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# On the Anxiety of Decisions and Supported Decision-Making: A Critical Reflection on the Right to Equal Recognition Before the Law for Persons with Disabilities

“Freedom’s possibility announces itself in anxiety.”

*Søren Kierkegaard, The Concept of Anxiety*

## To be, or not to be: that is the question

Equal recognition before the law – the right for persons with disabilities to be recognized and respected as *persons with legal capacity on an equal basis with others* – is one of the most discussed topics in contemporary disability rights discourse. Assuming that equality before the law is “a basic general principle of human rights protection and is indispensable for the exercise of other human rights”,<sup>1</sup> Article 12 of the UN Convention on the Rights of Persons with Disabilities (the CRPD) demands that States’ parties “reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law” (12:1) and “shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (12:2).

<sup>1</sup> General Comment No 1 (2014) Article 12: Equal recognition before the law, CRPD/C/GC/1, Committee on the Rights of Persons with Disabilities, p. 1.

The right to equal recognition before the law has no exceptions, not even for persons who lack the abilities needed to make legally valid decisions.<sup>2</sup> A person with disability must never be denied legal capacity *because of his or her disability*.<sup>3</sup> However, depending on the disability in question, this is sometimes difficult to uphold, especially for those with intellectual, cognitive and/or psychosocial disabilities. Normally, if a person lacks the abilities needed to understand and to make a rational decision, the decision is not legally valid; “the question of whether or not each individual’s decision will actually be respected is dependent on whether she meets the legal standard for capacity in respect of the decision in question”.<sup>4</sup>

The response to this problem in the context of the CRPD is *supported decision-making* (CRPD Article 12:3). States’ parties shall provide access to support in the exercise of legal capacity. Such support can vary in form, but “must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making”.<sup>5</sup> This statement raises, along with many others, the question of *how* support must be arranged to guarantee that the supported person’s will and preferences are truly respected, and, as follows from the CRPD Article 12:4, that the support is exercised “free of conflict of interest and undue influence”. However interesting this question might be, there are also other, more profound problems to discuss in the context of supported decision-making.<sup>6</sup>

<sup>2</sup> CRPD/C/GC/1 p. 5.

<sup>3</sup> A. Bruce, *Which Entitlements and for Whom? The Convention on the Rights of Persons with Disabilities and its Ideological Antecedents* (Lund, 2014) p. 174 ff; A. Nilsson, *Minding Equality. Compulsory Mental Health Interventions and the CRPD* (Lund, 2017) p. 151 ff. As both Bruce and Nilsson point out, the negotiating parties behind the CRPD were, of course, aware of the difficulties that can arise from this, for example, in relation to mentally ill persons in need of coercive care, but the final text does not reflect the discussions on this matter. See also Yana Litin’ska, *Assessing capacity to decide on medical treatment. On human rights and the use of medical knowledge in the laws of England, Russia and Sweden* (Uppsala, 2018) p. 122 ff.

<sup>4</sup> M. Donnelly, *Healthcare Decision-Making and the Law. Autonomy, Capacity and the Limits of Liberalism* (Cambridge, 2010) p. 2.

<sup>5</sup> General Comment No 1 (2014) Article 12: Equal recognition before the law, CRPD/C/GC/1, Committee on the Rights of Persons with Disabilities, p. 17.

<sup>6</sup> My co-researcher, Linus Broström, and I are currently investigating these questions for a law and ethics project, financed by Ragnar Söderbergs Stiftelse. This article is written as part of that project, which addresses questions regarding supported consent from persons

When recently reading Adam Gearey's thought-provoking book, *Poverty Law and Legal Activism*, some of the themes raised by Gearey struck me as relevant to address in relation to disability and equality before the law – although the problems, and also my theoretical framework for understanding them, are somewhat different.<sup>7</sup> As Gearey clearly shows, *alienation, anxiety, and difficulties of "being with"*, in the sense of truly meeting and understanding "the other", are relevant themes in poverty law, and it is not difficult to see that this is also the case in disability law, and especially so in the context of supported decision-making. A person with disabilities who needs support to make decisions might, like a poor person in a rich man's world, feel alienated in a society that presupposes human abilities he or she lacks.<sup>8</sup> A person entrusted to support someone in the disabled person's decision-making might, like a poverty lawyer, also face alienation, anxiety and difficulties of "being with".<sup>9</sup>

The theme I will develop here, though, is neither alienation nor difficulties of "being with" but, rather, *anxiety*.<sup>10</sup> Turning to the thinking of Nietzsche and Kierkegaard, and assuming that decision-making is an individual issue of freedom of choice and anxiety, I will argue that anxiety is an important missing piece in the context of disability law and supported decision-making. Freedom of choice comes with anxiety, as two sides of the same coin. You cannot have one without the other. However, in disability rights discourse which focuses on autonomy, equality and inclusion, the perspective of anxiety as an inescapable aspect of freedom of choice seems to be completely absent. When flipping the coin of freedom and taking a closer look at anxiety, interesting things are revealed that might call for changes in the way we think about equal recognition before the law and supported decision-making.

with intellectual, cognitive and/or psychosocial disabilities, and the ways in which support can be arranged to guarantee equality before the law in the CRPD sense.

<sup>7</sup> A. Gearey, *Poverty Law and Legal Activism. Lives that Slide Out of View*. (New York, 2018).

<sup>8</sup> As McRuer puts it: "Able-bodiedness [...] still largely masquerades as a nonidentity, as the natural order of things". R. McRuer, *Crip Theory. Cultural Signs of Queerness and Disability*. (New York, 2006) p. 1.

<sup>9</sup> A. Gearey, *Poverty Law and Legal Activism. Lives that Slide Out of View*. (New York, 2018) p. 95–129.

<sup>10</sup> I have, in fact, experienced some anxiety of my own, wondering why I may be wasting my time in academia, when I could be out in the real world facing and hopefully helping real people with real problems. Gearey's writing that "one's actions in the world are definitional of the self" (p. 124) had a great impact on me.

Anxiety works on different levels in the context of supported decision-making; it has a bearing not only on ethical questions and questions of identity, but also on questions regarding the legal subject *per se*. In the everyday meaning of the word, it is easy to understand that anxiety might be experienced at the surface level of supported decision-making, as this is an emotion often experienced when we face situations which are hard to handle. As already mentioned, to comply with the CRPD, supported decision-making must respect the rights, will and preferences of the person in need of support. How to fulfil this in practice is an ethical question that might cause a supporting person to feel anxiety. This, however, is a small problem. As will be further discussed later in this text, bigger problems in connection with supported decision-making concern anxiety in connection to legal capacity, agency, and freedom of choice.

Equality before the law presupposes recognition as a legal subject with legal capacity. In the context of the CRPD, legal capacity is viewed as

“an inherent right accorded to all people, including persons with disabilities. It consists of two strands. The first is legal standing to hold rights and to be recognized as a legal person before the law. [...] The second is legal agency to act on those rights and to have those actions recognized by the law.”<sup>11</sup>

Clearly, legal agency is important and necessary for access to justice in a broad sense.<sup>12</sup> However, it must be noted that legal agency has two sides: The upside being equal recognition before the law and freedom, and the downside being responsibility, potentially negative outcomes of free decisions – and anxiety. Bearing this in mind, one can argue that recognition as a legal agent, with rights but also duties on an equal basis with others, might not always be a preferred position for everyone. So, why is that the assumption in the CRPD?

I suggest that part of the answer to this question is deeply embedded in our cultural understanding of what it means to be a human being. *To be or not to be* a human – and therefore an equal person before the law – is a question of freedom and anxiety, and the choices we make. In further

<sup>11</sup> CRPD/C/GC1 p. 14.

<sup>12</sup> Legal capacity (Article 12) and access to justice (Article 13) are closely connected, as pointed out in P. Weller, ‘Legal Capacity and Access to Justice: The Right to Participation in the CRPD’, in A. Arstein-Kerslake (ed.) *Disability Human Rights Law*. (Printed Edition of the Special Issue Published in *Laws* 2016), p. 43–53.

explaining this statement, I will turn first to history and the way persons with disabilities have been treated in the past, then to the thinking of Friedrich Nietzsche and Søren Kierkegaard.

## Though this be madness, yet there is method in it

The CRPD, effective since 2006, must be understood in light of history. In the past, persons with disabilities – especially intellectual disabilities – were excluded from society and treated inhumanely in various ways. During most of the 20<sup>th</sup> century, many were forced into life-long “care” in institutions, where the living conditions were poor and differed extensively from normal everyday-life. They were often exploited, subject to hard labour and medical experimentation. Many were sterilized without consent, and denied rights on an equal basis with others, such as the right to marry and start a family.<sup>13</sup> They were declared legally incapable and therefore denied legal capacity, and under guardianship they were denied self-determination in almost all areas of life.<sup>14</sup>

Bearing this history in mind, it is no wonder that the right to equal recognition before the law is so strongly emphasized in the CRPD. Article 12 states the following:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

<sup>13</sup> Regarding these practices during the 20th century in the USA, see L. Carlson, *The Faces of Intellectual Disabilities. Philosophical Reflections* (Bloomington, 2010). Regarding the same in Sweden, see T. Fridström Montoya, *Leva som andra genom ställföreträdare – en rättslig och faktisk paradox* (Uppsala, 2015); K. Grunewald, *Från idiot till medborgare* (Stockholm, 2008).

<sup>14</sup> About the development of Swedish law regarding guardianship (förmyndarskap) into two different forms of legal representation, called “the good man” and “the administrator” during the 20th century, see T. Fridström Montoya, *Leva som andra genom ställföreträdare – en rättslig och faktisk paradox* (Uppsala, 2015) p. 269–293, see also T. Fridström Montoya, “Supported Decision-Making in Swedish Law – Is the ‘Good Man’ a Good or Bad Guy in Light of the CRPD?”, which is the English version of “Unterstützte Entscheidungsfindung im schwedischen Recht – der ‘Gute Mann’: Held oder Schurke im Licht der UN-BRK?”, in M. Zinkler, C. Mahlke, R. Marschner (Eds.) *Selbstbestimmung und Solidarität Unterstützte Entscheidungsfindungen in der psychiatrischen Praxis* (Köln, 2019) p. 222–232.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

In May 2014, following interactive forums with various interested parties, the Committee on the Rights of Persons with Disabilities issued a general comment for the interpretation of Article 12.<sup>15</sup> The Committee explains that Article 12 must be interpreted in light of the general principles of the CRPD,<sup>16</sup> which are outlined in Article 3: Respect for inherent dignity; individual autonomy including the freedom to make one's own choices; independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; respect for evolving capacities of children with disabilities; and respect for the rights of children with disabilities to reserve their identities. These principles speak a clear language of individuality, autonomy and inclusion.

In line with the general principles, it follows from Article 12 that everyone has a right to legal capacity in two meanings – to be recognized

<sup>15</sup> According to the CRPD/C/GC/1, p. 2, the Committee interacted with States' parties, disabled persons' organizations, non-governmental organizations, treaty monitoring bodies, national human rights institutions and UN agencies.

<sup>16</sup> CRPD/C/GC/1, p. 4.

and respected as a *person* as well as an *actor* before the law. States parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life (CRPD 12:2), meaning that they shall be recognized as agents with “the power to engage in transactions and create, modify or end legal relationships”.<sup>17</sup> In situations where an individual, due to disability, lacks the abilities needed to make legally valid decisions and/or to engage in legal actions, States parties have an obligation to provide access to support in the exercise of legal capacity (CRPD 12:3).

Even though it is widely held that the CRPD does not give persons with disabilities any additional rights, and that Article 12 “simply describes the specific elements that States parties are required to take into account to ensure the right to equality before the law for people with disabilities, on an equal basis with others”,<sup>18</sup> Article 12 is held to represent a *paradigm-shift*.<sup>19</sup> Practices of *substituted decision-making* are to be replaced by *supported decision-making*. States parties “must refrain from denying persons with disabilities their legal capacity and must, rather, provide persons with disabilities access to the support needed to enable them to make decisions that have legal effect.”<sup>20</sup> This means that different kinds of guardianship, where a person’s right to make decisions are substituted, are not compliant with the CRPD. And, as already stated, support in the exercise of legal capacity “must respect the rights, will and preferences of persons with disabilities and should never amount to substituted decision-making”.<sup>21</sup>

All very good, if you agree that autonomy and self-determination are worthy goals in every situation. In light of history, this position in the CRPD is understandable. Persons with disabilities have hardly been treated as human beings in the past, and they have been deprived of

<sup>17</sup> CRPD/C/GC/1, p. 12.

<sup>18</sup> CRPD/C/GC/1, p. 1.

<sup>19</sup> P. Bartlett, “Supported Decision-Making in English Legislation” p. 9, the English version of “Unterstützte Entscheidungsfindung in der englischen Rechtsprechung”, in M. Zinkler, C. Mahlke, R. Marschner (Eds.) *Selbstbestimmung und Solidarität Unterstützte Entscheidungsfindungen in der psychiatrischen Praxis* (Köln, 2019) p. 206–221; M. Bach & L. Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity. Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice* (Commissioned by the Law Commission of Ontario, 2010).

<sup>20</sup> CRPD/C/GC/1, p. 16.

<sup>21</sup> CRPD/C/GC/1, p. 17.

human dignity and self-determination. However, even if it is a desirable shift to move away from systems based on mental capacity and on the appointment of formal guardians making best-interest decisions on behalf of persons with disabilities, there are also some problems that need to be addressed in this new paradigm.

## Something is rotten in the state of [the CRPD]

One unanswered question concerning Article 12 and supported decision-making is whether equal recognition before the law “in all areas of life” can ever be fully achieved through supported decision-making; or, in other words, whether supported decision-making really is the gamechanger that it is held out to be. It is hard to envision how every kind of decision can be legally valid if they have been supported. For example, can supported decision-making ensure that all persons with intellectual, cognitive and/or psychosocial disabilities are able to enter into marriage?

According to Article 23 of the CRPD, it is a right “for all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses”. It is noteworthy here that Article 23 includes *all* persons with disabilities, at the same time as the requirement is a *free and full consent*. But what if a person’s disability affects precisely the abilities needed to be able to give a free and full consent – can support always help in that situation? This is an unanswered question. There is no specification on how “free and full consent” in Article 23 is to be understood.<sup>22</sup> It must also be noted that how, and to what extent, a person’s disability affects his or her abilities in a specific situation varies greatly from person to person, depending on the severity of the impairment. It is impossible to draw conclusions about the ability of an individual simply because someone has a certain impairment or illness. To what extent support is needed – and for what exactly – is also unclear.

What instead *is* clear, is that something more is needed for a legally valid consent than merely a statement from the intended spouse that he

<sup>22</sup> A. Nilsson, *Minding Equality. Compulsory Mental Health Interventions and the CRPD* (Lund, 2017) p. 63, footnote 176.



or she agrees to marriage.<sup>23</sup> In general, consent in a legal context means that someone rationally (not under the influence of drugs or a mental deviation) and freely (without manipulation or force from someone else) agrees to something that he and she can fully understand the consequences of.<sup>24</sup> Given this understanding of what constitutes a legally valid consent, it could in some cases be argued that if a person is supported into consenting to marriage, the consent does not, in fact, reflect that person's own rational and free will, and is therefore not legally valid.<sup>25</sup>

Of course, this argument depends on the meaning of legal demands for consent. Scholars have suggested that consent as a concept can be legally reframed from a disability perspective, with the consequence that "mental (in)capacity is no longer a relevant issue". Instead of demands for consent meaning to make sure that someone understands and agrees to something, they propose that demands for consent should "ensure that the consenting parties have freedom to negotiate and freedom to refuse, with active communication between parties to ascertain will and preferences and to demonstrate consent or refusal".<sup>26</sup> However, this view on the issue of consent from persons with intellectual, cognitive and/or psychosocial disabilities seems to miss parts of the problem. What about situations in which the person *de facto* lacks the abilities to "negotiate and to refuse" and to "communicate actively"? Is supported decision-making the solution in these situations?

<sup>23</sup> In Swedish Family Law, the requirement is that the intended spouse must consent to marriage, and the consent must be free. Regarding this, Agell and Brattström write that even if persons with severe mental disorders are no longer prohibited by law to marry (before 1973 they were), they cannot enter into marriage because they lack the legal capacity that is required; there must be an understanding to some extent of what a marriage means. A. Agell & M. Brattström. *Äktenskap Samboende Partnerskap* (Uppsala, 2011) p. 31.

<sup>24</sup> Regarding consent in different legal contexts in Swedish law, see for example, E. Rynning, *Samtycke till medicinsk vård och behandling* (Uppsala, 1994) p. 168 ff.

<sup>25</sup> In this specific area of law, it is interesting to note that in Swedish law, legal representatives such as the "good man" (god man), the "administrator" (förvaltare) and the "framtidshavare" are prohibited by law to represent someone in strictly personal matters ("frågor av utpräglat personlig karaktär"), such as entering into marriage. See the Parents and Children Code (1949:381), Chapter 12, § 2, section 3 and the Act (2017:310) regarding future power of attorney, § 2, section 2.

<sup>26</sup> L. Brosnan & E. Flynn, *Freedom to negotiate: a proposal extricating 'capacity' from 'consent'*, *International Journal of Law in Context*, 13, 1 p. 73.

In addition, a number of challenges arise from the demand that support in the exercise of legal capacity *must respect the rights, will and preferences* of persons with disabilities.<sup>27</sup> First, it can be noted that truly knowing the will and preferences of someone else is always a difficulty – and especially so if the person in need of support, due to his or her disability, understands and views the world in a different way than the person providing support. Communication is about interpretation and understanding, and the risk of getting lost in translation increases if the persons involved have different understandings of the world. Also, how can it be guaranteed that a supported decision is the deciding person's own decision, and not the result of manipulation or undue influence from the person providing the support? Second, there is the problem of knowing whether what someone expresses as his or her will is actually their own will, and not a statement reflecting a wish to please someone else whom the person with the disability is dependent on. If you are dependent on others, it is often a wise strategy to try to please them. This fact needs special attention, since dependency on others is a reality for many persons with disabilities. This is, at least, something to note if the aim is self-determination in a true sense.

On top of these problems, concerns can also be raised in relation to the expressed will itself. Is every sort of will expressed by a person with a disability to be supported into a legal decision, even if it is perceived to be a “bad” decision, in the sense that it can, or clearly will, harm the supported person – or someone else, close to the person with the disability?<sup>28</sup> Whose responsibility is the outcome of such decisions? One also wonders if the possibility of receiving support in order to be able to make decisions in all areas of life means that there is an expectation or even an obligation for persons with disabilities to do so? As anyone who has agonized over an important decision knows, freedom of choice is not only and always something enjoyable. For some individuals, however, free will can be directly harmful. Consider, for instance, a person with an intellec-

<sup>27</sup> CRPD/C/GC/1, p. 17.

<sup>28</sup> In the context of decisions concerning medical treatment, the answer to this question is no. The law does not support all kinds of decisions. As Donnelly points out, the right to refuse medical treatment is limited by four interests: the preservation of life, the protection of the interests of innocent third parties, the prevention of suicide and the maintenance of the ethical integrity of the medical profession. M. Donnelly, *Healthcare Decision-Making and the Law. Autonomy, Capacity and the Limits of Liberalism* (New York, 2010) p. 66.

tual disability who does not understand that he or she is manipulated or persuaded into giving away property but truly believes it to be his or her own decision, or a person who, under the influence of a mental illness, is convinced that she will die tomorrow and therefore spends all her lifesavings today. And think about the fact that the right to self-determination not only means being able to decide what you want, but also what you *don't* want, which might, for example, result in your refusal of help that is crucial for your health.

There is a clear conflict in law between the right to autonomy and the aim to protect vulnerable individuals. The human rights perspective on this conflict seems to be that States must primarily protect “the right of individuals to choose and pursue their own life path, and all the decisions that entails along the way”<sup>29</sup> – even if this means that individuals are harmed in the process. In the context of the CRPD, legal capacity is viewed as so important that it is described as “an inherent human right”.<sup>30</sup> How can this uncompromising stand on legal capacity be understood? To answer this, I think it is necessary to take a closer look at the legal person and the legal person’s presumed abilities – in other words, what constitutes a legal person.

## ...that is the question: Whether it is nobler in the mind to suffer

All human beings are *legal persons*, and human rights, as well as law in general, apply to *humans* exclusively.<sup>31</sup> Given this, it matters where we draw the line between humans and other beings – the underlying question being *who is law for?*

Quite surprisingly, given its importance and foundational character, this question is not easy to answer. In her book, *Law’s meaning of life*, Ngaire Naffine sought to “find out about legal persons and the systems of belief that bring them into being” in the common law Anglophone world. In so doing, she encountered the problem that the law of persons

<sup>29</sup> M. Bach & L. Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity. Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice* (Commissioned by the Law Commission of Ontario, 2010) p. 6.

<sup>30</sup> CRPD/C/GC/1, p. 14.

<sup>31</sup> However, law also applies to companies and other associations.

“is not a discrete field of study in the common law world, such as torts, or contract or criminal law, but a pervasive underlying concept throughout the different branches of law”.<sup>32</sup> Naffine points to the fact that “the entire topic of persons in law, of who and what can and should bear rights and duties, is very slippery because there is so little carefully considered reflection in legal judgements and treatises and yet it is utterly fundamental to legal thought”.<sup>33</sup> (After undertaking a similar project a few years ago, I might add that the same can be said regarding the legal person in Swedish Law.<sup>34</sup>)

Naffine summarizes her findings by suggesting that the idea of what constitutes a legal person is quite different, depending on four meta-physical approaches or world views: Legalism, Rationalism, Religionism and Naturalism. The Legalists<sup>35</sup> believe that law has its own constructed person who should not be confused with real human beings; the Rationalists<sup>36</sup> put human reason to the fore and “are convinced that it is reason which most defines and dignifies us and which law should reflect and preserve”<sup>37</sup>; the Religionists<sup>38</sup> insist that law must respect human sanctity, dignity and integrity; whilst the Naturalists<sup>39</sup> see humans as natural, evolved, biological creatures, not very different from other animals and therefore not entitled to the legal exceptional status that we have over

<sup>32</sup> N. Naffine, *Law's Meaning of life. Philosophy, Religion, Darwin and the Legal Person* (Portland, 2009), p. 14–15.

<sup>33</sup> N. Naffine, *Law's Meaning of life. Philosophy, Religion, Darwin and the Legal Person* (Portland, 2009), p. 9.

<sup>34</sup> T. Fridström Montoya, *Homo juridicus. Den kapabla människan i rätten* (Uppsala, 2017).

<sup>35</sup> Examples of Legalists being Hans Kelsen and HLA Hart, see N. Naffine, *Law's Meaning of life. Philosophy, Religion, Darwin and the Legal Person* (Portland, 2009), p. 33–43.

<sup>36</sup> Examples of Rationalists being Ronald Dworkin and Dena Davies, see N. Naffine, *Law's Meaning of life. Philosophy, Religion, Darwin and the Legal Person* (Portland, 2009), p. 81–98.

<sup>37</sup> N. Naffine, *Law's Meaning of life. Philosophy, Religion, Darwin and the Legal Person* (Portland, 2009), p. 22.

<sup>38</sup> Examples of Religionists being Eleanor Roosevelt and John Finnis, see N. Naffine, *Law's Meaning of life. Philosophy, Religion, Darwin and the Legal Person* (Portland, 2009), p. 99–117.

<sup>39</sup> Examples of Naturalists being Peter Singer, Steven Wise and Gary Francione, see N. Naffine, *Law's Meaning of life. Philosophy, Religion, Darwin and the Legal Person* (Portland, 2009), p. 127–142.

animals.<sup>40</sup> Those who take a strong stand on any one of these views tend to communicate poorly with those holding different views when it comes to the meaning of law and what it should reflect.<sup>41</sup>

Perhaps most of us have not given much, if any, thought to the question of what constitutes a legal person, nor that there are different views on this reflected in law. However, the different approaches to what constitutes a legal person result in quite different outcomes of legal dilemmas and therefore merit our attention and reflection. Given the fact that the legal personality and its ensuing rights are not something natural and eternal, but vary with time and place, the question of what constitutes a legal person truly matters. This is especially so in disability law, since legal status in the past has varied greatly, not only between free persons and slaves, and between men and women, but also between persons fully capable and persons with disabilities.<sup>42</sup>

In the context of legal personality being unstable, it should be noted that the concept itself is a modern baby, born in the 19<sup>th</sup> century.<sup>43</sup> During this time, western societies changed in ways that placed the free individual at the centre of law. To flourish, industrialization and capitalism required that individuals strove to gain capital to maximize their own well-being.<sup>44</sup> Drawing on Foucault's theories on normalization and governmentality, Samuli Hurri explains that, during this period of time, the human being (a man, mostly) was perceived primarily as a competitive creature, driven by egoistic desires of various sorts. These desires were a precondition for the spinning of the economic wheels and therefore important to endorse, but at the same time it was thought that these should be controlled through law; law was needed to contain the desires that are man's "rational reality".<sup>45</sup> Hence, a "fundamental difference between the

<sup>40</sup> N. Naffine, *Law's Meaning of life. Philosophy, Religion, Darwin and the Legal Person* (Portland, 2009), p. 20–21.

<sup>41</sup> N. Naffine, *Law's Meaning of life. Philosophy, Religion, Darwin and the Legal Person* (Portland, 2009) p. 167.

<sup>42</sup> A. Supiot, *Homo Juridicus. On the Anthropological Function of the Law* (London, 2007) p. 22; Wijffels, "Legal Capacity in Historical Perspective", in S. Deakin and A. Supiot (eds.) *Capacitas. Contract Law and the Institutional Preconditions of a Market Economy* (Oxford, 2009, p. 56 ff; T. Spaak, *The Concept of Legal Competence* (Suffolk, 1994) p. 12.

<sup>43</sup> H. Gustafsson, *Dissens* (Göteborg, 2011) p. 129.

<sup>44</sup> B. Wennström, *Rättens individualisering. Mot en ny juridisk antropologi* (Uppsala, 2005) p. 9; C. Sandgren, *Utvecklingstendenser inom avtalsrätten* (Stockholm, 1993) p. 115.

<sup>45</sup> S. Hurri, *Birth of the European Individual. Law, Security, Economy*. (New York, 2014), p. 49–60.

theory of subject of the law and theory of subject of liberal economics lies in the way they relate with desire. The one says 'no' to desire, the other says 'yes'."<sup>46</sup> According to Hurri, both the *homo juridicus*, the juridical individual, and the *homo æconomicus*, the economic actor on the free market, sprung from the idea of the social contract; both the *homo juridicus* and the *homo æconomicus* were seen as free, competitive and self-interested beings driven by their desires, but responsible for their actions and subjugated to the social contract to avoid chaos.<sup>47</sup>

As Nietzsche has pointed out though, the doctrine of free will, along with the notion of responsibility that comes with it, is a much older invention than the legal subject and has served several ends – the most important one being the *making* of the human being into the *promising, conscientious* being we believe ourselves to be.<sup>48</sup> And this free, sovereign man, Nietzsche remarks, is made *genuinely calculable* because:

"the proud knowledge of the extraordinary privilege of *responsibility*, the consciousness of his rare freedom, of his power over himself and over fate, has sunk right down to his innermost depths, and has become an instinct, a dominating instinct – what name will he give to it, to this dominating instinct, if he needs to have a word for it? But there is no doubt about it – the sovereign man calls it his *conscience*."<sup>49</sup>

When reflecting on decision-making and legal capacity, it is almost impossible to avoid the notion of free will and responsibility. Much can, and has, been said about the idea of man's free will. Today, some might argue that there really is no such thing, that humans are simply biological creatures reacting to chemical impulses in the brain that are beyond our conscious control. Others might argue that we are not as rational as we believe ourselves to be – that the thought processes in the brain work quite differently than we have previously understood.<sup>50</sup> Regardless of objections such as these, the idea of man's free will is deeply rooted in our civilization and in law. Free will is central in law; consider, for instance, legal demands for free and full consent in different situations, or the free

<sup>46</sup> S. Hurri, *Birth of the European Individual. Law, Security, Economy*. (New York, 2014) p. 55.

<sup>47</sup> S. Hurri, *Birth of the European Individual. Law, Security, Economy*. (New York, 2014) p. 49.

<sup>48</sup> F. Nietzsche, *The Genealogy of Morals* (New York, 2003).

<sup>49</sup> F. Nietzsche, *The Genealogy of Morals*, p. 36.

<sup>50</sup> D. Kahneman, *Thinking, Fast and Slow* (New York, 2011).

entering into a contract as a prerequisite for the validity of the contract. Consider, too, that if someone has committed a criminal act, it matters for the question of responsibility and punishment if the wrongdoer understood what he or she was doing and could foresee the consequences of the act, but (freely) chose to act anyway.

There seems to be an underlying assumption, at least in Swedish law, that legally capable persons need to not only understand what they are doing in a rational/practical sense, but also in a qualitative sense that can be described as a *moral ability*. If a person lacks the ability to make moral, responsible judgements, his or her actions will not render the normal legal consequences. This is explicitly evident in certain situations in which children are denied legal capacity, but the same idea is also evident in certain legal rules,<sup>51</sup> in reasonings in preparatory works and in court cases in relation to adults with disabilities or illnesses.<sup>52</sup> In considering the notion of free will and responsibility in connection with the right for persons with disabilities to be equally recognized as persons with legal capacity, it is now time to turn to the concept of anxiety.

In his mid-19<sup>th</sup> century essay, *The Concept of Anxiety*,<sup>53</sup> Søren Kierkegaard explored the Genesis story and the Fall of Adam and Eve “in such a way as to have in mind and view the dogma of hereditary sin”.<sup>54</sup> According to Kierkegaard, what constitutes a human being is the freedom of choice and the anxiety that accompanies it; our ability to experience anxiety is what makes humans different from animals. “That there are some who notice no anxiety at all may be understood in the way Adam would have experienced none had he simply been an animal.”<sup>55</sup> As Kierkegaard points out, freedom announces itself in anxiety, “anxiety

<sup>51</sup> See for instance the Act (1924:323) regarding the effect of contracts entered into under the influence of a psychological disorder.

<sup>52</sup> T. Fridström Montoya, *Homo juridicus. Den kapabla människan i rätten* (Uppsala, 2017).

<sup>53</sup> However, like many of Kierkegaard's works, the essay was published under pseudonym, in this case, “Vigilius Haufniensis”.

<sup>54</sup> S. Kierkegaard, *The Concept of Anxiety. A simple Psychologically Oriented Deliberation in View of the Dogmatic Problem of Hereditary Sin* (New York, 2014) Edited and translated by Alastair Hannay, p. 19.

<sup>55</sup> S. Kierkegaard, *The Concept of Anxiety. A simple Psychologically Oriented Deliberation in View of the Dogmatic Problem of Hereditary Sin* (New York, 2014) Edited and translated by Alastair Hannay, p. 65.

is freedom's actuality as the possibility of possibility".<sup>56</sup> The possibility, however, is not the ability to choose the good or the evil.

"The possibility is to *be able*. It is simple enough in a logical system to say that possibility passes over into actuality. In actuality itself it is less easy and an intermediate term is required. This intermediate term is anxiety, which no more explains the qualitative leap than it can justify it ethically. Anxiety is not a category of necessity, but neither is it a category of freedom; it is a hobbled freedom where freedom is not free in itself but tethered, not in necessity but in itself. If sin has entered the world by necessity (which is a contradiction) there can be no anxiety. If sin has entered through an abstract *liberum arbitrium* [free will] (which existed no more in the world in the beginning than it did later, since it is a conceptual monstrosity), then there is no anxiety either."<sup>57</sup>

Combining the thinking of Kierkegaard and Nietzsche, one could say that it indeed seems "nobler in the mind to suffer",<sup>58</sup> meaning that what is expected from the human being – and the legal person – is the ability to experience the anxiety that freedom entails. Anxiety is what makes us human, and the anxiety is what makes us calculable in a legal system as conscientious, responsible creatures. Not only are we expected to be able to decide what we do or do not want, but we are also expected to experience anxiety – to dwell on the options and consequences of our decisions and actions.

Returning to the thinking of Naffine, the four metaphysical approaches to determining what constitutes a legal person that she identified seem to have one trait in common: the idea of the human being as something exceptional.<sup>59</sup> Regardless of whether the foundation rests on our reason, our sanctity, or our evolved state compared to other animals, law has *de facto* constructed a legal person and has endowed the human being –

<sup>56</sup> S. Kierkegaard, *The Concept of Anxiety. A simple Psychologically Oriented Deliberation in View of the Dogmatic Problem of Hereditary Sin* (New York, 2014) Edited and translated by Alastair Hannay, p. 51.

<sup>57</sup> S. Kierkegaard, *The Concept of Anxiety. A simple Psychologically Oriented Deliberation in View of the Dogmatic Problem of Hereditary Sin* (New York, 2014) Edited and translated by Alastair Hannay, p. 60.

<sup>58</sup> When gathering my thoughts for this article, I found it irresistible to use quotes from Shakespeare's Hamlet – one of the most well-known anxiety-driven figures in Western culture – as headings for the different themes.

<sup>59</sup> Even though the Naturalists oppose the idea that law and rights cannot extend to other sentient beings, able to suffer and to experience in a similar way as humans.



but no other sentient beings – the status as its subject. And law serves purposes based on assumptions about its subjects, for example, that the human being has certain abilities and shares certain desires – such as the will to be a free, sovereign, autonomous being who makes decisions for him- or herself. This, I believe, is *the dogma of legal personality*. However, there appears to be an underlying, but unspoken, assumption that this self-determining human being has *moral ability*. And this assumption seems to be overlooked in the context of equal recognition before the law for persons with disabilities and supported decision-making.

## The rest, is silence

Assuming that the dogma of legal personality is that autonomy is a human desire, it is understandable why legal agency is held to be something unnegotiable for persons with disability, despite the potential downsides of legal capacity. As Bach and Kerzner put it: “The ability to make one’s own decisions based on personal values and in the context of meaningful choices is a defining feature of what it means to be a person and a full citizen”.<sup>60</sup> If the belief is that we all seek self-determination, if only given the opportunity, it seems almost unthinkable in the context of human rights to deny persons with disabilities the support needed to be able to exercise and enjoy legal capacity like everyone else, however unenjoyable this exercising might be in reality.<sup>61</sup>

Also, for those of us who today possess the abilities to make rational, responsible decisions, it is an agonizing thought that we might, one day, lose that capacity. Being aware that our present abilities might change in the future due to, for example, illness or trauma, but being unable to imagine that we would not still wish to exercise self-determination, supported decision-making seems like a good idea – especially as there is also a deeper fear to be acknowledged here. If what makes us humans in the eyes of culture and law is the ability to make decisions then we

<sup>60</sup> M. Bach & L. Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity. Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice* (Commissioned by the Law Commission of Ontario, 2010) p. 6.

<sup>61</sup> For instance, statements like this are common in disability rights discourse: “From our standpoint [...] all adults are de facto legal agents competent to consent, and possess the necessary legal capacity to have their consent or refusal recognised in law.” L. Brosnan & E. Flynn, *Freedom to negotiate: a proposal extricating ‘capacity’ from ‘consent’*, *International Journal of Law in Context*, 13, 1 p. 61.

fear that if we lose these abilities, we will no longer really be humans and full participants in society. This is a reasonable fear, as it is precisely what persons with disability have experienced in the past. Consequently, supported decision-making for those not able to make decisions on their own is something which, in human rights discourse, is almost unthinkable *not* to endorse.

However, if what is expected from the legal person is the ability to not only make rational but also moral, conscientious and responsible decisions, it is not certain that supported decision-making will do the trick. Can support ever compensate for a lack of the abilities needed for decisions with a moral, conscientious kind of quality? Is self-determination something we are willing to support no matter what the decisions are? I am convinced that everyone wants to be recognized as a human and respected in their own right, regardless of diverse abilities, but I am not convinced that autonomy always should be guaranteed over protection.<sup>62</sup> Respect for self-determination must not be synonymous with leaving every kind of decision to every individual. On the contrary, it could be argued that it is *disrespectful* to deny persons the protection they need, and perhaps would ask for, had they not been made to believe that what constitutes a real human being is the desire to be sovereign and autonomous.<sup>63</sup>

Maybe the problem is not whether everyone, through support, can be enabled to make decisions. Maybe the dogma of legal personality is the problem. Questioning the dogma is, however, easier said than done, because this dogma is clearly expressed in the first article of the founding

<sup>62</sup> C. A. Riddle, *Human Rights, Disability and Capabilities* (New York, 2017) suggests that “the capabilities approach” of M. Nussbaum is the way to go if we are serious about making disability a question of justice. According to Riddle, the primary focus in disability rights discourse should be on health issues for persons with disabilities. Taking Nussbaum’s list of ten basic capabilities seriously, we need to analyze human rights in the light of individuals capabilities as “a cornerstone of basic justice” promoting equality, dignity and autonomy.

<sup>63</sup> There is a long tradition of neither asking nor listening to persons with intellectual disabilities. They have been treated as objects of knowledge, politics, care and so forth, but not as knowing subjects. See, for an investigation into Swedish history and living conditions for persons with intellectual disabilities, T. Fridström Montoya, *Leva som andra genom ställföreträdare – en rättslig och faktisk paradox* (Uppsala, 2015) p. 68–144. See, for an investigation into American history and living conditions for the same group, L. Carlson, *The Faces of Intellectual Disability. Philosophical Reflections* (Bloomington, 2010) p. 15 and p. 21–101.

document of human rights, Article 1 of the UN Universal Declaration of Human Rights:

“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.”

And, as Alain Supiot has put it: “[w]e all believe in the first article of the Universal Declaration of Human Rights, which states that human beings are born free and endowed with reason, and so we have difficulty admitting that reason and freedom are precarious constructions which have an institutional basis.”<sup>64</sup>

I believe the key word here is “admitting”. In order to *avoid* admitting that the dogma of legal personality might be problematic, we search for ways to make sure that everyone can fit the description, rather than reflecting on human diversity and the fact that many individuals do not fit the description of what constitutes a human being in Article 1. This is because in the context of human rights, human beings *are* free, reasonable and conscientious. It does not matter whether this is a true description of the human condition or not; this is the declaration that provides the foundation for all human rights treatises.

The question remains, however, of how to deal with the fact that, in reality, not all persons are “endowed with reason” and perhaps not with conscience either. Does this mean that they are not really human beings in the context of human rights, and that rights do not apply to them? It is doubtful that many people would agree to that, I for one do not, and the CRPD clearly states that all persons with disability shall be respected as persons before the law on an equal basis with others in all areas of life. But is there no other way to guarantee that respect than by offering them support to make sure they can meet the ableist-norm? Surely, the effect of thresholds for legal capacity, unreachable for some, is systematic exclusion. Exclusion sounds bad. But is it necessarily a bad thing that some persons are excluded from the legal consequences of decisions that might be harmful to them – or to others? From whose perspective is that a bad thing? Do we really not care about outcomes of decisions that might compromise other rights, such as the right to life or the right to health?

<sup>64</sup> A. Supiot, *Homo Juridicus. On the Anthropological Function of the Law* (London, 2007) p. 4.

Is the very possibility of making decisions, with support if necessary, *all* that matters?

This question leads us back to anxiety. Anxiety is an emotion, experienced by individuals. But perhaps anxiety can also be used to describe something that is akin to a cultural blindfold, at a cultural level. The dogma of legal personality is not merely a legal construction, but a reflection of a deeply rooted cultural understanding of what it means to be a human. To question this dogma, we need to put our understanding of what it means to be human to the test. It is only if we truly consider the fact that not many persons – if any – live up to the ideal of the rational, free and responsible agent, that we may find an alternative point of departure for thinking about equality before the law for everyone. However, in societies based on the liberal world view, it is a painful – agonizing – thought to admit that the understanding of what constitutes a human being in the eyes of law might be... wrong.<sup>65</sup> It is difficult to hear things we do not want to hear; it is difficult to hear things that shake the foundation of our thinking. Hence, *the rest, is silence*.

<sup>65</sup> This does not mean that there are no voices trying to point to this fact. To mention one, Martha Fineman has pointed out that the abstract legal subject of liberal western democracies must be questioned in discussions on equality, and has developed a theory based on human vulnerability. See for example, M. Fineman, *Vulnerability and Inevitable Inequality*, Oslo Law Review, Vol. 4, p. 133–149; M. Fineman, *Vulnerability and Social Justice*, 53 Val. U. L. Rev. 341 (2019).