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### **Citation**

Dijkstra, E. (2021). Addressing Problems Instead of Diagnoses:  
Reimagining Liberalism Regarding Disability and Public Health.  
*Netherlands Journal Of Legal Philosophy*, 50(1), 22-39.  
doi:10.5553/NJLP/000101

Version: Publisher's Version

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Downloaded from: <https://hdl.handle.net/1887/3278519>

**Note:** To cite this publication please use the final published version (if applicable).

# Addressing Problems Instead of Diagnoses

## Reimagining Liberalism Regarding Disability and Public Health\*

Erwin Dijkstra

### 1. Introduction: A Deficit in Our Collective Responsibility

It is perhaps a truism to state that the world, as it is presently furnished, is ill-suited to the needs of those with mental and physical impairments.<sup>1</sup> Such impairments, whether they are caused by accident or by age, are a manifestation of our universally shared vulnerability. As such, these needs concern us all.<sup>2</sup> But if we consider one of the most important rights questions engendered by these needs – namely the access to care and support for those who care for others – we can observe that this concern seems not to have been translated towards proper institutional arrangements.<sup>3</sup> When we take the goals and obligations of the Convention on the Rights of Persons with Disabilities (CRPD) as a benchmark, the public health systems of liberal states, including those states within the tradition of social liberalism, demonstrably fall short.<sup>4</sup> As a result, persons who experience impairments – and their caretakers – are often bereft of proper participation in society and, consequently, lack full enjoyment of their rights.<sup>5</sup> In this essay it will be argued that this situation presents a deficit in our collective responsibility. In order to repair this deficit a tentative reimagining of liberalism regarding disability and

\* This essay is partly based on a lecture I gave at Lund University in September 2019. The occasion was a conference titled 'A Workshop on the Politics of Public Health: Disability, Age, and other Categories of Universal Human Vulnerability'. I would like to thank Gelijk Molier, Emma de Jong, Sven Zoeteman, Emmy Stevens, Milan van Esvelde, and Lukas van den Berge, who all read previous versions of this essay. Their comments were invaluable, as were the reports by the peer reviewers. Alle remaining mistakes are my own.

1 Tom Shakespeare, 'The Social Model of Disability', in *The Disability Studies Reader*, ed. Lennard Davis (New York: Routledge, 2017), 193; Michael Oliver, Bob Shapey and Pam Thomas, *Social Work with Disabled People – 4th Edition* (Basingstoke: Palgrave MacMillan, 2012), 16.

2 Beverly Clough, 'Disability and Vulnerability: Challenging the Capacity/Incapacity Binary', *Social Policy and Society* 16 (2017): 474; John Coggon, *What Makes Health Public? A Critical Evaluation of Moral, Legal, and Political Claims in Public Health* (Cambridge: Cambridge University Press, 2012), 25, 200.

3 Martha Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition', *Yale Journal of Law and Feminism* 20 (2008): 3, 12; Donald Lollar and John Crews, 'Redefining the Role of Public Health in Disability', *Annual Review of Public Health* 24 (2003): 199.

4 Ilja Pavone, 'Article 25 [Health]', in *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, ed. Valentina della Fina, Rachele Cera and Giuseppe Palmisano (Cham: Springer, 2017), 472.

5 Joan Tronto, *Caring Democracy: Markets, Equality and Justice* (New York: New York University Press, 2013), 1, 8, 82, 92, 96; Martha Fineman, 'Vulnerability and Inevitable Inequality', *Oslo Law Review* 4 (2017): 139, 141, 145, 149; Martha Fineman, *The Autonomy Myth: A Theory of Dependency*, (New York: The New Press, 2004), xv; Martha Fineman, 'The Vulnerable Subject and the Responsive State', *Emory Law Review* 60 (2010): 265, 269.

public health will be presented. This reimagining, christened a liberalism of fear, is founded on the idea that the duties of the state, first and foremost, concern the fragilities which plague our human existence. Because all of us are subject to ailments, injuries and other conditions which under the present circumstances, temporarily or permanently, impede the full enjoyment of our rights – especially if they result in our own impairment or the impairment of someone close to us. With regard to the expedient liberal approach to disability, a liberalism of fear therefore proposes an expansion of our collective responsibility concerning public health, both pertaining to those who are impaired and their caretakers.

The trajectory of this essay will be as follows. First, I will present the benchmark to which I will hold the current systems of public health in liberal states and the eponymous reimagining of liberalism. This benchmark will indicate what the full enjoyment of rights by the impaired and their caretakers demands regarding institutional support. Subsequently, I will survey the current liberal approaches to public health, and their failings. This survey will chiefly concern the two main liberal conceptions of the role of the state, each on the edge of the spectrum: the ‘thick’ conception, wherein the state has a more active role concerning the enjoyment of rights by its citizens, and the ‘thin’ conception, wherein the state is less active. Both conceptions will show shortcomings, however, concerning public health and it is these shortcomings that currently thwart the full enjoyment of their rights by impaired persons and their caretakers. In order to remedy this situation, I will present an alternative paradigm, which in turn will necessitate the substitution of the current liberal approaches to disability and public health for a more viable option; the aforementioned liberalism of fear is one such option.

This alternative paradigm, which I will derive from vulnerability theory, positions the central role of diagnoses as the chief problem of public health systems in liberal states. Delineating certain groups for institutional support does benefit some physically and mentally impaired persons and their caretakers. However, others, who face similar problems but lack the proper diagnoses or other delineated characteristics for themselves or the person(s) they care for, are left out in the proverbial cold. The proposed solution to this situation will consist of a practical translation and application of the foregoing criticisms, concerning the edification of diagnoses, to the question of an adequate system of public health. The resulting approach connects the extent of our collective responsibility regarding public health to the goal of the amelioration of our universally shared vulnerability and its attested manifestations – such as impairment – for everyone. Consequently, the criteria which provide access to care or support would shift from diagnoses to actualized, individual problems. Closing out this essay, I will explore the expected real-world implications of the proposed paradigm shift – from the current liberal approaches, through vulnerability theory, towards a liberalism of fear. These implications will arguably provide the necessary public support for the reforms suggested, as the lonesome and unsupported burden of impairment and care duties will quickly become a thing of the past.

## 2. The Benchmark: Care, Rights, and the CRPD

In order to establish my benchmark for a proper public health system, I first need to briefly contextualize the right to care within the modern human rights discourse. Human rights, which are universal and individual in more than name, are a fairly recent phenomenon.<sup>6</sup> Despite their wording, the rights proclaimed in the famous French Declaration of the Rights of Man and of the Citizen in 1789, were mostly denied to persons of colour, women, and other marginalized groups.<sup>7</sup> This denial indicates the pattern the story of human rights would mostly follow in the ensuing one and a half centuries.<sup>8</sup> It took the horrors of World War II and a new declaration, the Universal Declaration of Human Rights (UDHR) in 1948, for rights to become broadly understood and accepted as truly individual and universal.<sup>9</sup> The normative foundation of this modern human rights discourse was formed by the liberty, equality, and dignity of each and every human being.<sup>10</sup> The various enforceable human rights treaties, which have been signed since the 1948 declaration, were thus conceived in this vein. With regard to their normative foundation and contents, the modern human rights discourse in general, and these treaties in particular, can be viewed as the victory of the central tenets of liberalism.<sup>11</sup>

Perhaps the single most important contribution of liberalism to the modern human rights discourse is the fact that the individual took centre stage concerning the conduct of the state and its institutions. This meant, in the first place, that the power of the state and its institutions over citizens was curtailed by human rights treaties and corresponding constitutional rights. As such, individuals were entitled to a private sphere, free of government intervention, and to strict equality if they encountered the government in the public sphere.<sup>12</sup> Moreover, the state and its institutions were – to a certain extent – beholden to protect and facilitate the individual and their life's plan.<sup>13</sup> Especially significant in this respect is the emergence of an enforceable right to an institutionally facilitated system of public health. The right to a standard of medical care and necessary social services was already mentioned in Article 25, section 1 of the (non-binding) UDHR.<sup>14</sup> A binding obligation

6 Marie-Louisa Frick, *Human Rights and Relative Universalism* (London: Palgrave MacMillan, 2019), 41; Ruti Teitel, 'Human Rights Genealogy', *Fordham Law Review* 66 (1997): 311.

7 Lynn Hunt, *Inventing Human Rights: A History* (London: W.W. Norton, 2007), 180.

8 *Ibid.*, 183-185.

9 Frick, *Human Rights and Relative Universalism*, 58.

10 Jerome Shestack, 'The Philosophical Foundation of Human Rights', *Human Rights Quarterly* 20 (1998): 229-230; Hunt, *Inventing Human Rights*, 202; Martin Loughlin, *Foundations of Public Law* (Oxford: Oxford University Press 2010), 312, 318-319; Conor O'Mahony 'There is No Such Thing as a Right to Dignity', *International Journal of Constitutional Law* 10 (2012): 572; Cristopher McCrudden, 'Human Dignity and Judicial Interpretation of Human Rights', *The European Journal of International Law*, 19 (2008): 660, 662-663.

11 Edmund Fawcett, *Liberalism: The Life of an Idea – 2nd edition* (Princeton: Princeton University Press, 2018), 2. This supposed triumph was not uncontested, see: Susan Darraj, *The Universal Declaration of Human Rights* (New York: Chelsea House, 2010), 99.

12 Michael Foran, 'Discrimination as an Individual Wrong', *Oxford Journal of Legal Studies* 39 (2019): 917.

13 Darraj, *The Universal Declaration of Human Rights*, 65-66; Fawcett, *Liberalism*, xii.

14 Hunt, *Inventing Human Rights*, 228.

along the same lines can be found in the International Covenant on Economic, Social, and Cultural Rights (ICESCR) of 1966.<sup>15</sup> Article 12, section 2, sub d obligates states to create ‘conditions which would assure to all medical service and medical attention in the event of sickness’.<sup>16</sup> As such, there does exist an enforceable right to a proper system of public health. Furthermore, it is usually assumed that such a system should be attentive beyond the mere absence of medical emergencies and should take the plight of private caretakers in account.<sup>17</sup>

Unfortunately, the exclusionary heritage of human rights was hard to leave behind entirely.<sup>18</sup> And in the years following the UDHR and the subsequent enforceable, general human rights treaties, it was noticed that under the general interpretation of these rights, certain groups lacked the full enjoyment thereof.<sup>19</sup> Especially the benefits of the social and economic rights, codified in the aforementioned ICESCR, were unequally distributed.<sup>20</sup> As a result, the plurality of the human condition became relevant for the universally shared, full and equal enjoyment of human rights.<sup>21</sup> The international community reacted with an ongoing series of specialized rights treaties for certain groups. These covenants did not contain new rights *per se*, but obligated states to interpret the existing rights catalogues in a way which allows the group in question to fully enjoy their rights.<sup>22</sup> Examples are the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) of 1979, and the Convention on the Rights of the Child (CRC) of 1989.<sup>23</sup> Both covenants employ a specific interpretation of the right to an adequate system of public health as formulated in the ICESCR.<sup>24</sup> Similar ample attention to the right to care can be found in the CRPD, which was adopted in 2006.<sup>25</sup> The goals of the latter covenant, and the specific demands concerning care, will be the benchmark for my evaluation of the current liberal approaches to public health and the subsequent proposal for a liberalism of fear.

15 Ben Saul, David Kinley and Jacqueline Mowbray, *The International Covenant on Economic, Social and Cultural Rights: Commentary, Cases, and Materials* (Oxford: Oxford University Press, 2014), 978.

16 *Ibid.*, 980, 985.

17 *Ibid.*, 985, 1010-1011.

18 Upendra Baxi, ‘Voices of Suffering, Fragmented Universality, and the Future of Human Rights’, in *The Future of International Human Rights*, ed. Burns Weston and Stephen Marks (New York: Transnational, 1999): 109-112; Teitel, ‘Human Rights Genealogy’, 309.

19 Joy Gordon, ‘The Concept of Human Rights: The History and Meaning of its Politicization’, *Brooklyn Journal of International Law* 23 (1998): 724.

20 Baxi, ‘Voices of suffering’, 702; Gordon, ‘The Concept of Human Rights’, 696, 709-710.

21 Frick, *Human Rights and Relative Universalism*, 202.

22 Will Kymlicka, *Multicultural Citizenship: A Liberal Theory of Minority Rights* (Oxford: Oxford University Press 1995), 46; Erwin Dijkstra, ‘De Coronacrisis Noopt tot Meer Expliciete Aandacht van de Nederlandse Staat voor het VN-Verdrag Handicap’, *NTM/NJCM-Bulletin* 45 (2020): 377-378.

23 Frick, *Human Rights and Relative Universalism*, 44-45.

24 Such a deficit was already anticipated by the framers of the ICESCR. Specifically for public health, see: Saul, Kinley and Mowbray, *The International Covenant on Economic, Social and Cultural Rights*, 987-988.

25 Frick, *Human Rights and Relative Universalism*, 202; Dijkstra, ‘De Coronacrisis Noopt tot Meer Expliciete Aandacht van de Nederlandse Staat voor het VN-Verdrag Handicap’, 378-379.

Before we embark on our exploration of the liberal approaches to public health, I therefore need to establish the benchmark provided by the CRPD. The CRPD concerns the plight of almost all persons who face a form of impairment, regardless of diagnoses or if the impairment qualifies as a disability.<sup>26</sup> The goals of this convention are the establishment of the capacity for all of these impaired individuals to properly participate in society, on equal footing with relatively healthy fellow citizens, and the adjacent capacity to fashion their own life's choices – as much as possible.<sup>27</sup> Only through the realization of these capacities, it is assumed, can impaired persons realistically be expected to fully enjoy their human rights.<sup>28</sup> The interpretation of the existing human rights obligations, presented in the articles of the CRPD, is therefore specifically tailored to the challenges, faced by the impaired, which obstruct these capacities.<sup>29</sup> Care is the subject of Article 25 of the treaty. Within the broader context of the CRPD, this article 'obligates states to provide equal access to healthcare and related services for people with disabilities'.<sup>30</sup> Not only does this obligation rule out discrimination, but it also means that the available health services should fit the nature of an individuals' impairment and that decisions within a care trajectory should be made within the health care professional-patient relationship on the basis of free and informed consent.<sup>31</sup> This obligation, focusing chiefly on health care, is supplemented by Article 4, which requires state parties to consistently further the goals of societal participation and independent life choices; including, but not limited to, the provision of accessible information, accessible spaces, assistive devices, and training for professionals who might work with impaired persons.<sup>32</sup> In light of the goals of the CRPD, the duties of the public health system can therefore be said to transcend the strict boundaries of health care.<sup>33</sup>

Whereas the obligations of the state concerning the provision of a proper public health system for the impaired are fairly clearly defined by the CRPD, the rights of caretakers are merely implied. Important in this regard are Article 19, Article 16 section 2, and Article 28, section 1 and section 2, sub c. These articles have been interpreted as obligating the state, on the one hand, to prevent exploitation of

26 Rachele Cera, 'Preamble', in *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, ed. Valentina della Fina, Rachele Cera and Giuseppe Palmisano (Cham: Springer, 2017), 84-85.

27 Oliver Lewis and Genevra Richardson, 'The Right to Live Independently and Be Included in the Community', *International Journal of Law and Psychology* 69 (2020): 5.

28 *Ibid.*; Article 3 sub a CRPD.

29 Valentina della Fina, 'Article 1 [Purpose]', in *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, ed. Valentina della Fina, Rachele Cera and Giuseppe Palmisano (Cham: Springer, 2017), 92-93.

30 Michael Stein et al, 'Health care and the UN Disability Rights Convention', *The Lancet* 374 (2009): 1796.

31 *Ibid.*, 1796-1797; Pavone, 'Article 25 [Health]', 477-480; Giovanni Bruno, 'Article 10 [Right to Life]', in *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, ed. Valentina della Fina, Rachele Cera and Giuseppe Palmisano (Cham: Springer, 2017), 248.

32 Valentina della Fina, 'Article 4 [General Obligations]', in *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, ed. Valentina della Fina, Rachele Cera and Giuseppe Palmisano (Cham: Springer, 2017), 148.

33 Stein et al, 'Health care and the UN Disability Rights Convention', 1797.

private caretakers, and, on the other hand, to unburden them.<sup>34</sup> The latter duty is generally interpreted as rather broad. States are beholden to facilitate independent living by the impaired, which is taken to necessitate the provision of ‘social security benefits, allowances, and pension schemes’ to caretakers.<sup>35</sup> As such, my benchmark for the functioning of the current systems of public health in liberal states concerns both the needs of impaired persons themselves, as well as the position of their private caretakers.

### 3. A Flawed Anatomy: The Current Liberal Approaches to Public Health

In order to fully enjoy their human rights – as befitting the liberty, equality, and dignity of every human being – mentally and physically impaired persons should thus be facilitated to fully participate in society and make their own life’s choices, while the burden on their private caretakers should be ameliorated. If this is our benchmark, how can liberal states fail in this regard? Did the modern human rights discourse not present the victory of the central tenets of liberalism? But theory and practice are uneasy bedfellows. Liberalism as well as its most important practical implementations – the rule of law and the *Rechtsstaat* – are essentially contested concepts.<sup>36</sup> As such, there is no such thing as the sole ‘liberal approach’ to public health. There are, however, influential and commonly discussed variants. Two of the most important of these variants are the conceptions of the *Rechtsstaat* and the rule of law as ‘thick’ or ‘thin’.<sup>37</sup> Both conceptions, despite their differences, present remarkable similar problems with regard to the state’s obligations concerning public health, set by the benchmark of the CRPD.

#### 3.1. *Through Thick and Thin*

The monikers thick and thin mainly indicate how much is expected of a state to ensure the prerequisites of liberalism, including the enjoyment of human rights by individual citizens.<sup>38</sup> As such, the difference between thick and thin concerns the amount of state tasks and not their nature or contents. A liberal state which ad-

34 Giuseppe Palmisano, ‘Article 19 [Living Independently and Being Included in the Community]’, in *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, ed. Valentina della Fina, Rachele Cera and Giuseppe Palmisano (Cham: Springer, 2017), 367; Antonio Marchesi, ‘Article 16 [Freedom from Exploitation, Violation and Abuse]’, in *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, ed. Valentina della Fina, Rachele Cera and Giuseppe Palmisano (Cham: Springer, 2017), 322; Marco Fasiglione, ‘Article 28 [Adequate Standard of Living and Social Protection]’, in *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary*, ed. Valentina della Fina, Rachele Cera and Giuseppe Palmisano (Cham: Springer, 2017), 510-512, 514, 518.

35 Palmisano, ‘Article 19 [Living Independently and Being Included in the Community]’, 367.

36 Martin Krygier, ‘The Rule of Law: Pasts, Presents, and Two Possible Futures’, *Annual Review of Law and Social Science* 12 (2016): 200; Gillian Hadfield and Barry Weingast, ‘Microfoundations of the Rule of Law’, *Annual Review of Political Science* 17 (2014): 22; Sanne Taekema, ‘Sleutelen aan de Rechtsstaatgedachte: Het Nut van Samenwerking tussen Rechtsfilosofie, Rechtssociologie en Rechtswetenschap’, *Tijdschrift voor Constitutioneel Recht* 4 (2013): 280.

37 *Ibid.*, 288.

38 Brian Tamanaha, *On the Rule of Law: History, Politics, Theory* (Cambridge: Cambridge University Press, 2004), 91-113.

heres to a thick conception of the rule of law or the *Rechtsstaat* could therefore still fail the benchmark set in the previous section, if the larger amount of tasks does not cover the necessary components of a proper public health system.<sup>39</sup> Thus, whether a liberal state adheres to a thick or a thin conception of the rule of law or the *Rechtsstaat* respectively, does not say much about the adequacy of the system of public health. Such adequacy depends less on the amount of tasks and more on the local ideas of the precise role and limitations of the state. These ideas are, by and large, contingent upon the interpretation of the demands of the values underlying the modern human rights discourse: liberty, equality, and dignity.<sup>40</sup> In particular the former two values are commonly perceived as important in this regard.<sup>41</sup> There is a tendency within liberal states to try and find an equilibrium between negative and positive liberty, and formal and substantive equality.<sup>42</sup> These differences chiefly account for the divergence between the rule of law and the *Rechtsstaat*-tradition in the modern era and their disparate approaches to public health.

Even in the absence of an ironclad rule, we can observe that most states which adhere to the rule of law tilt towards the thin conception of state tasks, whereas most states in continental Europe, which place themselves firmly within the *Rechtsstaat*-tradition, coalesce towards a more thick conception – an attitude also denoted as social liberalism.<sup>43</sup> More importantly regarding public health, as mentioned above, are the categorically different views on the role of the state within these divergent traditions. Within the rule of law-tradition, the emphasis of state responsibility pertains to the existence of liberal institutions as such.<sup>44</sup> This course of action privileges negative liberty – that is, freedom from state interference – and prioritizes formal equality – which means that citizens can expect the similar treatment from the state, including institutional support, with limited regard for the actual improvement of their situation.

This categorical emphasis on the mere existence of institutions leaves a formidable blind spot towards the achievement of the actual enjoyment of human rights by individual citizens in their day-to-day life. States within the social liberal variant of the *Rechtsstaat*-tradition, on the other hand, employ a more positive interpretation of liberty – assuming state interference necessary in order to guarantee the prerequisites of liberalism – and, consequently, strive towards a more substantive

39 Martin Krygier, 'Rule of Law (and *Rechtsstaat*)', in *The Legal Doctrines of the Rule of Law and the Legal State (Rechtsstaat)*, ed. James Silkenat, James Hickey and Peter Barenboim (Cham: Springer, 2014), 56.

40 Martha Fineman, 'Contract and Care', *Chicago-Kent Law Review* 76 (2001): 1403, 1412.

41 Tronto, *Caring Democracy*, 88; Sarah Stephens, 'Freedom from Religion: A Vulnerability Theory Approach to Restricting Conscience Exemptions in Reproductive Healthcare', *Yale Journal of Law and Feminism* 29 (2018): 103.

42 Fineman, 'The Vulnerable Subject and the Responsive State', 257-258, 265-266.

43 Paul Tiedemann, 'The *Rechtsstaat*-Principle in Germany: The Development from the Beginning Until Now', in *The Legal Doctrines of the Rule of Law and the Legal State (Rechtsstaat)*, ed. James Silkenat, James Hickey and Peter Barenboim (Cham: Springer, 2014), 188-189.

44 Krygier, 'The Rule of Law', 214.

idea of equality.<sup>45</sup> As such, citizens who lack full enjoyment of their rights can expect institutional support beyond the mere existence of liberal institutions and procedures. Having said this, and continuing the earlier stated misgivings, I arrive at the question how both liberal traditions – states adhering to a thin conception of the rule of law as well as the apparently better positioned states within the social liberal *Rechtsstaat*-tradition – manage to systematically fail the goals and obligations laid out in the CRPD.

### 3.2. *The Flaws in the Current Liberal Approaches to Public Health*

Both conceptions arguably share a central characteristic in their approach to public health. In their balancing act between the two main interpretations of liberty – negative or positive – and equality – formal or substantive – they tend to devise a system of public health which limits support to certain delineated groups.<sup>46</sup> As such, the support the impaired receive – and in turn the burden on their caretakers – depends on the anatomy of the local public health system. The prevailing anatomy of public health systems in most liberal states can be summarized in three characteristics: an anti-discrimination angle, the notion of desert, and an artificial border between the public and the private sphere. An examination of these characteristics will reveal the flaws in the current liberal approaches to public health and the need for a different paradigm.

The anti-discrimination angle is an offshoot of the generally accepted emphasis that, in a liberal society, equality first and foremost concerns formal equality.<sup>47</sup> Consequently, most contemporary liberal states – even those within the tradition of social liberalism – typically delineate disadvantaged demographics whose members are supposed to lack this kind of equality and are entitled to state action.<sup>48</sup> Within both liberal approaches to public health, this leads to the selection of certain groups with selected impairments on an appropriate level of severity, which are supposed to be in an unequal position and are, as an exception, entitled to certain levels of institutional support. This situation has severe consequences for those citizens who experience impairment but do not fit the necessary conditions to be categorized with a disability, which entitles them to the necessary forms of institutional assistance. An interesting example are the sharp demarcations most modern systems of public health draw within the spectrum of neurodiversity. Many persons on this spectrum experience similar problems, but such problems

45 Krygier, 'Rule of Law (and *Rechtsstaat*)', 50.

46 Martha Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (Cambridge: Harvard University Press, 2006), 156-160; Will Kymlicka, *Contemporary Political Philosophy: An Introduction* (Oxford: Oxford University Press, 2002), 94; Jonathan Wolff, 'Fairness, Respect and the Egalitarian Ethos', *Philosophy and Public Affairs* 27 (1997): 112.

47 Martha Fineman, 'Equality, Autonomy, and the Vulnerable Subject in Law and Politics', in *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics*, ed. Martha Fineman and Anna Gear (Farnham: Ashgate Publishing, 2013), 14-16; Erwin Chemerinsky, 'In Defence of Equality: A Reply to Professor Westen', *Michigan Law Review* 81 (1983): 575, 578.

48 Fineman, 'The Vulnerable Subject and the Responsive State', 252.

are only addressed through the system of public health if one fits the stringent criteria of certain diagnoses.<sup>49</sup>

Intertwined with the anti-discrimination angle is the idea of individual desert. Not only does one have to qualify for societal assistance through the system of public health, but such support, increasingly, has to be earned.<sup>50</sup> This has two aspects. On the one hand, one has to tolerate a protruding government presence in one's life, in order to continuously prove one is the exception which deserves institutional support.<sup>51</sup> On the other hand, one has to show strictly defined, expected behaviour – such as making the 'right' or 'responsible' choices in life.<sup>52</sup> The collective responsibility in contemporary liberal states therefore concerns not only delineated forms of dependency, but within these categories also privileges those who make certain choices, regardless whether the state follows a thick or thin conception of the rule of law or the *Rechtsstaat*.<sup>53</sup>

Many persons, who experience impairment, therefore do not receive the institutional support they need to fully participate in society and are, as a result, severely limited in their life's choices. Their care is relegated to the so-called private sphere, to be conducted there – or not.<sup>54</sup> Here the idea of a separate public and private sphere, current within both the thick and the thin conception of the role of the state within the rule of law and the *Rechtsstaat*, shows its deficits. As another consequence of the balancing act between the different interpretations of liberty and equality, the state is supposed to refrain from interference in the private sphere. As a result, the bulk of care for those impaired, who fall outside the system of public health, burdens their immediate surroundings. These private caretakers are subsequently ill-positioned to lead their own lives in full enjoyment of their human rights, relative to citizens who have the dubious luck to not be acquainted with impaired persons who fail to qualify for institutional support.<sup>55</sup> Due to the gendered nature of care, this imbalance primarily harms women.<sup>56</sup>

As the anatomy of the current liberal approaches to public health is both exclusionary and neglectful, we have to look for a more fruitful pathway for liberal states to fulfil their human rights commitments. Martin Krygier proposes the teleological approach as an important complement to the contemporary anatomical orthodoxy

49 Robin Mackenzie and John Watts, 'Is Our Legal, Health Care and Social Support Infrastructure Neurodiverse Enough? How Far Are the Aims of the Neurodiversity Movement Fulfilled for Those Diagnosed with Cognitive Disability and Learning Disability?', *Tizard Learning Disability Review* 16 (2011): 30-37.

50 Tronto, *Caring Democracy*, 86-87, 99, 144; Kymlicka, *Contemporary Political Philosophy*, 94-95; Wolff, 'Fairness, Respect, and the Egalitarian Ethos', 112, 121.

51 *Ibid.*, 97, 108-112.

52 *Ibid.*, 102; Fineman, 'The Vulnerable Subject and the Responsive State', 252-53, 257.

53 Tronto, *Caring Democracy*, 88, 89, 91.

54 *Ibid.*, 82, 100; Fineman, 'The Vulnerable Subject and the Responsive State', 263, 265-66; Fineman, 'Vulnerability and Inevitable Inequality', 144-45.

55 Tronto, *Caring Democracy*, 95-98.

56 *Ibid.*, 1, 68-69, 72; Martha Nussbaum, *Woman and Human Development: The Capabilities Approach* (Cambridge: Cambridge University Press, 2000), 252, 282.

in most liberal states.<sup>57</sup> In the vein of social liberalism, and following the ideas of Phillip Selznick, we could thus relate the system of public health to certain goals.<sup>58</sup> The enjoyment of their human rights by the impaired and their private caretakers, is therefore best served with an actionable government – and thus some form of the thick conception – but its implementation should be adjusted to the proper goal.<sup>59</sup> And thus we arrive at the need for a paradigm shift. The paradigm of vulnerability theory can perhaps provide a suitable candidate for the goal, with which public health systems may achieve the benchmark of the CRPD for all individuals, who find themselves confronted with impairment, and their caretakers.

#### 4. A Different Paradigm: Vulnerability Theory

The central proposition of vulnerability theory purports that vulnerability is an integral part of the human condition.<sup>60</sup> We are, after all, fragile beings living finite lives.<sup>61</sup> The manner in which this universally shared vulnerability manifests itself, however, differs depending on our bodily situation and societal position. It is therefore necessary, vulnerability theorists assert, to contemplate the extent to which the state and other societal institutions have the responsibility to ameliorate manifestations of vulnerability in the daily lives of individual citizens, such as mental and physical impairments.<sup>62</sup> This duty would, arguably, also include derivative vulnerability, such as the burdens and responsibilities adjacent to care for a loved one.<sup>63</sup> By emphasizing the need to work from actual manifestations of vulnerability, instead of a delineated set of diagnoses, the paradigm of vulnerability theory thus has the capacity to address the marginalized position of the impaired and their caretakers within the current systems of public health in liberal states, while simultaneously pointing towards a more effective method to reach the benchmark of the CRPD.

According to vulnerability theorists, the generally marginalized position of the impaired – and subsequently their caretakers – stems from the fact that liberal societies appear to be designed without their vulnerabilities in mind.<sup>64</sup> As such, physically and mentally impaired persons do not only differ from their fellow citizens in an embodied sense, but they are also disadvantaged, relative to them, in their soci-

57 Krygier, 'Rule of Law (and Rechtsstaat)', 55-56.

58 Philip Selznick, *The Moral Commonwealth* (Berkeley: University of California Press, 1992), 174; Philip Selznick, 'Legal Cultures and the Rule of Law, in *The Rule of Law After Communism*, ed. Martin Krygier and Adam Czarnota (Aldershot: Ashgate, 1999), 26.

59 Taekema, 'Sleutelen aan de Rechtsstaatgedachte', 287-88.

60 Fineman, 'The Vulnerable Subject', 8; Fineman, *The Autonomy Myth*, xvii; Morgan Cloud, 'More than Utopia', in *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics*, ed. Martha Fineman and Anna Grear (Farnham: Ashgate Publishing, 2013), 87.

61 Nussbaum, *Frontiers of Justice*, 160.

62 Fineman, 'The Vulnerable Subject', 2, 12-15.

63 Fineman, 'The Vulnerable Subject and the Responsive State', 264.

64 Sophia Moreau, 'What is Discrimination?', *Philosophy and Public Affairs* 32 (2010): 150-51, 153; Nussbaum, *Frontiers of Justice*, 79, 160, 415; Fineman, 'Vulnerability and Inevitable Inequality', 139.

etal position.<sup>65</sup> Those disadvantages, conferred by institutions in the latter case, exert their effects both simultaneously and sequentially.<sup>66</sup> If we look at public spaces, such as pavements, we can observe that they do cater to some vulnerabilities, that is to say the needs of ‘normals’ or the ‘nondisabled’.<sup>67</sup> High curbs, for example, protect impuissant pedestrians from car accidents – yet they constitute a daily obstacle for those persons who are confined to a wheelchair. Sequentially, this inaccessibility of public spaces limits the range where such persons can find suitable jobs.<sup>68</sup> Through governance choices, like the design of public spaces, the state and other societal institutions thus delineate certain consequences of the vulnerable human condition which merit collective responsibility.<sup>69</sup>

Such choices are responsible for the previously elaborated theoretical deficits in the anatomy of public health systems in liberal states and their practical consequences. By delineating certain diagnoses, which entitle one to institutional support, these systems fail both those impaired who receive assistance and those who do not. Because, within such an exclusionary system, groups whose manifested vulnerabilities entitle them to assistance, are stigmatized as societal beneficiaries instead of participants.<sup>70</sup> Their position as an exception consequently erodes public support for the system of public health, while simultaneously legitimizing the previously elaborated harsh conditions.<sup>71</sup> As such, even the impaired who receive institutional support are deprived of the full societal participation and independent life choices envisioned by the CRPD. The same applies, of course, to those who – partly or entirely – lack such support.

As with the example of public spaces, the disadvantages impaired persons experience within the public health systems of most liberal states, exert themselves both simultaneously and sequentially. Due to the previously elaborated anatomy of the liberal approaches to public health, the hardships of a physical or mental impairment oftentimes include an arduous path through the public health system, in order to prove one is the relevant exception and thus entitled to institutional support, and – if such support is denied or insufficient – the eventual independent

65 Fineman, ‘The Vulnerable Subject and the Responsive State’, 268; Fineman, ‘Vulnerability and Inevitable Inequality’, 143, 145; Liz Crow, ‘Including All of Our Lives: Renewing the Social Model of Disability’, in *Exploring the Divide: Illness and Disability*, ed. Colin Barnes and Geof Mercer (Leeds: Disability Press, 1996), 58.

66 Moreau, ‘What is Discrimination?’, 148-49; Fineman, ‘Vulnerability and Inevitable Inequality’, 147.

67 Nussbaum, *Frontiers of Justice*, 109, 113, 116-17, 188-89; Karl Lippert-Rasmussen, *Born Free and Equal? A Philosophical Inquiry into the Nature of Discrimination* (Oxford: Oxford University Press, 2014), 39.

68 Erwin Dijkstra, ‘Wanneer Je Leven Bepaald Wordt door de Wet: Over Handicap, Regelgeving en Identiteit’, *Handicap & Recht* 5 (2020): 42.

69 Fineman, ‘The Vulnerable Subject’, 23.

70 Tronto, *Caring Democracy*, 86-87, 99, 144; Thomas Scanlon, *The Diversity of Objections to Equality* (Kansas: The University of Kansas Press, 1996), 5.

71 Kim Putters and Stella Hoff, ‘Sociale Onzekerheid’, in *Sociale (On)zekerheid. De Voorziene Toekomst*, ed. Peter van Lieshout (Amsterdam: Amsterdam University Press, 2016), 55; Paul de Beer, ‘De Grote Golf van het Sociale Stelsel’, in *Sociale (On)zekerheid. De Voorziene Toekomst*, ed. Peter van Lieshout (Amsterdam: Amsterdam University Press, 2016), 77.

acquisition of the necessities to function. Both these options incur extra costs and demand a lot of time and energy, while the impaired can often work less hours – and generate less income – than relatively healthy persons.<sup>72</sup> As a result, much of the care the impaired need to function falls on their immediate social circle, who run a so-called ‘second shift.’<sup>73</sup> This second shift hampers one’s own ability fully participate in society and make life choices independent from their extra responsibilities. In all three cases – the impaired who are entitled to institutional support, the impaired who do not qualify, and their caretakers – these societal disadvantages reinforce their disparate effect on human well-being.<sup>74</sup> The problems inherent in the manifested vulnerability of the impaired are exacerbated by their societal marginalization, such as the lack of a proper system of public health, while their caretakers, who are derivative vulnerable, face their own societal setbacks through their unsupported care.

Vulnerability theory thus offers a framework to admonish the practical consequences of the anatomical flaws in the liberal approaches to public health – both in the thick and thin conceptions – but can it offer an alternative paradigm? Justice can be done to the vulnerability of all citizens, vulnerability theorists postulate, if the current group-based attitude is swapped for the endeavour of fostering individual resilience.<sup>75</sup> Resilience is here defined as the ability to survive or recover from life’s inevitable setbacks, including impairment.<sup>76</sup> As impairment exists on a spectrum, on which both individuals inside and outside the currently delineated groups will – over the span of their lives – find themselves, the possibilities for institutional assistance need therefore to be expanded beyond these groups.<sup>77</sup> As a result, our collective responsibility to provide citizens with the means to handle impairment, should ideally extend to every individual who is, throughout the entire story of their existence, confronted with impairments.<sup>78</sup> This desired universally shared resilience is best achieved by a more equal distribution of the physical, human, and social resources, needed to cope with harm.<sup>79</sup> Such an extension of our collective responsibility, however, necessitates a reconsideration of the balance between negative and positive liberty and formal and substantive equality.

72 Dijkstra, ‘Wanneer Je Leven Bepaald Wordt door de Wet’, 44; Nussbaum, *Frontiers of Justice*, 104-105; Flip de Kam and Jan Donders, *Onzekere Zekerheden: De Nederlandse Verzorgingsstaat op Weg naar 2025* (The Hague: Willem Drees Stichting, 2014), 47, 207-09.

73 Tronto, *Caring Democracy*, 95-98.

74 Madison Powers and Ruth Faden, *Social Justice: The Moral Foundations of Public Health and Health Policy* (Oxford: Oxford University Press 2006), 31.

75 Fineman, ‘The Vulnerable Subject and the Responsive State’, 269; Fineman, ‘Vulnerability and Inevitable Inequality’, 147-49.

76 Martha Fineman, ‘Beyond Equality and Discrimination’, *SMU Law Review Forum* 73 (2020): 58.

77 Fineman, ‘The Vulnerable Subject and the Responsive State’, 259-60.

78 Nina Kohn, ‘Vulnerability Theory and the Role of the Government’, *Yale Journal of Law and Feminism* 26 (2014): 6.

79 Peadar Kirby, *Vulnerability and Violence: The Impact of Globalization* (London: Pluto Press, 2006), 13, 55; Fineman, ‘The Vulnerable Subject’, 14.

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Expanding the tasks of the state, of course, means a more prominent position for positive liberty – the options for assistance provided through state action.<sup>80</sup> Realizing the demands of vulnerability as a leading value, however, principally means a central role for a more substantive notion of equality than is now common within any contemporary liberal state.<sup>81</sup> This notion of substantive equality legitimizes and necessitates the equitable provision of the means to cultivate resilience. Consequently, the state and other societal institutions can no longer continue to privilege some impaired and neglect the needs of others – whether it be on the grounds of certain diagnoses or some notion of desert. Nor can the division between the public and private sphere be strictly maintained, with regard to public health.<sup>82</sup> Public health reforms striving to attain the aforementioned substantive equality have to take care in the private sphere, and its gendered nature, in serious consideration.<sup>83</sup> Only then can every person – whether they are impaired, a caretaker, or only at risk of becoming either impaired or a caretaker – acquire the necessary resilience to cope with these manifestations of our universally shared vulnerability.

Can the goal of the amelioration of our universally shared vulnerability through fostering resilience thus provide us with systems of public health which leave their current anatomical flaws behind and comply with the benchmark set by the CRPD? Vulnerability as a leading value – together with the notion of substantive equality, as advanced by vulnerability theorists – has proven to be increasingly influential and has instigated real change in the world, for example through the jurisprudence of the European Court of Human Rights.<sup>84</sup> However, vulnerability theorists have also been met with powerful objections. Perhaps the most important criticism of vulnerability theory in general is the allegation that the theory provides few tangible guidelines for its implementation.<sup>85</sup> And even when vulnerability theorists offer a practical guide, critics assert, they often fall back on the same aspects of the liberal approaches they themselves tend to criticize, such as delineating groups which are entitled to extra scrutiny.<sup>86</sup> Worse still, such guidelines tend to be paternalistic; they foster dependence on the state and erode the autonomy of the individual.<sup>87</sup> These observations show that vulnerability theorists can unwittingly align themselves with the exactly those tendencies in contemporary liberal states, which the goals and obligations of the CRPD aim to counter. Any CRPD-proof reimagina-

80 Fineman, 'The Vulnerable Subject and the Responsive State', 257; Fineman, 'Contract and Care', 1440.

81 Fineman, 'The Vulnerable Subject and the Responsive State', 262, 275.

82 Fineman, 'Contract and Care', 1403-1412.

83 Fineman, *The Autonomy Myth*, xiii.

84 Catherine MacKinnon, 'Substantive Equality: A Perspective', *Minnesota Law Review*, 96 (2011): 1-27; Alexandra Timmer, 'A Quiet Revolution: Vulnerability in the European Court of Human Rights', in *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics*, ed. Martha Fineman and Anna Gear (Farnham: Ashgate Publishing, 2013), 147-148.

85 Kohn, 'Vulnerability Theory and the Role of Government', 8-10.

86 *Ibid.*, 4.

87 Sean Coyle, 'Vulnerability and the Liberal Order', in *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics*, ed. Martha Fineman and Anna Gear (Farnham: Ashgate Publishing, 2013), 61-77; Cloud, 'More than Utopia', 91-93; Clough, 'Disability and Vulnerability', 469, 474-75.

tion of liberalism regarding disability and public health, which envisions vulnerability theory as its starting point, has therefore to contend with these challenges.

## 5. Reimagining Liberalism: A Liberalism of Fear

Thus far I have observed that compliance with the goals and obligations of the CRPD still eludes the public health systems in liberal states. This failure turned out not to arise from the measure of state involvement, but from the specific policies pursued and the resulting anatomy of the public health systems. Through their design these policies privilege, on a group-basis, some persons, who are confronted with manifestations of our universally shared vulnerability, and disadvantage others. As such, many impaired persons and their caretakers miss out on the full enjoyment of their human rights simply by not belonging to the right category. This confinement of state responsibility to certain delineated groups arguably presents a faint but distinct echo of the previously elaborated exclusionary heritage of the early trajectory of the human rights discourse. A liberalism of fear, as founded on the premises of vulnerability theory, is therefore an attempt to reimagine a liberalism which furthers the promises of the modern human rights discourse towards the individual, particularly concerning a proper public health system.<sup>88</sup>

A liberalism of fear extends from the age-old liberal concerns with power, remembering the horrors power imbalances have wrought.<sup>89</sup> As such, its main goal is to minimize the influence of the everyday torments humans – through public or private means – can concoct for their fellow human beings.<sup>90</sup> This reimagining of liberalism has thus less to do with the acts individuals can conduct, but more with the ills that can befall them. Such ills can be defined as those manifestations of our vulnerabilities – both bodily and societal – which inhibit a life that can be called dignified.<sup>91</sup> The amelioration of these ills, however, does not provide the state, or any other societal institution for that matter, with a *carte blanche*. A liberalism of fear may be an attempt to give the insights of vulnerability theory a practical bite, but it also acknowledges – and tries to appease – the alleged dangers of this alternative paradigm, above all the charges of paternalistic policies and the possibility of a return to some form of a group-based approach.

It does so by connecting the notions of positive liberty and substantive equality, as propounded by vulnerability theorists, with a renewed appraisal of that third val-

88 The label originates with Judith Shklar, see: Judith Shklar, 'The Liberalism of Fear', in *Liberalism and the Moral Life*, ed. Nancy Rosenblum (Cambridge: Harvard University Press, 1989), 198. Recently the German political philosopher Jan-Werner Müller adopted the term for his own reimagining of liberalism, see: Jan-Werner Müller, *Furcht und Freiheit: Für einen anderen Liberalismus* (Berlin: Suhrkamp Verlag, 2019) My own reimagination differs markedly from that of Müller, however, as I incorporate the central tenets of vulnerability theory, absent in Müller's work, and afford a more central role to dignity than allowed by Müller's approach.

89 Shklar, 'The Liberalism of Fear', 27.

90 Frank Cooper, 'Always Already Suspect: Revising Vulnerability Theory', *North Carolina Law Review* 93 (2015): 1346-1347.

91 Nussbaum, *Frontiers of Justice*, 159-160.

ue, often overlooked in the context of care and disability: dignity.<sup>92</sup> The demands of human dignity will be the measure to determine both the practical extent as well as the indispensable boundaries of our expanded collective responsibility.<sup>93</sup> With this expanded responsibility, liberal states should be able to better fulfil their human rights commitments. These commitments would naturally include the obligation to facilitate full societal participation and independent life choices by the impaired, as well as the adjacent unburdening of their caretakers, as envisioned by the CRPD. However, the possibility to use the subsequently increased public facilities should be just that – a possibility. Because being devoid of the institutional assistance, to which one is entitled, is arguably as much an affront to one's dignity as being forcefully provided to or being provided to under the most stringent of conditions.<sup>94</sup>

To guarantee the minimal conditions of such a dignified life, a liberalism of fear in the first place supports a greater emphasis on the previously elaborated notions of positive liberty – to accommodate the necessary state action – and substantive equality – to legitimize such action. Public health systems constitute one of the most important areas to put this expansion of the possibility of state action into practice. Because health is currently one of those conditions which heavily influence whether one is perceived as a societal participant or beneficiary, with all the disadvantages that go along with the latter undignified status.<sup>95</sup> The problems impairment presents are therefore an ill which can and should be ameliorated for every individual, regardless if their impairment is acknowledged by the public health system, or if their exhibited behaviour confirms to politically determined standards.<sup>96</sup> An individual's problems should not belong to a certain category to enjoy human rights, as codified in treaties like the ICESCR and the CRPD, nor should one deserve them through the right demeanour.<sup>97</sup> Passive injustice regarding the dignity of a human being in their unsupported suffering or through their unassisted care duties, by means of a strict delineation of the extent of our collective responsibility, is still injustice.<sup>98</sup>

The practical consequences of the ambitions of a liberalism of fear, as I described them so far, can be summed up with one word: *access*. Access to resources which provide every individual with circumstances that make them more resilient to their embodied as well as their societal vulnerability. Such access thus guarantees an in-

92 Eva Kittay, 'Equality, Dignity, and Disability', in *Perspectives on Equality*, ed. Marry Lyons and Fiona Waldron (Dublin: The Liffey Press, 2005), 97-100; Miguel Julião, 'Human Dignitas, Dignity in Care: A Precious Need', *International Journal of Emergency Mental Health and Human Resilience* 17 (2015): 598-599.

93 O'Mahony, 'There is No Such Thing as a Right to Dignity', 555.

94 Martha Nussbaum, 'Human Functioning and Social Justice: In Defense of Aristotelian Essentialism', *Political Theory* 20 (1992): 233.

95 Cloud, 'More than Utopia', 85; Kohn, 'Vulnerability Theory and the Role of Government', 8, 15.

96 Fineman, 'Vulnerability and Inevitable Inequality', 133-49; Kohn, 'Vulnerability Theory and the Role of Government', 3.

97 Judith Shklar, *The Faces of Injustice* (New Haven: Yale University Press, 1990), 35.

98 *Ibid.*, 56, 74, 119.

dividual's ability to – at a minimum – lead a life worthy of being called dignified.<sup>99</sup> Within the context of public health, this would mean that problems replace diagnoses and other delineated circumstances as the means of access to the public health system. These systems would, additionally, encompass both institutional care as well as support for private care. As a result, the artificial divide between care in the public sphere – through designated institutions, such as hospitals and revalidation centres – and care in the private sphere – such as the family – would become less rigid.<sup>100</sup>

Some or even most care, which is currently administered within the family, will consequently be transferred to professionals, according to both the needs of the person whose manifested vulnerability necessitated care, and the needs of the derivative vulnerable person, the potential caretaker. Through the possibility of such transfers, care will no longer be viewed as a commodity, to which one is entitled or not, but as a process where sometimes the professionals and sometimes the private sphere carry the proverbial cross – all supported through our enlarged collective responsibility.<sup>101</sup> Additionally, this will rid us of situations where only some consequences of impairment are covered by the public health system. An example of the latter situation is a person who experiences problems associated with dementia: even if a diagnoses can be obtained, the care such a person receives will often not pertain to the entire spectrum of problems, including the physical inconveniences involved with the symptoms of dementia.<sup>102</sup> By making such problems just another part of our collective responsibility – the process of care instead of the commodity – the person in question can, to a larger extent, continue to participate in society. At the same time, their immediate surroundings will be unburdened and the people close to them will have to make less sacrifices concerning their work, living, and other activities associated with fully participating in society.<sup>103</sup>

These ambitions and their practical consequences still leave us, however, without a specific idea of the demands of human dignity. We still need an answer to the following question: what precisely constitutes the actionable minimum and ditto boundary of state involvement, beyond the preceding, rather vague and open-ended notion of more access? The capabilities approach, in the version of Martha Nussbaum may, perhaps, further concretize the aspirations of a liberalism of fear in this regard. The main gist of this approach is the proposition that the possibility to explore certain capabilities makes a life worthy of human dignity.<sup>104</sup> Following this proposition, we can determine our collective responsibility by compiling a list of such capabilities, whose absence requires the possibility to acquire institutional

99 Fineman, 'The Vulnerable Subject', 20; Fineman, 'The Vulnerable Subject and the Responsive State', 270-72; Fineman, 'Vulnerability and Inevitable Inequality', 147-49.

100 Nussbaum, *Frontiers of Justice*, 1, 212; Tronto, *Caring Democracy*, 139-40.

101 *Ibid.*, 154

102 Peter Rabins, Constantine Lyketsos and Cynthia Steele, *Practical Dementia Care* (Oxford: Oxford University Press, 2006), xiv

103 *Ibid.*, 78; Alistair Burns and Philippe Robert, *Dementia Care: International Perspectives* (Oxford: Oxford University Press, 2019), ix.

104 Nussbaum, 'Human Functioning and Social Justice', 205; Nussbaum, *Frontiers of Justice*, 169-173.

assistance. Such a list of capabilities would in any case, according to Nussbaum, contain capabilities relevant to disability and public health. Examples encompass a relative painless existence and social relationships with a modicum of equality – including, presumably, those relationships between the impaired and their immediate surroundings.<sup>105</sup>

The minimum of these capabilities that citizens should reasonably expect to be able to explore during their lifetime, are to be formulated as individual rights, which are ideally determined through the political process.<sup>106</sup> Human rights treaties, such as the ICESCR and the CRPD, which are signed and ratified by the political representatives of their respective states, naturally fill such a role. By determining the minimum of our extended collective responsibility through individual rights, we also curtail state involvement. Because the access to care, as a guarantee if we lack certain capabilities – for example through impairment – remains a possibility and not an institutional imposition. Consequently, citizens always retain the possibility to acquire institutional assistance when they are impaired by manifestations of our universally shared vulnerability, but they cannot be coerced into a certain course of action.

By adopting the idea of an individual's capabilities as the minimum guarantee of our collective responsibility regarding a dignified life for each and every human being, a liberalism of fear thus avoids the dangers oftentimes associated with other concretizations of vulnerability theory: paternalistic policies and the return to a group-based approach. A lack of the capabilities associated with the current human rights catalogues will invariably entitle any individual to institutional assistance, but they can always choose not to entertain this option. Some complications would, of course, remain. An interesting dilemma is the manner in which the young and the mentally impaired should indicate the relevant problems – *i.e.* their manifested vulnerabilities – that interfere with their capabilities.<sup>107</sup> Such dilemmas, however, will often be better served with the greater extent of care and other assistance, as offered by a liberalism of fear, than less.<sup>108</sup> All in all, a liberalism of fear thus presents a guideline for practical reforms, which would provide the impaired and their immediate surroundings with the support they need, in order to fully enjoy their human rights in accordance with the CRPD.

105 *Ibid.*, 179-185.

106 Nussbaum, 'Human Functioning and Social Justice', 223; Nussbaum, *Frontiers of Justice*, 78; Rutger Claassen, 'Making Capability Lists: Philosophy versus Democracy', *Political Studies* 59 (2011): 491, 500. 502, 505; David Clark, 'Capability Approach', in *The Elgar Companion to Development Studies*, ed. David Clark (Cheltenham: Edward Elgar Publishing, 2006), 32.

107 Coggon, *What Makes Health Public?*, 220; Shirli Werner, 'Individuals with Intellectual Disabilities: A Review of the Literature on Decision-Making since the Convention on the Rights of People with Disabilities (CRPD)', *Public Health Reviews* 34 (2012): 3; Lesley Francis and Anita Silvers, 'Liberalism and Individual Scripted Ideas of the Good: Meeting the Challenge of Dependent Agency', *Social Theory and Practice* 33 (2007): 316-318, 332.

108 *Ibid.*, 331.

## 6. Concluding Remarks: A Feasible Future?

The benchmark provided by the goals and obligations of the CRPD, concerning the impaired and their (potential) caretakers, is more than a *fata morgana*. To facilitate full societal participation and independent life choices for the impaired, while unburdening their immediate surroundings, is possible within the tenets of liberalism and its practical elaborations – the rule of law and the *Rechtsstaat*. However, the generally important distinction between the thick and thin conceptions of these elaborations is, in this regard, less relevant than the contrast between the current anatomy of public health systems and the teleological alternative. In the foregoing I have argued that the amelioration of our universally shared vulnerability – preferably through fostering resilience – is a suitable goal with which we can adapt our ideas concerning public health and disability to the CRPD. The implementation of a liberalism of fear, the proposed reimagining of liberalism which would offer practical guidelines for such an adaptation, could be regarded – I think – as an important step towards a future which prioritizes our codified human rights and their underlying values for everyone: but especially for the impaired and their caretakers.

Is such an implementation feasible, however? I would contend that, by taking vulnerability as a leading value within public health systems in liberal states, the public support for such an expansion of our collective responsibility can be expected to grow in time.<sup>109</sup> People who are confronted with their embodied vulnerability will experience fewer consequences for their bodily situation and societal position, by means of the greater and more accessible institutional assistance. As such, they can be expected to support these changes. The same might ring true for those who were not yet able to outsource their own caring responsibilities.<sup>110</sup> Thus, when care – which is currently confined to certain exceptions – does become a visible, accessible, and pervasive part of our daily world, can we anticipate that the support thereof will constitute a societal obligation of which everybody sees the benefits.

The label of a liberalism of fear may sound a tad morbid. But by alleviating two of the most impactful hardships of our human existence – impairment and care for a loved one – people will become enticed by the idea of a future enclosed within the values underlying the modern human rights discourse: the liberty, equality, and dignity of every human being. Because, without health, liberty is just an empty phrase. And without health, equality can hardly be expected to be substantive. It is thus access to care and the accompanying independence which accounts in large measure for a dignified and fearless life.

109 Nussbaum, *Frontiers of Justice*, 157-159; Martha Nussbaum, *Sex and Social Justice*, (New York: Oxford University Press, 1999), 65.

110 Tronto, *Caring Democracy*, 98-113.