25. The right to health for people living in poverty: a human rights perspective

Mette Hartlev

This chapter will look at the relation between poverty and health from a human rights-based perspective. It will explore how the human right to health relates to poverty and how poverty impacts on the right to health. By the end, it will also reflect upon how precision medicine (including precision public health) as an emerging health technology may influence the relation between health and poverty.

I. THE HUMAN RIGHT TO HEALTH

The right to the highest attainable standard of health is a well-established socio-economic right recognized in several human rights instruments, such as the Universal Declaration of Human Rights (UDHR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). It is also considered as a basic patient's right.[1] According to article 12(1) of the ICESCR states parties to the Covenant must 'recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health'. As will be clear, the right to health is a very ambitious right which encompasses both physical and mental health, and with a clear ambition to ensure the enjoyment of the highest standard of health.

The UN Committee on Economic, Social and Cultural Rights (CESCR) has provided a very comprehensive interpretation of the right to the highest attainable standard of health in its General Comment no. 14, which highlights the multiple dimensions of the right to health and the importance of the underlying determinants of health.[2] According to the General Comment, the full realization of the right to health requires not only access to health care services, but also a clear commitment from states parties to address the underlying determinants of health. It is stressed that the right to health is:

> an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.[3]

The wide scope of the right to health reflects the broad definition of health applied by the World Health Organization (WHO), where health is defined as a 'state of complete physical,

[1] M Hartlev, 'Patients' Rights' in Brigit Toebes and others (eds), *Health and Human Rights in Europe* (Intersentia 2012) 111.

[2] 'General Comment No. 14, The Right to the Highest Attainable Standard of Health (Article 12)' (2000) UN Doc E/C12/2000/4.

[3] ibid para 1.1.

mental and social wellbeing and not merely the absence of disease and infirmity'.[4] Audrey Chapman has critically discussed the use of the expression 'underlying determinants' in the human rights framework instead of 'social determinants', which is the term commonly applied by the WHO and in a public health context. She perceives 'underlying determinants' as a narrower and more partial expression than the more comprehensive understanding embedded in 'social determinants'. In contrast to 'underlying determinants', 'social determinants' pay more attention to e.g. social class as an important determinant of health, and to the interactive and cumulative effects various underlying determinants may have on individuals and communities life prospects and on structural injustices.[5] Although there might be differences between the human rights and public health communities in their approach to the conditions that shape our health, it nevertheless seems that both communities are promoting a comprehensive and non-reductionist approach to the link between health, inequities and poverty.

Apart from defining and clarifying the scope of the right to health, the General Comment also defines various aspects of the right to health which must be addressed by state parties. First of all, the right to health is closely related to other human rights, such as, e.g., the right to safe and adequate food and safe and potable water. Consequently, it is necessary to pay attention to a number of other human rights addressing basic human needs and capabilities to ensure the right to health. As to state obligations, the General Comment applies the distinctions in public health between health promotion, disease prevention and access to care.

From a public health perspective, health promotion is of special importance as it supports the population in keeping healthy. General Comment no. 14 specifically stresses that 'the right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health'.[6] Apart from access to food, housing, water and sanitation, underlying determinants also include safe and healthy working conditions, a healthy environment and access to health-related education. The importance of the participation of the population in health-related decision-making at the local/community, national and international levels is also stressed.[7] Health promotion falls under the obligations of the states parties and requires a broad focus on promoting life conditions for the population. At the same time the CESCR also recognizes that the state cannot be exclusively responsible, as some aspects of population health may be outside the control of state actors. Consequently the right to health should not be understood at a 'right to be healthy', and it is stressed that a state cannot itself ensure good health as, for example, genetic or environmental factors and the adoption of unhealthy or risky lifestyles may have an impact on an individual's health conditions.[8] The state must pursue and enable full realisation of the highest attainable standard of health, but there may be factors outside its control, and the individual may also have some responsibility in regards to health promotion.[9]

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[4] WHO, 'Preamble to the Constitution of the World Health Organization' (22 July 1946) Official Records of the World Health Organization No 2 para 100.

[5] Audrey R. Chapman, 'The Social Determinants of Health, Health Equity and Human Rights' (2010) 12 (2) Health and Hum. Rts. J. 17.

[6] General Comment (n 2).

[7] ibid para 1.

[8] ibid para 9.

[9] Signild Vallgårda and others, 'Backward- and Forward-Looking Responsibility for Obesity: Policies from WHO, the EU and England' (2015) 25(5) Eur.J.Pub.Health 845.

While health promotion is focusing on general living conditions to enhance the health condition of the population (and the individual), disease prevention pays attention to more specific health risks such as occupational diseases, communicable diseases and environmental issues. ICESCR art. 12.2(b) refers both to the importance of improving all aspects of environmental and industrial hygiene and the prevention and reduction of the populations' exposure to harmful substances such as radiation and harmful chemicals or other detrimental environmental conditions that directly or indirectly impact human health.[10] Furthermore, art. 12.2(c) refers to the need for prevention, treatment and control of epidemic, endemic, occupational and other diseases. In regard to disease prevention, the obligations on the states parties are important, as these are typically health risks that are outside the control of the individual.

Access to health care services is obviously also an important component of the right to health. According to art. 12.2(d) of the ICESCR, the right to health implies a right to have access to health care facilities, goods and services, and it is specified in more details in General Comment no. 14 to include 'the provision of equal and timely access to basic preventative, curative, rehabilitative health services and health education; regular screening programmes; appropriate treatment of prevalent diseases, illnesses, injuries and disabilities, preferably at community level; the provision of essential drugs; and appropriate mental health treatment and care'.[11] The General Comment furthermore develops a set of guiding principles in access to health care services, the so-called AAAQ-standard. According to this standard, health care services must first of all be available to the entire population without discrimination. Secondly, health care services must be accessible, both in terms of physical and economic accessibility. They must also be informationally accessible, and accessible for all without discrimination. Thirdly, health care services must be acceptable in terms of being culturally appropriate and compliant with ethical standards, and finally of good quality.

Whereas the individual is the rights holder, the states parties to the ICESCR are the duty bearers. In general, states parties' obligations in regard to human rights are normally interpreted in terms of respect (non-interference), protect (protect individuals from incursions by third parties) and fulfil (to facilitate and provide). This typology, developed by scholars and adopted by the treaty bodies, reflects a set of legal obligations imposed primarily on states. All three obligations are relevant in regard to poverty and health.[12] The obligation to fulfil the right to health is clearly important to break the vicious cycle between poverty and health, and the obligation to protect of particular importance in regard to vulnerable groups. The obligation to respect requires States to refrain from, for example, adopting policies which will have damaging effects on people's health.

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[10] General Comment (n 2) paras 15–16; See also Dainius Puras, UN General Assembly (UNGA) 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (5 August 2016) UN Doc A/71/304 para 20; UN Human Rights Council (UNHRC) 'Report of the Special Rapporteur on the Implications for Human Rights of the Environmentally Sound Management and Disposal of Hazardous Substances and Wastes' (20 July 2017) UN Doc A/HRC/36/41 paras 9–11, 112(a); UNGA 'Report of the Special Rapporteur on the Implications for Human Rights of the Environmentally Sound Management and Disposal of Hazardous Substances and Wastes' (7 October 2019) UN Doc A/74/480.

[11] General Comment (n 2) para 17.

[12] Magdalena Sepúlveda Carmona, UNHRC 'Final Draft of the Guiding Principles on Extreme Poverty and Human Rights Submitted by the Special Rapporteur on Extreme Poverty and Human Rights' (18 July 2012) UN Doc A/HRC/21/39 paras 81–82.

II. THE RELATION BETWEEN THE HUMAN RIGHT TO HEALTH AND POVERTY

A. Is there a Link Between Poverty and Health?

As established in the introduction to this book,[13] there are various definitions of poverty, ranging from more narrow perceptions of poverty as lack of income (either in absolute terms or relative to the rest of the population) to broader conceptions promoted by scholars such as Amartya Sen[14] and Martha Nussbaum,[15] who associate poverty with the deprivation of basic needs and freedoms and the failure of basic capabilities. The broader conception of poverty, which is commonly applied in a human rights context, will also be applied here.[16]

The link between human rights and poverty is generally acknowledged. Human rights scholar Asbjørn Eide has stressed that poverty would not exist if the internationally-recognized human rights in their entirety were fully implemented.[17] In the Office of the High Commissioner of Human Rights (OHCHR) report on poverty reduction, the link between human rights compliance and poverty is also stressed, while at the same time recognizing that not all human rights violations are related to poverty and that combatting poverty is not only a matter of compliance with human rights.[18]

As poverty is characterized by deprivation of basic social goods and capabilities, and health is determined by social conditions (see section I), it is obvious that poverty will have an impact on the health of individuals and populations. Indeed, the relation between poverty and health was a priority for Paul Hunt, the first UN Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health. In his first report to the Commission on Human Rights he stressed the important – but poorly elaborated – impact that the right to health has on poverty reduction.[19] Succeeding Special Rapporteurs have confirmed the importance of addressing the relation between health and poverty.[20]

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[13] See the Introduction to this volume.

[14] Amartya Sen, *Inequality Reexamined* (Harvard University Press 1992); Amartya Sen, *Development as Freedom* (Oxford University Press 1999); Amartya Sen, 'Human Rights and Capabilities' (2005) 6(2) J. Hum. Dev. 151–66.

[15] Martha Nussbaum, *Women and Human Development: The Capabilities Approach* (Cambridge University Press 2000); Martha Nussbaum, 'Women's Bodies: Violence, Security Capabilities' (2005) 6(2) J. Hum. Dev. 167–83; Martha Nussbaum, *Creating Capabilities. The Human Development Approach* (Harvard University Press 2011).

[16] OHCHR 'Human Rights and Poverty Reduction: A Conceptual Framework' (2004); CESCR, 'Substantive Issues Arising in the Implementation of ICESCR: Poverty and ICESCR' (2001) UN Doc E/C.12/2001/10.

[17] Asbjørn Eide, 'Human Rights and the Elimination of Poverty' in A Kjønstad and LH Veit Wilson (eds) *Law, Power and Poverty* (CROP Publishers 1997).

[18] OHCHR 'Human Rights and Poverty Reduction: A Conceptual Framework' (2004) 5.

[19] Report of the Special Rapporteur, 'The Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (13 February 2003) UN Doc E/CN.4/2003/58 paras 44–58.

[20] UNHRC 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (31 March 2009) UN Doc A/HRC/11/12 paras 12–13; UNGA 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (16 March 2011) UN Doc A/HRC/17/43; UNHRC 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest

Within public health it is well-documented that social determinants are responsible for health inequities and differences in health status both within a population and between countries.[21] The WHO defines social determinants as the 'conditions in which people are born, grow, live, work and age'.[22] These conditions include basic needs such as safe water, adequate housing, sufficient supply of food and nutrition, access to education, safe working conditions and the environment/climate. Since access to basic social needs is shaped by the distribution of money, power and resources at global, national and local levels, there is also clearly an economic dimension to health.[23]

At the same time health is also a determinant of poverty. People with poor health and disabilities experience greater deprivation in access to basic social needs than healthy individuals.[24] This constitutes a vicious circle, a poverty trap, which is challenging to defeat.[25] The UN Sustainable Development Goals (SDGs)[26] set out in Goal 1 to end poverty in all its forms and everywhere, and the SDG framework pays close attention to the link between basic social conditions and poverty. This interconnectedness is highlighted for example in target 1.3, which refers to the importance of nationally appropriate social protection systems to achieve substantial coverage of the poor and the vulnerable. Similarly, target 1.4 stresses the significance of equal rights for all men and women – and in particular the poor and the vulnerable – to economic resources, as well as 'access to basic services, ownership and control over land and other forms of property, inheritance, natural resources, appropriate new technology and financial services, including microfinance'. These provisions recognize that poverty, lack of access to basic social goods, and poor health are closely tied together.

B. How Poverty Impacts the Right to Health and Vice Versa

Poverty intersects with each dimension of the right to health: health promotion, disease prevention and access to care (see section I). In regard to health promotion, states must provide conditions in which people can live a healthy life. This is challenging for many countries, due to the wide array of human rights and entitlements involved. In some situations, it is obvious

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Attainable Standard of Physical and Mental Health' (12 April 2011) UN Doc A/HRC/17/25 paras 5–6, 11–13; UNHRC 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (2 April 2015) UN Doc A/HRC/29/33 para 55; UNGA 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (5 August 2016) UN Doc A/71/304 para 103(l).

[21] WHO Commission on the Social Determinants of Health, 'Closing the Gap in a Generation. Health Equity Through Action on the Social Determinants of Health' (2008); M Marmot, 'Social Determinants of Health Inequalities' (2005) Lancet 1099.

[22] WHO, 'About Social Determinants of Health' <www.who.int/social_determinants/sdh_definition/en/> accessed 13 June 2020.

[23] OHCHR, 'Human Rights and Poverty Reduction: A Conceptual Framework' (OHCHR 2004).

[24] WHO and the World Bank, 'Disability report' (2011); For the EU, see Eurostat, 'Disability Statistics – Poverty and Income Inequalities' (August 2015) <https://ec.europa.eu/eurostat/statistics-explained/pdfscache/34425.pdf > accessed 12 April 2020; Mónica Pinilla-Roncancio, 'Disability and Poverty. Two Related Conditions. A Literature Review' (2015) 63 Revista de la Facultad de Medicina 113.

[25] Paula Braveman and Sofia Gruskin, 'Poverty, Equity, Human rights and Health' (2003) 81(7) Bulletin of the WHO: Int'l J. Pub. Health 539.

[26] UNGA Res 70/1 (21 October 2015) A/RES/70/1.

that states parties to the ICESCR need to respond to for example a lack of access to potable water and sanitation and to safe and nutritious food. In other situations, basic conditions to live a healthy life may be in place in terms of food, water, shelter, education, access to health care services, health information and other factors. However, deprived individuals may still have difficulties in profiting from these conditions due to lack of capabilities, power and strength. People facing poverty are often exposed to a number of additional systemic burdens and obstacles of innumerable kinds, which cumulatively can make health goals such as quitting smoking, regularly exercising, making varied healthy home-cooked meals – goals that are often challenging for an average individual – virtually impossible to achieve for those living in poverty.[27] To adopt a healthy lifestyle and cook a healthy meal, take a run or quit smoking may be an overwhelming endeavour amidst all the other problems. This may be the reason why health inequalities seem to persist even in welfare states like the Nordic countries – a situation which is referred to as a paradox in the public health literature.[28]

When it comes to disease prevention, the most deprived will often be facing more difficulties than the more affluent part of the population. For example, vaccination and immunization are not widely available and accessible in all parts of the world or to all population groups within countries.[29] Risks of being exposed to environmental risks such as polluted water and health challenges provoked by climate change are also bigger for people living in poor areas.[30] Work environments for those with the lowest salary tend to involve bigger risk of health hazards than for employees with higher salaries. Low salaries may even be a health risk.[31] States parties clearly have a human rights obligation to respect and protect the right to health and to provide disease prevention without discrimination, but this is far from being reality, especially for the most deprived.

Finally, it is well known that access to health care services is not distributed equally among the population. In health care systems based on private insurance, it is obvious that the most affluent have better access to health care than the most deprived. But even in welfare societies with publicly financed health care provided free of charge, the most affluent parts of the population often have easier access to specialist care and to more advanced care than the more deprived parts of the population. Physical accessibility also differs as the most deprived part of the population tend to live either in remote, thinly inhabited areas or in limited space in bigger

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[27] UN HRC, 'Final Draft of the Guiding Principles on Extreme Poverty and Human Rights Submitted by the Special Rapporteur on Extreme Poverty and Human Rights' (18 July 2012) UN Doc A/HRC/21/39 paras 81–82; see also Z Strauss and D Horsten, 'A Human Rights-Based Approach to Poverty Reduction: The Role of the Right of Access to Medicine as an Element of the Right of Access to Health Care' (2013) 16(3) Potchefstroom E.L.J. 7.

[28] J P Mackenbach, 'The Persistence of Inequalities in Modern Welfare States: The Explanation of a Paradox' (2012) 75 Soc. Sci. & Med. 761; J P Mackenbach, 'Review Article: Persistence of Social Inequalities in Modern Welfare States: The Explanation of a Paradox' (2017) 45 Scandinavian J. Pub. Health 113; M Marmot, 'The Health Gap: The Challenge of an Unequal World' (2015) 386 Lancet 2442.

[29] María Clara Restrepo-Méndez and others, 'Inequalities in Full Immunization Coverage: Trends in Low- and Middle-Income Countries' (2016) 94 Bulletin of the WHO 794.

[30] WHO, 'Quantitative Risk Assessment of the Effects of Climate Change on Selected Causes of Death, 2030s and 2050s' (2014); UNGA, 'Poverty and Climate Change. Report of the UN Special Rapporteur on Extreme Poverty and Human Rights' (17 July 2019) UN Doc A/HRC/41/39; See also chapter 31 by Sumudu Atapattu.

[31] JP Leigh and R De Vogli, 'Low Wage as Environmental Health Hazards' (2016) 58(5) J.O.H. & Envtl. Med. 444.

cities where the number of general practitioners is lower than in middle- and upper-class neighbourhoods.[32] These are important examples of spatial poverty.

As mentioned above (section II A), poverty and health have a dual relation. Poverty is not only a contributor to poor health. Poor health may also lead to poverty – which subsequently will enforce ill-health, lead to more poverty, and thus create a vicious cycle.[33] Ill health can lead to loss of job and income, and medical treatment may be expensive and ruin a family economy. The impact may differ depending on the level of social security and availability of access to low cost treatment in the country. However, poor health conditions will normally always have an impact on access to basic social goods.[34] This is relevant for all health conditions,[35] but in case of longer periods of sickness or of disabilities the impact that poor health can have on access to basic social goods may be significant and could also be enforced by other – intersecting – factors such as disability, gender, age, ethnicity and migration status.[36] It is documented that persons with disabilities experience deprivation to a larger degree than others in regards to basic social goods.[37]

Seen from a poverty-eradication perspective, the human right to health provides a legal tool to fight poverty. Promotion of the right to health and its progressive realization could, consequently, help to reduce poverty.[38] However, to be successful it will be necessary not only to focus on the right to health but also to pay attention to the realization of other human rights on which the right to health depends, such as socio-economic rights to food, water and sanitation, shelter and education, and also civil and political rights, such as the right to life, right to privacy and freedom of speech. As stressed by Audrey Chapman, it is crucial to acknowledge the inter-connection and the 'interactive and cumulative effect' between these separate rights instead of focusing on them separately.[39] Furthermore, the capability to profit from basic social goods that may be available should also be at the centre of attention. This means that it is not sufficient that basic social goods are available. Individuals must also have the ability to profit from such opportunities. In this context applying a human rights-based approach could be helpful.

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[32] For rural areas see e.g. World Bank, *World Development Report* (2006) 29; AE Joseph and DR Phillips, *Accessibility and Utilization: Geographical Perspectives on Health Care Delivery* (Harper & Row 1984); OECD, 'Financial and Geographic Access to Health Care' in *Government at a Glance 2015* (OECD Publishing 2015). For urban spaces see e.g. Cookson R and others, 'Unequal Socioeconomic Distribution of the Primary Care Workforce: Whole-Population Small Area Longitudinal Study' (2016) BMJ Open 5; Rebecca Lee, 'How Poverty and Location Limit Access to Health Care' <https://blog.rendia.com/poverty-location-limit-access-health-care/> accessed 15 June 2020; UNHRC, 'Final Draft of the Guiding Principles on Extreme Poverty and Human Rights Submitted by the Special Rapporteur on Extreme Poverty and Human Rights' (18 July 2012) UN Doc. A/HRC/21/39 paras 81–82.

[33] See n 24; J Braithwaite and D Mont, 'Disability as Poverty: A Survey of the World Bank Poverty Assessments and Implications' (2009) Eur. J. Disability Res. 219.

[34] ibid.

[35] A Wagstaff, 'Poverty and Health Sector Inequalities' (2002) 80(2) Bulletin of the WHO 97.

[36] See chapter seven by Gerard Quinn on poverty and disability in this volume.

[37] See n 33.

[38] ibid.

[39] See n 5.

III. A HUMAN RIGHTS-BASED APPROACH TO HEALTH AND POVERTY

The concept of a human rights-based approach was originally introduced in the context of development with the aim of having a stronger focus on individuals' rights instead of exclusively addressing human needs. Since 1997 all UN agencies are expected to mainstream human rights into all their programmes and activities.[40] A common understanding of a human rights-based approach was developed in 2003 at an inter-agency workshop, where three constituting elements of a human rights-based approach to development was outlined.[41] First, all policies, programmes and actions should further the realization of human rights. Secondly, human rights standards and principles should guide all actions, cooperation and programming in all sectors and in all phases of the process.[42] Finally, all policies, programmes and actions should contribute to the development of capacities of the 'duty bearers' to meet their obligations and of the rights holders to claim their rights.

The WHO has specified the human rights-based approach in regards to health.[43] First, all health strategies and policies should aim at realizing the right to health and other health related rights. Consequently, a human rights-based approach to health also includes promotion of other rights, such as the right to nutritious food, access to water, shelter and education. The AAAQ standard (outlined in section I) also provides important directions for the full realization of the right to health. In addition, all health policy work and programmes should be 'guided by human rights standards and principles', such as participation, equality and non-discrimination and accountability.[44] Thus pursuing the right to health and other health related rights should be done with the inclusion and participation of those who are directly affected by decisions regarding health care plans and provision. Furthermore, equality and non-discrimination must be sought in all laws, policies and practices. Transparency regarding all decisions and decision-making processing serves to promote accountability, which is also promoted when states parties sign and ratify important human rights instruments promoting the right to health and other health related rights. Lastly, the final outcome should be to build capacity among duty bearers to fulfil their duties and to empower rights-holders to claim their rights to health and other health related rights.

The focus on empowerment of the rights holders is crucial from a poverty perspective. This serves to inform and create awareness among individuals regarding their rights and to empower them to claim them. Even in situations where the duty bearers – the governments – are committed to fulfil their obligations, empowerment is still important. The welfare state

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[40] UNGA, 'Renewing the United Nations: A Programme for Reform' (17 July 1997) UN Doc. A/51/950.

[41] United Nations Sustainable Development Group (UNSDG), 'The Human Rights Based Approach to Development Cooperation – Towards a Common Understanding among the United Nations Agencies' (2003).

[42] Human rights standards and principles includes universality and inalienability, indivisibility; inter-dependence and inter-relatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.

[43] WHO, 'A Human Rights-Based Approach to Health' <www.who.int/hhr/news/hrba_to_health2.pdf> accessed 15 June 2020.

[44] See n 41.

paradox mentioned in section II is a good example of the persistent nature of poverty even in states providing universal access to health care and other social goods.

The definition of poverty applied in this chapter stresses the importance of both basic social goods and capabilities. The welfare state paradox is an example of a situation where access to basic social goods is provided but where the capabilities are missing. Empowering individuals not only to claim their rights but also strengthening their capabilities to profit from the available social goods is crucial to fight poverty. In this context, it is not sufficient to provide opportunities to participate and be engaged. Deeply entrenched marginalization as well as the nearly insurmountable logistical barriers that are associated with living in poverty can often make opportunities to participate inaccessible in practice. This stresses the importance of actively reaching out to deprived individuals to ensure they have a voice in health-related decisions at both local, national and international levels.[45]

The Swedish hospital Angered in Gothenburg can serve as a promising example of how a human rights-based approach to health can work in a deprived neighbourhood. Angered hospital opened its doors in 2015. The intention was to establish a community-based hospital with a strong focus on public and community health and with a strong research component as well. From the beginning, Angered decided to adopt a human rights-based approach in its interaction with the local community.[46] The hospital applies a so-called 'comprehensive methodology',[47] which strives to shrink the social gap. Local community members and professionals collaborate on developing the priorities for how community health shall develop and decide which project to prioritize and how research should be done. Community health is understood in a broad sense. One of the projects focuses on teaching people not only to bike but also to repair and take care of their bikes. The strategy here is to reach out to the patients and to community members to engage them in developing and organizing health care services at the hospital as well as in community and home-care settings. Citizens are informed about their rights – and what a human rights-based approach implies – and empowered by the hospital's 'reach-out approach', where information about rights does not stand alone. Likewise, the professionals are similarly aware of and committed to their duties as duty bearers.

Angered hospital demonstrates the value of a human rights-based approach to fight poverty. Even though it will take time to reduce the health and social gap, it is important to take serious action. Preliminary results from some of the projects show that the reach-out initiatives together with the comprehensive methodology seem to move things in the right direction and both citizens and professionals are profiting from this new mindset.[48] More research is needed in this area to explore how a human rights-based approach can serve to strengthen the capabilities of the most deprived.

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[45] The importance of the participation of the population in health-related decision-making at both local/community, national and international levels. General Comment (n 2) section 11.

[46] Information in English about Angered hospital is available here <www.angeredsnarsjukhus.se/om-angereds-narsjukhus/about-angered-hospital/> accessed 15 June 2020.

[47] In Swedish it is called 'helhetsmetodikken'.

[48] See e.g. results (in Swedish) from a project concerned with collaboration with families on timely analyses of small children with autism and other developmental disorders in the report 'dörren man öppnar och där finns allting' (you open the door, and then you find everything), <www.angeredsnarsjukhus.se/om-angereds-narsjukhus/hjallbosamverkan/> accessed 12 April 2020.

IV. NEW HEALTH TECHNOLOGIES: IMPACT ON HEALTH AND POVERTY?

As in many other areas of society, health care services are also committed to profit from new technologies and scientific advancements. The right to benefit from scientific progress is also a human right,[49] and new medical technologies have the potential to influence – positively or negatively – the realization of the right to health. It is therefore important to assess how new medical technologies may impact on health and poverty. Lack of access to medicine in general, and more specifically to pharmaceuticals and treatment for so-called neglected diseases, has been widely discussed in the public health and human rights literature.[50] This section will focus on a recent and less analysed issue: the impact new data-driven technologies could have on health and poverty.

Precision medicine is a new medical phenomenon that is prioritized in national health strategies across the globe.[51] This technology represents a new development in the way health care services provide health promotion, disease prevention, diagnostics and treatment to patients. The general idea behind precision medicine is to provide more tailored health care services to the individual patient (or to groups of similar patients) instead of treatment that works for the average patient but not necessarily for the individual patient. Precision medicine is a very information-intensive technology. It relies on new advances in gene technologies, such as comprehensive gene scans (Whole Genome Sequencing (WGS) and Genome Wide Association Studies (GWAS)), which provide comprehensive knowledge about the individual's genetic makeup. Such genetic information can be linked together with all sorts of other data from various sources – health data as well as socio-economic and environmental data – in a big data environment and create knowledge regarding risks, susceptibilities and the efficacy of pharmaceuticals and other treatments. Based on this knowledge it is possible to develop algorithms/AI-solutions which can assist the health care services and health professionals in stratifying patients to the right kind of health promotion, prevention and medical treatment.

Currently the development of precision medicine is first and foremost taking place in research settings. Its application in the clinic is still limited, and it is mostly used in regard to treatment of certain types of cancers. Its application as a public health tool is also in its infancy. However, many countries have adopted national strategies and provided funding to support research in this area with the clear intention to make it available as soon as possible.

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[49] UNGA 'Report of the Special Rapporteur in the Field of Cultural Rights Farida Shaheed, The Right to Enjoy the Benefits from Scientific Progress and its Applications' (12 May 2012) UN Doc A/HRC/20/26; A Chapman, 'Towards an Understanding of the Right to Enjoy the Benefits of Scientific Progress and its Applications' (2009) 8 J. Hum. Rts. 1.

[50] See e.g. a number of articles in Health and Human Rights Journal 20(1) (2018) (neglected diseases); AE Yamin, 'Not Just a Tragedy: Access to Medications as a Right under International Law' (2003) 21 B.U.Int'l L.J. 325; J Lee and P Hunt, 'Human Rights Responsibilities of Pharmaceutical Companies in Relation to Access to Medicines' (2012) 40(2) J.L.M & E. 220; S Moon and others, 'Innovation and Access to Medicines for Neglected Populations: Could a Treaty Address a Broken Pharmaceutical R&D System?' (2012) 9(5) PLoSMed, e1001218; S Moon, 'Respecting the Right to Access to Medicines: Implications of the UN Guiding Principles on Business and Human Rights for the Pharmaceutical Industry' (2013) 15(1) Health & Hum. Rts. J. 32.

[51] Precision medicine is also known as personalized medicine, individualized medicine, tailored medicine, individualized medicine and P4-medicine. There is no general agreement about the terminology.

The 100,000 Genomes Project in the UK[52] is an example, together with the Obama Precision Medicine Initiative.[53] Several other countries have also launched precision medicine initiatives, and the EU is supporting cross-Europe cooperation to integrate precision medicine into European Union's health care systems.[54]

Governments expect this new technology to be beneficial for both the individual and society. Individuals may gain from more tailored health promotion, prevention and treatment that will allow them to benefit from medical interventions without being subjected to medicine with poor effect and maybe even damaging side effects. It is also thought to be beneficial for society due to expected cost savings when prevention and treatment can be directed precisely to those who can actually benefit from it.[55]

Precision medicine initiatives have been criticized for focusing primarily on diagnostics and treatment and paying less attention to health promotion and prevention. It has also been argued that the importance of genetics is overemphasized, and the impact of social determinants almost ignored. The development of precision public health, where the same kind of data – genomic as well as other data (including socio-economic data) – are used to identify more suitable means of health promotion and prevention can be seen as the public health response to the clinical focus of many national precision medicine initiatives.[56] The World Health Assembly has adopted a resolution on digital health calling on the WHO to develop a strategy on digital health, and the WHO sent a draft strategy for public consultation in 2019.[57] This emphasizes the importance from the perspective of the public health community in making use of data and digital tools to promote public health.

As with any other technology there are of course also concerns, and both precision medicine and precision public health give rise to human rights concerns. Precision medicine raises issues about basic patients' rights, such as the right to information (and the right to not know), right to privacy and confidentiality, duties and rights in regard to relatives, and the risk of genetic discrimination. Due to possible biases in the available data sources and in the selection of data, the effect on equitable access to health care services – both nationally and globally – has also been questioned.[58] General Comment no. 14 stressed that health care services must be available to all – and in sufficient quantity. As precision medicine is expected to be an essential health care service, it must be available for all. Consequently, there are good reasons to

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[52] 'The 100,000 Genomes Project' (*Genomics England*) <www.genomicsengland.co.uk/about-genomics-england/the-100000-genomes-project/> accessed 15 June 2020.

[53] 'Fact Sheet: President Obama's Precision Medicine Initiative' (*The White House*, 30 January 2015) <https://obamawhitehouse.archives.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative> accessed 15 June 2020.

[54] Council Conclusions on Personalised Medicine for Patients (2015) OJ C/421/2.

[55] It seems, however, that it is difficult to assess the economic effect of introducing precision medicine in the health care services. M Kasztura and others, 'Cost-Effectiveness of Precision Medicine – a Scoping Review' (2019) 109(6) Int J.Pub.Health.

[56] See e.g. MJ Khoury and others, 'Precision Public Health for the Era of Precision Medicine' (2016) 109(6) Am J Prev Med 398.

[57] WHO, 'Digital health' (26 May 2018) WHA71.7; 'WHO Releases First Guideline on Digital Health Interventions' (17 April 2019) <www.who.int/news-room/detail/17-04-2019-who-releases-first-guideline-on-digital-health-interventions> accessed 15 June 2020.

[58] KA McClellan and others, 'Personalized Medicine and Access to Health Care: Potential for Inequitable Access' (2013) 21 Eur. J. Hum. Genetics 143; D Taylor-Robinson and F Kee, 'Precision Public Health – the Emperor's New Clothes' (2019) 48(1) Int. J Epidemiol, 1.

explore how the application of this new technology may affect poverty and the right to health. Precision public health provokes some of the same issues – especially the right to privacy, right to self-determination, transparency and risk of bias and discrimination.

To understand these potential human rights concerns, it is necessary to look closer at how precision medicine and precision public health will be developed and applied. As mentioned above, both precision medicine and precision public health rely on data generated through intensive data sourcing, where data – including genetic data – from a large part of the population is used to develop reference genomes or other models to stratify patients to the right kind of health prevention or treatment. Such models are suited to individuals who resemble the population group from whom data has been collected in terms of, for example, age, ethnicity and gender. They are less suited to serve as tools for individuals within another age group or with another ethnicity or gender. Some parts of the population produce less health data than others, either because they belong to a group with a limited number of individuals (e.g. a minority group), or because they are not using the health care services (or other services) to the same extent as others. As noted by the UN Special Rapporteur on Extreme Poverty, digital systems may not be satisfactory for vulnerable populations because they 'often operate on the law of average, in the interests of the majorities and the basis of predicted outcomes or likelihoods'.[59] In some countries with a private health care system, individuals with lower socio-economic status and/or without health insurance will visit health care services less often and thus leave less data behind. For example, being part of a minority ethnic group and under 40 has been shown to result in reduced accuracy of the precision medicine models used in regard to breast cancer,[60] and women are also often mentioned as underrepresented in medical trials.

If we apply the AAAQ standard (see section I) to precision medicine and precision public health, it may turn out that these digital technologies will not be available or beneficial for all population groups. If the data collection and selection is not organized in an inclusive manner, there is a risk that vulnerable and marginalized groups – those who are already left behind – will be deprived from profiting from this technology to the same extent as the average population.[61]

Some national strategies pay attention to the risk of bias and possible discriminatory effect of precision medicine. The U.S. precision medicine initiative is named the 'All of Us Research Program', and it is clearly stressed that the programme should reflect the diversity of the U.S. population and will enrol participants from diverse gender, social, racial/ethnic, ancestral, geographic and economic backgrounds as well as from all age groups and health statuses.[62] In contrast the Danish precision medicine policy stresses that Denmark is the perfect location for the development of precision medicine because the country is considered to be genetically homogeneous.[63] Compared to the U.S. programme, this sends a very different message to

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[59] UNGA, 'Digital Welfare States and Human Rights. Report of the UN Special Rapporteur on Extreme Poverty and Human Rights' (11 October 2019) UN Doc A/74/493 para 59.

[60] See n 58.

[61] E Vayena, A Blasimme, IG Cohen, 'Machine Learning in Medicine: Addressing Ethical Challenges' (6 November 2018) 15(11) PLoS Med; Z Obermeyer and others, 'Dissecting Racial Bias in an Algorithm Used to Manage the Health of Populations' (2019) 366 Science; Taylor-Robinson (n 58).

[62] 'All of Us Research Program' (*National Institutes of Health*) <www.researchallofus.org> accessed 15 June 2020.

[63] 'Analysis of Personal Medicine' (*DAMVAD*, 2 February 2016) <www.regioner.dk/media/3128/damvad-rapport-analyse-af-personlig-medicin.pdf> accessed 15 June 2020.

minority population groups in Denmark. They may not only feel excluded from profiting from this new health technology – they will actually be excluded and deprived of access to health care services which the majority of the population will profit from. This is indeed not compliant with the duty of states parties to make health care services available without discrimination.

If we look at the other criteria in the AAAQ standard, we can see that there may also be potential challenges. In terms of physical accessibility, precision medicine may reinforce existing barriers. As with all health care services, it would probably be easier to have access in bigger cities and in more affluent countries than in more remote areas and low income countries. Economic accessibility could be a special challenge – especially in countries with a private or insurance-based health care system. Even though a comprehensive gene scan has and will become cheaper, it will still not be economically accessible for many individuals – and a comprehensive genetic analysis is often necessary to benefit from precision medicine. In addition, the specialized counselling and treatment needed for each patient will also be a significant economic burden. As gene scans may reveal genetic predisposition to develop specific disorders, it may also create problems in having access to health insurance or sufficient insurance coverage. In countries with a tax-paid health care system, it may turn out that accessibility in practice is more limited for individuals in lower socio-economic strata, because the barriers for individuals in these groups are the same as with all other sorts of health care services (see above in section I). The algorithm could potentially also be used to stratify which patients would be provided with health prevention and treatment. For example, if data shows that people from lower socio-economic parts of the population are less likely to comply with public health guidelines on non-smoking, healthy eating and physical activity, it could potentially be used in algorithmic-based prioritization of treatments to patients or to determine whom should be approached by screening programmes. Finally, in regard to information accessibility, precision medicine may be difficult to understand and require comprehensive counselling and information in a treatment situation, which also may unevenly impact persons from lower socio-economic groups.

The acceptability criteria is concerned with the ethical and cultural aspects of the health care service provided. As already mentioned, precision medicine and precision public health give rise to a number of concerns in regard to respect for privacy, non-discrimination and stigmatization, and may thus turn out to be a health care service with low acceptability.

In regard to quality, precision medicine is anticipated to have the potential to provide better and more tailored care, and precision public health is thought to provide better targeted public health measures. The aim is treatment, health promotion or prevention that works for all individuals, instead of only for some, which is clearly a strength. However, experiences in using digital welfare services give rise to quality concerns, as data may be both biased and inaccurate.[64] The question is then whether precision medicine and precision public health will fulfil the high expectation and actually ensure good health promotion, prevention and healthcare for the entire population, or whether it will reinforce existing inequalities and divert needed resources from the healthcare system that could otherwise be used for more traditional types of health promotion.

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[64] UNGA, 'Digital Welfare States and Human Rights. Report of the UN Special Rapporteur on Extreme Poverty and Human Rights' (11 October 2019) UN Doc A/74/493; Virginia Eubanks, *Automating Inequality: How High-Tech Tools Profile, Police, and Punish the Poor* (New York, St Martin's Press, 2018).

Another concern is how the 'predictive power' associated with the stratification of individuals based on genetic and other data will be approached and governed by societies. The information regarding the individual generated by comprehensive big data analyses will inevitably reveal vulnerabilities and susceptibilities which – seen from the perspective of society – could be used to stratify citizens toward various kinds of public services. One could imagine that it would not be considered economically sustainable to provide expensive university education or medical treatment to an individual whose genetic profile predict a poor life prospect. This and a number of other questions are still unanswered.

Precision medicine will be expensive and will likely benefit rich over poor. This could potentially result in an even larger divide between health in developed and developing countries and within countries. Application of precision public health will not be an economic burden to the citizens but could potentially turn out to benefit rich over poor and direct money from more low-tech and low-cost but highly efficient health promotion programmes. It could also be asked whether precision medicine and precision public health will alter the social contract between the state and the individual and serve as a means of shifting more responsibility from the state to the individual, especially in terms of avoiding non-communicable diseases such as those caused by poor diet and lack of physical activity.

Many questions are blowing in the wind and raise doubt as to whether this new medical technology will benefit all parts of the population equally, or whether it will follow the usual pattern of health inequities – and maybe even be used as a tool to stratify individuals into poverty. This is an area where more research is needed.

V. THE POWER OF A HUMAN RIGHTS-BASED APPROACH TO POVERTY?

Looking at poverty and health through the lenses of human rights provides a tool to address the lack of access to basic goods and capabilities as an infringement of fundamental rights and not merely as a social problem.[65] Poverty has a profound and negative impact on the realization of the right to health, and ill-health may in itself be a determinant of and lead to poverty. There is a clear relation between poverty and health, and a comprehensive human rights-based approach may help to raise awareness of the responsibilities of governments in complying with their obligations to respect, protect and fulfil human rights. Therefore, more research is needed to develop a more comprehensive human rights-based approach that acknowledges the inter-connection between the right to health, other related socio-economic rights and civil and political rights.

The relation between the right to health and poverty exposes a kind of 'clash' between a human rights and public health approach. As critically discussed by Audrey Chapman (see section I), it seems that the human rights framework prefers to use the expression 'underlying determinants' of health, whereas the WHO and public health community in general favour the expression 'social determinants', which is perceived to pay more attention to root and structural causes of health disparities, such as social class and socio-economic conditions.

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[65] Z Strauss and D Horsten, 'A Human Rights-Based Approach to Poverty Reduction: The Role of the Right of Access to Medicine as an Element of the Right of Access to Health Care' (2013) 16(3) Potchefstroom Electronic Law Journal.

The intersection between a human rights and a public health approach to health and poverty is another important research avenue to explore.

As shown in this chapter, compliance with obligations to provide opportunities for people to live a healthy life is not enough to fight inequity in health and to enable people to move out of poverty. This means that availability of basic social services is not sufficient if individuals still do not have the capabilities needed to get out of the poverty trap. An important component of a human rights-based approach is to reach out to and truly engage individuals in all areas of life.[66] In regards to the right to health, General Comment no. 14 stresses the importance of the participation of the population in health-related decision-making at both local/community, national and international levels.[67] There are promising examples from Sweden of how outreach and engagement can serve to facilitate access to the health care services and to empower the most deprived part of the population. This is an area where more research would be welcomed.

Finally, the impact new health technologies may have on the right to health and poverty is also an important future research agenda, where a broad human rights approach encompassing both socio-economic rights (e.g., right to health, food, water, a decent standard of living) and civil and political rights (e.g., right to life, privacy, non-discrimination, freedom of speech) will be needed, together with insight in the design and dynamics of the technology itself.

All in all, innovative research is needed to promote the ambition of the UN Sustainable Development Goals of ending poverty and leaving no one behind. This requires research that moves beyond traditional disciplinary and sectoral boundaries and dichotomies.

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[66] M Kjaeum, 'Go Local, Preserve the Global: Re-engage to Build Trust in Democracy and Human Rights' in P Hladschik and F. Steinert (eds), *Menschenrechten Gestald und Wirksamkeit verleihen. Making Human Rights Work. Festschrift für Manfred Nowak und Hannes Tretter* (Neuer Wissenschaftlicher Verlag / Wien-Graz, 2019) 153.

[67] General Comment (n 2) section 11.