

Health, Rights and the State

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1 Introduction¹

A child living with a foster family in Skåne, Sweden, turns down an offer of ice cream. Ice cream, she explains, makes her teeth hurt. At the dentist, it is discovered that her teeth are filled with cavities.

Likely she does not know it, but her health is a matter of international law, and in particular a matter of international human rights law, which both guarantees to her a number of rights and creates, for her government, a number of corresponding duties. Long before she was born, a series of legal agreements among states established an international human right to health, and in the years since then activists, scholars, government officials, and a range of United Nations institutions, among others, have worked to flesh out what that right means more specifically. Lawyers can speak in some detail of her various substantive rights, of her various process rights, of ‘cross-cutting human rights principles,’ of “rights-based approaches” to health systems or health services, and more. At the core of all of this is the basic nature of international human rights law, in which individuals and communities have rights and states have obligations to ensure that those rights are properly enjoyed.

This essay looks at our child’s right to health in Sweden as a way of interrogating, gently, what it means to use international human rights law, with its focus on the state, as a normative reference point for domestic health policy and practice. In Part I, we locate the right to health in its place in human rights and in international law in general, exploring the contradictions and complexities inherent in using international rights standards to address domestic economic and social policy. In Part II, we explore the right to health specifically with regard to the practical well-being of the hypothetical foster child. Looking at issues that range from her access to health care to her procedural protections within the health system, we examine what questions a “right to health” approach would raise, and what benefits might or might not accrue to her if her health experience were closely grounded in international human rights law.

1 This essay draws on writings, teaching and discussions during the years by Mattsson and Green, both together and within their respective fields of health care and human rights. Relevant publications include Green, Maria and Randolph, Susan, *Bringing Theory Into Practice: Operational Criteria for Assessing Implementation of the International Right to Development*, United Nations doc. no. A/HRC/15/WG.2/TF/CRP.5 2010; Green, Maria, *What We Talk About When We Talk About Indicators: Current Approaches to Human Rights Measurement*, *Human Rights Quarterly* 23 (2001) pp. 1062-1097; Mattsson, Titti and Vinnerljung, Bo, *Barn i familjehem. Åtgärder för de mest utsatta*, Studieförbundet Näringsliv och Samhälle, Stockholm 2016; Mattsson, Titti, *Barnet som subjekt och aktör. En rättslig studie om barn i familjehem*, Iustus förlag, Uppsala 2006; Mattsson, Titti, ‘Participation’ for all? *Challenges and tools for realizing the goal for vulnerable people with focus on health services*, in M. Hesselman and B. Toebes (eds.) *Human Rights in Essential Public Service Provision*, Human Rights Law Series, Routledge Press, Oxford 2016.

2 The Right to Health as Part of International and National Law

Home from the dentist, and writing down her foster address in an imaginative mood, our child might start with her house, street and town, and then, stretching her mind to situate herself fully in the world, expand to include Sweden, Europe, the Earth, the Solar System, the Milky Way, the Universe. Her lawyer, charged with helping to ensure her legal right to health, would benefit from similarly situating the right in the geography of law, starting with local and national standards and then expanding to include the internationally recognized right to the “highest attainable standard of health,” which is part of international economic, social and cultural rights, which is part of international human rights law, which is part of international law. Each of these spheres has implications for how the human right to health plays out in at the level of an individual’s everyday life. Each also raises problems of implementation that international law, in various ways, has attempted to address. Almost all of these problems, as well as the solutions, center in some way on the role of the state.

Starting with the outer edge of this legal space, we will explore the problems and solutions associated with each one. But it may help to first identify what it is that the fact of an international right to health might offer, and therefore to understand the nature of the problems raised (meaning aspects of law that might diminish the practical impact of the existence of the right) and solutions offered (meaning analyses, secondary standards, etc, that might bolster the practical impact of the existence of the right).

Views differ on what the existence of an internationally recognized human right to health adds to the well-being of individuals and communities. We take the position in this essay that the core of the value of the international right lies in four components: universality, legitimacy, conceptual clarity regarding substance and process, and internationalization.

Universality means that the right applies to every human being. At the geographic/political level, this means every human being in every location in the world, regardless of the nature of his or her government. At the individual level, this means every individual human being, regardless of his or her gender, age, ethnicity, national origin, religion, presence or absence of disabilities, wealth or any other characteristic.

Legitimacy refers to the nature of an internationally recognized right, which is that each right establishes a series of legitimate claims with regard to one’s society as a whole.² An individual or community wishing to enjoy the right has a well-established external ground — the adoption of the right by governments using formal legal processes — on which to justify the claims that he, she or it

2 Cf. Henry Shue, from a text that has had an impact in international economic, social and cultural rights jurisprudence in particular: “A moral right provides (1) the rational basis for a justified demand (2) that the actual enjoyment of a substance be (3) socially guaranteed against standard threats.” Shue, Henry, *Basic Rights: Subsistence, Affluence, and U.S. Foreign Policy*, Princeton University Press 1980, p.13.

wishes to make. In certain, but not all contexts, the language of human rights also has a powerful emotional or moral force separate from any formal legal status.

Conceptual clarity refers to the growing international jurisprudence that has built up around the various rights that are established in international human rights law. This jurisprudence might come from formal processes (for instance, UN treaty bodies procedures) or adoption of clarifying soft law, or from widely-accepted work by scholars, UN specialized agencies, civil society organizations, and so forth. With regard to the right to health, this means a greatly expanded understanding of what the text of the relevant human rights hard law provisions mean with regard both to substance (for instance, access to health services, freedom from medical experimentation) and process (for instance, non-discrimination or access to means of accountability).

Internationalization refers to the fact that international recognized rights bring with them, by their nature, both the existence of international fora (UN processes for UN-level rights, regional processes for regional rights laws) where issues can be raised, and a legitimated interest of other states in the enjoyment of the rights at the national level. By adopting rights as a matter of international law, states are explicitly stating that enjoyment of the rights is not purely a domestic matter. In this essay, we focus exclusively on international (UN-level) human rights law for reasons for time and space, but regional human rights standards and fora are in some contexts the richest space for effective use of the internationalization aspect of legal rights regimes.

With these understandings in mind, we turn now to each of the spheres of law within which our child's right to health is located.

2.1 *International Law*

International law is based on notions of sovereignty and consent of nation-states. That is, formally speaking, international law, whether in the form of customary law or of treaty law — these two being primary sources of international legal duties — binds each individual state only to the extent that that state has agreed to be bound by it. This raises two major issues with regard to the universality aspect of international human rights law. The first is that what “universal rights” the individual legally enjoys are determined by which state he or she happens to be under the jurisdiction of at any given time. As human rights treaties become more widely adopted, and as the number of rights considered to have become customary law slowly expands (meaning in broad terms that states are generally bound unless they actively object) this distinction may become less important, but it remains relevant. The second is that, as Hannah Arendt noted at the start of the human rights legal era, not all human beings have an affiliation with a nation-state.³ To the extent that rights get their legal existence in the form of international legal obligations that vary

3 See note 5, below. Berkowitz locates this point at p.293 in Arendt's *The Origins of Totalitarianism*, Harvest Books 1973.

from state to state, and to the extent that international law allows statelessness, the goal of universality is undermined.

2.2 *International Human Rights Law*

In the universe of international law, international human rights law is an anomalous area of space. In general, states choose to bring issues into international legal regulation because they have an interest in how other states behave on that issue. A treaty governing, for instance, the apportioning of use of water from a river that forms the border between two states will have been reached by both states with the idea that each will gain in some way from the agreement, and that each will lose if the other side violates the agreement. Large multilateral agreements, such as trade agreements, generally function on the same premise, and states will sometimes create and obey systems of enforcement because they see a benefit to there being a penalty when they or other parties diverge from the agreed-upon actions.

International human rights law, however, functionally addresses duties of states, not to each other, but primarily to those individuals and communities under their separate jurisdictions.⁴ While states may sometimes have a strong interest in seeing rights protected by other states, whether for reasons of a general belief in the rule of law, or reasons of general humanity (whether by governmental officials or the force of public opinion, or both) or because of shared ethnic or cultural affinities with those whose rights are being violated (for instance, former citizens who, following a war, are now citizens of another state), or because the violations are having a direct deleterious effect on their own citizens (for instance, though the arrival of large numbers of refugees from a state where rights are being violated), in general human rights law creates far less of a self-interested incentive for response to violations than do most other areas of international law.

In addition, the legal standards that states have drafted so far have explicitly refused to solve Hannah Arendt's problem:⁵ the core international human rights legal instruments do not require free movement into states, only free movement out of them. States, under the notion of sovereignty, have a fundamental power to decide whom to grant the claims of citizenship to and whom to exclude, and in general human rights standards do not amend or limit this power. A standard in international refugee law, mandating that states have certain duties towards asylum seekers, provides a narrow constraint on this power, and international human rights to non-discrimination may limit the

4 Formally speaking, the duties are duties towards other states to undertake the duties towards individuals and groups that are spelled out in the relevant international human rights instruments. On extraterritorial duties, *see* below.

5 Arendt did not see a solution in grounding human rights in any kind of world government either, and her critiques are deeper and more interesting than presented here. For an overview of Arendt's views on human rights, *see* Berkowitz, Roger, "Hannah Arendt on Human Rights," in Cushman, Thomas (ed.), *Handbook of Human Rights*, Routledge 2011.

power of states to, for instance, choose to automatically grant citizenship to the spouses or children of male nationals but not female, or vice versa, but these are among the rare exceptions.

As noted above, the patchwork nature of international human rights treaty standards also means that the fact that right has been endorsed by formal international bodies, for instance the United Nations General Assembly, does not mean that there will be consistent adoption of legal obligation by individual states. For instance, the 1989 Convention on the Rights of the Child (CRC) has seen almost universal ratification by UN member states, with only one country not having chosen to ratify it. Ratification of the relatively recent International Convention on the Rights of Persons with Disabilities (CRPD, 2006) has so far seen 162 ratifications, while the International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (CMW, 1990) has received only 48 ratifications.⁶

Finally, international human rights law, because it is a part of international law, primarily creates international legal obligations for individual states as opposed to other actors. Since in human rights issues many of the actors who might cause harm, or whose active involvement in causing good is needed to implement a right — these might range from business enterprises to collective international actors such as the International Monetary Fund to persons in intimate private relations with other persons, such as a spouse in contexts of domestic abuse — a great deal of energy in human rights law in recent years has turned towards finding a way to bring these non-state actors into the practical equation of how rights law is implemented.

In addition, the international human rights standards themselves generally spell out duties of states towards those under their jurisdiction but not for those under the jurisdiction of other states. In essence this creates a system where territoriality is central. As with non-state actors, a fair amount of attention has gone to finding ways to expand the reach of international human rights law to the actions of states with extraterritorial impacts, such as trade policies, overseas development aid, interactions among intelligence agencies, and so forth.

2.3 *International Economic, Social and Cultural Rights*

From the initial debates over human rights in the freshly-founded United Nations, the international human rights system has broadly divided specific rights into two groups: civil and political rights on the one hand and economic, social and cultural rights on the other. Civil and political rights include, for instance, the rights to political participation, fair trial, freedom from torture, freedom of expression, and many more. Economic and social rights include the right to health (properly, the right to the “highest attainable standard of

6 Texts of the core UN human rights treaties and information about ratification status can be found on the website of the United Nations Office of the High Commissioner for Human Rights at “www.ohchr.org”.

health”), the right to food, the right to housing, the right to education, and more.

Of the three human rights instruments at the UN level that together make up the International Bill of Rights — the core of the UN human rights legal system — the first is the 1948 Universal Declaration on Human Rights (UDHR), which includes both civil and political rights. This instrument was deliberately made a General Assembly declaration, meaning that it is not legally binding as a treaty would be, though parts of it have been so widely accepted by states as to have likely reached the status of customary international law. The other two instruments are the International Covenant on Civil and Political Rights (ICCPR, 1966) and the International Covenant on Economic, Social and Cultural Rights (ICESCR, 1966). Based perhaps on assumptions that civil and political rights were uncomplicated, largely negative in nature (requiring states to refrain from harmful actions rather than to take helpful actions) and cheap; and that economic, social and cultural rights were correspondingly complex, largely positive in action (requiring states to take helpful action rather than refrain from harmful action) and expensive, these two treaties set divergent duties on the states that ratify them. States that ratify the ICCPR undertake to “respect” and “ensure” the rights in the treaty to all of those under their jurisdiction, while in ratifying the ICESCR each state undertakes merely to “take steps ...to the maximum of its available resources ... with a view to achieving progressively the full realization of the rights recognized in the present Covenant ...”.

Since States have widely differing available resources, this means that formally speaking, although every human being whose state has ratified both treaties has the same rights, the duties of the states to fulfill those rights diverge when it comes to economic, social and cultural rights. Your right to vote does not create varying duties, formally speaking, whether you live in Zimbabwe or Sweden. However, your right to health creates wildly varying obligations in Zimbabwe, a country with limited resources, and Sweden, a country with extensive resources.

This problem, and others mentioned above, are not without existing solutions, partial solutions, work-arounds, or mitigating factors in the world of human rights theory and practice. We give a limited account now of some of these solutions.

That rights more or less track to relationships between the individual and specific nation states remains a vexed point. Attempts to address it have included looking to the Declaration on the Right to Development, a non-binding UN declaration from 1986, for evidence of a collective duty by states for ensuring human rights and development around the world; considerable work on human rights and international financial institutions such as the World Bank and International Monetary Fund, which are created by states acting collectively; and efforts to clarify any transborder human rights duties of individual states either through the Declaration on the Right to Development or through an enhanced understanding of extraterritorial duties (ETOs) arising under scattered language, mostly to do with international cooperation, in core human rights instruments. It has also come up in the context of human rights and specific areas of international law (for instance, human rights and trade,

particularly with regard to intellectual property rights) and in integrating human rights into global development standards including the recently adopted 2030 Agenda for Sustainable Development.

That states often do not have as large a stake in enforcing other states' compliance with human rights law as with other international legal standards is perhaps inherent in the nature of the law; all the same, the very existence of human rights law as binding law can be understood as an attempt by states to mitigate this expected indifference by embedding the obligations into an international legal framework that would, perhaps, invoke the underlying interest of other states in seeing the rule of international law upheld generally.

With regard to economic, social and cultural rights, the issues of "progressive realization" and "maximum available resources," have been important objects of secondary jurisprudence. Another has been the deeper issue of economic, social and cultural rights being assumed to be too complex and expensive to be treated as actual rights rather than objects of unfettered political give-and-take. The solutions to these sets of issues have included an affirmation, by the UN Committee on Economic, Social and Cultural Rights, of a duty to actively move forward on the rights⁷ and, perhaps more important, a now well-established analysis that divides governmental duties for all of the elements of the rights into three types: a "*respect*" duty to do no harm, a "*protect*" duty to ensure that third parties do not cause harm, and a "*fulfill*" duty to actively ensure that the systems are in place through which everyone enjoys the right.⁸

The protect duty also addresses directly the fact that many critical actors in human rights contexts (whether the rights are civil and political rights or economic, social and cultural rights) are not the state itself. "Protect" brings those actors into the human rights legal regime by setting out states' duties, grounded in international human rights law, to regulate those actors. At the same time, recognizing that governmental power to affect behavior may be limited, particularly in developing countries, measures to address non-state actors directly have been adopted, most notably the non-binding Ruggie Guiding Principles on Business and Human Rights, which arose through the UN system and have been widely endorsed both by governments and businesses themselves.

Another development has been a strong emphasis on non-discrimination, which is understood to always apply — that is, to not be dependent on resources or subject to progressive realization. If a government is implementing a health system, even a limited one, it must ensure that it does so without discrimination, and that it protects against discrimination by any private actors involved. Jurisprudence on specific economic, social and cultural

7 See United Nations Committee on Economic, Social and Cultural Rights, General Comment 3, The Nature of States Parties' Obligations, 1990, paragraph 2.

8 See, among others, United Nations Committee on Economic, Social and Cultural Rights General Comment 14, the Right to the Highest Attainable Standard of Health, 2000, UN Document No. E/C.12/2000/4, paragraph 33. See also, Shue, note 2, above.

rights has also stressed other process-related rights such as participation and accountability.

Recent years have seen a growing acceptance of the notion that there are “cross-cutting human rights principles” that invoke duties applicable to how every rights regime is implemented and that are likely not subject to progressive realization. These are characterized in different ways; we prefer the following:

- *Non-discrimination and attention to “vulnerable” groups* (that is, to members of groups that might be disproportionately harmed by a policy or program, or that might be disproportionately liable to be left out of the benefits unless special actions are taken).
- *Participation*, which in human rights contexts refers to having a voice in decisions that affect one.
- *Access to information*, which includes for instance access to budget or other core governmental information, to information about proposed rules in time to advocate around them, and so forth.
- *Means of accountability*, including fundamentally means of complaint and remedy. That is, if a right is violated or a rule is broken, there is a means to raise the issue and to have the situation be corrected.

The notion of a “human rights-based approach” (HRBA) to, for instance, development, has also been an attempt to move beyond the state-centered nature of human rights law. A rights-based approach can be taken by any actor that chooses to adopt it, regardless of whether or not it has legal duties under international law. The approach has two main components: that the goals of a policy, program or project should reflect the substance of relevant human rights standards, and that how the policy, program or project is implemented should reflect human rights process-related standards, which in practical terms likely means the cross-cutting human rights principles listed above, or some form of them.

Adopting a rights-based approach means reflecting the human rights in goals and processes at all levels of the activity at hand, i.e. when assessing needs and when planning, implementing, monitoring and evaluating the activity. For example, a rights-based approach to choosing whether or not to consolidate rural hospitals would both reflect the right to geographically accessible health care that is an element of the right to health (see below) and would ensure that attention is paid to those who might be most vulnerable to harm resulting from consolidation.

The major development agencies in the UN human rights system, among other international and national governmental and non-governmental actors, have explicitly adopted a human rights-based approach to their work.⁹

2.4 *The Right to Health*

The right to the “highest attainable standard of health” appears in the International Bill of Rights in the Universal Declaration of Human Rights and in the International Covenant on Economic, Social and Cultural Rights. It also appears in the Convention on the Rights of the Child, where it establishes rights and duties regarding the health of everyone under the age of 18; and there are health-related standards in the Disability convention (CRPD), the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW), the Convention on the Elimination of all Forms of Racial Discrimination (CERD) and the Migrants convention (CMW).

Since the 1990s, in particular, the substantive and procedural content of the rights and duties established by the UN treaties’ right to health provisions – that is, what the provisions actually mean, in practical terms, with regard to what states should and should not do – has received considerable attention. Among the major sources of analysis are a General Comment by the UN Committee on Economic, Social and Cultural Right; reports by successive UN Special Rapporteurs on the Right to Health; work by the World Health Organization, the UN Office of the High Commissioner for Human Rights, UNICEF and other specialized UN agencies; jurisprudence of national courts whose constitutions reflect international rights provisions; work by scholars and work by civil society organizations.¹⁰ There is a journal, the *Health and Human Rights Journal*, published out of the Harvard School of Public Health, devoted to the topic. One can read entire books centered on the right to health as a whole or on specific topics within it.

The right to health as set out in UN-level human rights treaties can be understood to include, among other things, rights to access to health services, medicines and other health goods; to measures against epidemics; to freedom from medical experimentation; to patient privacy; and to “underlying determinants of health” such as clean drinking water and adequate sanitation, adequate and safe food, and so forth. It includes a substantive right to health information (for instance, access to information about reproductive health), and can now be understood (or at least strongly argued) to encompass the core cross-cutting human rights principles described above: non-discrimination and

9 See “The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies,” 2003.

10 For a quick entrée into the world of international human rights law and the right to health, see the OHCHR right to health homepage at “www.ohchr.org/EN/Issues/ESCR/Pages/Health.aspx#key”. For health systems and human rights specifically, see especially Backman, Gunilla, Hunt, Paul *et al.*, *Health systems and the right to health: an assessment of 194 countries*, *The Lancet* 372 (2008) pp. 2047-8.

attention to who might be being left out or disproportionately harmed (this one is beyond doubt), participation, access to information generally, and means of accountability. The substantive elements of the right ought to be *available* (there are enough goods and services in the country to meet them), *accessible* (in terms of non-discrimination, geographic or physical accessibility, and affordability) and of adequate *quality* (eg, not outdated if medicines, well-trained if doctors, and so forth).¹¹

The right is subject to progressive realization, and its elements are generally discussed in terms of the respect/protect/fulfil duties described above. A rights-based approach to health implies that the different stages of health policies, programs and projects reflect the substantive elements of the right when setting goals and implementing projects (for instance, reflect the substantive elements of the right in the indicators used to assess, monitor and evaluate) and integrate the cross-cutting human rights principles into processes (including, again, for instance, in how indicators are determined and in decisions about what data to collect and with what forms of disaggregation).

2.5 *Domestic Health Law in Sweden*

Sweden is a country with 9.7 million people, of whom about 2 million are under the age of 18. Sweden has three levels of domestic government. Apart from the national government, there is a regional level consisting of 20 County Councils, including Skåne in the south, and at the local level there are 290 municipalities, each with an elected council or assembly. Sweden has a long tradition of delivering high quality, economically viable healthcare. For many years Sweden's health care system has regularly ranked at or near the top of most comparative analyses of various international health care systems. Children under the age of 20 receive free health care, including regular medical examinations and vaccinations, as well as free dental care. The Swedish childcare centers offer support to parents and organize gatherings for new parents living within a given area. The program includes support in parenting, information and education concerning child health care, health promotion and health check-ups and developmental screenings. Thus, Sweden's health and medical care for children, but also for the rest of the population, generally is expected to meet a high standard and is fully subsidized by the state.

No explicit constitutional right to health care services exists in Sweden, although the section of the Instrument of the Government (part of the Constitution) that sets out non-enforceable aims of government includes the following statement:

The personal, economic and cultural welfare of the individual shall be fundamental aims of public activity. In particular, the public institutions shall secure the right to employment, housing and education, and shall promote social

11 UN Committee on Economic, Social and Cultural Rights, General Comment 14, note 8, above.

care and social security, as well as favourable conditions for good health. (Chapter 1, Section 2)

The central legislation dealing with the Swedish health and medical care system is the Health and Medical Services Act (1982:763). The Act provides a framework for patients' care and legal status, and places stringent requirements on equal healthcare for all. This is expressed by specifying requirements for "good healthcare" for all. The requirements mean that in particular, healthcare must be (1) of good quality, with a good standard of hygiene and able to satisfy the patient's need for feeling secure, (2) easily accessible, (3) built on the respect for patients' own decision-making ability and integrity, (4) able to promote good patient-caregiver contacts, and (5) able to satisfy the patient's need for continuity and safety (2a §). In addition, the patient shall have the possibility to influence his or her own care, and shall be given individually adapted information about his or her health status and the methods of examination, care and treatment available.

This legislation is constructed as a 'defined-duties legislation', which means that it lays down different duties for the local and regional authorities. Thus, the national government has a limited role in the health care delivery services. Instead, each County Council and municipality provides the health and medical care that falls under its statutory responsibilities to all persons residing within its jurisdiction. The majority of the services are provided at the regional level, by the County Councils. Each County Council has the responsibility to offer good health and medical services to persons residing within its boundaries. In addition, the counties have some responsibilities for health and medical care in accordance with EU law, which will not be dealt with further in this paper. The municipalities have the responsibility to provide basic care and treatment to older persons, the chronically ill, persons with disabilities and other persons living in special types of accommodation. They are also responsible for in-home visiting services and treatment of patients. The health and medical services may be provided by the local or regional governments themselves, or arranged for with private providers.

3 The Right to Health and the Health of a Foster Child in Sweden

We hope that you have not forgotten our foster child in Skåne, in the south of Sweden. We have chosen to focus on her, in our discussion of the right to health, in part because many of the problems and complexities with human rights that we have discussed above do not apply.

Sweden has ratified both the ICESCR and the CRC as well as CEDAW, so the relevant government has chosen to be bound by the principal relevant human rights legal instruments. Our child is a citizen of Sweden (as we now specify), living inside Sweden, so issues of extraterritorial application do not arise, making it possible to focus on the core concepts.

Other countries likely do not have a strong stake in seeing that Sweden fully implements its international legal obligations with regard to the right to health.

However, Sweden has a well-established respect for the rule of law at international as well as national levels, along with a strong and widely accepted sense of governmental duty towards health care at both governmental and popular levels, and it is justly proud of its well-organized system of single-payer universal health care.

It is among the countries with the highest standards of living in the world, and Skåne, Sweden, is among the more comfortable of Sweden's counties, so the question of reduced obligations for the right to health under the "progressive realization" and "maximum available resources" provisions of the ICESCR and the CRC are not likely to play a major role.

Finally, our child, being a foster child, is explicitly the responsibility of the state during her stay in the foster home and therefore there are few complications concerning who has the primary duties with regard to her care under the "respect, protect, fulfill" principles, even though her parents (if she has any) normally remain as custodians during the care period. By removing these complex elements from the right to health, we will be able to focus on what the core of the right to health can add, or not, to a domestic health system or practice.

3.1 *How are Health Conditions for Foster Children in Sweden?*

If our imaginative child is like other foster children in Sweden, it is likely that her untreated cavities are not the only health issue that she is dealing with, nor is she part of a minuscule group. Approximately three to four percent of children in Sweden, at some time during their youth, are placed in foster care or institutional care, even if we exclude unaccompanied asylum seekers under the age of 18. Most are placed in foster homes, but many will have experience of both foster homes and institutional care before they are 18 years old. Around one percent of the child population spend a very large part of their childhood - over five years - in care. If we look at the annual statistics, almost 14 000 children and adolescents were placed in a foster home in 2014.¹²

Research suggests that overall the health conditions of foster children in Sweden are inadequate, falling below those of most children in the general population. The otherwise well-functioning national health checks offered to all children seem not to be functioning well for this group. Many children coming into care have a history of having not taken part in the regular system of check-ups, vaccinations and so forth when they lived at home. As part of a recent academic study that was made in Southern Sweden, 120 children who were being considered for placement in care by the social services went through a standard health check. The pediatrician who conducted the check

12 Socialstyrelsen, *Statistik om socialtjänstens insatser till barn och unga 2014*, Stockholm 2015, "www.socialstyrelsen.se".

ended up making 99 referrals to specialist care.¹³ As such a check is not a standard part of the intake system with regard to foster children, without this study the children's poor health conditions would probably have remained unknown to the foster homes or institutions where they were placed until more clearly visible symptoms emerged or they happened to be up for a regular check in school, which might take some time depending on the child's age and other factors.

In addition, half of all the school-age children in the study had untreated dental cavities, something that was likely extraordinarily rare among their classmates. A recent Swedish study of the national registry data shows that adults who grew up in foster homes have significantly poorer dental health in adulthood, compared to others of the same age.¹⁴ Vaccination coverage among children being placed in foster homes seems to be alarmingly low but is below the national figures also for children already in care. The poor health conditions of children in care is not a new phenomenon. In a 15 year-old study of self-rated health for around 100 children in foster care and institutional care, two out of three children reported that they suffered from a chronic health problem.¹⁵ It can also be noted that it is three to four times more common that girls who grow up in foster care become teen mothers, compared to other peers in Sweden. Since teenage parenthood is associated with a number of negative consequences for both the child and the mother, the figures are alarming.

Poor conditions in childhood can have long-term negative consequences. Several Swedish registry studies report very high incidences of suicidal behavior in adulthood among former foster children.¹⁶ Other common problems are serious mental illness, psychiatric drugs consumption and early retirement due to mental illness, compared to other peers.¹⁷

13 Kling, Stefan, Vinnerljung, Bo, Hjern, Anders, *Somatic assessment of 120 children taken into care reveal large unmet health and dental care needs*, Acta Paediatrica 2016.

14 Socialstyrelsen, *Sämre hälsa hos barn i HVB och familjehem*, Stockholm 2016, "www.socialstyrelsen.se".

15 Socialstyrelsen, *Dartingtonprojektet. En försöksverksamhet för att stärka och utveckla familjehemsvården*. Stockholm 2000.

16 Hjern, Anders, Vinnerljung, Bo, Lindblad, Frank, *Avoidable mortality among child welfare recipients and intercountry adoptees: a national cohort study*, Journal of Epidemiology and Community Health, 58, 412-417, 2004; Berlin, Marie, Vinnerljung, Bo, Hjern, Anders, *School performance in primary school and psychosocial problems in young adulthood among care leavers from long term foster care*. Children and Youth Services Review, 35, 2011 p. 2489-2494.

17 See, e.g. Hjern et al (2004); Berlin, Marie, Vinnerljung, Bo, Hjern, Anders, *School performance in primary school and psychosocial problems in youth adulthood among care leavers from long term foster care*. Children and Youth Services Review, 33, 2011, p. 2489-2494; Vinnerljung, Bo, Hjern, Anders, *Consumption of psychotropic drugs among adults who were in societal care during their childhood*, Nordic Journal of Psychiatry. "E-publ.DOI:10.3109/08039488", 2014.902501, 2014; Vinnerljung, Bo, Brännström, Lars, Hjern, Anders, *Disability pension among adult former child welfare clients: A Swedish national cohort study*. Children and Youth Services Review, 56, 2015, p. 169-176.

During the 2000s, several studies, reports and research have criticized the foster care situation in Sweden, and it has been discussed if increased responsibilities for the municipalities are not required in order to strengthen the rights of foster children, through national law placing specific requirements concerning foster children in the municipalities. There are certainly several interrelated reasons having to do with national legislation underlying the current situation. Sweden has, in contrast to, for instance, England, no special regulation of these children's health care. In practice, the 290 Swedish municipalities do what they want - or do not want. Another probable reason is that social services are usually staffed solely with social workers, who in most cases lack basic health education, compared to the UK, for example, where the child welfare authorities often have access to their own health professionals. Children's health often seems to be a low priority in the social services work, and there is little communication between the social services and the health care system for children.

3.2 *Health, Human Rights and the State: an Exploration*

As discussed above, Sweden has for several decades provided free pediatric care immediately after birth as well as free ongoing children's medical care and other health services, and has subsidized dental care that is both free and accessible to all children. Adults have access to free or almost-free medical and other health services. Whether at the national, regional or local level, the government is closely engaged in access to health.

What interests us in this section is whether, and if so, what, a human right to health would add to that situation. Using our child as a stand-in, we will explore these questions through two lenses: 1) who is being left out and 2) access to remedies.

3.2.1 Who is Being Left out: Falling Through the Cracks of an Otherwise Well-Functioning System

According to Swedish legislation, all residents have equal access to health care services. However, the reality that healthcare in Sweden has not been able to fully live up to the law's intention with respect to equality has garnered considerable attention during recent years.¹⁸ Along with foster children, other groups have been identified as disproportionately likely to gain fewer benefits from the health system than most members of the general population.

For instance, older persons have been highlighted in this context as a group that is unfairly treated as a result of structural and organizational conditions.

18 DO, *Rätt till sjukvård på lika villkor*, Stockholm 2012; European Union Agency for Fundamental Rights (FRA), *Inequalities and multiple discrimination in access to and quality of health care*, Vienna 2013; Socialstyrelsen, *Ojämna villkor för hälsa och vård. Jämlikhetsperspektiv på hälso- och sjukvården*, Stockholm 2011.

Several Swedish County Councils implemented performance-based compensation when the choice in healthcare became mandatory in primary care in 2010. This system rewards clinics for carrying out many, short treatments and is disadvantageous to older persons with complex care needs.

There are also social and economic factors which influence the interaction with and treatment of certain groups of the population. Education is such a factor. In relative terms, highly educated persons receive more referrals to specialist care than those with little education.¹⁹ The highly educated also receive better and more suitable medicines in cases of heart attacks, heart disease and stroke than do people with less education. Both Swedish and international researchers have established that gender also affects reception and treatment of patients.²⁰ When it comes to foreign-born persons, it is more common that they feel that they receive less satisfactory reception and treatment in healthcare, compared to Swedish-born persons.²¹

Our child's untreated cavities and any other remediable health problems are likely not because of discrimination or social marginalization, although those may play a factor in determining who is left out or falls between the cracks here or with other groups mentioned above, but rather most likely primarily because the system for ensuring child health services assumes responsible parents or other legal guardians, and does not adequately adapt to circumstances where those are absent. From a human rights perspective, the right to health would add several components:

-- The state and non-state actors. The right to health would say, under the "protect" duty, that the state has a duty under the right to health of children that exists even if the failure of children to enjoy the same health services as others can be laid at the feet of third party actors, namely the negligent parents or guardians.

-- Universality. Under the cross-cutting human rights principle of non-discrimination and attention to who might be being left out, government has a duty to actively consider who might be marginalized or otherwise not fully benefitting from the system, and to take steps both to identify the relevant groups and take remedial actions. This might involve making use of existing research, conducting or commissioning research, and so forth.

At the practice level, this means, among other things, that when indicators used for assessing, planning, monitoring and evaluating health programs are designed and used, the government (at whichever level is involved) has a duty to ensure that the indicators capture the marginalized groups, whether through

19 Socialstyrelsen, *Hälso- och sjukvårdsrapport 2009*, Stockholm 2009.

20 See, e.g. Sarah Wamala and John Lynch (Eds.) *Gender and social inequities in health*, Studentlitteratur, Lund 2002; Brodin, Helene and Mattsson, Titti, *Lägst ner på skalan? Hälso- och sjukvårdens bemötande av äldre kvinnor som migrerat till Sverige*, Socialvetenskaplig tidskrift, Vol. 21, Nr. 3-4/2014, p. 372 – 391.

21 Socialstyrelsen, *Ojämna villkor för hälsa och vård. Jämlikhetsperspektiv på hälso- och sjukvården*. Stockholm 2011.

collection of appropriately disaggregated data or through the collection of data needed to ensure that relevant issues are understood and visible.

-- Including the substantive content of the right to health (such as a right to health services) in all relevant programs. The right to health would say that in specific situations or governmental programs, such as when children are taken into foster care, access to health needs to be specifically included in the goals and processes of the programs, so that for instance appropriate checklists or training or other systemic steps are introduced to ensure that health does not fall by the wayside in the course of otherwise effective government programming.

3.2.2 Legal or Other Remedies

The national legislation that imposes state duties to create decent conditions for vulnerable children in Sweden is the Social Services Act (2001:453). According to the Act, the municipalities have the responsibility for the individual child's health and development by providing adequate care and adequate support initiatives. The care that the provision refers to can be a foster home placement, and it is this form of care that we focus on here. The child can be placed into foster care through an administrative decision by the social services and with the custodians' consent, or the child can be placed after a court order of involuntary treatment under the Act with special provisions for the care of youth (LVU, 1990:52). Once a child is in foster care, the legal power to make health decisions on her behalf lies not only with the custodians (and depending on her age, the girl herself), but also with the social services and the foster parents, depending on the health issue and type of care (voluntary or a care order).

Even though the public authorities are under a statutory duty to supply the population with good health and medical care, there are few enforceable rights available to the individuals who are discontented with their care. As we have seen, under Swedish law all residents have equal access to health care services. However, the law does not specifically provide a citizen's right to health and medical care in the sense that a denial to certain access to health may be overruled by a national court. Broadly speaking, there are extremely limited ways of taking health care, if at all, to the courts. Instead, the system is based on a possibility to complain to a national supervisory agency, the Health and Social Care Inspectorate (Inspektionen för vård och omsorg, IVO). IVO conducts supervision of health and medical care services as well as licensed health care professionals. Patients or their representatives can report lack of treatment or deficient treatment, injuries in connection to care, and so forth, to the agency. The agency may start an investigation but does not investigate all reports.

As discussed in part 1, the Swedish system is based on a regulation that is duty-based (not rights-based); the duty is for the county and municipal governments to pursue under the guidance and control of the same national supervisory agency (IVO) mentioned above. In addition to IVO, a central government body, the National Board of Health and Welfare (Socialstyrelsen),

supervises the health and medical field and assists the county and municipal governments with development of regulations, guidelines and general recommendations concerning the application of relevant legislation.

With this national assistance, each County Council and municipality shall provide the health and medical care that falls within its statutory responsibilities to all persons residing within its jurisdiction. In addition, the County Council may offer health and medical care to people residing in other Counties. The health providers may organize the activities in ways adopted to suit local conditions. There are very few rules how the organization should look like. One mandatory rule, however, is to set up one or several Patients Boards within each county. The purpose of such boards is to promote contacts between patients and medical personnel, and to help the patient get appropriate help. For example, the Board may assume the role of a mediator when there is a dispute or other problems in the relation between a patient and a doctor or a nurse. However, there are no possibilities to claim a right to a certain treatment or other activities for the patient; instead the Board is a forum for meeting and solving a problem concerning for example a certain treatment by the personnel or other communication issues. Thus, no formal decisions are made and no earlier decisions may be formally overruled. In general, the legal system divides choice concerning health services into two spheres: the medical professionals' (physicians and others') decision-making and the patients' decision-making. The medical professionals make the final decision about whether or not a particular treatment, procedure or so forth is warranted. The patient may not formally override the decision in the sense of having a legal right to insist on a procedure that the professionals have decided against. However, a *compos* adult patient may always choose to refuse care.

It can also be mentioned that according to the Patient Injury Act there is a right to compensation for damage sustained in health and medical care. This Act is based on a no-fault principle; accordingly the right to compensation is not conditioned on negligence from the side of the medical personnel. All providers of health care must carry an insurance policy, covering injuries caused by a medical treatment.

In discrimination cases, where someone does not get appropriate health care due to discriminatory circumstances, according to the Swedish Discrimination Act there are ways to report the incident to the Ombudsman for Discrimination issues in Sweden. Anyone can file a complaint with the Ombudsman if he or she feels that he or she has been discriminated against and this is related to his or her sex, transgender identity or expression, ethnicity, religion or other belief, disability, sexual orientation or age. The Ombudsman examines complaints on a discretionary basis, like IVO. If an investigation shows that discrimination can be assumed to have occurred, the Ombudsman first seeks to negotiate a settlement between the discriminated person and the body responsible for the discrimination. It may result in financial compensation, an apology or some other form of recompense or action. If a settlement cannot be reached, the Equality Ombudsman can take the case to court.

The decision of whether or not a child like ours receives a check-up or other remedial health services on entering into foster care is a matter of individual choice for each separate municipality (the social services in this case). The

procedures will have been set at that level, rather than the county or national level.

If our child's municipality does not choose to include specific health measures into its foster care system, the decision cannot be litigated within the Swedish domestic system, or otherwise challenged as a matter of law or other standards in a process that would bring enforceable remedies. Our child, or her foster parents, or other interested parties such as for instance patients' advocacy groups or childrens' advocacy groups who wish to ensure nationwide systemic changes in foster care, would need either to persuade the individual municipalities or to convince the national government to amend the national health law.

At the individual level, if for any reason the child or her caretakers wish to challenge a particular decision made by the government with regard to her personal health, for instance a decision by the municipality, acting as her legal guardian, that in her case a particular treatment or vaccination was unnecessary, their means of complaint and remedy would be limited. Unless they had cause to believe that discrimination was involved, their only recourse would be to resort to the local Patient Complaint Board or the national IVO system. However, in IVO's processes and, if relevant, in the Discrimination Ombudsman processes, even if a decision were ultimately made in her favor, the remedy would not necessarily be access to the desired treatment or vaccination itself. The same goes for a complaint to the Patient Complaint Board.

From a human rights perspective, effective means of complaint and remedy are a core procedural element of any health system, and would seem to be lacking here. At the same time, the formal processes in Sweden that are described above may not give an entire sense of the picture. It is interesting to consider that, in general, Sweden's social welfare system has not traditionally been based on a system of judicially enforceable individual remedies and that the extensive health system has therefore been built up on the assumption that other approaches were available and acceptable.

In the case of our foster child in Skåne, for instance, we might note that children's medical care in Sweden is free of charge and freely available, so the reason for her earlier lack of health and dental care is likely based on inattention, not lack of financial resources or of will on the part of government at any level or of service providers. Once her case is known to the health and medical care system in her County Council, the foster family or her biological family will most likely receive contact from a local unit seeking to make an appointment for a health check-up; it will likely not be a matter of the foster parents, once they become aware of the problem, needing a complaints system through which to force the system into caring for her.

It may also be that municipalities, once they are aware of a systemic issue that leaves some population group underserved, would be expected to decide to take internal steps to remedy it; a debate on that topic for foster children has precisely been sparked by the recent scholarly findings mentioned above.

At the individual level, a child's complaint that she is entitled to a particular medical treatment which has been refused to her does not have forum in which it can be raised and reviewed and that could force the original decision-makers

to change their minds; but it may also be that in practice, requests by patients or their representatives through informal or non-enforceable processes are actually virtually always granted, in which case the lack of formal process remedies would not be relevant in most cases, as the same people who are proactive or knowledgeable enough to make use of formal remedies would also be proactive or knowledgeable enough to use the other processes.

Whether or not the speculations above are accurate, anecdotally the health system in Sweden seems to work quite well, as a whole, with a structure that has never assumed a series of extensive means of complaint and remedy, but rather seems to rely on the good will of the system, and on a general ethos that places a high value of universal health care, to ensure that good standards are upheld and that the needs of the population are met.

Of course, even if this is true for the general population, the question of inattention or lack of will may vary with regard to specific groups; the situation may be different for, for instance, drug abusers or others who are less sympathetic patients than children whose own parents are unable to care for them. It may be, too, that there is variation depending on geographic regions within Sweden, and so forth. Or, for instance, the variation in health processes and outcomes between the more and less educated that was mentioned above may reflect varying abilities to navigate less formal means of seeking solutions as opposed to more clear-cut systems of complaint and remedy.

Human rights brings into every government's health system the question of means of accountability, including complaint and remedy. What that raises here, interestingly, is a question of what precisely, that would mean in the context of our foster child, in the context of other potentially marginalized individuals or groups, and in the context of the population as a whole. If there is an informal, unofficial or unenforceable means of complaint and remedy that, ultimately plays an equivalent role to more formal processes, then international human rights law may add little in this regard. If, however, the absence of formal means of recourse leaves individuals at a standstill, or means that certain groups are unable to make claims that bring their health issues forcefully to the official eye of the system, then the rights regime would be bringing something new into the discussion.

4 Conclusion

What role international human law would play in national, county and municipal processes concerning the health of a potentially marginalized child in Skåne is not an idle question. Sweden, with its well-established social welfare system, is in a position to consider what it means, legally and practically, that it has ratified, for instance, the Convention on the Rights of the Child. At a very minimum, implementing the CRC inside Sweden means that the issues discussed above, and others like them, need to be "on the table" in the national discussion; that is, even if, following research and debate, it were to be decided within the relevant national actors that the current procedural protections were sufficient, an extended conversation would have taken place, at which point potential problems might have been flagged and addressed, and

international fora would continue to provide occasions for the dialogue to continue. The same would be true for a discussion of who might be being left out of health care, which would engage conversations at local, county and national levels, and so forth. In the end, many of the complexities and contradictions within human rights law – for instance, the difficulties with universality in a system of disparate states – might be irrelevant to the rights regime’s contributions to precisely that for the national and subnational government: the need to assess and to discuss. The next step, in for instance considering the right to health and the CRC, would be to sketch out a set of priorities for that assessment and discussion with regard to children and health. Beside our foster child, who now has finished with her visits to the dentist, and is, we believe, happily eating ice cream while studying the world, who else might be in need of intervention inside a generally strong system of care?

