human rights analysis' (2007) WHO Special Topics No. 6 Social, Economic and Behavioural Research, 25.

¹⁰¹ I Cismas, 'Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example' (24 February 2012) UN Doc. A/HRC/19/73, 47.

- [1] Physical accessibility: water, and adequate water facilities and services, must be within safe physical reach for all sections of the population. Sufficient, safe and acceptable water must be accessible within, or in the immediate vicinity, of each household, educational institution and workplace. All water facilities and services must be of sufficient quality, culturally appropriate and sensitive to gender, life-cycle and privacy requirements. Physical security should not be threatened during access to water facilities and services;
- [2] Economic accessibility: water, and water facilities and services, must be affordable for all. The direct and indirect costs and charges associated with securing water must be affordable, and must not compromise or threaten the realization of other Covenant rights;
- [3] Non-discrimination: water and water facilities and services must be accessible to all, including the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds;
- [4] Information accessibility: accessibility includes the right to seek, receive and impart information concerning water issues". 102
 - Accessibility to water, sanitation and hygiene is fundamental to disease prevention and management. This is particularly true of most NTDs, which affect over one billion people globally.¹⁰³
 - NTDs are known to be most prevalent in "rural, vulnerable and marginalized populations", with their burden "highly concentrated among the poorest 40%" - the same populations "who have the least access to sustainable, adequate and affordable water supply and sanitation services and are therefore highly exposed to disease".
 - Considering water and sanitation at the household level, the Special Rapporteur on water and sanitation discusses at length the affordability of water and water facilities, a key element of the accessibility descriptor. In particular, the Special Rapporteur addresses the situation of poor and marginalized individuals and groups in developing countries who do not enjoy access to a formal water supply.¹⁰⁵ States must, suggests the expert, ensure that "regulation of informal and small-scale service provision should assist in increasing access to water and sanitation for poor and marginalized households, and not hinder such access".¹⁰⁶

<u>Education</u>: "Educational institutions and programmes have to be accessible to everyone, without discrimination, within the jurisdiction of the State party. Accessibility has three overlapping dimensions:

 $^{^{102}}$ OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 12(c).

¹⁰³ S Boisson *et al.*, 'Water, Sanitation and Hygiene for accelerating and sustaining progress on Neglected Tropical Diseases: A new Global Strategy 2015-20' 8(1) International Health, 19

¹⁰⁴ WHO, 'Water, sanitation & hygiene for accelerating and sustaining progress on neglected tropical diseases: a global strategy 2015-2020' (Geneva, WHO 2015), 7.

¹⁰⁵ OHCHR, 'Report of the Special Rapporteur on the human right to safe drinking water and sanitation' (2015) UN. Doc A/HRC/30/39, para. 7

¹⁰⁶ OHCHR, 'Report of the Special Rapporteur on the human right to safe drinking water and sanitation' (2015) UN. Doc A/HRC/30/39, para. 79.

- [1] Non-discrimination: education must be accessible to all...;
- [2] Physical accessibility: education has to be within safe physical reach, either by attendance at some reasonably convenient geographic location... or via modern technology...;
- [3] Economic accessibility: education has to be affordable to all". 107
 - The educative experiences of children with disabilities is considered in a recent report of the Special Rapporteur on the right to education:
 - "Children with disabilities may lack supportive parents, but instead have parents who do not enrol their children owing to their low expectations and lack of understanding of the value of an education. Parents with several children may give priority to their children without disabilities, in particular when there are costs for books, school uniforms or transportation... Once at school, such children may face stigma, prejudice and bullying from teachers, parents and other children. These barriers often compound their effects over time. Even where children with disabilities receive some primary education, the percentage of them accessing secondary education is often strikingly lower than that of their peers without disabilities". 108
 - In the concluding observations on the combined seventh to ninth periodic reports of Rwanda, the Committee on the Elimination of Discrimination against Women makes several practical recommendations for improving the accessibility of education: "[a]llocate sufficient human, technical and financial resources to ensure the provision of inclusive education for girls and boys with disabilities and... ensure that all girls have access to education, including in remote areas and refugee camps, for example by establishing schools".¹⁰⁹

Adequate housing: "Adequate housing must be accessible to those entitled to it. Disadvantaged groups must be accorded full and sustainable access to adequate housing resources. Thus, such disadvantaged groups as the elderly, children, the physically disabled, the terminally ill, HIV-positive individuals, persons with persistent medical problems, the mentally ill, victims of natural disasters, people living in disaster-prone areas and other groups should be ensured some degree of priority consideration in the housing sphere. Both housing law and policy should take fully into account the special housing needs of these groups. Within many States parties increasing access to land by landless or impoverished segments of the society should constitute a central policy goal. Discernible governmental obligations need to be developed aiming to substantiate the right of all to a secure place to live in peace and dignity, including access to land as an entitlement". 110

¹⁰⁷ OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, para. 6(b).

¹⁰⁸ OHCHR, 'Report of the Special Rapporteur on the right to education, Koumbou Boly Barry - Inclusion, equity and the right to education' (29 September 2017) UN Doc. A/72/496, 45.

¹⁰⁹ OHCHR, 'CEDAW Concluding observations on the combined seventh to ninth periodic reports of Rwanda' (9 March 2017) UN Doc. CEDAW/C/RWA/CO/7-9, para. 33(e).

¹¹⁰ OHCHR, 'CESCR General Comment No. 4: The Right to Adequate Housing (Art. 11 (1) of the Covenant)' (13 December 1991) UN Doc. E/1992/23, para. 8(e).

 Inadequate housing, due to unsanitary living conditions, close proximity to livestock and lacking access to clean drinking water, has been identified as a key risk factor for noma.¹¹¹ Indeed, accessibility to adequate housing features across the 2012 HRCAC study's Guidelines to improve the protection of children at risk of or affected by noma.

1.3.3. Adequacy of...

<u>Adequate Food:</u> "...the precise meaning of "adequacy" is to a large extent determined by prevailing social, economic, cultural, climatic, ecological and other conditions [and is intrinsically linked to] "sustainability" [which] incorporates the notion of long-term availability and accessibility". 112

- Adequacy is a markedly significant dimension of the right to food, encompassing the range of factors which "must be taken into account in determining whether particular foods or diets that are accessible can be considered the most appropriate under given circumstances".¹¹³
- The World Health Organisation's Regional Office for Africa issued an information brochure for the early detection and management of noma, advising family, friends and health workers to manage a daily high-protein diet (consisting of beans, peas, milk, eggs, fish) for children who have developed, or are at risk of noma.¹¹⁴
- In their research on noma in Nigeria, Enwonwu *et al.* note that "[d]ietary history obtained in this study confirmed a widespread cultural practice in the village communities of offering any meat products available in the household preferentially to the male head of the family, and only very sparingly to the children and their mothers." This cultural practice may be linked to severe malnutrition in pregnant women and children, which in turn represents one of the main risk factors of noma.

Adequate Housing:

Habitability "Adequate housing must be habitable, in terms of providing the inhabitants with adequate space and protecting them from cold, damp, heat, rain, wind or other threats to health, structural hazards, and disease vectors. The physical safety of occupants must be guaranteed as well". 116

¹¹¹ I Cismas, 'Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example' (24 February 2012) UN Doc. A/HRC/19/73, 47.

¹¹² OHCHR, 'CESCR General Comment No. 12: The Right to Adequate Food (Art. 11)' (12 May 1999) UN Doc. E/C.12/1999/5, para. 7.

¹¹³ ihid

¹¹⁴ WHO AFRO, 'Information Brochure for Early Detection and Management of Noma' (Non communicable Diseases Cluster, Regional Programme for Noma Control, 2016).

¹¹⁵ CO Enwonwu, 'Pathogenesis of Cancrum Oris (Noma): Confounding Interactions of Malnutrition with Infection' (1999) 60(2) American Journal of Tropical Medicine and Hygiene, 226.

¹¹⁶ OHCHR, 'CESCR General Comment No. 4: The Right to Adequate Housing (Art. 11 (1) of the Covenant)' (13 December 1991) UN Doc. E/1992/23, para. 8(d).

- Habitable housing is a key aspect in the prevention and management of noma. Indeed, adequate housing is widely recognised as an integral element of approaches to the management of diseases.
- Ehrenberg and Ault note the importance of integrated management of neglected diseases in the Caribbean and South America, and specifically of role of housing in management and prevention, "[i]mprovements in rural housing (floors, ceilings, walls, and windows) have reduced the transmission of Chagas disease". 117

Location "Adequate housing must be in a location which allows access to employment options, health-care services, schools, childcare centres and other social facilities. This is true both in large cities and in rural areas where the temporal and financial costs of getting to and from the place of work can place excessive demands upon the budgets of poor households...". 118

• Noma is known to affect severely malnourished children living in rural conditions of extreme poverty. The location of housing, work and medical facilities is often a key factor in the treatment decisions made by the families of noma patients: in the case study countries medical care centres can be at such a distance that caregivers may have to forgo days of work in order to make the journey. (Further references to be provided from the findings of research package 2).

"Cultural adequacy. The way housing is constructed, the building materials used and the policies supporting these must appropriately enable the expression of cultural identity and diversity of housing. Activities geared towards development or modernization in the housing sphere should ensure that the cultural dimensions of housing are not sacrificed, and that, inter alia, modern technological facilities, as appropriate are also ensured". 119

• In one of the earliest studies of noma, Enwonwu *et al.* examine 1,000 Nigerian children from a variety of socio-economic strata in the northwest corner of Nigeria. The authors describe, "[a]II of the people in impoverished Sokoto rural communities resided in very poorly ventilated mud huts with thatched bamboo roofs and direct floors". 120

1.3.4. Acceptability of...

¹¹⁷ JP Ehrenberg and SK Ault, 'Neglected diseases of neglected populations: Thinking to reshape the determinants of health in Latin America and the Caribbean' (2005) 5(119 BMC Public Health, 6.

¹¹⁸ OHCHR, 'CESCR General Comment No. 4: The Right to Adequate Housing (Art. 11 (1) of the Covenant)' (13 December 1991) UN Doc. E/1992/23, para. 8(f).

¹¹⁹ OHCHR, 'CESCR General Comment No. 4: The Right to Adequate Housing (Art. 11 (1) of the Covenant)' (13 December 1991) UN Doc. E/1992/23, para. 8(g).

¹²⁰ CO Enwonwu, 'Pathogenesis of Cancrum Oris (Noma): Confounding Interactions of Malnutrition with Infection' (1999) 60(2) American Journal of Tropical Medicine and Hygiene, 223.

<u>Highest Attainable Standard of Health:</u> "...must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements..." 121

 Socio-medical surveys conducted by Sentinelles' health centres in Burkina Faso and Niger provide evidence of cultural practices whereby children brush their teeth once they get to a certain age. Sensitivity in dealing with such practices is needed and wide awareness raising about the importance of good oral hygiene in noma prevention (further data will be added once the analysis of research package 2 results are finalised).

<u>Education</u>: "the form and substance of education, including curricula and teaching methods, have to be acceptable (e.g. relevant, culturally appropriate and of good quality) to students and, in appropriate cases, parents". 122

- The 2012 HRCAC Study highlights the importance of gender in the context of noma, recognising that "the vulnerability of children is closely connected to the vulnerability of women". Therefore, education of women is imperative in the prevention and management of noma, particularly in regards to health information, nutrition, feeding practices and hygiene.
- In a recent study of diarrhoeal diseases in children under five in Western Ethiopia, the education of mothers/caretakers was found to be a crucial factor in the prevention and care of sick children. The authors concluded, "[m]others with higher education are thought to have better opportunity for information about children than mothers/caretakers with lower educational levels"; in particular, the study concluded that mothers with "less educational status may not have basic knowledge on the impacts of potential risk factors, such as water supply, latrine utilization, hygiene, and sanitation", consistent with findings from other East African countries. 124

1.3.5. Quality of...

<u>Highest Attainable Standard of Health:</u> "...must also be scientifically and medically appropriate and of good quality. This requires, inter alia, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation". 125

¹²¹ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 12(c).

¹²² OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, para. 6(c).

^{&#}x27;Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example' (24 February 2012) UN Doc. A/HRC/19/73, 18.

¹²⁴ N Merga & T Alemayehu, 'Knowledge, Perception, and Management Skills of Mothers with Under-five Children about Diarrhoeal Disease in Indigenous and Resettlement Communities in Assosa District, Western Ethiopia' (2015) 33(1) Journal of Health, Population, and Nutrition, 28.

¹²⁵ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 12(d).

- Several medical studies have found that for noma patients and their families, the first point of contact with the healthcare pyramid is often local, community-based traditional healers.¹²⁶
- Farley *et al.* conclude a recent study of traditional healing in northwest Nigeria with the suggestion that, if included in training and referral partnerships, these healers could "play a crucial role in the early detection of noma and the health-seeking decision-making process of patients". 127

<u>Water:</u> "the water required for each personal and domestic use must be safe, therefore free from micro-organisms, chemical substances and radiological *hazards* that constitute a threat to a person's health. Furthermore, water should be of an acceptable colour, odour and taste for each personal and domestic use".¹²⁸

- Recognising the contextuality surrounding acceptability and water quality in Burkina Faso and Niger, water quality is a significant risk factor in the context of the development of noma. The need for safe water extends to drinking, food preparation, and personal and domestic hygiene.
- In one of the earliest empirical studies investigating the development of noma in children living in the Nigerian state of Sokoto, Enwonwu et al. note that "communities had no access to a reliable supply of safe drinking water, and usually obtained water from contaminated, shallow wells". 129

¹²⁶ D Baratti-Mayer *et al.*, 'Sociodemographic Characteristics of Traditional Healers and Their Knowledge of Noma: A Descriptive Survey in Three Regions of Mali' (2019) International Journal of Environmental Research and Public Health 16(4587), 1; E Farley *et al.*, 'I treat it but I don't know what this disease is': a qualitative study on noma (cancrum oris) and traditional healing in northwest Nigeria' (2012) International Health 12(1), 1.

E Farley et al., "I treat it but I don't know what this disease is: a qualitative study on noma (cancrum oris) and traditional healing in northwest Nigeria' (2012) International Health 12(1), 1.

¹²⁸ OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 12(b).

¹²⁹ CO Enwonwu, 'Pathogenesis of Cancrum Oris (Noma): Confounding Interactions of Malnutrition with Infection' (1999) 60(2) American Journal of Tropical Medicine and Hygiene, 224.

1.4. CORRELATIVE STATE OBLIGATIONS

The correlative state obligations to respect, protect and fulfil are now considered in relation to each of the rights identified thus far in the mapping.

1.4.1. The obligation to respect

<u>Adequate Food:</u> "existing access to adequate food requires States parties not to take any measures that result in preventing such access". 130

- Gendered differences in the production and consumption of food remains prevalent in rural sub-Saharan Africa.¹³¹ As malnutrition is one of noma's key risk factors, poor nutrition of mothers through customs of delaying feeding or limiting of certain foods, combined with the nutritional demands of frequent pregnancies,¹³² may produce patterns of malnutrition in utero that persist into early childhood. According to the FAO's voluntary guidelines on the progressive realization on the right to food, States should address this issue by "adopt[ing] measures to eradicate any kind of discriminatory practices, especially with respect to gender, in order to achieve adequate levels of nutrition within the household".¹³³
- The obligation to respect the right to adequate food also extends to the lived experiences of children and adult survivors of noma. Recognising that primary research in this area within the context of noma remains limited, the work of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members may be informative in this regard. In a recent report to the Human Rights Council, the Special Rapporteur observed, "[d]iscrimination against persons affected by leprosy is so pervasive that it even materializes in... the separation of food". 134
- The Guidelines annexed to the 2012 HRCAC study acknowledges the existence of discrimination against children and adults affected by noma, which can result in the prevention of access to sufficient food.¹³⁵

<u>Water:</u> "requires that States parties refrain from interfering directly or indirectly with the enjoyment of the right to water. The obligation includes, inter alia, refraining from engaging in any practice or activity that denies or limits equal access to adequate water; arbitrarily

¹³⁰ OHCHR, 'CESCR General Comment No. 12: The Right to Adequate Food (Art. 11)' (12 May 1999) UN Doc. E/C.12/1999/5, para. 15.

¹³¹ J Leslie *et al.*, 'Female nutritional status across the life-span in sub-Saharan Africa' (1997) 18(1) Food and Nutrition Bulletin, 3; M Kevane, 'Gendered production and consumption in rural Africa' (2012) 109(31) PNAS 12350.

¹³² J Leslie *et al.*, 'Female nutritional status across the life-span in sub-Saharan Africa' (1997) 18(1) Food and Nutrition Bulletin, 3.

¹³³ Food and Agriculture Organization, 'Voluntary Guidelines to support the progressive realization of the right to adequate food in the context of national food security' (adopted by 127th Session of the FAO Council, November 2004), para. 10.8.

¹³⁴ OHCHR, 'Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members' (2018) UN Doc. A/HRC/38/42, para. 55.

¹³⁵ I Cismas, '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' (24 February 2012) UN Doc. A/HRC/19/73, para. 13(i).

interfering with customary or traditional arrangements for water allocation; unlawfully diminishing or polluting water...; and limiting access to, or destroying, water services and infrastructure as a punitive measure...". 136

- The Guiding Principles on extreme poverty and human rights note that, "[p]ersons living in poverty are disproportionately affected by limited access to water and adequate sanitation". The 2012 HRCAC study observes, "[o]verall, the fight against extreme poverty is certainly also a fight against noma". 138
- In the context of noma, respect of the right to water may oblige States to implement measures to ensure that costs of water services do not rise with increased use. This obligation may also be derived from the factual reality that "[t]he human right to water is indispensable for leading a life in human dignity. It is a prerequisite for the realization of other human rights".

<u>Highest Attainable Standard of Health:</u> "requires States to refrain from interfering directly or indirectly with the enjoyment of the right to health". 141

Specifically, this includes the obligation to refrain from "denying or limiting equal access for all persons... to preventive, curative and palliative health services; abstaining from enforcing discriminatory practices as a State policy; and abstaining from imposing discriminatory practices relating to women's health status and needs. Furthermore, obligations to respect include a State's obligation to refrain from prohibiting or impeding traditional preventive care, healing practices and medicines...". In addition, "States should refrain from... withholding or intentionally misrepresenting health-related information, including sexual education and information, as well as from preventing people's participation in health-related matters". ¹⁴²

 Within the context of noma in sub-Saharan Africa, traditional healers play an important role in the care of noma patients, most often as the first point of contact with the healthcare system.¹⁴³ Due to their socio-cultural position within rural

¹³⁶ OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 21.

¹³⁷ OHCHR, 'Final draft of the guiding principles on extreme poverty and human rights, submitted by the Special Rapporteur on extreme poverty and human, Magdalena Sepúlveda Carmona' (18 July 2012) UN Doc. A/HRC/21/39, para. 77.

¹³⁸ I Cismas, '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' (24 February 2012) UN Doc. A/HRC/19/73, para. 48.

¹³⁹ OHCHR, 'Final draft of the guiding principles on extreme poverty and human rights, submitted by the Special Rapporteur on extreme poverty and human, Magdalena Sepúlveda Carmona' (18 July 2012) UN Doc. A/HRC/21/39, para. 78(d).

¹⁴⁰ OHCHR, 'CESCR General Comment No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 1.

¹⁴¹ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 33.

¹⁴² OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 34.

¹⁴³ D Baratti-Mayer *et al.*, 'Sociodemographic Characteristics of Traditional Healers and Their Knowledge of Noma: A Descriptive Survey in Three Regions of Mali' (2019) International Journal of Environmental Research and Public Health 16(4587), 1.

- communities, traditional healers could therefore be crucial in the early detection and prevention of noma.
- Recognising that the CESCR delineates one aspect of the right to health as the obligation to "refrain from prohibiting or impeding traditional preventive care, healing practices and medicines",¹⁴⁴ including and incorporating traditional healers in nomarelated training and intervention programmes could "save lives and reduce the severity of noma complications".¹⁴⁵

<u>Education:</u> "requires States parties to avoid measures that hinder or prevent the enjoyment of the right to education". 146

- The negative obligation of States to respect the right to education is intersected by the pervasive discrimination experienced by children and adult survivors of the acute necrotizing phase of noma. The 2012 HRCAC study observes that, "[v]ictims of noma are similar to victims of leprosy, shunned and rejected by their communities". The denial of access to school and education for children affected by leprosy has been extensively documented. This manner of prohibitive discrimination is also thought to affect the lives of both children and adult survivors of noma. The acute necrotized by their communities.
- The CESCR's General Comment No. 13 specifically addresses discrimination in the right to education, stating that States "must closely monitor education including all relevant policies, institutions, programmes, spending patterns and other practices so as to identify and take measures to redress any de facto discrimination". 150

Adequate Housing: "requires States to refrain from interfering directly or indirectly with the enjoyment of the right to adequate housing". OHCHR's Factsheet on the right to adequate housing goes on to suggest that the obligation to respect the right to adequate housing requires States to, for example; "refrain from carrying out forced evictions and demolishing homes; denying security of tenure to particular groups; imposing discriminatory practices that limit women's access to and control over housing, land and property... denying housing, land and property restitution to particular groups; or polluting water resources". 152

¹⁴⁴ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 34.

¹⁴⁵ E Farley *et al.*, "I treat it but I don't know what this disease is: a qualitative study on noma (cancrum oris) and traditional healing in northwest Nigeria' (2012) International Health 12(1), 28.

¹⁴⁶ OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, 47.

¹⁴⁷ I Cismas, 'Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example' (24 February 2012) UN Doc. A/HRC/19/73, para. 58.

OHCHR, 'Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members' (2018) UN Doc. A/HRC/38/42, para. 54.

¹⁴⁹ I Cismas, 'Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example' (24 February 2012) UN Doc. A/HRC/19/73, para. 58.

¹⁵⁰ OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, 37.

¹⁵¹ OHCHR, 'CESCR General Comment No. 4: The Right to Adequate Housing (Art. 11 (1) of the Covenant)' (13 December 1991) UN Doc. E/1992/23, para. 1.

¹⁵² OHCHR, 'The Right to Adequate Housing: Fact Sheet No. 21 (Rev. 1)' (Office of the High Commissioner for Human Rights, 2009), 33.

- Living conditions are an integral aspect of the right to adequate housing, which in turn
 is derived from the right to an adequate standard of living.¹⁵³ The WHO's 'Health
 Principles of Housing' view, suggests the CESCR, "housing as the environmental factor
 most frequently associated with conditions for disease".¹⁵⁴
- The 2012 HRCAC study highlights unsanitary housing conditions as an important risk factor for the development of noma. 155
- Therefore, in the context of the obligation to respect the right to adequate housing, States should ensure that rural communities, "[a]ccord priority to improvements in infrastructure and services in areas inhabited by persons living in poverty". 156

2. The obligation to protect

<u>Adequate Food:</u> "requires measures by the State to ensure that enterprises or individuals do not deprive individuals of their access to adequate food". 157

- Noma often affects children living in rural and remote areas.¹⁵⁸ OHCHR's Fact Sheet No. 34 on the right to adequate food considers the situation of the rural poor specifically, linking large, competitive agribusinesses with the fact that "most individuals and households in rural areas are dependent on [land & productive resources] either to produce food for themselves or as a source of income to purchase the food they need".¹⁵⁹
- The development of agro-industrial projects has been observed and discussed by UN treaty bodies examining State reports of Burkina Faso. The CESCR's 2016 concluding observations notes that Burkina Faso's policy of agro-industry promotion, "has a harmful effect on family farms in the fertile areas", as well as hampering "the realization of the right to food of the most vulnerable society, in particular on account of the resulting undue concentration of resources". The 2017 concluding observations of the Committee on the Elimination of Discrimination against Women (CEDAW) expresses similar concerns, recommending a gender perspective be included

¹⁵³ International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS (ICESCR), Article 11(1).

¹⁵⁴ OHCHR, 'CESCR General Comment No. 4: The Right to Adequate Housing (Art. 11 (1) of the Covenant)' (13 December 1991) UN Doc. E/1992/23, para. 8(d).

¹⁵⁵ I Cismas, 'Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example' (24 February 2012) UN Doc. A/HRC/19/73, para. 45.

¹⁵⁶ OHCHR, 'Final draft of the guiding principles on extreme poverty and human rights, submitted by the Special Rapporteur on extreme poverty and human, Magdalena Sepúlveda Carmona' (18 July 2012) UN Doc. A/HRC/21/39, para. 79(f).

¹⁵⁷ OHCHR, 'The Right to Adequate Food: Fact Sheet No. 34' (Office of the High Commissioner for Human Rights, 2010), 18.

¹⁵⁸ ML Srour *et al.*, 'Noma: Overview of a Neglected Disease and Human Rights Violation' (2017) American Journal of Tropical Medicine and Hygiene 96(2), 268.

¹⁵⁹ OHCHR, 'The Right to Adequate Food: Fact Sheet No. 34' (Office of the High Commissioner for Human Rights, 2010), 10.

¹⁶⁰ OHCHR 'CESCR Concluding observations on the initial report of Burkina Faso' (12 July 2016) UN Doc E/C.12/BFA/CO/1, para. 34.

in "all rural development policies and plans", and that women participate in all aspects of preparing and implementing policies and programmes on food security. 161

<u>Water:</u> "...requires States parties to prevent third parties from interfering in any way with the enjoyment of the right to water. Third parties include individuals, groups, corporations and other entities as well as agents acting under their authority... Where water services (such as piped water networks, water tankers, access to rivers and wells) are operated or controlled by third parties, States parties must prevent them from compromising equal, affordable, and physical access to sufficient, safe and acceptable water. To prevent such abuses an effective regulatory system must be established, in conformity with the Covenant and this general comment, which includes independent monitoring, genuine public participation and imposition of penalties for non-compliance". 162

- Women are disproportionately burdened with water collection.¹⁶³ The CESCR's general comment on the right to water goes on to state that the obligation to protect also requires the adoption of "the necessary and effective legislative and other measures to restrain, for example, third parties from denying equal access to adequate water".¹⁶⁴
- In a recent report, the Special Rapporteur on the right to safe drinking water and sanitation remarked, "[o]wing to the disproportionate role that they play in domestic and caregiving responsibilities, for example, women are more affected by the absence of water, sanitation and hygiene". 165 As the latter are known noma risk factors, girls may be more exposed due to the disease (this will be further verified through the data obtained from research package 2).
- The UN Special Rapporteur urges that "next to women's practical necessities...
 gender-responsive measures by the State and interventions by non-State actors
 should challenge customary relationships of unequal power and control, as well as
 stereotypes, between genders".¹⁶⁶
- She cautions that efforts "to ensure women's participation through laws or regulations, however, may not correspond to local customary norms and their implementation subsequently fails. Customary norms reflect cultural gender hierarchies and power relations within a community and may have a much bigger influence in practice."¹⁶⁷ As such, it may be necessary for states to take positive

¹⁶¹ OHCHR, 'CEDAW Concluding observations on the seventh periodic report of Burkina Faso' (22 November 2017) UN Doc CEDAW/C/BFA/CO/7, para. 42(b).

¹⁶² OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 23-24.

¹⁶³ OHCHR, 'CESCR General Comment No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 16(c).

¹⁶⁴ OHCHR, 'CESCR General Comment No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 23.

¹⁶⁵ OHCHR, 'Report of the Special Rapporteur on the human right to safe drinking water and sanitation' (27 July 2016) UN Doc. A/HRC/33/49, para. 15.

¹⁶⁶ OHCHR, 'Report of the Special Rapporteur on the human right to safe drinking water and sanitation' (27 July 2016) UN Doc. A/HRC/33/49, para. 15.

¹⁶⁷ OHCHR, 'Report of the Special Rapporteur on the human right to safe drinking water and sanitation' (27 July 2016) UN Doc. A/HRC/33/49, para. 59.

- measures including administrative and educational ones –, which challenge gender hierarchies and power relations in society.
- This conclusion is supported by the CEDAW's art. 5(a), which requires states to "take all appropriate measures [t]o modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women".

<u>Highest Attainable Standard of Health:</u> "requires States to take measures that prevent third parties from interfering with article 12 guarantees". 168

Specifically, this includes the duty to, "adopt legislation or to take other measures ensuring equal access to health care and health-related services provided by third parties; to ensure that privatization of the health sector does not constitute a threat to the availability, acceptability, acceptability and quality of health facilities, goods and services... States are also obliged to ensure that harmful social or traditional practices do not interfere with access to pre- and post-natal care and family planning; to prevent third parties from coercing women to undergo traditional practices, e.g. female genital mutilation; and to take measures to protect all vulnerable or marginalized groups of society, in particular women, children, adolescents and older persons, in the light of gender-based expressions of violence. States should also ensure that third parties do not limit people's access to health-related information and services". 169

- Building on research into conditions such as leprosy and HIV, Nayar et al. conclude that "the social processes of stigmatization and discrimination can have complex and often devastating effects on the health and welfare of individuals, families, and whole communities".¹⁷⁰
- In a 2007 report undertaking a human rights analysis of neglected diseases, Hunt considers the stigma associated with certain diseases in many societies. Conditions such as tuberculosis and leprosy are "a source of fears, stereotypes and prejudices deriving from ancient religious, cultural and traditional beliefs, or more recent misconceptions about the origins, transmission and effects of these diseases".¹⁷¹
- Hunt goes on to comment, "social stigma attached to neglected diseases worsens the spread and impact of the diseases... In short, stigma deters diagnosis, treatment and support (WHO, 2001: p. 7). It is also an underlying cause of discrimination".¹⁷²

¹⁶⁸ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 33.

¹⁶⁹ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 35.

¹⁷⁰ U Nayar *et al.*, 'Reducing Stigma and Discrimination to Improve Child Health and Survival in Low- and Middle-Income Countries: Promising Approaches and Implications for Future Research' (2014) Journal of Health Communication 19(1), 143.

¹⁷¹ P Hunt, 'Neglected diseases: A human rights analysis' (2007) WHO Special Topics No. 6 Social, Economic and Behavioural Research, 24.

¹⁷² P Hunt, 'Neglected diseases: A human rights analysis' (2007) WHO Special Topics No. 6 Social, Economic and Behavioural Research, 24.

Anecdotal evidence, that we expect to see confirmed by results of research package 2 studies, portray a very similar situation in relation to noma.

<u>Education:</u> "...requires States parties to take measures that prevent third parties from interfering with the enjoyment of the right to education". ¹⁷³

 In the context of noma, third parties could include parents, family members, the wider community or employers.¹⁷⁴ Recognising the discrimination, stigmatisation and social isolation that survivors of noma may often experience, the protection of the accessibility of education is crucial.

Adequate Housing: "requires States to prevent third parties from interfering with the right to adequate housing". The OHCHR's Factsheet on the right to adequate housing goes on to suggest that the obligation to protect the right to adequate housing requires States to, "adopt legislation or other measures to ensure that private actors – e.g., landlords, property developers, landowners and corporations – comply with human rights standards related to the right to adequate housing. States should, for instance... ensure that the private provision of water, sanitation and other basic services attached to the home does not jeopardize their availability, accessibility, acceptability and quality; ensure that third parties do not arbitrarily and illegally withdraw such services; prevent discriminatory inheritance practices affecting women's access to and control over housing, land and property; ensure that landlords do not discriminate against particular groups; ensure that private actors do not carry out forced evictions".¹⁷⁵

- In the context of noma and the right to adequate housing, the obligation to protect speaks to the prevention of inheritance practices that affect or exclude women from accessing and/or controlling housing, land and property.¹⁷⁶
- Paul Hunt, then former Special Rapporteur on the right to health, draws attention to discriminatory practices that can enhance vulnerability to neglected diseases. For example, discrimination on the basis of sex can intersect with the prejudicial attitudes of public and private actors towards people living in poverty, further increasing susceptibility to neglected diseases. Indeed, the socio-cultural status of women in the case study countries is known to limit their ownership of resources, which may serve to "affect their access to prevention and treatment", as Hunt observes in the context of other neglected diseases.¹⁷⁷

3. The obligation to fulfil

 173 OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, para. 47.

¹⁷⁴ OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, para. 50.

¹⁷⁵ OHCHR, 'The Right to Adequate Housing: Fact Sheet No. 21 (Rev. 1)' (Office of the High Commissioner for Human Rights, 2009), 33.

¹⁷⁶ OHCHR, 'The Right to Adequate Housing: Fact Sheet No. 21 (Rev. 1)' (Office of the High Commissioner for Human Rights, 2009), 33.

¹⁷⁷ P Hunt, 'Neglected diseases: A human rights analysis' (2007) WHO Special Topics No. 6 Social, Economic and Behavioural Research, 23.

<u>Adequate Food:</u> "...incorporates both an obligation to *facilitate* and an obligation to *provide*... to *fulfil* (*facilitate*) means the State must proactively engage in activities intended to strengthen people's access to and utilization of resources and means to ensure their livelihood, including food security. Finally, whenever an individual or group is unable, for reasons beyond their control, to enjoy the right to adequate food by the means at their disposal, States have the obligation to *fulfil* (*provide*) that right directly...".¹⁷⁸

- Whilst noting that fully documented cases of violations of the right to food are often difficult to locate, Ziegler et al. (2011) discuss the obligation to provide by drawing on two country missions to Niger, conducted during the course of Ziegler's mandate as the first Special Rapporteur on the right to food. Here, the obligation to provide is referenced through discussion of Niger's 2001 food crisis, where governmental inefficiencies resulted in food aid being delivered months late to stricken areas, in insufficient quantities and at inappropriate prices.¹⁷⁹ It should be noted that Ziegler, one of the initiators of the 2012 HRCAC Study on noma had first met children with noma on these country missions.
- The obligation to facilitate is referenced in the CESCR's 2016 concluding observations on Burkina Faso, where the Committee discusses the need to strengthen the facilitation of the right to food, recommending steps to be taken "to promote access by smallholders to appropriate technology and to improve their access to local markets, in order to raise incomes in rural areas, particularly by promoting the spread of agroecological practices". 180
- As advocated by the FAO's Voluntary Guidelines on the progressive realization of the right to food, States are advised to "systematically undertake disaggregated analysis on the food insecurity, vulnerability and nutritional status of different groups in society".¹⁸¹ In doing so, States may be able to assess the extent to which noma survivors experience greater food insecurity through discrimination, and take steps to address and prevent this. Noma, thus, could be seen as an indicator of severe food insecurity.

<u>Water:</u> the CESCR disaggregates this obligation into facilitate, promote and provide: "The obligation to facilitate requires the State to take positive measures to assist individuals and communities to enjoy the right. The obligation to promote obliges the State party to take steps to ensure that there is appropriate education concerning the hygienic use of water, protection of water sources and methods to minimize water wastage. States parties are also

¹⁷⁸ OHCHR, 'CESCR General Comment No. 12: The Right to Adequate Food (Art. 11)' (12 May 1999) UN Doc. E/C.12/1999/5, para. 15.

¹⁷⁹ J Ziegler *et al.*, *The Fight for the Right to Food – Lessons Learned* (1st edn, Palgrave Macmillan 2011), 124-125. ¹⁸⁰ OHCHR, 'CESCR Concluding observations on the initial report of Burkina Faso' (12 July 2016) UN Doc E/C.12/BFA/CO/1, para. 35.

¹⁸¹ Food and Agriculture Organization, 'Voluntary Guidelines to support the progressive realization of the right to adequate food in the context of national food security' (adopted by 127th Session of the FAO Council, November 2004), para. 13.2.

obliged to fulfil (provide) the right when individuals or a group are unable, for reasons beyond their control, to realize that right themselves by the means at their disposal". 182

- Action on water constitutes one of the key prevention areas relating to noma in sub-Saharan Africa.¹⁸³
- The WHO advises prevention, management and treatment of the early stages of noma through provision and use of water (safe drinking water; warm salted water mouth rings; soft foods prepared with clean water).¹⁸⁴
- The CESCR's general comment urges particular attention to the provision and proper maintenance of water facilities in rural areas, with the obligation to fulfil including the adoption of "a national water strategy and plan of action to realize this right; ensuring that water is affordable for everyone, and facilitating improved and sustainable access to water".¹⁸⁵

<u>Highest Attainable Standard of Health:</u> "requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health". 186

In the context of the right to health, the obligation to fulfil, "contains obligations to facilitate, provide and promote". 187

As the CESCR observes, "the obligation to fulfil (facilitate) requires States inter alia to take positive measures that enable and assist individuals and communities to enjoy the right to health. States parties are also obliged to fulfil (provide) a specific right contained in the Covenant when individuals or a group are unable, for reasons beyond their control, to realize that right themselves by the means at their disposal. The obligation to fulfil (promote) the right to health requires States to undertake actions that create, maintain and restore the health of the population. Such obligations include: (i) fostering recognition of factors favouring positive health results, e.g. research and provision of information; (ii) ensuring that health services are culturally appropriate and that health-care staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups; (iii) ensuring that the State meets its obligations in the dissemination of appropriate information relating to healthy lifestyles and nutrition, harmful traditional practices and the availability of services; (iv) supporting people in making informed choices about their health". 188

¹⁸² OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 25.

¹⁸³ CO Enwonwu, 'Noma: a neglected scourge of children in sub-Saharan Africa' Bulletin of the World Health Organisation 73(4), 541.

¹⁸⁴ WHO AFRO, 'Information Brochure for Early Detection and Management of Noma' (Non communicable Diseases Cluster, Regional Programme for Noma Control, 2016).

¹⁸⁵ OHCHR, 'CESCR General No. 15: The Right to Water (Arts. 11 and 12 of the Covenant)' (20 January 2003) UN Doc. E/C.12/2002/11, para. 26.

¹⁸⁶ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 33.

¹⁸⁷ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 33.

¹⁸⁸ OHCHR, 'CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)' (11 August 2000) UN Doc. E/C.12/2000/4, para. 37.

- The obligation to fulfil (provide) extends to the provision of funding for reconstructive surgeries for survivors of noma. These surgeries offer "a rare chance for the survivors to live without discrimination" and improve "chances for education, employment and marriage". However, surgical intervention is costly and complex, prohibitively so for rural families living in conditions of extreme poverty, and so States should equally invest in noma prevention strategies.
- Within the context of the right to the highest attainable standard of health, the obligation to fulfil (promote) maps clearly onto the experiences of children at risk of and children and adult survivors of noma.
 - O In 2016, the WHO Afro published its 'Information Brochure for Early Detection and Management of noma', which is described as a training tool intended for all stakeholders in contact with at risk populations at the primary health care level. The brochure outlines five stages of noma, using infographics, progression timelines and medical advice to describe the development of the disease.¹⁹² This could be seen as the WHO Afro's discharging part of its obligation to fulfil.¹⁹³
 - O In light of the prevalence of other neglected diseases in the case study contexts, Ahlgren et al. consider the most feasible approach to action on noma at the local healthcare level to be "focus on the promotion of oral examinations and training to improve knowledge and practices of early stages of noma, such as gingivitis".¹⁹⁴
- In the human rights analysis of neglected tropical diseases, Hunt considers the impact of stigma on people living with a neglected disease. Hunt contends that whilst stigma is not a legal concept, it is "an important human rights concern [that] can lead to the denial of human rights". Hunt draws upon the CESCR's general comment on the right to health to contend that the obligation to fulfil calls upon states "to promote health education and organize information campaigns relating to health". 196

¹⁸⁹ I Cismas, 'Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example' (24 February 2012) UN Doc. A/HRC/19/73, para. 58.

¹⁹⁰ ML Srour *et al.*, 'Noma: Overview of a Neglected Disease and Human Rights Violation' (2017) 96(2) American Journal of Tropical Medicine and Hygiene, 269.

¹⁹¹ B Pittet *et al.*, 'Traitement chirurgical des séquelles de noma' (2015) 10(3) EMC – Techniques chirurgicales – Chirurgie plastique, reconstructrice et esthétique 1.

¹⁹² WHO AFRO, 'Information Brochure for Early Detection and Management of Noma' (Non communicable Diseases Cluster, Regional Programme for Noma Control, 2016).

¹⁹³ Note that the extent to which international organisations incur obligations under international human rights law remains an area of continuous development and debate. See generally A Clapham, *Human Rights Obligations of Non-State Actors* (OUP 2006).

¹⁹⁴ M Ahlgren, 'Management of noma: practice competence and knowledge among healthcare workers in a rural district of Zambia' (2017) 10 Global Health Action, 4.

¹⁹⁵ P Hunt, 'Neglected diseases: A human rights analysis' (2007) WHO Special Topics No. 6 Social, Economic and Behavioural Research, 25.

¹⁹⁶ P Hunt, 'Neglected diseases: A human rights analysis' (2007) WHO Special Topics No. 6 Social, Economic and Behavioural Research, 25; OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, para. 36.

<u>Education</u>: "the obligation to fulfil (facilitate) requires States to take positive measures that enable and assist individuals and communities to enjoy the right to education... [and] to fulfil (provide)... when an individual or group is unable". 197

- The obligation to fulfil (facilitate) maps onto several aspects of the right to education in the context of noma. The 2012 HRCAC study observes that "providing education to parents on good practices in respect to oral hygiene [is a] key intervention to preventing noma in malnourished children". States should also design and implement public health education programmes in rural communities that address the biological development and risk factors of noma, which may facilitate the elimination of misconceptions and cultural beliefs surrounding the disease. 199
- Recognising that discrimination and stigmatisation often curtail the educative opportunities available to children and adult survivors of noma, States also have an obligation to fulfil (provide) the right to education. Whilst this obligation is not uniform for all levels of education,²⁰⁰ States must ensure that existing access to education is provided in a non-discriminatory manner.
- It is interesting to note that inexpensive health interventions relating to other NTDs have had significant positive impacts on children's right to education. Scholars note that "deworming programmes have shown that intervention against neglected tropical diseases in childhood is a highly cost-effective approach to improvement of education. An investment of US\$3-50 per child on disease control could result in the gain of an extra school year". ²⁰¹ By analogy, it can be shown that the inexpensive prevention of noma could result the progressive realisation of the right to education of children at risk of noma.

Adequate Housing: "requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to fully realize the right to adequate housing". OHCHR's Factsheet on the right to adequate housing goes on to suggest that the obligation to protect the right to adequate housing requires States to, for example, "adopt a national housing policy or a national housing plan that: defines the objectives for the development of the housing sector, with a focus on disadvantaged and marginalized groups; identifies the resources available to meet these goals; specifies the most cost-effective way of using them; outlines the responsibilities and time frame for the implementation of the necessary measures; monitors results and ensures adequate remedies for violations". 2022

 $^{^{197}}$ OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, para. 47.

¹⁹⁸ I Cismas, 'Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example' (24 February 2012) UN Doc. A/HRC/19/73, para. 42.

¹⁹⁹ WHO AFRO, 'Information Brochure for Early Detection and Management of Noma' (Non communicable Diseases Cluster, Regional Programme for Noma Control, 2016), 7.

²⁰⁰ OHCHR, 'CESCR General Comment No. 13: The Right to Education (Art. 13)' (8 December 1999) UN Doc. E/C.12/1999/10, para. 48.

²⁰¹ PJ Hotez *et al.*, 'Rescuing the bottom billion through control of neglected tropical diseases' (2009) The Lancet (373), 1571.

²⁰² OHCHR, 'The Right to Adequate Housing: Fact Sheet No. 21 (Rev. 1)' (Office of the High Commissioner for Human Rights, 2009), 33-34.

to adopt an	ontext of noma, fulfill dimplement national in basic services.		

2. REGIONAL HUMAN RIGHTS TREATIES

In addition to international human rights treaties, states may incur obligations under regional instruments. This section discusses the rights and correlative state obligations relevant to the noma context arising from regional instruments in Africa and Asia.

2.1. AFRICAN UNION HUMAN RIGHTS INSTRUMENTS

The African Charter on Human and People's Rights (ACHPR) and the African Charter on the Rights and Welfare of the Child (ACRWC) are instruments developed within the framework of the African Union and ratified by both Burkina Faso and Niger.

Table B - Ratification of African Human Rights Treaties²⁰³

Treaty	Burkina Faso	Niger
African Charter on Human and People's Rights (ACHPR)	06/07/1984	15/07/1986
African Charter on the Rights and Welfare of the Child (ACRWC)	08/06/1992	11/12/1999

In comparison to other regional protection mechanisms of Europe and the Americas, the ACHPR is notable in its recognition, in the same instrument, of both CP and ESC rights, as well as the rights of both individuals and group.²⁰⁴ Similarly to the UN CRC, the ACRWC entails provisions relating to both sets of rights.²⁰⁵ Of the rights identified at the beginning of this legal mapping, the two instruments provide directly for the following rights.

2.1.1. The right to food

The right to food is not explicitly mentioned in the ACHRP.

Drawing on its decisions in the SERAC & CESCR v Nigeria case,²⁰⁶ the African Commission on Human and Peoples' Rights (AComHPR) developed the Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and People's Rights (hereafter, the Principles and Guidelines). This interpretative instrument expands upon the provisions of the Charter, delineating the nature of State parties obligations

²⁰³ The source of the ratification history is available at https://www.achpr.org/ratificationtable?id=49 and https://www.acerwc.africa/ratifications-table/

²⁰⁴ C Heyns & M Killander, 'Africa' in D Moeckli, S Shah & S Sivakumaran (eds), *International Human Rights Law* (2nd edn, OUP 2014), 444. See also The African (Banjul) Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) OAU Doc. CAB/LEG/67/3.

²⁰⁵ The African Charter on the Rights and Welfare of the Child (adopted 11 July 1990, entered into force 1999) OAU Doc. CAD/LEG/24.9/49.

 $^{^{206}}$ See Social and Economic Rights Action Center (SERAC) and Center for Economic and Social Rights (CESR) v. Nigeria, Com. No. 155/96, 27 May 2002, available at:

https://www.achpr.org/public/Document/file/English/achpr30 155 96 eng.pdf, accessed 30 November 2020.

in respect to ESC rights, through guarantees of normative descriptors, tripartite typologies of obligations and the principles of progressive realization and international cooperation.

In respect to the right to food, the Principles and Guidelines state that this is "inherent in the Charter's protection of the right to life, health and the right to economic, social and cultural development... including, in particular, the rights to health, education and political participation".²⁰⁷

The minimum core obligations of the right to food are interpreted as the obligations to:

- "Take the necessary action to guarantee the right of everyone to be free from hunger and to mitigate and alleviate hunger even in times of natural or other disasters;
- Refrain from and protect against destruction and/or contamination of food sources;
- Refrain from using access to food as a political tool to reward supporters, punish opponents or recruit militias".²⁰⁸

2.1.2. The right to water

As with food, the ACHPR does not directly provide for the right to water and sanitation. However, the Principles and Guidelines infer protection through the rights to life, dignity, work, food, health, economic, social and cultural development and to a satisfactory environment.

Accordingly, the right to water, "entitles everyone to sufficient, safe, acceptable, physically accessible and affordable water for personal, domestic, and agricultural uses". ²⁰⁹ Specifically, safe water is defined as that which is "free from hazardous substances (micro-organisms, chemical substances and radiological hazards) that could endanger human health, and whose colour, odour and taste are acceptable to users." ²¹⁰

The minimum core obligations attaching to the right to water require states to:

- "Ensure access to the minimum essential amount of water, that is sufficient and safe for personal and domestic use, including preventing disease, together with access to adequate sanitation.
- Ensure safe physical access to water facilities or services that provide sufficient, safe and regular water; that have an adequate number of water outlets to avoid prohibitive waiting times; and that are at a reasonable distance from the household; educational institution, workplace or health institution.
- Refrain from using access to water as a political tool".²¹¹

²⁰⁷ ACHPR, 'Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and People's Rights' (24 October 2011), para. 83-84.

²⁰⁸ ACHPR, 'Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and People's Rights' (24 October 2011), para. 86(a)(b)(c).

²⁰⁹ ACHPR, 'Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and People's Rights' (24 October 2011), para. 88.

²¹⁰ ACHPR, 'Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and People's Rights' (24 October 2011), para. 90.

²¹¹ ACHPR, 'Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and People's Rights' (24 October 2011), para. 92(a)(b)(c).

2.1.3. The right to health

Article 16(1), ACHPR: "Every individual shall have the right to enjoy the best attainable state of physical and mental health". 212

Article 16(2), ACHPR: "States parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick".²¹³

Article 14, ACRWC provides for the right to of every child to "the best attainable state of physical, mental and spiritual health" and lays out detailed obligations of states parties to pursue the full realisation of this right, in particular by implementing the following measures:

- a. "to reduce infant and child mortality rate;
- b. to ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
- c. to ensure the provision of adequate nutrition and safe drinking water;
- d. to combat disease and malnutrition within the framework of primary health care through the application of appropriate technology;
- e. to ensure appropriate health care for expectant and nursing mothers;
- f. to develop preventive health care and family life education and provision of service;
- g. to integrate basic health service programmes in national development plans;
- h. to ensure that all sectors of the society, in particular, parents, children, community leaders and community workers are informed and supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of domestic and other accidents;
- i. to ensure the meaningful participation of non-governmental organizations, local communities and the beneficiary population in the planning and management of basic service programmes for children;
- j. to support through technical and financial means, the mobilization of local community resources in the development of primary health care for children".²¹⁴

In the context of noma, Article 14, ACRWC could be seen to presents the key features of a roadmap towards the prevention of this disease. This is so because it addresses the key risk factors of noma through its insistence on ensuring sufficient and adequate nutrition of children, pregnant and nursing women, awareness-raising, education and participation of all sectors of society, including families and other non-state actors, in relation to "knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation", integration and development of basic and primary health services.

²¹² The African (Banjul) Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) OAU Doc. CAB/LEG/67/3, article 16(1)&(2).

²¹³ The African (Banjul) Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) OAU Doc. CAB/LEG/67/3, article 16(1)&(2).

²¹⁴ The African Charter on the Rights and Welfare of the Child (adopted 11 July 1990, entered into force 29 November 1999) OAU Doc. CAB/LEG/24.9/49, article 14.

2.1.4. The right to housing

Omitted from the ACHPR, the right to housing nonetheless receives implicit protection in the instrument. Similarly, to the right to food, the Principles and Guidelines state: "In SERAC & CESCR v Nigeria, the Commission held that, although the right to housing or shelter is not explicitly provided for under the African Charter, housing rights are protected through the combination of provisions protecting the right to property (art 14), the right to enjoy the best attainable standard of mental and physical health (art 16), and the protection accorded to the family (art 18(1))".²¹⁵

A full definition of the right to housing is then offered, as "the right of every person to gain and sustain a safe and secure home and community... includ[ing] access to natural and common resources, safe drinking water, energy for cooking, heating, cooling and lighting, sanitation and washing facilities, means of food storage, refuse disposal, site drainage and emergency services". ²¹⁶ The minimum core obligations of the right are interpreted as States Parties, "refrain[ing] from and protect[ing] against forced evictions", "guarantee[s] to all persons a degree of security of tenure" and the "ensure[s] at the very least basic shelter for everybody". ²¹⁷

2.1.5. The right to education

Article 17(1), ACHPR: "Every individual shall have the right to education". 218

Detailed provisions on the right to education are to be found in art. 11 of the ACRWC. Of particular relevance to the context of our inquiry on noma is article 2(e), ACRWC which requires the education of the child to be directed to "the promotion of the child's understanding of primary health care".²¹⁹

2.1.6. The inherent right to life

Article 4, ACHPR: "Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right".²²⁰

Article 5, ACRWC, titled "Survival and Development" indicates that the child's "inherent right to life" brings about correlative obligations for State parties to the instrument to "ensure, to the maximum extent possible, the survival, protection and development of the child.". As

²¹⁵ ACHPR, 'Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and People's Rights' (24 October 2011), para. 77.

²¹⁶ ACHPR, 'Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and People's Rights' (24 October 2011), para. 78.

²¹⁷ ACHPR, 'Principles and Guidelines on the Implementation of Economic, Social and Cultural Rights in the African Charter on Human and People's Rights' (24 October 2011), para. 79(a)(b)(c).

²¹⁸ The African (Banjul) Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) OAU Doc. CAB/LEG/67/3, article 17(1)

²¹⁹ The African Charter on the Rights and Welfare of the Child (adopted 11 July 1990, entered into force 29 November 1999) OAU Doc. CAB/LEG/24.9/49, article 2(e).

²²⁰ The African (Banjul) Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) OAU Doc. CAB/LEG/67/3, article 4.

such, this provision clearly underscores not only the negative obligations of states to ensure that life is not arbitrary taken, but the *positive* obligations of states to ensure a dignified life for children. Taken together with the other positive obligations entailed by the ACRWC and reviewed earlier, article 5 presents a strong legal basis for preventative action that must be undertaken to address noma, given the extremely high mortality rate of the disease.²²¹

2.1.7. The right to freedom of expression

Article 9(2), ACHPR: "Every individual shall have the right to express and disseminate his opinions within the law". ²²² A similar provision is entailed by article 7, ACRWC.

Whilst the limitation clauses are less detailed than those in article 19, ICCPR – and thus arguably broader and their misuse more readily available – it is worth noting that the AfComHPR has interpreted broad limitation clauses in a strict fashion, much in keeping with the practice of the CCPR.²²³

2.1.8. The right of children with disabilities to a full and decent life

The right does not appear in the ACHPR, nor under this precise designation in the ACRWC. Nonetheless, article 13, ACRWC (titled "Handicapped Children") entails provisions which cover various dimensions of the rights.

Article 13, ACRWC:

- 1. "Every child who is mentally or physically disabled shall have the right to special measures of protection in keeping with his physical and moral needs and under conditions which ensure his dignity, promote his self-reliance and active participation in the community.
- 2. State Parties to the present Charter shall ensure, subject to available resources, to a disabled child and to those responsible for his care, assistance for which application is made and which is appropriate to the child's condition and in particular shall ensure that the disabled child has effective access to training, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration, individual development and his/her cultural and moral development.
- 3. The State Parties to the present Charter shall use their available resources with a view to achieving progressively the full convenience of the mentally and physically disabled

²²¹ WHO, 'Promoting Oral Health in Africa: Prevention and control of oral diseases and noma as part of essential noncommunicable disease interventions' (Brazzaville, WHO Regional Office for Africa 2016).

²²² The African (Banjul) Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) OAU Doc. CAB/LEG/67/3, article 9(2).

²²³ See I Österdahl, 'The Surprising Originality of the African Charter on Human Rights and Peoples' Rights', in J Petman & Klabbers (eds.), *Nordic Cosmopolitanism: Essays in International Law for Martti Koskenniemi*, (Leiden: Martinus Nijhoff Publishing, 2003), 5–32, 13. See also *Media Rights Agenda and Constitutional Rights Project vs. Nigeria*, Communications 105/93, 128/94, 130/94, 152/96, Twelfth Activity Report 1998-1999, Annex V, paras. 69–70; M Evans & R Murray, *The African Charter on Human and Peoples' Rights: The System in Practice 1986-2006*, 2nd ed., (Cambridge: Cambridge University Press, 2008), 26–28; F Ouguergouz, *The African Charter on Human and Peoples' Rights: A Comprehensive Agenda for Human Dignity and Sustainable Democracy in Africa*, (Leiden: Martinus Nijhoff, 2003), 430–437.

person to movement and access to public highway buildings and other places to which the disabled may legitimately want to have access to". 224

These provisions may be of particular relevance for survivors of noma who suffer sequelae and disabilities as a consequence to the disease.

2.1.9. The overarching right to equality and non-discrimination

Article 2, ACHPR: "Every individual shall be entitled to the enjoyment of the rights and freedoms recognised and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or any status."

Article 28, ACHPR: "Every individual shall have the duty to respect and consider his fellow beings without discrimination, and to maintain relations aimed at promoting, safeguarding and reinforcing mutual respect and tolerance".²²⁵

Article 3, ACRWC: "Every child shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in this Charter irrespective of the child's or his/her parents or legal guardians' race, ethnic group, color, sex, language, religion, political or other opinion, national and social origin, fortune, birth or other status."

As noted in relation to international human rights treaties, the non-discrimination clause is cross-cutting and attaches positive obligations. Of particular note in the African regional context, is article 28, ACHPR which places a duty directly on individuals (not just states as the duty-bearers under human rights law) to treat other individuals in a non-discriminatory fashion. Arguably, this is one of the rare examples of direct obligations incurred under international law by individuals, outside the context of international criminal law.

2.2. ASEAN HUMAN RIGHTS DECLARATION

Whilst Asian states are party to international human rights treaties and thus subject to monitoring by UN treaty bodies – as well as by other international human rights mechanisms such as the UN Special Procedures and the UPR process of the Human Rights Council –, the continent does not have a binding human rights treaty or a regional human rights court.

Laos is a member state of the Association of Southeast Asian Nations (ASEAN). In 2009, the ASEAN Intergovernmental Commission on Human Rights (AICHR) was established through Article 14 of the ASEAN Charter.²²⁶ Renshaw notes that the members of the commission do not serve in an independent capacity, rather representing and "remain[ing] accountable" to their governments.²²⁷ Asplund is one of a range of scholars, commentators and practitioners

²²⁴ The African Charter on the Rights and Welfare of the Child (adopted 11 July 1990, entered into force 29 November 1999) OAU Doc. CAB/LEG/24.9/49, article 13.

²²⁵ The African (Banjul) Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) OAU Doc. CAB/LEG/67/3, article 28.

²²⁶ C Renshaw, 'The ASEAN Human Rights Declaration 2012' (2013) 13(3) Human Rights Law Review, 557-558.

²²⁷ C Renshaw, 'The ASEAN Human Rights Declaration 2012' (2013) 13(3) Human Rights Law Review, 558.

who have observed that, "the commission... has thus been called 'window-dressing', conveniently shielding ASEAN from outside criticism".²²⁸

The ASEAN Human Rights Declaration (AHRD) was adopted in 2012, and serves two principal functions according to Renshaw: to clarify the mandate of the AICHR and potentially to act "as a precursor to a formal treaty for the region, in the same way that the American Declaration of the Rights and Duties of Man preceded the American Convention on Human Rights". However, the drafting process of the AHRD was marked by a number of controversies, with the final document being "met with mixed reviews". 230

The AHRD broadly provides for all of the civil, political, economic, social and cultural rights laid out in the Universal Declaration of Human Rights, whilst some significant divergences between the two texts should be noted.²³¹ In particular the AHRD affirms rights relevant in the context of noma:

General Principle 4: "The rights of women, children, the elderly, persons with disabilities, migrant workers, and vulnerable and marginalised groups are an inalienable, integral and indivisible part of human rights and fundamental freedoms".²³²

Article 29(1): "Every person has the right to the enjoyment of the highest attainable standard of physical, mental and reproductive health, to basic and affordable health-care services, and to have access to medical facilities". ²³³

Article 30(3): "Motherhood and childhood are entitled to special care and assistance. Every child, whether born in or out of wedlock, shall enjoy the same social protection".²³⁴

It is important to recognise Renshaw's contention that, "ASEAN states have been traditionally reluctant to engage with the international human rights treaty monitoring system". Reflecting this is Laos's poor record of accepting or ratifying individual complaints procedures: the state has not become party to any one of the complaints procedures related to the ratified international human rights treaties.

2.3. OTHER RELEVANT REGIONAL REGIMES

The Economic Community of West African States (ECOWAS), an organisation to which the states of Burkina Faso and Niger retain membership, has adopted a range of legal and policy

²²⁸ A Asplund, 'ASEAN Intergovernmental Commission on Human Rights: civil society organizations' limited influence on ASEAN' (2014) Journal of Asian Public Policy, 7:2, 191.

²²⁹ C Renshaw, 'The ASEAN Human Rights Declaration 2012' (2013) 13(3) Human Rights Law Review, 557. ²³⁰ Ibid., 558.

²³¹ Renshaw notes these differences through the right to rest and leisure.

²³² ASEAN Human Rights Declaration and the Phnom Penh Statement on the Adoption of the ASEAN Human Rights Declaration (AHRD) (adopted 18 November 2012) Available at:

https://www.asean.org/storage/images/ASEAN_RTK_2014/6_AHRD_Booklet.pdf [last accessed 1 June 2020]. 233 lbid.

²³⁴ Ibid.

²³⁵ C Renshaw, 'The ASEAN Human Rights Declaration 2012' (2013) 13(3) Human Rights Law Review, 577-578.

frameworks intended to strengthen child protection in the region. The organization's Child Rights Policy is, suggests Amusen, generally reflective of the provisions of the ICESCR, providing "guidance on protection of child rights in emergency and non-emergency situations". Other ECOWAS protective mechanisms include a 2013 Regional Action Plan for the Elimination of Child Labour Especially the Worst Forms. 237

As Islam currently accounts for a considerable proportion of religious adherents in both Niger and Burkina Faso, and both states are members of the Organisation of Islamic Cooperation (OIC), the 2004 Covenant on the Rights of the Child in Islam (CRCI) adopted within the framework may be of relevance for the context of noma.²³⁸ The CRCI contains a number of articles relevant to the protection and promotion of child rights in the case study countries. These include the expansive right to child health, which ranges from maternal health and support to the "[g]uaranteeing the right of the child to be protected from... infectious and endemic diseases".²³⁹

3. DOMESTIC TRANSPOSITION OF INTERNATIONAL AND REGIONAL OBLIGATIONS

Whilst the ratification of international and regional human rights treaties and the activity of corresponding supervisory mechanisms is important for human rights protection, whether human rights are translated into practice at domestic level, so that all individuals can realise their rights, depends to a large extent on the domestication of international and regional obligations and the activity of national and local actors.

It is in this sense that Thompson notes that "[o]f critical importance is whether national governments possess the political will to translate into reality decisions of regional authorities". Other scholars have further excavated this interpretation of the domestic transposition of human rights principles on the continent, underscoring the importance of African cultural heritage and the socio-cultural milieus of individual states. Le Roux-Kemp asserts that, "what is needed for the true realisation of rights is to understand how rights are enmeshed in a network of cultural practices". The author goes on to contend that it is only through "collective understanding" of the socio-cultural milieu of traditional African society,

²³⁶ L Amusen, 'Child Rights in ECOWAS: A Continuation of the United Nations and African Union's Position on Child Rights? (2018) 7(1) Journal of African Union Studies, 49.

²³⁷ ECOWAS Regional Action Plan for the Elimination of Child Labour Especially the Worst Forms, https://www.ilo.org/wcmsp5/groups/public/---africa/documents/publication/wcms 227737.pdf.

²³⁸ There is no publicly available information on the entry into force or ratification history of the CRCI – thus it cannot be determined whether Burkina Faso and Niger actually incur obligations under this treaty.

²³⁹ Covenant on the Rights of the Child in Islam, OIC/9-IGGE/HR1/2004/Rep.Final.

²⁴⁰ B Thompson, 'Africa's Charter on Children's Rights: A Normative Break with Cultural Traditionalism' (1992) 41(2) The International and Comparative Law Quarterly, 433.

²⁴¹ T Kaime, 'The Convention on the Rights of the Child and the cultural legitimacy of children's rights in Africa: Some reflections. 5(2) African Human Rights Law Journal, 222; A Le Roux-Kemp, 'Conventions, customs and beliefs – social determinants and realising the right to health in Malawi and Uganda' (2012) 45(1) The Comparative and International Law Journal of Southern Africa, 1.

²⁴² A Le Roux-Kemp, 'Conventions, customs and beliefs – social determinants and realising the right to health in Malawi and Uganda' (2012) 45(1) The Comparative and International Law Journal of Southern Africa, 11.

and importantly how it is understood and enacted contextually, that "a comprehensive rights-based approach will convince people to take ownership of their rights". ²⁴³

3.1. BURKINA FASO

Operating through a combination of civil and customary law, Burkina Faso's domestic legal system is monistic in nature, recognizing the supremacy of international treaties over national laws.²⁴⁴

The Constitution of 1991 provides for a range of social and cultural rights to education, water, housing and health, as well as outlining specific duties of the State towards its populations.²⁴⁵

The CESCR's consideration of Burkina Faso's National Health Policy, first adopted in 2001 and consolidated in 2011, noted that "health-care services have improved" in the policy's initial wave, and that "the reduction of perinatal and infant mortality and guaranteed health care for children through a focus of primary health care" are currently being targeted in the second wave of the policy.²⁴⁶ Other national health laws and frameworks relevant for our inquiry on noma include:

- Act No. 012-2010/AN of 1 April 2010 on the protection and promotion of the rights of persons with disabilities, which provides "in articles 5 et seq. that the national health policy should include prevention, diagnosis and treatment of children with disabilities, whatever their age, using vaccination, nutrition, consultation and treatment. In addition, any person with a disability care and who is recognised to be indigent receives free care and any necessary equipment for the treatment prescribed"247.
- The CESCR notes that Burkina Faso's primary health care system is administered through health-care districts in a two-tiered approach: "the first level of care is provided by health and welfare centres, which are the basic health-care facilities within the health care system... The second level of care offered by the health districts is provided in medical centres with surgical units". 248
- Whilst the CESCR noted that in 2013, "the theoretical average distance to a healthcare facility in Burkina Faso was 6.5km", facilities remain unequally distributed across the regions of the country, particularly so in rural and semi-rural areas.²⁴⁹

Burkina Faso was also one of ten noma-priority countries included in the 2001 WHO AFRO's Regional Noma Control Programme (RNCP). As part of this framework, selected countries implemented National Noma Control Programmes (NNCP) "through the development of

²⁴³ A Le Roux-Kemp, 'Conventions, customs and beliefs – social determinants and realising the right to health in Malawi and Uganda' (2012) 45(1) The Comparative and International Law Journal of Southern Africa, 11.

²⁴⁴ M Barnard, 'Legal reception in the AU against the backdrop of the monist/dualist dichotomy' (2015) 48(1) The Comparative and International Law Journal of South Africa, 156-7.

²⁴⁵ Burkina Faso Constitution of 1991, Chapter IV, Articles 18-29.

²⁴⁶ CESCR, 'Consideration of reports submitted by States parties in accordance with articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights. Burkina Faso' (12 May 2015) E/C.12/BFA/1, 8. ²⁴⁷ Ibid., 25.

²⁴⁸ Ibid., 32-33.

²⁴⁹ Ibid., 30.

three-year national plans". ²⁵⁰ From 2013, these national plans were financially supported by the German non-governmental organization Hilfsaktion Noma e.V.. In 2018, an external evaluation of the RCNP found that whilst some progress had been made, particularly in the areas of action plan development, further work was necessary to strengthen reporting and monitoring systems, and improve intersectoral collaboration.²⁵¹

Burkina Faso reported integration of noma surveillance into its existing systems of Integrated Disease Surveillance and Response, and the District Health Information System 2, at the 2019 WHO AFRO Intercountry Workshop on the Regional Noma Control Programme. Here, it was also reported that noma has become a "mandatory reported disease" in the country. Hilfsaktion has also been involved in the fight against noma in Burkina Faso, through provision of care centres, surgery for patients and capacity building of local specialists. Hilfsaktion has also been involved in the fight against noma in Burkina Faso, through provision of care centres, surgery for patients and capacity building of local specialists.

The Evaluation of the WHO Africa Regional Programme on Noma Control (2013-2017) offers several valuable insights specifically into the progression of noma in Burkina Faso. For example:

- In the executive summary of the Programme's evaluation, Burkina Faso, alongside Mali and Niger, was found to have "effectively introduced and integrated noma into the curriculum of the medical and other health professionals' schools".²⁵⁴
- Also reported was increased collaboration between local non-governmental organizations and Ministries of Health (MoH), particularly with regard to community mobilization and local knowledge of noma.²⁵⁵

Overall, a range of factors were found to positively influence the implementation of national noma programmes. In Burkina Faso, noted factors included the "vision, political engagement and dynamism of the actors of the MoH", "the number of civil society organizations actively involved in noma prevention and coordination with the MoH" and "the integration of the program planning process at the national level".²⁵⁶

The WHO AFRO Evaluation reports that Burkina Faso and Niger are two of five countries that have completed the implementation of their first three-year action plan. The report also undertakes analysis of a range of interim outcomes, measuring progress towards program objectives.

Table C – Implementation of the 3-year National Noma Control Programme

²⁵⁰ WHO AFRO, 'Intercountry Workshop on the Regional Noma Control Programme, Abuja, Nigeria, 20-22 November 2019' (2020) Brazzaville: WHO Regional Office for Africa, 1.

²⁵¹ Ibid., 2.

²⁵² Ibid., 5-6.

²⁵³ Ibid., 9.

²⁵⁴ WHO AFRO, 'Evaluation of the WHO Africa Regional Programme on Noma Control (2013-2017): Executive Summary' (12 January 2019), VII.

²⁵⁵ Ibid., VIII.

²⁵⁶ Ibid. VIII.

Objectives ²⁵⁷	Has conducted activity under this objective	In the process of implementing	Has not conducted activity under this objective
Strengthening and development of the capacities of social and health personnel	Burkina Faso Niger		
Community health workers	Burkina Faso		Niger
Awareness and social mobilization	Burkina Faso Niger		
IEC and training materials	Burkina Faso Niger		
Epidemiological surveillance	Burkina Faso Niger		
Coordination and monitoring	Burkina Faso Niger		

3.2. NIGER

Similarly to Burkina Faso, a combination of civil and customary law characterises Niger's domestic legal system, which is also monistic in nature.²⁵⁸

The country's Constitution of 2010 identifies and provides for a range of human rights relevant to the context of children at risk of noma, as well as children and adult survivors of the disease. The wide-ranging Article 12 states that, "[e]ach one has the right to life, to health, to physical and moral integrity, to a healthy and sufficient food supply, to potable water, to education..." 259

In the 2017 report submitted to the CESCR, Niger details the nature of its national health care system, which operates through a network of national, regional and local health care centres. Health huts constitute a significant proportion of the provision of first-referral health care, followed by integrated health centres and district hospitals. However, more than 50% of the population do not live within 5km of integrated health centres. All Niger's National

²⁵⁷ Adapted from WHO AFRO, 'Evaluation of the WHO Africa Regional Programme on Noma Control (2013-2017): Executive Summary' (12 January 2019), XI.

²⁵⁸ M Barnard, 'Legal reception in the AU against the backdrop of the monist/dualist dichotomy' (2015) 48(1) The Comparative and International Law Journal of South Africa, 156-7.

²⁵⁹ The Niger Constitution of 2010, Title II: of the Rights and Duties of the Human Person, Article 12.

²⁶⁰ CESCR, 'Initial report submitted by the Niger under articles 16 and 17 of the Covenant, due in 1988' (18 July 2017), E/C.12/NER/1, 261.

²⁶¹ CESCR, 'Initial report submitted by the Niger under articles 16 and 17 of the Covenant, due in 1988' (18 July 2017), E/C.12/NER/1, 254.

Health Policy is accompanied by a Healthcare Development Plan, which contains specific interventions on ten neglected tropical diseases under the 2011-2015 master plan.²⁶²

In 1998, the Government of Niger established the National Committee for the Awareness of Noma. The Committee seeks to target four groups of stakeholders in the disease, ultimately aiming to eradicate or considerably reduce its prevalence in the country by 2025. Four subcommittees deliver interventions, trainings, awareness-raising and activities for these stakeholder groups: health care workers, communicators, children (and their teachers) and parents.²⁶³ The non-governmental organisation Sentinelles operates a long-running programme for children suffering from noma predominantly in the Eastern and Central regions of Niger. Sentinelles' centre in the town of Zinder, some 1000 kilometres from the capital of Niamey, provides children and their families with medical and social assistance, as well as detection programmes and awareness campaigns.²⁶⁴

Similarly to Burkina Faso, Niger was one of the ten noma-priority countries selected in the 2001 RNCP framework. The 2019 WHO AFRO Intercountry Workshop on the Regional Noma Control Programme reports a range of activities that have been undertaken in Niger, including awareness-raising through 'Parliament Day' and the success of regional coordinator appointments in implementing rural activities and programming.²⁶⁵

The WHO's Evaluation of the Regional Programme on Noma Control (2013-2017) reports a number of key findings in relation to the context of noma in Niger. These include:

- The recording of 1034 cases in Niger between 2004-2013. 266
- The development of a number of dedicated centres for the treatment and care of noma patients.²⁶⁷
- Noma has been integrated into the curriculum of Niger's medical schools.²⁶⁸
- Niger has received around \$380,000 in funding under the RNCP between 2010 and 2018 for noma control activities.²⁶⁹

²⁶² CESCR, 'Initial report submitted by the Niger under articles 16 and 17 of the Covenant, due in 1988' (18 July 2017), E/C.12/NER/1, 258.

²⁶³ 'Campaigning against noma: Baraka Noma Niger' Available at: https://apps.who.int/iris/bitstream/handle/10665/329933/Noma-Contact-1999-Feb-p6-eng.pdf?sequence=1&isAllowed=y.

²⁶⁴ 'Aid programme for children suffering from noma in Niger: 2012' *Sentinelles*. https://www.noma-hilfe.ch/files/nomahilfe/pdf/niger-annual-report-2012.pdf.

²⁶⁵ WHO AFRO, 'Intercountry Workshop on the Regional Noma Control Programme, Abuja, Nigeria, 20-22 November 2019' (2020) Brazzaville: WHO Regional Office for Africa, 7-8.

²⁶⁶ WHO AFRO, 'Evaluation of the WHO Africa Regional Programme on Noma Control (2013-2017): Executive Summary' (12 January 2019), VI.

²⁶⁷ WHO AFRO, 'Evaluation of the WHO Africa Regional Programme on Noma Control (2013-2017): Executive Summary' (12 January 2019), XVI.

²⁶⁸ WHO AFRO, 'Evaluation of the WHO Africa Regional Programme on Noma Control (2013-2017): Executive Summary' (12 January 2019), VII.

²⁶⁹ WHO AFRO, 'Evaluation of the WHO Africa Regional Programme on Noma Control (2013-2017): Executive Summary' (12 January 2019), X.

• With regard to strengthening the sustainability of noma programmes, Niger has made significant progress in fostering collaboration amongst stakeholders.²⁷⁰ A range of contracts have been signed with local Nigerien non-governmental organisations.

3.3. LAO PEOPLE'S DEMOCRATIC REPUBLIC

Lao's legal system operates primarily through civil law and is dualist, requiring "international treaty obligations to be incorporated into domestic law in order to be invoked before domestic courts".²⁷¹

The country's constitution of 1991 outlines its 'Socio-Economic Regime', where the State undertakes to build and improve "disease prevention systems and provid[e] health care to all people, creating conditions to ensure that all people have access to health care, especially women and children, poor people and people in remote areas".²⁷²

In a 2017 report to the CCPR, a number of Lao's health frameworks and policies were highlighted:

- Law on Health Care 2015. Article 6 of this law "provides for equal rights of citizens without discrimination to receive treatment".²⁷³
- Vision for Public Health Sector 2000-2020. Part of the National Growth and Poverty Eradication Strategy, which sets the "overall goals and work plans for health care of the Lao multi-ethnic people, which include universal health care... health improvement focused on the 47 poorest districts to have access to health care services".²⁷⁴

No specific information about noma could be gained from publicly available governmental information. Some non-governmental medical organisations have conducted noma surgery on noma survivors, as noted by Srour.²⁷⁵

²⁷⁰ WHO AFRO, 'Evaluation of the WHO Africa Regional Programme on Noma Control (2013-2017): Executive Summary' (12 January 2019), XI.

²⁷¹ G Mukherjee, 'Lao PDR' in Business and Human Rights in ASEAN: A Baseline Study (Research Report Human Rights Resource Centre 2013), 149.

²⁷² Lao People's Democratic Republic Constitution of 1991, Chapter II, Article 25.

²⁷³ CCPR, 'Consideration of reports submitted by States parties under article 40 of the Covenant pursuant to the optional reporting procedure. Lao People's Democratic Republic'. (27 April 2017), CCPR/C/LAO/1, 169.
²⁷⁴ Ibid.

²⁷⁵ See M.L. Srour (2020), *The Life of Lao Noma Survivors and Outcomes of Surgical Rehabilitation* (to be submitted for publication in 2021).