

## A changing paradigm of protection of vulnerable adults and its implications for the Netherlands

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## 1. Introduction

With the phrase 'protection of adults', the Convention on the International Protection of Adults refers in article 1(1) to 'adults who, by reason of an impairment or insufficiency of their personal faculties, are not in a position to protect their interests'. The perception of how the interests of these vulnerable adults should be protected has changed over time. There has been a shift in the protection paradigm, from paternalism and a substitute decision-making approach to autonomy and a supportive decision-making human rights-based approach. In the framework of this shift, in addition to traditional adult guardianship measures, new instruments have been developed allowing adults to play a greater role in the protection of their (future) interests. This has also been the case in the Netherlands, where adults in the course of the last decade have acquired the possibility to make a so-called living will, internationally better known as a continuing, enduring or lasting power of attorney. The aim of this article is to discuss this instrument, in comparison with the traditional adult guardianship measures currently in force in the Netherlands, from the perspective of the new protection paradigm based on a human rights approach. To this end, in the following paragraph, we will try to delineate the historical context of the new protection paradigm and the human rights approach. Then in paragraph 3, we will focus on the influence of article 12 of the Convention on the Rights of Persons with Disabilities (UNCRPD) and the controversy around its implications for the protection paradigm.<sup>1</sup> In paragraph 4, we will provide an outline of the attempt to go beyond this controversy – the so-called alternate framework developed by Martin *et al.* In paragraph 5 we will elaborate on what kind of measures could meet the requirements of article 12 of the UNCRPD and what kind of safeguards should be incorporated therein. In paragraph 6, we will deal with the question whether the traditional adult guardianship measures in the Netherlands, based on substitute decision-making schemes, are compliant with the new protection paradigm. In paragraph 7, we will discuss the potential of the living will as an instrument of supportive decision-making. The conclusion will comprise some final remarks and suggestions for the future.

## 2. Historical context – embedding the new human rights based paradigm

In many jurisdictions the concept of 'capacity' is used to determine when and how

measures to protect the interests of adults with an intellectual impairment can be taken.<sup>2</sup> The term ‘capacity’ can be used in at least two different ways, both of which are used in the Netherlands. The term denotes either ‘legal’ capacity’ or ‘mental capacity’. The Committee on the Rights of Persons with Disabilities (the Committee) explains the difference between these two as follows: legal capacity involves ‘the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency)’, while mental capacity refers to ‘the decision-making skills of a person’.<sup>3</sup> Over time the scope and meaning of both these concepts have changed. In this regard three models can be distinguished. The first and second model together with an overview of their historical context will be discussed in the remainder of this paragraph. The emergence of the third model will be discussed in the next paragraph.

One of the first, if not the first, provisions aimed at the protection of an adult with an intellectual impairment can be found in Old Roman law. Table V of the Twelve Tables, drawn up around 450-451 BC, reads: *Si furiosus escit, adgnatum gentiliumque in eo pecuniaque eius potestas esto*.<sup>4</sup> Or in English: ‘a *furiosus* is placed under the guardianship of his family members with his person and money’.<sup>5</sup> Responsible for the guardianship of the *furiosus*, or incapacitated adult, was the *curator furiosi*, which was either the nearest relative in the male line or the nearest male relative from the wider family unit (*gentes*).<sup>6</sup> During the Roman era, in a timespan of almost a thousand years, the character of the *cura furiosi* was subject to change and the involvement of the State increased. Although in Old Roman law the main aim of the *cura furiosi* was to preserve the family fortune for the next generation, in Classical Roman law the interests of the individual became more important.<sup>7</sup> In Old Roman law there was no official procedure to confirm incapacity and the nearest male relative automatically became *curator furiosi*. This changed however, and in Classical Roman law a *curator furiosi* started to be appointed by the magistrate if the male relatives were not considered suitable.<sup>8</sup>

The Roman legal concept of the *cura furiosi* forms the basis of what can be described as the traditional model.<sup>9</sup> Within this model a status-based approach is used to determine whether a person has capacity. Once it is established that an individual has an intellectual impairment, a lack of legal capacity is consequently presumed.<sup>10</sup> This means that a binary approach is adopted; either a person has legal capacity or he has not, there is no area in between.<sup>11</sup> Another example of the status-based approach is the legal incapacity of married women, in the Netherlands in place as late as 1956. The incapacitated adult loses his legal capacity completely and a proxy or guardian is appointed to represent and protect the adult. This guardian is to act in the objectively presumed best interest of the incapacitated adult, the subjective wishes and preferences of the adult himself are considered less important.<sup>12</sup> Until the 1960s this model was prevailing in many West European countries.<sup>13</sup> These countries often had just one guardianship-like measure similar to the Roman *cura furiosi*.<sup>14</sup>

The development of human rights in general and patient’s rights in particular commenced after World War II, brought change.<sup>15</sup> The so-called ‘welfare model’ emerged and the status-based approach was replaced by a functional approach.<sup>16</sup> The Mental Capacity Act 2005 in force in England and Wales provides a good example of this approach.<sup>17</sup> Section two of the Mental Capacity Act makes clear that legal capacity is decision-specific, stating that ‘a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain’. Section three of the Act numerates the circumstances in which this is the case. In order to make a decision for himself a person must be able: ‘to understand the information relevant to the decision; to retain that information; to use or weigh that information as part of the process of making the decision, or to communicate his decision’.<sup>18</sup> In other words, legal incapacity is not automatically presumed upon an intellectual

impairment, instead the focus lies on the person's decision-making capabilities. As said, such an assessment should be carried out in relation to a particular decision. Inherent to the functional approach is that although a person may lack the mental capacity to make for example financial decisions, he may be perfectly able to make decisions on other topics. From this it then follows that protection measures need to be tailor-made, maximizing the autonomy of the adult and only offering protection where necessary.<sup>19</sup> As in the traditional status-based model, the welfare model presupposes that a guardian is appointed to represent and protect the adult. The difference is that in the welfare model the guardian has to take into account the wishes and preferences of the adult, even if they run contrary to what is considered to be in the adult's objective best interest.<sup>20</sup>

### 3. Article 12 UNCRPD: Two conflicting interpretations

The adoption of the Convention on the Rights of Persons with Disabilities by the United Nations General Assembly in 2006 marked, according to many, the emergence of a third, new human rights-based model or paradigm.<sup>21</sup> The key article in relation to capacity law is Article 12 UNCRPD, in particular the first four paragraphs, which read as follows:

'Equal recognition before the law

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.
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.<sup>22</sup>

According to Flynn and Arstein-Kerslake article 12 UNCRPD should be understood as both calling for the respect for legal capacity of adults with a disability on an equal basis with other persons, and at the same time putting an obligation on States Parties to provide access to the support that is needed for exercising this legal capacity.<sup>23</sup> In other words: '[I]f an individual is having difficulty making a decision or communicating a decision, the answer is not to deny legal capacity to the individual, it is instead to provide access to support for the exercise of legal capacity'.<sup>24</sup>

Article 12 UNCRPD has, however, led to much debate with regard to its precise interpretation. In the two models described above, the traditional model and the welfare model, the presumption of incapacity is followed by a form of substitute decision-making. In both cases an adult loses legal capacity and is appointed a guardian to represent and protect his interests. The only difference is that in the first

case the guardian acts according to the objective best interests of the adult and in the second case has to take into consideration the adult's wishes and preferences. It has been argued that article 12 UNCRPD calls for the abolition of both these systems of substitute decision-making and instead requires the development of supported decision-making alternatives.<sup>25</sup> This interpretation of article 12 UNCRPD has been promoted by disability advocacy groups and within academia, but more importantly, it has also been embraced by the Committee on the Rights of Persons with Disabilities. In its General Comment on article 12 UNCRPD the Committee states:

'[T]he Committee on the Rights of Persons with Disabilities has repeatedly stated that States parties must review "the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences".<sup>26</sup>

This opinion by the Committee adds another important element to the interpretation of article 12 UNCRPD, which is that the best interest approach is to be replaced by an approach that respects the rights, will and preferences of the individual and is tailored to the individual's needs.<sup>27</sup>

Although the interpretation of article 12 UNCRPD described above is advocated by many, there are also those who remain sceptical. Martin *et al.* note that the Convention itself does not call for the abolition of substitute decision-making. They argue that the analysis of the *travaux préparatoires* of the UNCRPD suggests that the absence of such a call was quite deliberate.<sup>28</sup> Lush expresses his fear that the stance calling for abolition of substitute decision-making could potentially undermine the system of existing safeguards and harm vulnerable adults. He notes that 'some profoundly disabled individuals lack the ability to make any decisions at all, even with support, and for them there is no viable alternative to substitute decision-making'.<sup>29</sup> But perhaps more importantly, the European Court of Human Rights also seems to accept that a limitation of legal capacity and a form of substitute decision-making is sometimes necessary as a last resort. In its judgement on *Ivinović v. Croatia* the Court states:

'deprivation, even partial, of legal capacity should be a measure of last resort, applied only where the national authorities, after carrying out a careful consideration of possible alternatives, have concluded that no other, less restrictive measure would serve the purpose or where other, less restrictive measures, have been unsuccessfully attempted.'<sup>30</sup>

These two different interpretations of article 12 UNCRPD raise the question whether we are dealing with irreconcilable differences or whether the 'tension' between the two can somehow be lessened. Upon a closer study of the General Comment and the literature on article 12 UNCRPD it becomes apparent that even the proponents of the so-called supported decision-making paradigm seem to acknowledge that in some instances the appointment of a substitute decision-maker is called for.<sup>31</sup> Arstein-Kerslake and Flynn refer to the situation in which 'the individual's will and preferences are unknowable and a decision needs to be made',<sup>32</sup> for example if a person is in coma. They, however, also argue that we should not assume too soon that this is the case. Gooding notes:

'[T]here will remain individuals for whom no relationships of trust exist and for whom not enough intention is expressed to guide decision-making. There are clear risks to stretching the meaning of the term "supported decision-making" to cover situations where decisions are being made "for" a person, rather than "by" a person.'<sup>33</sup>

Gooding, however, also argues that these situations should not be used as an example to legitimize measures of substitute decision-making in every instance.<sup>34</sup> The Committee does not address this issue in great detail, except in paragraph 21 of the General Comment on article 12 UNCRPD, where it states that: ‘where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the “best interpretation of will and preferences” must replace the “best interests” determinations’.<sup>35</sup> Ruck, Keene and Ward note in this regard that the actual issue in situations of what they call ‘factual incapability’ does not seem to be whether or not a decision-maker should be appointed, but rather whether he should adopt the best interpretation approach instead of the best interest approach.<sup>36</sup>

It is important to note that ratification of the Convention on the Rights of Persons with Disabilities does not mean that States Parties are bound by the Committee’s interpretation of the UNCRPD. States Parties are only bound by the text of the Convention itself.<sup>37</sup> That does not mean that the General Comment on article 12 UNCRPD should not be taken seriously, neither should it however be seen as unequivocal. The text of the Convention and the *travaux préparatoires* leave room for other interpretations.

#### **4. Beyond the two conflicting interpretations: the alternate framework**

In order to move beyond what can be described as the substitute versus supported decision-making impasse Martin *et al.* have provided an alternate framework that can be used to achieve compliance with article 12 UNCRPD on the bases of a compromise between these two conflicting interpretations. They propose to firstly ask the following overarching question:

‘What measures should be taken to support the exercise of legal capacity, both by supporting persons with disabilities to make decisions themselves wherever possible, and by supporting their ability to exercise their legal agency even in circumstances when they lack the ability to make the requisite decisions themselves?’<sup>38</sup>

According to article 12(3) UNCRPD States Parties are obliged to make sure that adults with a disability have access to the support they require in exercising their legal capacity. However, the meaning of the term ‘support’ is not specified in article 12 UNCRPD nor in the General Comment on this article. The Committee defines it as ‘a broad term that encompasses both informal and formal support arrangements of varying types and intensity’.<sup>39</sup> According to Arstein-Kerslake and Flynn the Committee deliberately chose not to create a rigid definition in order to take into account that new measures of support are still being developed and to show an understanding of the fact that the support provided can vary from one person to another due to the diversity of adults with a disability.<sup>40</sup> This means the range of potential measures to support the exercise of legal capacity is considerably broad.

As becomes apparent from the overarching question cited above, two categories of support for the exercise of legal capacity have been distinguished by Martin *et al.* The first category of support consists of measures and instruments provided to help an adult to make a decision himself and to implement this decision with legal effect.<sup>41</sup> The presumption here is that the adult is still able to make his own decisions. The second category of support comes into play in those instances where the adult, notwithstanding the support that is provided, cannot make his own decision. Further, in this article we will predominantly focus on this second category of support measures.

#### **5. Support measures for adults unable to make their own decisions**

If we agree with Martin *et al.* that article 12 UNCRPD requires that support measures should be provided in situations where an adult is unable to make his own decision, it is necessary to specify what kind of measures these should be. It seems, therefore, necessary to come back to another requirement derived from article 12 UNCRPD, namely the duty to respect the legal capacity of adults with a disability on an equal basis with others.<sup>42</sup> In this paragraph, we will elaborate on the question what kind of support measures need to be in place and what kind of safeguards should be employed in order to meet the requirements of article 12 UNCRPD.

In order to ensure respect for the legal capacity of adults with a disability on an equal basis with others, article 12(3) UNCRPD calls on States Parties to take all appropriate measures to provide adults with access to the support they require in exercising their legal capacity. As was noted in paragraph 2, according to the Committee legal capacity involves both a legal standing ('the ability to hold rights and duties') as well as legal agency. The latter should be understood as 'the power to engage in transactions and create, modify or end legal relationships'.<sup>43</sup> According to Martin *et al.* the challenge with regard to the second category of support is to find ways to support the exercise of this legal agency, even in the absence of decision-making capacity.<sup>44</sup> They refer in this regard to instruments such as the continuing power of attorney, an instrument that with regard to the Netherlands will be discussed in more detail in paragraph 7 of this article. By means of a continuing power of attorney, adults can make their own tailor-made provisions for a future period of incapacity. An attorney is given the authority to act on the adult's behalf in accordance with the adult's wishes and instructions, thereby supporting the exercise of his legal agency.

Notwithstanding the challenge to find ways to enhance legal agency where possible, Martin *et al.* acknowledge that there are limits to the support provided for the exercise of legal capacity. They refer in this regard to the so-called 'hard cases', including for example comatose patients or adults who are in an advanced stage of dementia.<sup>45</sup> According to Martin *et al.*:

'In such circumstances, the law must provide for someone else to take the decisions that the affected individual is unable to take, while establishing the methodology to be employed, and the safeguards to protect persons who find themselves in that vulnerable position.'<sup>46</sup>

What this means for the traditional guardianship measures in force in the Netherlands will be discussed in paragraph 6. As the quote makes clear, any legislative intervention has to incorporate the safeguards of article 12(4) UNCRPD. The same applies to the measures and instruments aimed at providing both categories of support mentioned above. According to article 12(4) UNCRPD appropriate and effective safeguards to prevent abuse need to be in place. These safeguards can be divided in three categories: safeguards ensuring respect for the rights, will and preferences of the person, safeguards ensuring that measures are free of conflict of interest, and safeguards ensuring that measures are free of undue influence. In addition, several requirements to which every measure must comply are distinguished. Using the language of article 12(4) UNCRPD itself, Martin *et al.* distinguish:

- an overarching aim ('to prevent abuse in accordance with human rights law');
- a duration constraint ('for the shortest time possible');
- a review requirement ('subject to regular review by a competent independent and impartial authority or judicial body');
- a proportionality requirement;

- an effectiveness requirement; and
- the plurality of safeguards.<sup>47</sup>

Both the plurality of safeguards and the proportionality requirement are important in determining the weight that is to be accorded to the first category of safeguards: safeguards ensuring respect for the rights, will and preferences of the person. The precise interpretation of the phrase ‘respect for the rights, will and preferences’ has led to much debate.<sup>48</sup> As was noted in paragraph 3, a second point of discussion in addition to the substitute-supported divide, is the replacement of the so-called ‘best interests’ paradigm by a ‘will and preference paradigm’, with the Committee stating:

‘All forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests.’<sup>49</sup>

Martin *et al.* point out that both the plurality of the safeguards and the proportionality requirement entail that respect for the will and preference of the person cannot be assured at any cost. The plurality of safeguards means that safeguards addressing conflict of interest and undue influence (the second and third category of safeguards) also need to be in place. The proportionality requirement makes clear that there are also other rights enshrined in the Convention that need to be respected and this might in exceptional cases require action contrary to the will and preference of the person.<sup>50</sup> That being said, the importance of respect for the will and preference of the person is acknowledged within the alternate framework. A middle ground between the mere consideration (often embedded within the ‘best interest’ approach) of will and preferences and the unqualified deference to will and preferences, by means of a ‘rebuttable presumption approach’ is proposed:

‘[W]herever an individual is authorised or obligated to construct a decision with or on behalf of a person whose decision-making is impaired or absent, that individual should operate with the rebuttable presumption that the reasonably ascertainable will and preferences of that person should be given effect in the matter.’<sup>51</sup>

In addition to safeguards ensuring respect for the rights, will and preferences of the adult (the first category of safeguards), article 12(4) UNCRPD requires the States Parties to establish safeguards ensuring that measures relating to the exercise of legal capacity are free from conflict of interest and undue influence. Although the question what safeguards ensuring respect for the will and preferences of the person should look like has been addressed extensively by the Committee, much less has been said about the second and third category of safeguards. This holds true in particular for the second category of safeguards. The phrase ‘conflict of interest’ is not mentioned at all in the General Comment on article 12 UNCRPD. With regard to this second category of safeguards, Martin *et al.* note that these safeguards should not be looking to eliminate conflicts of interest, but rather to manage (potential) conflicts of interest. They note that safeguards ensuring that measures are free from conflict of interest should not have the effect of excluding an individual who is best placed to support the adult in the exercise of legal capacity.<sup>52</sup>

With regard to the third category of safeguards, the Committee notes that although undue influence can be encountered by anyone, the risk is exacerbated for people relying on the support of others to make decisions. According to the Committee, undue influence occurs in situations, ‘where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation’.<sup>53</sup> Safeguards addressing these situations should be balanced with respect for the rights, will and preferences of the adult, which is to

include the right to take risks and make mistakes.<sup>54</sup> Both Martin *et al.* and Series note that it is difficult to determine *when* influence should be regarded as undue. In other words, which signs of fear or which level of manipulation justify an intervention by the State and how should safeguards in this respect look like?<sup>55</sup> To date no conclusive answers to these questions have been found. Further research looking at safeguards to protect the adult from situations of undue influence and safeguards managing situations of conflicts of interest, seems called for.

## 6. The Dutch adult guardianship measures

In the previous paragraphs we have focused on the emergence of the new paradigm based on the human rights approach. Such a long run-up is needed in order to thoroughly embed the Dutch situation into the framework of the historical and human rights developments. In the remaining paragraphs of this article we will examine whether the adult protection scheme currently in force in the Netherlands, is compliant with this new protection paradigm based on the human rights approach. Therefore, in this paragraph we will first give a brief overview of the traditional adult guardianship measures in the Netherlands. After that, we will focus on both the role these measures play in the system of adult protection in the Netherlands and on their compliance with the safeguards of article 12(4) UNCPRD.<sup>56</sup>

There are currently three adult guardianship measures in the Netherlands; all three can be found in Book 1 of the Dutch Civil Code (CC). Plenary or full guardianship (in Dutch: *curatele*) is the oldest of the three. This measure is based on the Roman *cura furiosi* mentioned in paragraph 2, and was until 1982 the only adult guardianship measure in the Netherlands.<sup>57</sup> According to article 1:378 CC, a court can order *curatele* if a person, due to a mental or physical condition or habitual alcohol or drug abuse, is unable to take care of his own interests or is endangering his own safety or the safety of others.<sup>58</sup> A so-called *curator* (guardian) is subsequently appointed. *Curatele* covers the protection of both financial and personal interests. It entails a complete loss of legal capacity, which makes it the most far-reaching measure available in the Netherlands.<sup>59</sup>

A less intrusive adult protection measure is the protective trust (in Dutch: *beschermingsbewind*). The development of this adult guardianship measure, introduced in 1982, can be linked to the emergence of the welfare model discussed in paragraph 2.<sup>60</sup> In contrast with *curatele*, *beschermingsbewind* solely covers the protection of the financial interests of the adult. *Beschermingsbewind* may be ordered if a person, due to a mental or physical condition, prodigality or problematic debts, is unable to take care of his financial interests.<sup>61</sup> The introduction of the third and final adult guardianship measure can also be linked to the emergence of the welfare model. Personal guardianship (in Dutch: *mentorschap*) was introduced in 1995 and deals with the non-financial interests of the adult, which include decisions relating to care, nursing and treatment of the adult.<sup>62</sup> *Mentorschap* may be ordered if an adult, due to his mental or physical condition, is unable to take care of his non-financial interests.<sup>63</sup> According to Blankman, *mentorschap* can be seen as complementary to *beschermingsbewind*. Not surprisingly both measures are frequently ordered together.<sup>64</sup> Both *beschermingsbewind* and *mentorschap* entail a restriction of legal capacity. However, an important exception should be noted with regard to *mentorschap*. From article 1:453 CC follows that the legal capacity of the adult placed under *mentorschap* is restricted, unless the law or a treaty specifies otherwise. This section of article 1:453 CC is particularly relevant as several Dutch laws do specify otherwise. In line with the functional approach, article 7:465 CC for example, requires the medical professional to assess whether the adult is capable to make a decision with regard to treatment himself, even if personal guardianship is in place. It is only when the adult is not deemed capable that the guardian is asked to decide upon the matter in



question.<sup>65</sup>

The adult guardianship measures described above can be classified as substitute decision-making.<sup>66</sup> Although according to the Committee systems of substitute decision-making should be abandoned in favour of supported decision-making alternatives, as discussed above, the UNCRPD leaves room for the interoperation that there are limits to the support that can be provided in order to facilitate the exercise of legal capacity. There are so-called 'hard cases' in which the individual, notwithstanding the provided support, simply is not able to exercise legal capacity. In those cases, the law must provide for a substitute entitled to take the decisions that the adult is unable to take.<sup>67</sup> However, in line with the ECHR judgment in the case *Ivinović v. Croatia*, the application of protection measures limiting legal capacity wholly or partly should be regarded as a last resort.<sup>68</sup> Martin *et al.* even go so far as to say that practicable support in decision-making must have been demonstrably provided before any such measures are permitted.<sup>69</sup>

The question that should be asked is whether the current adult guardianship measures are applied in the Netherlands as a last resort. In 2015 *beschermingsbewind* was ordered 36.341 times, 1.976 adults were placed under *curatele* and *mentorschap* was ordered 7.398 times.<sup>70</sup> These figures suggest that the adult guardianship measures still seem to be the norm, rather than the exception.<sup>71</sup> In contrast to, for example, the different jurisdictions in the United Kingdom, in the Netherlands the court is not legally obligated to previously verify whether practicable support has been provided to an adult, or whether less intrusive alternatives such as the yet to be discussed living will are in place.<sup>72</sup> In a study conducted in 2015, Blankman and Vermariën concluded that the question whether, prior to application of measures of adult guardianship, enough has been done to support adults with a disability to make decisions themselves, could not be answered in the affirmative.<sup>73</sup> To date, this still seems to be the case.

According to article 12(4) UNCRPD all measures relating to the exercise of legal capacity need to comprise appropriate and effective safeguards. With regard to the first category of safeguards, respect for the rights, will and preferences of the adult, Martin *et al.* propose a 'rebuttable presumption approach'. The substitute decision-maker 'should operate with the rebuttable presumption that the reasonably ascertainable will and preferences of that person should be given effect in the matter'.<sup>74</sup> The Dutch Civil Code devotes attention to the wishes and preferences of the adult in various ways. With regard to the appointment of a guardian in case of *curatele*, article 1:383(2) CC states that the court shall follow the preferences of the adult unless there are good reasons not to do so. A similar rule applies in case of *beschermingsbewind* (article 1:435(3) CC) and *mentorschap* (article 1:452(3) CC). In addition, both article 1:454 CC and article 1:381(4) CC applied to the provision of *mentorschap* and to the protection of personal interests by means of *curatele*, require the guardian to involve the adult as much as possible when taking decisions concerning the care, nursing and treatment of the adult. These articles also require the guardian to encourage the adult to act for himself when the adult has the mental capacity to do so. Although there is no such obligation with regard to *beschermingsbewind*, a certain degree of collaboration between the guardian and the adult is required. Article 441 CC obliges the guardian to ask the adults' consent for important financial decisions, such as the sale of property. This consent can however be replaced by the judge. Blankman and Vermariën note that the latter happens too often in practice.<sup>75</sup> They conclude that more can be done to ensure respect for the will and preferences of the adult and propose the adoption of an explicit guiding principle for substitute decision-makers.<sup>76</sup>

There are several safeguards in place with the aim to ensure that the adult

guardianship measures are free from undue influence and that conflicts of interests are managed. Article 1:383 CC requires the judge to assess the suitability of the person to be appointed as guardian in cases of full guardianship.<sup>77</sup> In addition, certain persons, such as staff of the institution where the adult is placed, cannot be appointed as guardian.<sup>78</sup> This to avoid a potential conflict of interest. Finally, the law also provides for supervision by the judge, who in principle receives an annual report from the guardian.<sup>79</sup> To date, it is unknown whether these safeguards and the supervision by judge are sufficient in practice. Again, we note that this is a matter on which further research is required.

## 7. The living will

Beside the three traditional adult guardianship measures, there is also a new voluntary instrument in the Netherlands: the living will (in Dutch: *levenstestament*). By means of a *levenstestament* adults can make their own tailor-made arrangements for a future period of incapacity. The *levenstestament* is also well known in other countries and is internationally better known as a continuing, lasting or enduring power of attorney. The Council of Europe has provided the following definition: ‘a mandate given by a capable adult with the purpose that it shall remain in force, or enter into force, in the event of the granter’s incapacity’.<sup>80</sup> As this definition makes clear, a *levenstestament* can only be made by a ‘capable adult’. In order to ensure legal effectiveness, living wills are therefore often notarised documents in the Netherlands.<sup>81</sup> The scope of the living will can be considerably broad and may include both financial, health and personal matters as well as the adult’s wishes, preferences and instructions as to these matters.

As we mentioned previously, Martin *et al.* argue that article 12(3) UNCRPD includes the challenge to find ways to extend legal agency where possible, even in the absence of decision-making capacity.<sup>82</sup> The *levenstestament* is an important instrument in the Netherlands with the potential to do so. By means of the *levenstestament* the attorney is given the authority to act on the granter’s behalf in accordance with his/her wishes and instructions. The attorney is thereby supporting the granter in the exercise of his rights and duties. Unlike the adult guardianship measures, the *levenstestament* does not entail a loss or limitation of legal capacity. This means there can be a gradual increase of support provided by the attorney, taking into account the declining decision-making capacity of the granter. However, in order to fulfil this potential, the *levenstestament* must be embedded in the safeguards of article 12(4) UNCRPD.<sup>83</sup>

To date the *levenstestament* is not yet regulated by law in the Netherlands. In the absence of statutory regulation, the only regulation of the living will is provided by notarial practice. The Dutch government has taken a passive role.<sup>84</sup> Ensuring compliance with article 12(4) UNCRPD is thus left to the discretion of a notary and ultimately to the granter, as it is the granter who decides about the content of the living will and the safeguards that need to be incorporated. However, the *levenstestament* under the Dutch law is modelled upon the power of attorney, a traditional instrument employed for authorising an attorney by a legally capable grantor, who can execute supervision, replace or dismiss the attorney. As noted above, the *levenstestament* allows for a gradual increase of support by the attorney as the mental capacity of the grantor declines. This means there will come a time when the granter will not be able to supervise whether the attorney is acting according to his wishes and preferences, will probably be more vulnerable to undue influence and will not be able to assess whether there is any conflict between his interests and the interests of the attorney. All that makes the question of safeguards very pressing, especially as there is no supervision by the court or any other administrative body. There are, however, no legal rules obliging notaries to cease cooperation in cases where the granter is unwilling or unable to incorporate necessary safeguards.<sup>85</sup>

Although little is known about the application of the living will in practice, there are at least indications that the issue of safeguards is far from being a theoretical one. In a case before the Court of Appeal in Amsterdam, *mentorschap* was deemed necessary, notwithstanding the existence of a living will, in order to ensure respect for the will and preferences of the adult. In this case, the adult wanted to stay home as long as possible which was considered possible by the caregivers. The attorney, the daughter of the grantor, had however already taken steps to place her father in a care institution.<sup>86</sup> In addition, there have already been several cases where *beschermingsbewind* was deemed necessary due to a conflict of financial interest of the attorney and the grantor. In these cases, large sums of money were taken by the attorney, without explicit consent given by the grantor in the *levenstestament*.<sup>87</sup> In two cases, the court ruled that the attorney had financially exploited the grantor, which in both cases led to a criminal conviction of the attorney.<sup>88</sup> Taking the aforementioned into account, the passive role of the Dutch government does not seem to meet the requirements of article 12(4) UNCRPD. There is after all an obligation for the *State* to ensure the compliance with the human rights instruments and to provide for appropriate and effective safeguards preventing abuse of vulnerable citizens. This requires a more active approach on the part of the Dutch State than has been the case until now. In order to acquire a more complete picture of problems arising from the lack of safeguards more empirical research is needed.<sup>89</sup>

The question that remains then is how the State can ensure compliance with article 12(4) UNCRPD. Which safeguards can be best implemented in order to enforce respect for the rights, will and preferences and guarantee protection from undue influence and conflict of interest in the context of the living will? In its Recommendation on Principles concerning continuing powers of attorney and advance directives and the accompanying Explanatory Memorandum, the Committee of Ministers of the Council of Europe has addressed the question how safeguards addressing conflicts of interest could be implemented.<sup>90</sup> According to the Explanatory memorandum a conflict of interest could be presumed to arise in case of any transaction between the attorney acting for himself and the grantor at the same time. Legislation dealing with conflict of interest should, according to the Recommendation, strive to establish a balance between protection and self-determination, which can be achieved by: 'having clear rules as to conflict of interest but allowing the grantor to permit – by express provision in the power of attorney – what would otherwise be a conflict of interest'.<sup>91</sup>

Several safeguards, aimed at avoiding or addressing potential situations of undue influence, have been proposed in the literature. In the context of the living will, these safeguards can be aimed either at avoiding situations of undue influence at the time when the living will is made or addressing situations of undue influence at the time when the living will has already come into effect.<sup>92</sup> A safeguard employed in several countries are requirements as to the choice of attorney. In Belgium, Germany and Austria for example, the attorney cannot be someone who is employed by the institution where the grantor is living.<sup>93</sup> This in order to avoid a conflict of interest but also to avoid a situation in which a care provider is trying to persuade the grantor, who is dependent on his support, to make a living will in his favour.<sup>94</sup> Further comparative research focusing on the effectiveness of these and other safeguards and assessing their suitability for implementation in the Netherlands seems required.<sup>95</sup>

## 8. Conclusion

The perception of how the interests of vulnerable adults should be protected has changed over time. Under the influence of the human rights approach, a profound shift of protection paradigms has taken place in the last decades. In line with these developments, the traditional adult guardianship measures are increasingly rendered inconsistent with the right to autonomy and self-determination of vulnerable adults.

There seems to be a growing consensus that measures of substitute decision-making should be considered a last resort and need to be reserved for situations in which the individual, notwithstanding the support provided, lacks the ability to make any decisions at all.<sup>96</sup> The focus has thus shifted to instruments of supported decision-making, allowing adults to make decisions themselves and extending their legal agency in the absence of decision-making capacity. Even this brief analysis reveals that current emphasis on the traditional adult guardianship measures in the Netherlands cannot be considered compliant with this approach. These measures still seem to be the norm rather than the exception. The overall conclusion is that both the traditional adult guardianship measures and the practice of their application should be adjusted according to the new human rights-based protection paradigm and the requirements of article 12 of the UNCRPD. Thereby vulnerable adults should be provided with practicable support to make decisions themselves and instruments extending legal agency in the absence of decision-making capacity should be stimulated and promoted. The *levenstestament* can be considered an addition to the arsenal of instruments in the Netherlands with the potential to play an important part in this adjustment.

In order to fulfil this potential, the *levenstestament* needs to be embedded in the robust safeguards of article 12(4) UNCRPD. As we have indicated throughout this article, the operationalization of these safeguards requires further research. Research is required on a number of issues including questions as to when influence should be regarded as undue and how situations of conflict of interest can best be managed. Another issue, not raised in this article, concerns the question how safeguards ensuring respect for the rights, will and preferences of the person, can provide for reflection on later changes in the will and preferences of the adult. This question seems particularly relevant in the context of the *levenstestament* where present wishes may collide with past wishes that have been laid down in the *levenstestament*.<sup>97</sup> Research focusing on these and other questions should be aimed at evidence-based improvement of the regulation and application of the *levenstestament* the Netherlands in order to ensure compliance with article 12 UNCRPD.

## Noten

\* The authors would like to thank dr. Veroni Eichelsheim for her comments on an earlier draft of this article.

**1** <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>. The Convention has been ratified by 177 countries, including the Netherlands (14 June 2016).

**2** A. Ruck Keene, 'Fundamental Definitions', in: R. Frimston, A. Ruck Keene, C. van Overdijk & A.D. Ward (eds.), *The International Protection of Adults*, Oxford – New York: Oxford University Press 2015, pp. 5-6. In the Netherlands the term 'handelings(on)bekwaamheid' and 'wils(on)bekwaamheid' are customary.

**3** United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1. Article 12: Equal Recognition before the law*, 2014, p. 3.

**4** M. Kaser, *Römisches Privatrecht. Ein Studienbuch. 15 Auflage*, München: C.H. Beck'sche Verlagsbuchhandlung 1989, p. 297.

**5** K. Blankman, 'Guardianship Models in the Netherlands and Western Europe', *International Journal of Law and Psychiatry* 1997 vol. 20, no. 1, pp. 47-57.

**6** K. Blankman, *Curatele voor personen met een geestelijke stoornis en bescherming op maat*, Zwolle: Tjeenk Willink 1994, pp. 5-6; Kaser 1989, p. 197; D. Lush, 'The Civil

Law and the Common Law', in: R. Frimston, A. Ruck Keene, C. van Overdijk & A.D. Ward (eds.), *The international Protection of Adults*, Oxford - New York: Oxford University Press 2015, pp. 37-52.

7 Blankman 1994, p. 8-9; Lush 2015, p. 38.

8 Lush 2015, p. 38.

9 W. Fuchs, *Systems of advocacies for the elderly in a comparative perspective*, Presentation at the Advocacies for frail and incompetent elderly in Europe (ADEL) project final conference on 24 September 2010 in Berlin.

10 A. Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future', *Syracuse Journal of International Law and Commerce* 2007 vol. 34, pp. 429-462.

11 K. Booth-Glen, 'Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond', *Columbia Human Rights Law Review* 2012 vol. 44, pp. 93-169.

12 Fuchs 2010, p. 2.

13 Blankman 1997, p. 48.

14 Although we restrict ourselves in this article to a discussion of the Roman concept of *cura furiosi* which has formed the basis for adult guardianship legislation in many civil law jurisdictions, a status-based approach was also adopted in common law jurisdictions. An example is England where around 1270 the wardship of the estates of 'idiots' was placed in the hand of the king as the 'parens patriae'. For more information, we refer to Lush 2015, pp. 40-43.

15 Blankman 1997, p. 48.

16 Fuchs 2010, p. 3.

17 Although the functional approach embedded within the Mental Capacity Act 2005 is used to illustrate this approach, it is by no means assumed that this approach can only be linked to the second model. Indeed Martin *et al.* (2014) provide a convincing argument that the functional approach of the Mental Capacity Act 2005 can also be used within the human rights approach.

18 Mental Capacity Act 2005, s 3.

19 Blankman 1997, p. 48.

20 Fuchs 2010, p. 3.

21 E.g. Booth-Glen 2012; Dhanda 2007; E. Flynn & A. Arstein-Kerslake, 'The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?', *Berkeley Journal of International Law* 2014 vol. 32, no. 1, pp. 124-143.

22

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

23 Flynn & Arstein-Kerslake 2014, p. 128.

- 24** A. Arstein-Kerslake & E. Flynn, 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law', *The International Journal of Human Rights* 2016 vol 20, no. 4, pp. 471-491 (p. 475).
- 25** E.g. Arstein-Kerslake & Flynn 2016; C. de Bhailís & E. Flynn, 'Recognising legal capacity: commentary and analysis of Article 12 CRPD', *International Journal of Law in Context* 2017 vol. 13, no. 1, pp. 6-21; Flynn & Arstein-Kerslake 2014.
- 26** United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1. Article 12: Equal Recognition before the law*, 2014, p. 6.
- 27** Arstein-Kerslake & Flynn 2016, p. 476. A point upon which we will elaborate in paragraph 5.
- 28** W. Martin, S. Michalowski, J. Stavert, A. Ward, A. Ruck Keene, C. Caughey, A. Hempsey & R. McGregor, *The Essex Autonomy Project. Three Jurisdictions Report. Towards Compliance with CRPD Art. 12 in Capacity/Incapacity legislation across the UK*, Essex: University of Essex 2016.
- 29** Lush 2015, p. 47.
- 30** ECHR 18 September 2014 (Ivinović v. Croatia), no. 13006/13.
- 31** According to paragraph 27 of General Comment No. 1 on article 12 the appointment of a substitute decision-maker by someone other than the person concerned is one of the characteristics of a regime of substitute decision-making. See however Martin *et al.* 2016, p. 12 & pp. 63-66 (Appendix C) and A. Ruck Keene & A.D. Ward, 'With and Without "Best Interests": the Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and Constructing Decisions', *International Journal of Mental Health and Capacity Law* 2016, pp. 17-37 (in particular pp. 18-19) for an analysis of the problems that exist with regard to this definition.
- 32** Arstein-Kerslake & Flynn 2016, p. 477.
- 33** P. Gooding, 'Navigating the 'Flashing Amber Lights' of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns', *Human Rights Law Review* 2015, vol. 15, pp. 45-71 (p. 53).
- 34** Gooding 2015, pp. 53-54.
- 35** United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1. Article 12: Equal Recognition before the law*, 2014, p. 5.
- 36** Ruck Keene & Ward 2016, pp. 18-19.
- 37** Martin *et al.* 2016, p. 10.
- 38** Martin *et al.* 2016, pp. 13-14.
- 39** United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1. Article 12: Equal Recognition before the law*, 2014, p. 4.
- 40** Arstein-Kerslake & Flynn 2016, p. 476.

**41** Martin *et al.* 2016, p. 24.

**42** Article 12(2) UNCRPD.

**43** United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1. Article 12: Equal Recognition before the law*, 2014, p. 3.

**44** Martin *et al.* 2016, pp. 37 & 24-25.

**45** Martin *et al.* 2016, p. 35.

**46** Martin *et al.* 2016, p. 37.

**47** Martin *et al.* 2016, p. 38.

**48** See e.g. Arstein-Kerslake & Flynn 2016; Ruck-Keene & Ward 2016.

**49** United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1. Article 12: Equal Recognition before the law*, 2014, p. 5 & 7.

**50** Martin *et al.* 2016, p. 39 & 41. See also ECHR 23 March 2017 (Case of A.-M.V. v. Finland), no. 53251/13, where the Court considers that a balance needs to be struck between the respect for the dignity and self-determination of the individual and the need to protect the individual and safeguards his interests, which in this case meant that action had to be taken contrary to the wishes and preferences of the adult.

**51** Martin *et al.* 2016, pp. 40-41.

**52** Martin *et al.* 2016, pp. 48-50.

**53** United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1. Article 12: Equal Recognition before the law*, 2014, p. 5.

**54** United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1. Article 12: Equal Recognition before the law*, 2014, p. 5.

**55** Martin *et al.* 2016, pp. 44-45; L. Series, 'Relationships, autonomy and legal capacity: Mental capacity and support paradigms', *International Journal of Law and Psychiatry* 2015 vol. 40, pp. 80-91.

**56** With regard to the compliance of the adult guardianship measures with article 12(4), we are referring to a study conducted by: Blankman & Vermariën, *Conformiteit van het VN-Verdrag inzake de rechten van personen met een handicap en het EVRM met de huidige voorgestelde wetgeving inzake vertegenwoordiging van wilsonbekwame personen in Nederland*, Amsterdam: Vrije Universiteit 2015, p. 9.

**57** Blankman 1997, p. 49.

**58** C. Blankman, 'Guardianship legislation in The Netherlands', in: K. Dayton (ed.), *Comparative Perspectives on Adult Guardianship*, Durham North Carolina: Carolina Academic Press 2014, pp. 181-190; R. Frimston, C. Engelbertink & A. Vrenegoor, 'Netherlands', in: R. Frimston, A. Ruck Keene, C. van Overdijk & A.D. Ward (eds.), *The international Protection of Adults*, Oxford - New York: Oxford University Press 2015, pp. 568-574 (p. 569).

**59** Frimston, Engelbertink & Vrenegoor 2015, p. 569; P. Vlaardingbroek, K.

Blankman, A.P. van der Linden, E.C.C. Punselie & W.M. Schrama, *Het hedendaagse personen- en familierecht*, Deventer: Wolters Kluwer 2017, pp. 573-575. There are a few exceptions to this legal incapacity (article 1:381 CC).

**60** Blankman 1997, p. 49.

**61** Frimston, Engelbertink & Vrenegoor 2015, p. 569; Blankman 2014, p. 183.

**62** Article 1:453 CC

**63** Article. 1:450 of the Dutch Civil Code; Frimston, Engelbertink & Vrenegoor, p. 569.

**64** Blankman 2014, pp. 183-184.

**65** Blankman 1997, p. 50.

**66** See also list of characteristics that according to the Committee define a substitute decision-making regime, United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1. Article 12: Equal Recognition before the law*, 2014, p. 6.

**67** Martin *et al.* 2016, p. 37.

**68** Martin *et al.* 2016, pp. 34-35; ECHR 18 September 2014 (Ivinović v. Croatia), no. 13006/13.

**69** Martin *et al.* 2016, p. 35.

**70** K. Blankman, 'Een wettelijke regeling voor het levenstestament?', in: *Het levenstestament. Nader verfynd*, Den Haag: Sdu uitgevers 2017, pp. 45-64.

**71** See also the annually increasing number of adult guardianship measures that are in place (Raad voor de Rechtspraak, *Factsheet Toezicht: bewind, curatele en mentorschap*, <https://www.rechtspraak.nl/SiteCollectionDocuments/Factsheet-toezicht.pdf> (last accessed: 7 January 2019)).

**72** See for example section 1.3 of the Mental Capacity Act and section 1.6 of The Adults with Incapacity (Scotland) Act 2000.

**73** Blankman & Vermariën, *Conformiteit van het VN-Verdrag inzake de rechten van personen met een handicap en het EVRM met de huidige voorgestelde wetgeving inzake vertegenwoordiging van wilsonbekwame personen in Nederland*, Amsterdam: Vrije Universiteit 2015, p. 9.

**74** Martin *et al.* 2016, pp. 40-41.

**75** Blankman & Vermariën 2015, p. 26.

**76** Blankman & Vermariën 2015, p. 5.

**77** A similar article applies in case of the protective trust (article 1:435 CC) and personal guardianship (article 1:452 CC).

**78** Article 1:383 CC, article 1:435 CC and article 1:452 CC.

**79** Blankman & Vermariën 2015, p. 27; Article 1:386(1) CC, article 1:455 CC and article



1:459 CC.

**80** Committee of Ministers of the Council of Europe, *Recommendation CM/Rec(2009)11. Principles concerning continuing powers of attorney and advance directives for incapacity*, 2009, p. 9.

**81** R. Frimston, C. Engelbertink & A. Vrenegoor 2015, p. 572.

**82** Martin *et al.* 2016, p. 37 & 24-25.

**83** Martin *et al.* 2016, p. 53.

**84** Dutch Senate, *Wijziging van enige bepalingen van Boek 1 van het Burgerlijk Wetboek inzake curatele, onderbewindstelling ter bescherming van meerderjarigen en mentorschap ten behoeve van meerderjarigen en enige andere bepalingen (Wet wijziging curatele, beschermingsbewind en mentorschap)*, Memorie van Antwoord 2013-2014, 33054-c.

**85** Blankman 2017, p. 46.

**86** Court of Appeal Amsterdam 2 March 2016, ECLI:NL:GHAMS:2016:346, s. 4.12.

**87** Court of Appeal Amsterdam 2 February 2016, ECLI:NL:GHAMS:2016:333, s. 4.6; Court of Appeal Amsterdam 2 March 2016, ECLI:NL:GHAMS:2016:346, s. 4.11; District Court Midden-Nederland 14 September 2017: ECLI:NL:RBMNE:2017:4768.

**88** District Court Overijssel 9 May 2017, ECLI:NL:RBOVE:2017:1932; District Court Noord-Nederland 8 April 2016, ECLI:NL:RBNNE:2016:1711.

**89** An empirical study focusing on the application of the living will is currently ongoing as part of a comprehensive multidisciplinary PhD study aimed at evidence-based proposals for improvement of the regulation and application of the living will in the Netherlands.

**90** Committee of Ministers of the Council of Europe, *Recommendation CM/Rec(2009)11. Principles concerning continuing powers of attorney and advance directives for incapacity*, 2009.

**91** Committee of Ministers of the Council of Europe, *Recommendation CM/Rec(2009)11. Principles concerning continuing powers of attorney and advance directives for incapacity*, 2009, pp. 52-53.

**92** Blankman 2017, p. 56.

**93** Committee of Ministers of the Council of Europe, *Recommendation CM/Rec(2009)11. Principles concerning continuing powers of attorney and advance directives for incapacity*, 2009, p. 40; A. van den Broeck, 'Inspiratie uit het buitenland voor het Nederlandse levenstestament', in: *Het levenstestament. Nader verfijnd*, Den Haag: Sdu uitgevers 2017, pp. 17-43.

**94** A. van den Broeck, *Vermogensbescherming van kwetsbare meerderjarigen via lastgeving*, Antwerpen – Cambridge: Intersentia 2014, p. 120.

**95** A comparative study of legislation and best practices abroad is currently ongoing as part of a comprehensive multidisciplinary PhD study aimed at evidence-based proposals for improvement of the regulation and application of the living will in the

Netherlands.

**96** Martin *et al.* 2016, p. 35.

**97** A.D. Ward, *Enabling Citizens to Plan for Incapacity. A review of follow-up action taken by member states of the Council of Europe to Recommendation CM/Rec(2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity*, Strasbourg: Council of Europe 2018, p. 64-68.

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