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The enduring and dynamic nature of enduring documents from a comparative perspective



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Programme today

- 1. Outline of the context
 - What are enduring documents?
 - How can we define the life-course perspective?
 - Why is a life-course perspective necessary when it comes to enduring documents?
 - What are risks of enduring documents in this regard?
 - How should this shape our perception of enduring documents?
- 2. Provisional research question
- 3. The enduring and dynamic nature of enduring documents in FL-EUR countries, focusing on the role will and preferences as a criterion for decision-making
- 4. Provisional observations
- 5. Conclusion and next steps



Enduring documents – a confusion of terminology

Continuing power of attorney:

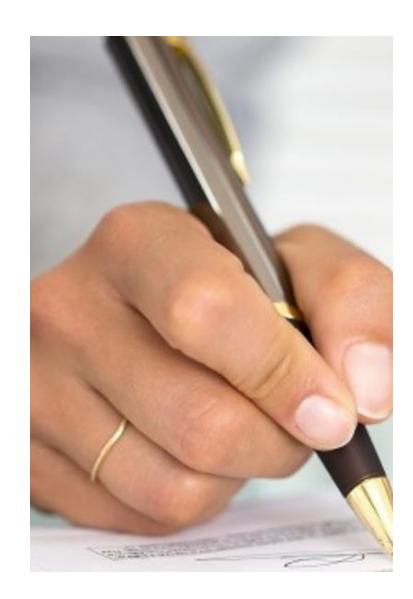
'a mandate given by a capable adult with the purpose that it shall remain in force, or enter into force in the event of his incapacity'

Advance directives:

'instructions given or wishes made by a capable adult concerning issues that may arise in the event of his or her incapacity'

Council of Europe Rec 2009/11

Meaning of 'enduring document' in this presentation: continuing power of attorney, including advance directives (e.g. wishes and instructions) addressed to the attorney





Life course perspective

• 'All versions of life course theory accept that it is about examining people's lives over time, through the different stages and events which give lives meaning. It seeks to explore the factors that shape our lives. It examines what causes and marks changes in a life and what influences its direction'

Herring 2021, p. 9-10

 Already mainstream in certain disciplines, such as sociology, anthropology, demography and psychology. Now gaining more attention within the discipline of (family) law.



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- Already mainstream in certain disciplines, such as sociology, anthropology, demography and psychology. Now gaining more attention within the discipline of (family) law.
- Raises certain questions:
 - More legal-philosophical questions, such as how to the different stages of life shape our laws or how do law's assumptions shape legal understanding of the stages of life?
 - More specifically within family law, the issue seems how laws and regulations governing certain life events such as marriage (prenuptial agreements) and provisions for a future period of incapacity (enduring documents) can take into account life-changes resulting from people going through the different stages of life.



The necessity of a life course perspective concerning enduring documents

Sociological perspective:

You could think of the life course as a path. But note that it is not a straight path; it
is a path with both continuities and twists and turns'

Hutchinson 2018, p. 9

 Research shows that wishes and preferences can change over time, especially in situations that we have never faced before (De Boer et al. 2007):

'We know that our anticipatory beliefs often fail to recognize our ability to adapt and that it is notoriously difficult to imagine how one's current preferences will hold in a given situation (such as dementia) that one has never experienced before

Hertogh 2011





The necessity of a life course perspective concerning enduring documents

Human rights perspective:

- A dynamic process of support for the adult in the exercise of his legal capacity
- Article 12(3) UNCRPD: 'States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.'
- Two forms of support:
 - 1) Support enabling an adult to make a decision himself, and
 - 2) Support in the absence of decision-making capacity of the adult, based on the adult's will and preferences



Martin et al. 2016



The risk of enduring documents: its static nature!

Where enduring documents capture the adult's wishes, preferences and instructions at a given time, life itself is dynamic!

- Wishes and preferences of the adult that were once important may change over time
- It can be difficult to oversee future needs

There is a risk that the static nature of enduring documents is enhanced by factors such as the cost and formalities of making an enduring document

Observations interview study on the Dutch *levenstestament*.

- The inclusion of (detailed) wishes, preferences and instructions in the levenstestament is discouraged by notaries
- A broad conferral of authority to cover all future scenarios is advised

The above creates the risk that the information as to the adult's voice is limited. Although there is a lot the attorney *can* do, he knows little about what the adult *wishes* him to do.



Contents lists available at ScienceDirect

International Journal of Law and Psychiatry

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Decision-making by and for adults with impaired capacity: The potential of the Dutch levenstestament

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Keywords: Capacity law Anticipatory decision-making instrum Continuing power of attorney Advance directive UNCRPD

ABSTRACT

Anticipatory decision-making instruments — continuing powers of attorney and advance directives — are increasingly seen as a promising way forward to enhance the autonomy of adults with impaired capacity by making the adult's voice an influential component of future decisions. However, little is known about the experiences with these instruments in practice. This article presents the findings of an interview study looking at the expectations and experiences of both adults and attorneys with a Dutch anticipatory decision-making instrument, the so-called levenstestament. In order to realise its full potential, anticipatory decision-making instruments, such as the levenstestament, should be embedded in robust, timely and ongoing conversations between adults and attorneys about the adult's (changing) withes and preferences and the role of the attorney.



The risk of enduring documents: its static nature!

Observation interview study:

- adults and attorneys find it difficult to engage in timely and ongoing conversations about the adult's (changing) wishes, preferences and instructions and are in some cases not aware of the importance of having such conversations
- Over time with cognitive decline, having such conversations becomes even more difficult



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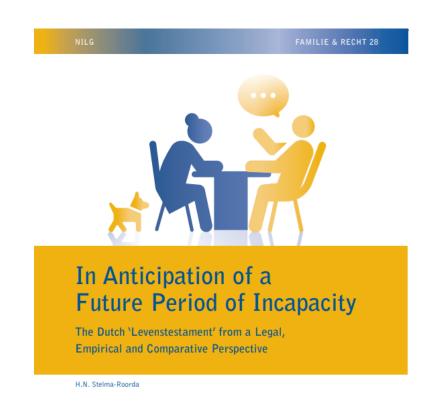
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Anticipatory decision-making instruments — continuing powers of attorney and advance directives — are increasingly seen as a promising way forward to enhance the autonomy of adults with impaired capacity by making the adult's voice an influential component of future decisions. However, little is known about the experiences with these instruments in practice. This article presents the findings of an interview study looking at the expectations and experiences of both adults and attorneys with a Dutch anticipatory decision-making instrument, the so-called levenstestament. In order to realise its full potential, anticipatory decision-making instruments, such as the levenstestament, should be embedded in robust, timely and ongoing conversations between adults and attorneys about the adult's (changing) wishes and preferences and the role of the attorney.



How should the aforementioned shape our perception of enduring documents?

- Awareness of the various forms of support in the exercise of legal capacity within the context of enduring documents is needed.
 - ➤ Enduring documents allow for a flexible transition between support enabling an adult to make a decision-himself and support in the absence of decision-making capacity (Stelma-Roorda 2021)
- Laws and regulations on enduring documents should provide and allow for changes in the adult's will and preferences
- Enduring documents should be seen as the beginning of a process to make provisions for the future and not the end (Stelma-Roorda 2024). Discussions about wishes, preferences and values preferably start when the enduring document is made and continue thereafter.



Boomjuridisch



Provisional research question

'To what extent do legal regimes for enduring documents in FL-EUR countries (adequately) take into account the durable and dynamic nature of these instruments, and what lessons or best practices can be learned in this regard?'



Avenues to explore

Broadly two routes possible:

- 1) Inclusion of wishes, preferences and instructions in the enduring document, with the possibility to change/adapt these wishes, preferences and instructions
- 2) Interaction between the adult and the attorney, i.e. ways in which dialogue between the adult and the attorney is promoted





The role of wishes and preferences as a criterion for decision-making

Question 42 of the FL-EUR questionnaire, included the following sub-questions:

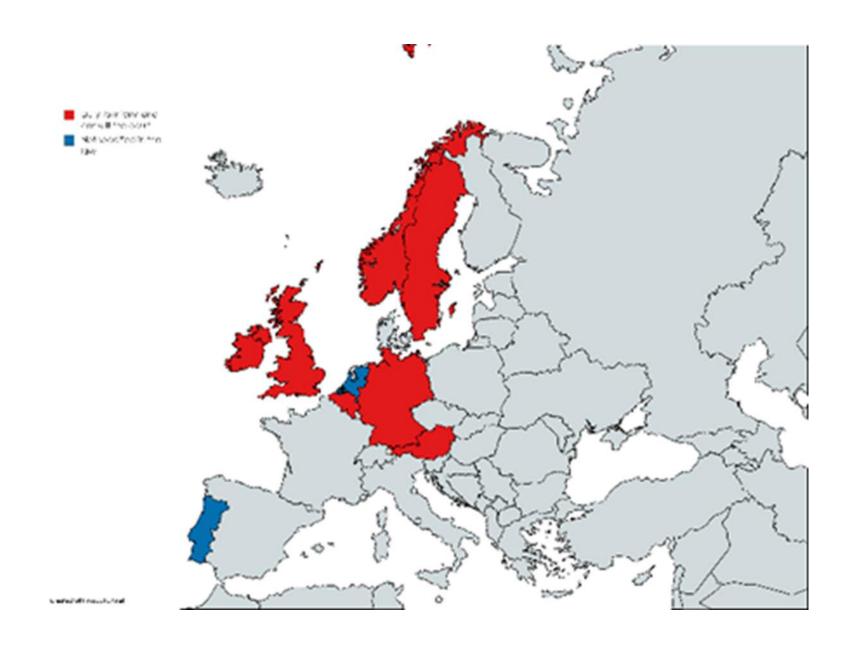
- 'What are the criteria for decision-making (e.g. best interests of the adult or the will and preferences of the adult)?
- 'Is there a duty of the representative/support person to inform and consult the adult?'



The role of wishes and preferences as a criterion for decision-making

Red: Jurisdictions include a general duty for the representative to consider the adult's wishes and preferences

Blue: Such an obligation has not been clearly specified in the law

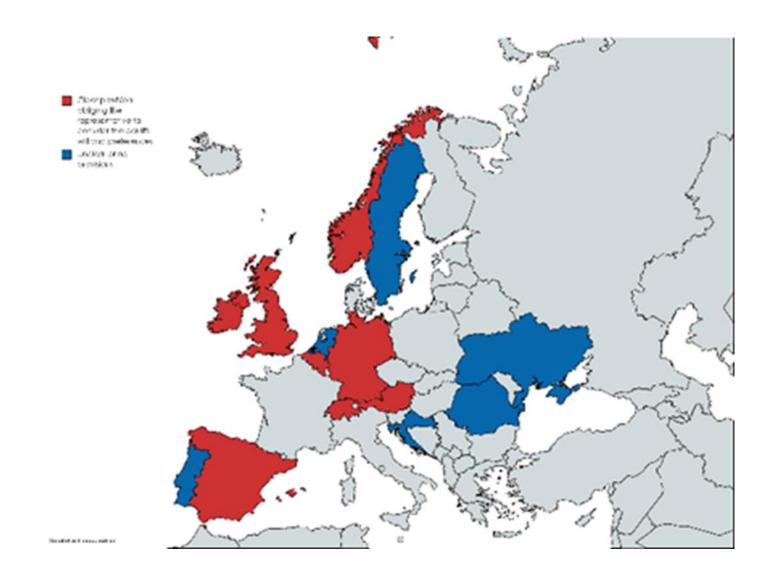




Duty to inform and consult the adult

Red: Jurisdictions include a general duty for the representative to inform and consult the adult

Blue: Such an obligation has not been clearly specified in the law





Provisional observations

- A duty for the representative to consider the adult's will and preferences and consequently a duty to ascertain those wishes
 and preferences during the execution of the enduring document. However, such a duty is just as important before the entry
 into force of the enduring document.
- Important that obligations to consider the adult's will and preferences and a duty to inform and consult the adult are made more concrete.
 - Which steps can the representative take to ascertain the adult's will and preferences, which may become more and more difficult when there is a decline of the adult's cognitive abilities.
 - How often should the representative inform and consult the adult.



Thank you for your attention!

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