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13 Does the right to health help or hinder people with disabilities?

John Tobin[*] and Nora Groce[**]

Abstract

The understanding and legitimacy of the right to health for persons with a disability remains contested and confused. This chapter seeks to address three issues. First, the extent to which a case can be made to justify the idea of the right to health; second, the meaning of this right and the nature of the obligations imposed on states; and third, the consequences and challenges associated with the use of a human rights-based approach to address the health needs of persons with a disability. It is argued that the right to health has been burdened by a false and misplaced set of assumptions about its meaning and content. Once these concerns are addressed it is possible to offer an understanding of the right to health that is not only pragmatic but also offers a model that recognizes the capacity, agency and dignity of persons with a disability.

Is there a right to health for persons with disabilities and if so what are the consequences? For an international human rights advocate, the answer to these questions is obvious – article 25 of the Convention on the Rights of Persons with Disabilities[1] ('CRPD') provides 'that persons with disabilities *have the right to the enjoyment of the highest attainable standard of health* without discrimination on the basis of disability.' It further provides that States parties to the CRPD have a general obligation to take 'all appropriate measures to ensure access for persons with disabilities to health services' and specific obligations with respect to the availability, accessibility, quality and affordability of health care for such persons. Such a resolute response, however, is far from universal among researchers, policy makers and advocates.

For philosophers such as Silvers and Francis, 'the understanding of health care as a human right, as found in the CRPD, fails to provide the theoretical machinery for responding to the pressing challenges of health care costs' (Silvers and Francis 2013,

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[1] UN Doc. A/61/611 (2006).

10). James Griffin also rejects the idea of the right to health, which for him, 'is not even a reasonable social aim, let alone a right' (Griffin 2008, 99). Public health advocates with their preference for the discourses of equity and ethics may also question the relevance of the idea of right to health for persons with a disability especially when the provisions of the CRPD cannot be enforced in courts. Economists will certainly question the capacity of such a right to assist in the resolution of the complex dilemmas associated with the allocation of scarce resources to meet the health care needs of persons with disabilities (Sarfarty 2009, 678) while international development experts and advocates may question the capacity of an international system for the protection of disability rights to address the health needs of the millions of men, women and children who experience a disability in environments that are far removed from the UN offices in Geneva and New York.

Our aim in this chapter is to address these competing responses to the idea of the right to the highest attainable standard of health for persons with a disability and to assess the way in which this concept informs responses to the health needs of persons with a disability.[2] It consists of three parts. First, an inquiry into the existence of the right to health and whether it can be justified from a legal, moral and political perspective. Second, an examination of the content and meaning of this right and the nature of the obligations imposed on States to secure its implementation. Third, a consideration of the consequences and challenges associated with the use of a rights based approach to address the health needs of persons with a disability. Our central premise is that the understanding of the right to health has been burdened by a false and misplaced set of assumptions about its meaning and content. Once these concerns are addressed it is possible to offer an understanding of the right to health that is more pragmatic than commonly assumed. At the same time it still demands a significant adjustment to the assumptions that have, and often continue to inform, the treatment of persons with a disability in favour of a model that recognizes the capacity, agency and dignity of such persons.

[2] For the purposes of this chapter we use the abbreviated phrase, 'the right to health', to refer to the right to the highest attainable attainable standard of health.

1. The Existence of the Right to Health for Persons with a Disability

1.1 A good but imperfect justification[3]

The human rights of persons with disabilities consist of three interconnected dimensions—*legal*, *political*, *and moral* (Frost 2010, 711). The *legal* dimension refers to those normative standards that have been formally recognized as legitimate standards within domestic or international legal systems, (Griffin 2009, 203) the most significant being the CRPD, which includes the right to health under article 25. The *political* dimension relates to advocates' use of the idea of the right to health as a tool to advocate for change and to assess the legitimacy of measures that have an impact on the health of persons with a disability within and between states (Tobin 2013, 48). The justification for this approach draws on the claim that the idea of human rights for persons with a disability is a global enterprise that provides the 'settled norms of political discourse' (Frost 1996, 104-11; Beitz 2009, 8; Moyn 2010, 222).

But relying solely upon legal and political justifications for the idea of the right to health for a person with a disability risks overlooking the reality that, despite states' apparent acceptance of this idea, (signified by treaty ratification), there remains widespread disagreement as to both the *moral* justification for the right to health *and* the idea that persons with disabilities should have rights. As such, there is a need to establish a 'secure intellectual foundation' (Sen 2004, 317) for the idea that persons with disabilities are entitled to such a right. Such a foundation not only offers advocates a deeper understanding of the values that underpin this right, it also has the capacity to address the concerns of those who doubt its legitimacy.

1.2 The capacity dilemma

For many scholars, capacity is a prerequisite to the enjoyment of rights. This *will* or *choice* theory of rights reflects a traditional Western liberal understanding of rights and is deeply embedded in the ideas of reason and autonomy. For proponents of this model, such as Harry Brighouse, '[t]he further an agent departs from the liberal model of the

[3] The analysis in this section draws heavily from J. Tobin (2013), *The Right to Health in International Law* (Oxford: Oxford University Press, 2013), 49-74.

competent rational person, the less appropriate it seems to attribute rights' (Brighouse 2002, 31).· The consequence of such an approach is to cast doubt on, and potentially deny, rights to persons with disabilities particularly persons with serious intelletual or psychological disabilities.

Similarly, James Griffin, the latest in a long line of philosophers whose work challenges the rights of persons with disabilities, (Groce and Marks 2000), would deny rights to persons with a serious intellectual disability on the basis that they are 'not normative agents' and thus incapable of enjoying rights (Griffin 2009, 83). For Griffin, the vulnerability of such persons would still impose 'substantial obligations' on those with capacity to look after those who are unable to look after themselves. But he would not 'run together a justification of an obligation and a justification of a right' because for him agency is a prerequisite to the enjoyment of rights (Griffin 2009, 85).

Griffin's reliance on agency to justify human rights is problematic for at least three reasons. First, it rests on the 'myth of the autonomous rational actor' which assumes a 'self sufficient, independent and self-reliant' individual' who is capable of exercising autonomy (Lord and Stein 32). However, as the Committee on the Rights of Persons with a Disability ('CRPD Committee') has explained, the assumption that mental capacity is 'an objective, scientific and naturally occurring phenomenon' must be challenged when 'social and political contexts' play a role in 'assessing mental capacity' (CRPD para 14). Moreover scholars have increasingly challenged Griffin's liberal conception of autonomy in favour of a more relational or communitarian conception of autonomy in which we are all vulnerable and interdependent (Lord and Stein; Fineman).

Second, Griffin's model denies human rights for the least powerful and most vulnerable members of society. Some persons with a disability may not have the capacity to *independently* claim rights, but Griffin's approach would deny them the right to have others assist them to claim their entitlements on their behalf.[4] It would force them to rely on other sources of obligation to motivate others to address their health needs and

[4] The extent to which a person's 'disability' is socially constructed or biological will remain contested. What is clear however is that historical assumptions concerning the capacity of someone with an intellectual or psychological condition to independently claim their rights must be challenged.

interests, such as charity, ethics, or equity. Although it is important to recognize moral obligations arising from alternative conceptions of justice, even Griffin himself has recognized that '[i]f one can claim a right, one is not dependent upon the grace or kindness or charity of others' (Griffin 2009, 92). Moreover, if it is accepted that the idea of rights is motivated by a desire to create systems of accountability that regulate the exercise of power by constraining the powerful and empowering the disempowered (Federle 2011, 449; Cordero Arce 2012, 367), then Griffin's approach is problematic. If rights are contingent on capacity or competency, they become 'exclusive and exclusionary.' For example, persons with a severe intellectual disability, would according to Griffin's thesis, be 'unable to define themselves as competent beings', and thus be effectively denied access to the discourse of rights and its capacity for empowerment and accountability (Federle 2011, 448).

A third problem with Griffin's model is that it represents a foundationalist or essentialist understanding of human rights, in which rights are grounded in *his* understanding of the values *he* considers essential to personhood: autonomy, liberty and minimum provision (Griffin 2009, 51). Scholars have increasingly challenged naturalist or foundationalist theories in favor of allowing for a multiplicity of justifications (Eekelaar 2011; Beitz 2009; Mitchell 2010; Chase 2012).

A further problem with Griffin's model is that his understanding of personhood, which emphasizes normative agency, reflects a *will* or *agency* theory of human rights. Autonomy is certainly a central feature of the literature on the foundations of human rights, and respect for autonomy is actually listed as a fundamental principle of the CRPD (article 3(a). However, whereas the capacity to exercise rights is a prerequisite to rights under a *will theory*, this theory is not the only basis upon which to ground rights. The main alternative is the *interest theory*, under which 'it does not matter that rights-holders are not in a position to assert rights… what it is to be a right-holder… is merely to be a direct intended beneficiary of someone else's duty bound performance' to recognize the interests of the right holder (Goodin & Gibson 1997, 188). Significantly, not only do many scholars endorse this model (MacCormick 1976; Freeman 2010; Raz 1984; Kramer 1998), it is also the preferred theory of rights reflected in international instruments, including the CRPD.

The only prerequisite for an entitlement to human rights *under international law* is that a claimant is a human being. Some persons with a disability *may* in some cases lack the capacity to independently exercise their rights but they do not lack interests, and it is their *interests*, not their *capacity*, which form the foundation of rights under an interest theory (Tobin 2013, 409). Moreover, the Committee on the Rights of Persons with Disabilities has stressed the need to avoid the conflation of *legal capacity* to hold rights and *mental capacity*, which refers to a person's decision making skills with respect to the exercise of those rights (CRPD Committee, General Comment No. 1, para. 15). It has therefore emphasized that all persons with a disability have the *legal capacity* to hold and enjoy human rights by virtue of their humanity irrespective of their mental capacity (CRPD Committee, General Comment No. 1 paras. 12-13). However, offering a theory which provides a justification for *granting* human rights to all persons with a disability irrespective of their mental capacity does not resolve the question about whether the *idea of the right to health* itself can be justified.

1.3 Health as a human right

The moral justification for the idea of health as a human right has attracted the attention of many scholars (Ruger 2006; Ruger 2010; Griffin 2008, Buchanan 1981; Beauchamp and Faden 1979, 118; Buchanan and Kessler 2009; Engelhardt 1986; Daniels 1985; Daniels 2008). Although this is complex debate there is strong support for the idea that 'interests' ground rights (Raz 1988, 176-183) but less consensus as to which interests are suitable for recognition as a human right – should they be those that are of 'ultimate value' (Raz 1988, 176-183); 'basic human rights' (Buchanan and Hessler 2009, 213); or 'urgent individual interests' (Beitz 2009, 122). An alternative to any attempt to offer a comprehensive theory by which to determine what interests will be deemed suitable for grounding a right is the idea of a social interest theory of rights.

This model attributes normative weight and justification to the deliberative process by which states elevate an interest (Eekelaar 2006, 136), such as the highest attainable standard of health for persons with a disability, to the status of a human right. Under this model the identification of the interest in which a human right, such as the right to health is grounded, is not considered to be essential, basic, natural or determinate, but the product of a social process that is historically and culturally contingent. The agreement required to achieve this outcome in international treaties will always be

incompletely theorized (Sunstein 1995; Tobin 2012, 49-50) but this does not mean that these instruments are theoretically unconvincing. On the contrary, they reflect an over-lapping consensus as to the moral value of any person with a disability as having an interest in enjoying in the highest attainable standard of health (McCrudden 2008, 677-687; Tobin 2012, 57). It is this is this moral consensus that provides a good, albeit imperfect, justification for the right to health for persons with a disability.

Ultimately this justification will be insufficient to address the concerns of some who challenge the legitimacy of the right to health. For example, some libertarian concerns can never be accommodated where they are founded on a vision of justice and a theory of rights that focuses on non-intervention by a state. Such a theory is antithetical to the positive and distributive role anticipated for the state with respect to the health of an individual under the international human rights paradigm (Tobin 2012, 60-63). However, other concerns that are directed at the legitimacy of the right to health, such as its indeterminate formulation, its inability to address the resource allocation dilemma and the cultural relativist challenge, can be overcome by offering an interpretation of both the content of the right to health *and* the obligations of states with respect to this right (Tobin 2012, 63-73). It is to these issues that we now turn.

2. Giving meaning to the right to health

2.1 The Content question

Under international law, the right to health is a shorthand phrase for the *right to the highest attainable standard of health*. Much of the anxiety and resistance to this phrase stems from a misunderstanding of its meaning. For example, for Griffin, for this standard is considered to be ‘particularly lavish’ (Griffin 183) and ‘is not even a reasonable social aim, let alone a right’ (Griffin 99). He laments that it does not ‘specify the level of health we have a right to’ (Griffin 100), fails to ‘set limits on what is required of states’ and is therefore indeterminate (Griffin 100). Indeterminancy, however, is a feature of all human rights and the challenge is to offer a persuasive account as to the meaning of a right such as the highest attainable standard of health (Tobin 2012, 75-78). Such an account must start with a reading of the right within its context and must be informed by the work of those bodies which have been entrusted with generating an action guiding and practical understanding of the scope of the

interest that underpins the right and the measures required of states to secure that right.

Of principal relevance here is the work of the Committee on Economic Social and Cultural Rights, ('ESC Committee'), the body of independent experts responsible for implementation of the Covenant on Economic Social and Cultural Rights[5] ('ICESCR'). Critically, the ESC Committee has stressed that '[t]he right to health is not be understood as a right to be healthy'[6] (ESC Committee, General Comment No. 14, para. 8). Instead, consideration must be given to 'both the individual's biological and socio-economic preconditions and a State's available resources' in determining the highest level of health attainable by an individual (ESC Committee, General Comment No. 14, para. 9). This reflects the reality that, as recognized by the ESC Committee, '[t]here are a number of aspects which cannot be addressed solely within the relationship between States and individuals; in particular good health cannot be ensured by a State, nor can States provide protection against every possible cause of ill health' (ESC Committee, General Comment No. 14, para. 9).

A question still remains as to the nature of the difference between health and ill health. Norman Daniels has defined health as the absence of any pathology by which he means 'any deviation from the natural functional organization of a typical member of the species' (Daniels 2008, 37). However, Daniels' emphasis on normalacy is problematic in the context of persons with disabilities, who as Barton explains experience a 'struggle to capture the power of naming difference itself' (Barton 1994, 18) in a world where the 'ideology of normalcy dominates' (Koch 2005, 123). Should an individual with paraplegia, or a person who is deaf or blind be considered to be suffering from ill health merely because their condition deviates from normal functioning? Historically the answer was yes. However, the cause of the functional limitations experienced by such persons was invariably attributed exclusively to their 'deviations' without recognition of how social values and structural impediments contributed to the functional impairments experienced by the person.

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[5] GA res. 2200A (XXI), 21 UN GAOR Supp. (No. 16) at 49, UN Doc. A/6316 (1966); 993 UNTS 3; 6 ILM 368 (1967).

[6] Committee on Economic, Social and Cultural Rights, *General Comment No 14, The right to the highest attainable standard of health*, (Twenty-second session, 2000), U.N. Doc. E/C.12/2000/4 (2000) ('ESC Committee, General Comment No. 14').

As outlined in other chapters in this collection, this narrow medical model of disability has been challenged by the social model of disability. As such, there is now greater awareness that the health of a person with a disability cannot simply be defined by their disability but will also be a product of the social factors that impact on their capacity to function within society. This approach is reflected in the framing of disability under the CRPD which provides that:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (CRPD, art 1)

Such a model is best described as a 'biopsychosocial' model of disability, to the extent that it integrates both elements of the medical and social models of disability as a way of recognizing the complex interaction between a person with a disability and society.[7]

This broadening in the understanding of disability is significant within the context of the right to health for two reasons. First, it avoids the potential stigma which is created when a person's health condition is reduced to a deviation from normal functioning. Second, it forces a broadening of the inquiry to determine what goods, services, facilities and conditions are to be provided by states to enable, not only an individual with a disability to maximize his or functioning in society, but for a society to accommodate, or at least mitigate, the functional limitations experienced by an individual because of his or her impairment.

2.2 Freedom to enjoy health

According to the ESC Committee, the scope of the right to health includes not only entitlements, but freedoms including 'the right to control one's health and body including sexual and reproductive freedom …' (ESC Committee para. 8). This conception of the right to health is particularly relevant to those many persons with disabilities whose sexual and reproductive identity is often denied, because of misperceptions about the capacity of persons with a physical or intellectual disability

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[7] World Health Assembly, *International Classification of Functioning, Disability and Health* (Fifty-fourth assembly, 2001), WHA Resolution 54.21, WHO Doc A/54/VR/9 (May 22, 2001).

to enjoy their sexual and reproductive health. Moreover, the rights to equality and non-discrimination (CRPD, arts 5 and 12) demand that persons with a disability are not denied the freedom to enjoy these aspects of their health on the basis of their disability. On the contrary, States are required to take effective measures to *support* such persons to enjoy these freedoms. Indeed article 12(3) of the CRPD provides that:

> States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

With respect to this obligation the Committee has explained that '"support" is a broad term that encompasses both informal and formal support arrangements of varying types and intensity' and can include for example, 'the development and recognition of diverse, non-controversial methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences' (CRPD, para. 17).

This approach in favour of *supported decision making* has particular significance with respect to a practice such as involuntary or forced sterilization of women and girls with an intellectual disability. It challenges the historical presumption of incapacity which was used to justify sterilization on the basis that it was in the woman or girl's best interest and demands that all reasonable efforts must be made to enable these women and girls to enjoy the sexual and reproductive health (Tobin & Luke 2013).

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2.3 Social determinants and health

With respect to the meaning of health, the ESC Committee has explained the right to health is:

> [N]ot confined to the right to health care. On the contrary the drafting history and express wording of article 12.2 acknowledge 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, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions and a healthy environment (ESC Committee, General Comment No. 14 para. 4.)

The expansion of the scope of the right to health to include the social determinants of health is problematic to the extent that it risks becoming a *right to everything* that impacts on the enjoyment of health (Tobin 2012, 130-132). At the same time, the idea that the right to health must extend to the social determinants of health is especially relevant to persons with disabilities whose functional impairments and associated level of physical and mental wellbeing are often determined by social perceptions (Lang & Groce 2012; WHO 2008). The concept and scope of the right to health would therefore appear to have much to offer for persons with a disability.

2.4 A qualitative framework

The ESC Committee has outlined a qualitative framework to assist in understanding the scope of the right to health which is underpinned by four broad principles: availability; accessibility; acceptability and quality (ESC Committee, General Comment No. 14, para. 12)

(i) Availability: This principle demands that health services be available for persons with disabilities.

(ii) Accessibility: This principle consists of four elements:

- Non-discrimination, which means that persons with a disability have an entitlement to be protected against the denial of access to a health care service on the basis of their disability;
- physical accessibility, which means that persons with a disability have an entitlement to demand that reasonable measures are taken by a State in light of its available resources to enable such persons to enjoy access to health care services irrespective of their disability or some other factor such as geographical isolation;
- financial accessibility, which means that persons with a disability have an entitlement to demand that reasonable measures are taken by a State in light of its available resources to ensure that such persons are not precluded from health services because of their cost;
- information accessibility which refers to the entitlement of persons with a disability to have effective access to information that will allow them to improve the quality of their health, for example, information on protection against sexual transmitted diseases or the elements of a healthy diet.

(iii) Acceptability: According to the ESC Committee this principle demands that health services must be respectful of medical ethics and be culturally appropriate (ESC Committee, General Comment No. 14 para 12(c)). Beyond these requirements, this principle must also be understood to provide persons with disability a right to demand that health care services, which are designed for them, are actually acceptable to them. Such an approach runs counter to the charity, welfare or medical models adopted in the past which relied on assumptions about what was best for persons with disability without actually consulting with such persons. The effective enjoyment of the right to health demands a consultative and participatory approach whereby service providers and consumers engage in a collaborative dialogue to ensure that the design and delivery of such services is *actually acceptable* to consumers.

(iv) Quality: The principle of quality requires that health services and goods for persons with disabilities should be scientifically and medically appropriate and that all medical personnel should be appropriately trained to ensure the effective delivery of such services. Moreover, there is a need to routinely seek to bring persons with disabilities into the health services (clinical care, public health and administrative) in order to ensure that their voices are a key component of all policy and programming.

2.5 The nature of a State's obligation to implement the right to health

The preceding discussion outlined the broad scope of the right to health for persons with a disability. However, any understanding of human rights must include not only the scope of the interests that are protected by the right, but also the nature of the obligation assumed by a State for the protection of these interests. An adequate normative account of any human right requires that it must have a 'well-specified counterpart obligation' (O'Neil 2005, 431). However, for commentators like Onora O'Neil, the obligation of states with respect to the right to health is 'muddled', 'vague' and 'insufficiently specified' and must therefore be considered a mere aspiration rather than a normative standard (O'Neil 2005, 428-429). These concerns are unsurprising given that the obligation on States under the ICESCR to 'take steps' to 'progressively' 'recognize' the right to the highest attainable standard of health 'by all appropriate means' is hardly an obligation for which there is a precise and readily apparent

meaning. There are however several ways to address this interpretative challenge.

2.5.1 Specific measures

First, international instruments such as the CRPD, ICESCR and Convention on the Rights of the Child[8] ('CRC') actually list several specific measures that states are required to take to ensure persons with disabilities enjoy their right to health. For example, article 25 of the CRPD provides that States must:

> (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
>
> (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
>
> (c) Provide these health services as close as possible to people's own communities, including in rural areas;
>
> (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
>
> (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
>
> (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Although the CRPD Committee is yet to issue a general comment on these obligations, it has stressed the need for legislation to ensure equal protection before the law (CRPD

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[8] GA res. 44/25, annex, 44 UN GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989); 1577 UNTS 3; 28 ILM 1456 (1989).

Committee, General Comment No. 1, paras. 24-30). Moreover, the ESC Committee and Committee on the Rights of the Child ('CRC Committee') have developed a rich jurisprudence with respect to the other types of measures that States should take to secure the implementation of the right to health generally which are equally applicable to persons with disabilities (ESC Committee, General Comment No. 14, paras. 53-62; CRC Committee, General Comment No. 15 paras. 90-120[9]). These measures include the development of national plans, program and policies to address the health needs of such persons; the creation of accountability mechanisms to enable a remedy for such persons where there is a violation of the right to health; data collection on the number of persons with a disability and the nature of their disability; and the creation of indicators and benchmarks to assess a State's progress towards full implementation of the right to health (Tobin 2012, 199-224).

2.5.2 The Tripartite Typology of Obligations

The ESC Committee has also endorsed the idea of a tripartite typology of obligations as a tool to better understand the nature of a State's obligation under the right to health (ESC Committee, General Comment No. 14, paras. 30-37). This typology consists of:

- an obligation to respect, which demands that States must take all reasonable measures within the context of available resources to ensure that its agents do not unreasonably interfere with the right to health;
- an obligation to protect, which demands that States must take reasonable measures within the context of available resources to ensure that non-State actors do not unreasonable interfere with the right to health; and
- an obligation to fulfill, which demands that States must take all reasonable measures within the context of available resources to progressively ensure the full realization of the right to the highest attainable standard of health for all persons with a disability.

The ESC Committee has provided an extensive list of the measures that fall within the scope of these obligations ranging from the adoption of legislation to ensure equal

[9] Committee on the Rights of the Child, *General Comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24)* (Sixty-second session, 2013), U.N.Doc. CRC/C/GC/15 (April 17, 2013) ('CRC Committee, General Comment No. 15').

access to health care, and prohibitions on the marketing of unsafe drugs and measures to ensure that privatization does not threaten access to health care. For the purposes of this chapter, however, there are three issues of particular significance – how is the reasonableness of a State's efforts to secure the right to health to be assessed; when will interference with the right to health be legitimate; and under what circumstances will privatization of health care services for persons with a disability be consistent with the right to health.

2.5.3 Progressive realization and the concept of reasonableness

Although persons with a disability have an entitlement to health care services, the obligation imposed upon States to fulfill this entitlement is not immediate and remains qualified by the proviso that realization of the right need only be progressive and subject to available resources. It was recognized during drafting of the ICESCR that this progressive obligation could be used as a loophole by some states (United Nations General Assembly 1955, 19). However the inclusion of this obligation was considered inevitable given that the capacity of a state to create the conditions in which a person can enjoy his or her health will always be dependent on resources.

Importantly the concept of resources is not confined simply to financial resources and extends to human, technological, organizational, natural and information resources.[10] With respect to the progressive nature of a State's obligation, the ESC Committee has explained that it 'imposes an obligation to move as expeditiously and effectively as possible towards' full realization of the right to health.[11] Moreover, 'any deliberate retrogressive measures in that regard would require the most careful consideration and would need to be fully justified by reference to the totality of the rights provided for the in the Covenant' (ESC Committee, General Comment no. 3 para. 24). Such an approach seeks to inform the obligation of progressive implementation with an appropriate blend of pragmatism and local context sensitivity. In terms of operationalization, it imposes a substantial onus on states to justify the measures they

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[10] CRC Committee, *Report on the Forty-Sixth Session* (Forty-sixth session, 2007), U.N. Doc. CRC/C/46/3 (22 April 2008), ch. VII, para. 65 (Day of General Discussion on 'Resources for the Rights of the Child—Responsibility of States', October 5, 2007).

[11] Committee on Economic, Social and Cultural Rights, *General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant)*, (Fifth session, 1990), U.N. Doc. E/1991/23 (December 14, 1990), para. 24 ('ESC Committee, General Comment No. 3').

have taken to secure the right to health in light of their available resources. As the ESC Committee has explained:

> If resource constraints render it impossible for a State party to comply with its Covenant obligations, it has the burden of justifying that every effort has nevertheless been made to use all available resources at its disposal in order to satisfy as a matter of priority, the obligations [imposed on States under the right to health] (ESC Committee, General Comment No. 14, para. 47).

In light of this comment, an assessment as to whether a state has complied with the progressive nature of its obligation will always remain relative to the circumstances prevailing within a State. The obligation does not seek to mandate that certain levels of health must be secured at certain levels of resource availability. Instead it operates to facilitate and frame a dialogue, which must include persons with disabilities, with respect to the direction and speed at which a state should pursue measures to secure the implementation of the right to health.

According to the ESC Committee, the terms of this dialogue must be informed by several considerations including:

- The extent to which measures to secure the right to health are deliberate, concrete and targeted;
- Whether state discretion in the allocation of resources was exercized in a non-discriminatory and non-arbitrary manner;
- The time frame in which the steps were taken; and
- Whether the steps taken took into account the precarious situation of the most marginalized and disadvantaged persons with a disability.[12]

A question remains however as whether these considerations are sufficient to address what is generally perceived to be the failure of international human rights law to resolve the resource allocation dilemma and the reality that states must prioritize their expenditure. In a world of scarce resources, on what basis is the legitimacy of a

[12] ESC Committee, *An Evaluation of the Obligation to Take Steps to the 'Maximum of Available Resources under an Optional Protocol to the Covenant* (Thirty-eighth session, 2007), U.N. Doc. E/C.12/2007/1 (May10, 2007), para. 8 ('ESC Committee, An Evaluation').

decision by a state to allocate funds to educate children with disabilities in remote community as opposed to the provision of health care services for these same children to be assessed? The reality is that the right to health does not provide a definitive answer to this question. It does however provide the *principles* that must inform the process for the resolution of this dilemma. In summary, under international human rights law, priority setting in the allocation of resources must be *reasonable.* When assessing reasonableness consideration must be given to whether a decision is:

- Principled (that is, consistent with the principles identified by the ESC Committee and informed by the rights under international law especially non-discrimination);
- Evidence- based as opposed to speculative or politically motivated;
- Consultative and participatory with persons with disabilities who are affected by the decision to the extent that this is reasonably practicable;
- Transparent in the sense that there is an awareness and understanding of the process adopted in determining how to allocate the resources;
- Evaluative in the sense that whatever decision is made it remains subject to review and monitoring to ensure that it contributes to the effective enjoyment of the relevant right (Tobin 2012, 237; Gruskin & Daniels 2008; Liebenberg 2010).

2.5.4 When will an interference with a person's rights to health be justified?

There is often an assumption that all human rights are trumps, which can be invoked to defeat all other competing interests. This may be the case with respect to some rights such as torture but the reality is that the vast majority of rights can be subject to lawful interference by state and/or non-state actors provided the interference is reasonable (Siracusa Principles;[13] Tobin 2012, 181). The right to health is therefore not absolute and the real question is under what circumstances will an interference with this right be justified? The answer is that any interference with the right to health must satisfy two broad criteria – it must pursue a legitimate aim, a pressing social need or the general welfare of the state *and* the measures to achieve that aim must be proportionate. The

[13] Commission on Human Rights, Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights, U.N. Doc. E/CN.4/1985/4 (September 28, 1984).

first criterion is generally easy to satisfy. The second criteria, however, is more demanding and requires two further inquiries: first, was there a rational connection between the measure to taken and the intended aim (which will generally require evidence); and second, were there any alternative measures reasonably available to the achieve the aim which would have avoided or minimized the interference with the person's right to health (Tobin 2012, 182-4).

2.5.5 The role and regulation of the private sector

Increasingly, in many countries, the private sector is occupying a greater role in the delivery of health care services to persons with a disability ranging from hospital care to private health insurance. Within this context the ESC Committee has expressed concern that 'the gradual privatization of health care risks making it less accessible and affordable'.[14] However, international human rights law actually holds a neutral position with respect to the role of the private sector in the sense that it does not necessarily prohibit nor prefer privatization as a measure to secure the right to health (ESC Committee, General Comment No. 3, para. 8). What it does demand is that states must regulate such developments to ensure that the right to health for persons with a disability is not compromised. Thus the CRPD Committee has stressed that:

> States parties should take action to prevent non-State actors and private persons from interfering with the ability of persons with disabilities to realize and enjoy their human rights, including the right to legal capacity (CRPD, General Comment No. 1, para 24).

Although privatization is not incompatible with the right to health *per se*, this practice does not allow a state to abdicate its responsibility to secure the implementation of this right. The ESC Committee has therefore explained that a state must 'ensure that privatization of the health sector does not constitute a threat to the availability, accessibility, acceptability and quality of health facilities, goods and services.' (ESC Committee, General Comment No. 14, para. 35). In terms of practical measures, this means that States must ensure that any decision to privatize part of a health care system

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[14] ESC Committee, *Concluding Observations: Poland* (Forty-third session, 2009), U.N. Doc. E/C.12/POL/CO/5 (December 2, 2009), para. 28.

must be preceded by a 'comprehensive and transparent assessment of the political, financial and economic implications and the possible limitations' of this process on the right to health. [15] Moreover, following privatization, the actual delivery of health services must be consistent with international human rights 'at all stages including policy formulation, monitoring and accountability arrangements' (CRC Committee, 31st report, para. 641) to ensure such a system is contributing to the effective enjoyment of the right to health.

3. Consequences and Challenges Associated with the Right to Health

The preceding section sought to outline the content and meaning of the right to health *and* the obligation imposed on states to secure the effective enjoyment of this right. This discussion revealed that although the right to health is broad and ambitious, it is still possible to provide an account of the right that is 'socially manageable' and not as muddled and vague as some commentators would suggest. The final section of this chapter offers some thoughts on the consequences and challenges associated with any attempt to use a *rights based approach* to respond to the health needs of persons with a disability. Although it is a rather eclectic list, it is designed to encourage a broader ongoing discussion about such issues.

The danger when using the language of rights is for advocates to rely solely on the text of human rights treaties and the 'jurisprudence' advocated by the various committee bodies to supports their claims. However, this legalistic approach often serves to not only alienate non-lawyers, but also overlook the more contested and complex issues associated with any attempt to implement a rights based approach in practice. It further assumes that such issues will reach the courts in the first place, which is often not the case. It is to these issues that we now turn.

3.1 The conceptualization of persons with a disability

How we perceive and construct disability impacts on how we respond to the health

[15] Committee on the Rights of the Child, *Report on the Thirty-First Session* (Thirty-first session, 2002), U.N. Doc. CRC/C/121 (11 December 2002), Ch. VI. Day of General Discussion on 'The Private Sector as Service Provider and Its Role in Implementing Child Rights', para 653(11) ('CRC Committee, 31st Report').

needs of persons identified as having a disability. How we perceive our obligations towards such persons also informs our motivations for taking actions to address the perceived health needs of such persons. With respect to the first issue, as outlined above, there are two broad and competing models – the medical model and the social model. The medical model perceives disability as a deviation from normal functioning whereas the social model perceives disability as an inability of social systems and structures to accommodate a variation in functioning. A still earlier charity model also continues to influence the thoughts and decisions of some in law, policy and practice.

The idea that we have moved from a charity and medical to a social model is a recurring theme in the literature. However, the idea of a linear progression from one model to another represents an over simplification of both the concept of disability and the cultural practices that inform social responses to persons with a disability. Indeed, some individuals and organizations use the charity and medical models concurrently to justify why they provide services and supports for people with disabilities. (Groce & Kett 2013) It may be true that disability is no longer defined as abnormality (at least not in international circles) but it is not true to suggest that disability is a purely social phenomenon. A more accurate response, and the approach advanced under a rights based approach, is that disability should be understood as a complex interplay of medical and social factors that impede the functional capacity of an individual. This complexity is reflected in the idea of a biopsychosocial model of disability.

With respect to the motivation to take measures to address the health needs of persons with a disability, a rights based approach is significantly different from alternative approaches. Under a charitable model, motivation generally comes from the sense of a moral obligation, which is often based on religious beliefs, to assist those in need. Under a charity or welfare model the motivation will be to secure the *best interests* of such persons. Under a medical model, the motivation will be to fix, treat and cure their abnormality. Importantly, the motivation under such models will often produce outcomes which have some benefit to a person with a disability. But they remain problematic. Under a charitable approach, for example, a person with a disability risks becoming objectified as a vulnerable person dependent on the goodwill and discretion of others; under a welfare model, such persons are likely to be considered passive recipients of assistance from others who determine what is in their best interests; while

under a medical model, the source of the ‘problem’ is located entirely with the individual whose differences are labeled as abnormal and in need of treatment.

In contrast a rights based approach conceptualizes a person with a disability as an individual who has moral value and worth simply by virtue of being human and who is entitled to enjoy the right to the highest attainable standard of health because they are human. Such persons are not passive victims who must remain silent and dependent on the charity and goodwill of others. On the contrary they are subjects with agency who have a right to make a claim upon the State that appropriate measures must be taken in light of available resources to secure their right to health. In this sense, a rights based approach is about both the empowerment of persons with disabilities and a challenge to those social and cultural practices that would prefer to render them invisible, incompetent, abnormal or victims in need of salvation, treatment or cure.

3.2 A rights based approach to service delivery and design

The conception of persons with a disability under a rights based approach also has consequences for the design and delivery of health care services for such persons. (Stein 2012) Rather than simply conceiving of the health needs of such persons as problems that must be solved, a rights based approach starts from the premise that all persons are entitled to be treated with dignity and respect (Lynch 2004; Tobin 2013; Yamin 2008). The principle of respect demands that rather than being acted upon, persons with disabilities must become active participants within the process of policy design and delivery. They must be *listened to* and their voices must be *heard* and *taken seriously.* Assumptions commonly held about the competence and capacity of persons with a disability must be replaced with *presumptions about capacity* (CRPD Committee, General Comment No. 1, para. 12). Their expertise must be recognized by policy makers and integrated into service design and delivery. This is not to say that the views of persons with disabilities must be determinative. However, if a policy maker were to adopt an approach contrary to such views, he or she would be under an obligation to justify such a deviation as being reasonable in all the circumstances.

A rights based to the health needs of a person with a disability must also develop a response that is holistic. The right to health is not to be understood in isolation and has a relationship of interdependence with other rights (Tobin 2006, 281-282). For

example, the health of a child with a disability will be influenced by factors such as access to adequate housing, a safe family environment, adequate nutrition and an effective education. A rights-based response demands that a State take appropriate measures not just to address the specific health needs of such a child but also to address those factors that inhibit the ability of the child to enjoy the other rights which enhance his or her ability to enjoy the right to health.

Finally, a rights based approach demands not only direct measures to address the immediate health needs of a person with a disability but also measures to address the broader structural, institutional and social factors that impede the full and effective realization of the right to health. (Tobin 2006, 281-282) This approach ensures that the 'cause' of the health problem is not automatically located within the person with the disability and demands a broader inquiry to assess those external factors that impede his or her ability to enjoy the highest attainable standard of health. Such factors range from social discrimination to insufficient resources to provide affordable quality health care. A rights based approach does not accept that these factors are fixed and demands that states take appropriate measures to address discrimination and increase the availability of resources, for example, by increasing tax revenues, so as to increase the resources available to improve the availability and quality of health care (Tobin 2012, 226-232).

3.3 The participation challenge

Although participation is a central tenet of a rights based approach, as Upendra Baxi has warned, the 'ritualistic invocation of the mantra of "participation" simply bypasses some further hard problems' (Baxi 2010, 216). For example, it fails to address how the idea of 'deliberative democratic accountability' extends to non-state actors and the way in which, for example, a private health company or pharmaceutical company determines its priorities with respect to the provision of health care services or investment in new medicines (Baxi 2010, 216). There is also the reality that genuine, as opposed to tokenistic participation, is difficult to achieve. Thus states are required to develop effective mechanisms by which persons with disabilities can participate in decisions about how their health needs are to be met (Tobin 2012, 214-218).

At the same time, and despite the plea of the Special Rapporteur on the Right to

Health[16], even with the best of intentions, time and resources may preclude the possibility of active and effective participation of *all persons with disabilities* in decisions about measures to secure their right to health. Thus efforts to facilitate participation by states must be subject to a reasonableness test which takes into account the availability of resources and any time constraints (Tobin 2012, 217). In those circumstances where effective participation of *all persons* with a disability is not reasonably possible, the process for the development of services by state actors must still remain alert to and take into account the discrete needs of persons with a disability (by for example consulting with representative groups and relevant medical personnel). States must also create effective systems to review, monitor and evaluate the impact of such policies to ensure they are contributing the effective enjoyment of the right to health of persons with a disability.

3.4 Cultural relativity and the vernacularization of rights

Rights discourse and international human rights treaties are often seen as the product of Western values that reflect an atomistic conception of the individual. It is true that Western states played a significant and dominant role in the construction of the international human rights system. But it would be wrong to conceive of human rights including the right to health as being fixed to western cultural values. On the contrary, quite apart from the fact that non Western States have been actively involved in and made a significant contribution to the construction of the international human rights system, including the CRPD, human rights is primarily a cultural system itself – fluid and contentious – that produces and constructs rather than discovers a vision of what it means to live a life of dignity (Merry 2006, 225-259).

Thus, cultural values have a role to play in shaping the content and meaning of the right to health, which is not beholden to a particular cultural perspective or set of values (Tobin 2012, 68). At the same time the capacity to accommodate cultural differences does not allow for an entirely relativist approach to the right to health. Thus for example the CRC requires respect for cultural practices (art 5) but demands that states must

[16] Special Rapporteur on the Right to Health, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health* (Sixty-second session, 2007), U.N. Doc. A/62/214 (8 August 2007), para. 25.

prohibit traditional practices that are harmful to the health of a child (article 24(3)).

The issue of individualism is an interesting one. The CRPD places a strong emphasis on the principle of equality and the rights of the person with a disability in a deliberate attempt to counter the invisibility and inequality that so often characterizes the lives of such persons. But very little attention is given to the rights of the parents, families and other persons who often assume responsibility for the care of persons with a disability. This is despite the fact that from a practical perspective it will sometimes be parents and carers who will take the primary role in attending to the health needs of persons with a disability. Moreover, the lives of these carers will often be severely compromised, financially, physically and emotionally, by the responsibility of caring for children or relatives who have a disability. Carers find themselves taking time away from work, working part time or remaining out of the workforce in order to provide care. Such support can be physically demanding and it often is emotionally stressful, particularly in societies where little or no outside assistance or community support is available. Such care is often considered women’s work and thus this is also a gender issue.

Despite this reality, the awareness raising obligation under article 8 of the CRPD focuses exclusively on raising awareness of the rights of persons with a disability without any acknowledgment of the burden that is sometimes assumed by their carers. Article 28 of the CRPD does provide that the right to an adequate standard of living extends to both persons with a disability and their families and requires the provision of assistance to families who may be living in poverty. Thus there is some recognition of the interdependency between the rights of persons with disability and their families. But it could arguably be more explicit as is the case under the CRC which imposes a specific obligation on States to provide assistance to and support parents in their care of children (arts 18 and 27).

This gap in the CRPD also tends affirm an atomistic conception of a person with a disability when the lived experiences of such persons would tend to suggest a more relational conception of autonomy whereby *interdependence* is recognized as a legitimate condition of the lived human experience irrespective of a whether a person has a disability (Lord and Stein 2013; Fineman 2008; Herring 2011; Tobin 2013). At the same time, the text of an international human rights instrument should never be

taken to be an exhaustive expression of how rights should be understood and claimed. Indeed, the strength of human rights discourse is that is it constantly evolving and possesses an extraordinary ability to be appropriated by any disempowered or aggrieved group as a tool to challenge injustice. In this sense there remains the constant potential for the discourse of human rights including the right to health to be 'vernacularized' (Merry 2006,193, 219) by persons with a disability in diverse cultural settings in ways that enable such persons to advocate for measures that are responsive to their particular and discrete health needs.

5. Conclusion: The need to adjust expectations

The right to health is invariably burdened with a false set of expectations – that it must be capable of resolving complex resource allocation dilemmas; that it demands an entitlement to be healthy; that it must be determinate and grounded in a comprehensive moral theory if it is to be a considered a genuine right; that it must transform the lives of persons with disabilities or be abandoned in favour of other emancipatory discourses. These expectations are invariably formed in the absence of a close examination of the actual text and 'jurisprudence' associated with respect to the right to health under international law and the role of human rights more generally.

Such an examination reveals a more modest agenda for the right to health. It does not offer a guarantee of health; it does not seek to resolve the resource allocation dilemma and it does not offer a comprehensive moral theory to justify its existence. But it does offer a transformative discourse that seeks to change the conception of a person with a disability and his or her health needs and outlines a series of pragmatic measures which are required by States to address these needs. This model is not insensitive to the challenges posed by resource constraints and it is sufficiently flexible to accommodate a range of diverse cultural practices. Indeed far from being a utopian dream, a careful examination of the scope of the right and the nature of the obligations assumed by states indicates that this right seeks to align principles with pragmatism.

There remains of course significant work to be done to empirically assess the extent to which a rights based approach can enhance the existing response by health professionals to persons with disabilities at both the clinical and public health level. But there is already some general evidence to suggest that such a collaboration between

health and human rights practitioners is worth pursuing in other health contexts (Hawkins & Newman 2005; Yamin 2013; Bustreo et al. 2013). Thus there is good reason to believe that a rights based approach could also enhance the health outcomes of persons with a disability. The challenge now is to ensure that, as the CRPD gathers momentum and prominence in advocacy and policy debates concerning services for persons with disabilities, any engagement with the idea of human rights is sufficiently sensitive to the existing discourses that are motivated by the interests of such persons. The right to health may offer an agenda for improving the health of persons with disabilities but this agenda will only be realized if a collaborative rather than a colonizing approach is adopted by human rights and disability advocates (Kennedy 2002, 120).

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