

# Who Can Tell?

Regulating Person-Centred Long-Term Care

Prof. Anne Margriet Pot

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**Prof. Anne Margriet Pot**

Inaugural lecture

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## Colophon

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# Who Can Tell?

## Regulating Person-Centred Long-Term Care

**Madam Rector, Madam Inspector-General of the Health  
and Youth Care Inspectorate, Ladies and Gentlemen,**

## Introduction

The government has been called upon to restore a human scale to the tasks entrusted to it. Regulating long-term care is key to this, since it is the care of vulnerable people that shines the light most clearly on what it means to be human. Society's insistence on the human scale calls for a shift in the practice of regulation. Person-centred care cannot be judged on the basis of a checklist which asks whether people prefer peanut butter or chocolate sprinkles on their bread. It is infinitely more complex. It is about how to ensure that people can function as well as possible over time in interaction with their environment. And who can judge that better than the people themselves and those who support them? They can tell.

For the past thirty-five years, through practice, research and education, and through my national and international involvement in healthcare policy, my focus has been on the care of vulnerable, often older people. In this chair, I will also continue to work for vulnerable people, but now from the perspective of regulation. My professorship in this chair will therefore be devoted to this necessary paradigm shift in regulation to which I have just referred.

Allow me on this late Friday afternoon, with the enticing prospect before you of having a drink and starting the weekend, to direct your thoughts for a moment to the official and political reality, which, as Tjeenk Willink has analysed so insightfully, pays lip service to the human scale, but in reality consistently overlooks it, and seems to think that those on the front line of policy implementation – which in our case means the care workers – are ‘machines that can be switched on and off at will and instructed to shift up a gear whenever an incident has taken place’.

(1) Do I really need to give you examples of government agencies that behave like the proverbial pillar and post between which the despondent citizen is driven, never finding anyone who will listen?(1) Or of management thinking overriding time and time again the intuitive understanding that it is about people, about citizens? Do I need to remind you of the parents who were failed in the childcare benefits scandal, the passionate teachers, perhaps the well-intentioned farmers in the nitrogen crisis, the hard-working care workers?

## Long-term care according to the WHO's *Healthy Ageing* policy framework

In this chair and therefore in this address I will naturally concentrate on my own role, which pertains to the regulation of long-term care. But what exactly is long-term care? The notion shows all the characteristics of what Bruno Latour in the sociology of knowledge calls *une boîte noire*, a black box, something that is so self-evident that nobody wonders any longer what we mean by it.(2, 3) The same applies, of course, to formulaic statements such as ‘the right care in the right place’ and ‘appropriate care’.(4) When I ask students or colleagues what long-term care is, the answer that often comes back is a list of different *forms* of care, such as home care, out-patient care, nursing home care, hospice care, and psychiatric or youth care in institutions. But such answers refer to how we have *organised* long-term care; they tell us nothing about how we view long-term care. And if we end up identifying care with the different forms of care, this will lead us to focus on the form of care and not on the care itself, and our policies (if they may be called that) will soon produce nothing but incoherent and sporadic interventions. So let's open up the *boîte noire* of long-term care: what do we actually mean by long-term care?

As a Member State of the World Health Organization (WHO), it is obvious that the Netherlands takes its direction from the WHO's *Healthy Ageing* policy framework, as published in the first *World Report on Ageing and Health* and endorsed by the Netherlands together with 193 other countries.(5-7) This currently serves as the basis for the United Nations *Decade of Healthy Ageing 2021-2030*.(8) I consider it a great honour, having been seconded to the WHO in Geneva by the Ministry of Health, Welfare and Sport between 2014 and 2018, to have had a chance to contribute to this report and policy framework. It is precisely the privilege of guiding WHO's work in the field of long-term care worldwide that has strengthened my conviction that care must always put people at the centre, and continue to do so.

The *Healthy Ageing* policy framework focuses on people's functional ability. ‘*Healthy Ageing*’ means maximising people's functional ability over the course of their life. (5) The word ‘*Healthy*’ thus refers to ‘maximising functional ability’, even in the event of a severe loss in intrinsic capacity. It does *not*, therefore, refer to the absence of medically defined conditions. And ‘*Ageing*’ does not mean ‘getting older’, but rather ‘progressing through life’. This may sound obvious, but let's not forget that this introduces onto the world stage a radical redefinition of what healthy ageing means: fostering functional ability over the course of your life, anyway.

Let's be clear: people generally experience a loss of mental and physical capacity in the course of their lives. At some point, this will also lead to a loss of functional ability, which occurs sooner in some people than in others.(9, 10) While one person may still function excellently at 90 years of age, another may face a loss in functional ability at an early age.

The de-medicalisation of *Healthy Ageing* automatically directs our attention to fields other than just medicine. The *Healthy Ageing* policy framework makes it clear that a loss of capacity is compensated for by interactions with the environment – ‘environment’ being used as an umbrella concept to include the physical, and hence too the technological, environment, as well as the social environment. The fact that my glasses enable me to read my text and see you clearly may be a trivial example, but it is not unimportant in terms of being able to function properly. Each of us is – to a greater or lesser extent – dependent on resources. With the right support of others and a suitable home environment, people with serious psychiatric problems can continue to do as much as possible of what they value. In other words, interactions with the environment facilitate the construction and realisation of a higher level of functional ability than would be possible on the basis of mental and physical capacities alone.

In this context, long-term care can be defined as the activities undertaken by others to ensure that people suffering from, or at risk of, a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.(11) And since that care, and thus the activities that others are required to undertake, are geared to the unique needs of a person, long-term care is by definition person-centred care.

So, once again, and at the risk of unnecessary repetition: long-term care aims to maximise the functional ability of people with a severe, ongoing loss of capacity, not just here and now, but over time. It is emphatically not about taking over tasks for people while this is not strictly necessary, but about maximising functional ability. It is emphatically not just about meeting basic needs, but also about offering the opportunity to learn, grow and make decisions, to be mobile, to build and maintain relationships, and to contribute to society.(5)

## The quality of long-term care: uncertain standards and varying perspectives

Very good. This at least makes the *boîte noire* of long-term care slightly less of a black hole, sucking up all energy and ideas and money, and being immune to our influence: we now have a definition that we can use for guidance and management. But now it's time to take one step further. We now know what person-centred long-term care is, but what is *good* person-centred long-term care? What criteria should a regulator, who is legally called upon to evaluate the quality of care, use in order to arrive at a judgement? The concept of 'quality' always has the connotation of something 'good', but the concept is 'too big and unhandy to move around with'.(12)

Within the framework we have just sketched out, good care means achieving the best possible functioning for a person with an ongoing loss in capacity. This *naturally* entails uncertainty about what 'good care' is, because fixed standards do not apply here.(13) What constitutes good care and support from carers for one person, given

his or her unique situation, may not be good for another. In fact, it is extremely unlikely that it will be. Moreover, what constitutes 'good care' for a person at one point will not necessarily be good care for him or her at another point. Because people's capacities and contexts change over time, different interactions from carers will be necessary to ensure the best possible functional ability.(2, 14)

There is a further consideration. Long-term care consists of activities undertaken by others to maximise a person's functional ability over time. Care thus involves actors who contribute to a permanent reinterpretation of what good long-term care is, in constantly changing networks with each other and with the environment, including the physical environment. On the basis of their own positionality – their values, personality and professionalism – they contribute to the notion of good long-term care. Within these networks, the care workers who most directly shape the provision of care to a person with a loss of capacities in his or her unique context occupy a special and important place, or at least should do. To repeat Tjeenk Willink's warning, care workers 'are not machines that can be switched on and off at will and instructed to shift up a gear whenever an incident has taken place'.(1) In this context, managers and administrators have a facilitating role to play.

## Current regulation of person-centred long-term care

So what does all this mean for *the regulation* of person-centred long-term care? First, let's take a look at the form that regulation currently takes.

Regulation at present is largely risk-based compliance regulation, built on the work of Ayer and Braithwaite and of Sparrow.(15-19) Inspectors make visits to individual care providers and assess compliance with standards based on laws, regulations and so-called field standards. This gives the Inspectorate the reputation of being, as my colleague Ian Leistikow once jokingly put it, a dark force 'that imposes regulations, increases administrative burdens and hands out penalties'.(20)

Black boxes, dark forces...: we have entered a bleak universe, yet what we are concerned with is what it means to be human *par excellence*, the continued optimal functional ability of the most vulnerable among us.

But let me give a lesson about how regulation currently works. The Healthcare Quality, Complaints and Disputes Act (WKKGZ) entrusts the officials of the Inspectorate with the regulation of care providers who are legally obliged to offer good care – care of a good quality and of a good standard – which (a) is in all cases safe, effective, appropriate and client-oriented, provided in a timely manner, and tailored to the actual needs of the client and (b) involves care providers and carers acting in accordance with the responsibilities incumbent on them, derived from professional and quality standards.(21) These professional and quality standards are so-called ‘field standards’, which define what is understood in the field as good care and which are developed and registered in an extremely complex process involving client organisations, care providers or carers, healthcare insurers or service providers as defined by the Long-term Care Act. The criteria for inclusion in the Register are in turn set out in an assessment framework with which the National Health Care Institute assesses whether a quality standard is a responsible description of good care.(22) The Inspectorate then translates all these laws and regulations into its own quality assessment frameworks for care of older people, care of people with disabilities, mental health care and youth care, for example. For each sector, these frameworks describe the standards that care must meet. Inspectors then assess compliance with these standards on the basis of triangulation, and if the care provider does not meet the standard, the Inspectorate takes action.

Are you still with me? Let’s be more specific. One of the standards for person-centred care is that ‘Carers know the client and his or her wishes and needs’. The field, and hence also the Inspectorate, seeks a firm footing in fixed and verifiable standards, in ‘the continuous search for certainty and the desire to minimise risks’ in the words of the Council for Public Health & Society.(23) Inspectors must determine whether care providers comply with the standard and are thus compelled to identify evidence, whether in terms of structure-, outcome- or process-oriented standards.(24) *It must be measurable*. But how do you measure the extent to which a carer knows the client and his or her wishes and needs? We’re back to the peanut butter and chocolate sprinkles. This particular lady likes bread with chocolate sprinkles: you can see that she eats it with relish and she says it’s delicious. And before you know it, the Inspectorate is helping to elevate bread toppings to the highest standard of person-centred care.

Is the current form of compliance regulation consistent with the uncertainty and the indeterminate normativity associated with person-centred care? Does it relate to optimising individuals’ functional ability over time, as described by the *Healthy Ageing* policy framework that our country has endorsed? Does the Inspectorate’s judgement on the quality of care have anything in common with that of the client? An initial study by researchers around my chair suggests that this is only the case to a very slight degree with regard to the quality of nursing home care.(25)

In the remainder of what I have to say, I will make it clear that where there is uncertainty and ambiguity – as is constantly the case in long-term care – a more reflexive approach is appropriate.(26) While in traditional compliance regulation, the regulator checks whether the individual addressee – the care provider – is adhering to standards, there is no such checking in reflexive regulation.(27) One of the more difficult questions here is when and how the regulator is compelled to let go of the reflexive role and switch to an enforcement role.

## The client perspective in current regulation

It is beyond dispute that an approach that takes account of the client perspective closely matches the ambitions of the Health and Youth Care Inspectorate (IGJ). The IGJ’s current multi-year policy plan says: ‘We like to look at care through the eyes of the citizen’, and ‘we are more interested in the perspective of the patient/client’. Along the same lines, Grit and colleagues very recently argued in favour of reinforcing reflexive regulation, on the basis of research carried out for the IGJ on regulating care networks.(28)

Research into the way in which clients and their relatives are currently involved in regulation makes two things clear: actual client participation is not systematically embedded in regulation, and space for reflexive experimentation is needed in order to achieve improvement and resilience.(28-30)

An international overview study from 2020 –with my colleagues Kleefstra and Van de Bovenkamp as co-authors – into the way in which clients are involved in regulation, shows that their involvement is low on the participation ladder.(30, 31) This is true of the Netherlands, but also of countries such as the United Kingdom, Norway and Australia. Client involvement in regulation remains at the level of information provision or consultation: looking up clients’ satisfaction ratings on the website [www.ZorgkaartNederland.nl](http://www.ZorgkaartNederland.nl), for example, or questioning clients during a regulatory visit. Arnstein calls such involvement ‘nonparticipation’: it looks like participation, but in reality it is not.(32)

The study also makes it clear that it is not easy to involve clients in regulation, although we should note that the main area where this was studied was incident investigation. Talking about incidents can of course bring up a lot of emotions in clients, and does not promote their involvement in regulation. However, involving a disparate group of clients also proves difficult with other forms of regulation. This



being the case, one may ask how representative the client perspective will be if it is taken into account.(32) Currently, clients are usually involved in regulation in a manner and at a time of the inspectors' choosing, for example when an inspector happens to see a client sitting in the corridor or during lunch, when inspectors observe the interactions between clients and care workers.(33) Bread toppings come to mind once again!

There is also the lurking danger of token client involvement. Dutch research shows that the experiences of clients that accompany an inspection visit are not automatically taken into account by inspectors in their assessment of a care provider.(34-36) It has been found that they are mainly used to illustrate the inspectors' own views.

Finally, procedures, time and costs can also hinder the involvement of clients in regulation.(31)

Sometimes, it should also be said, some great projects take place in the context of regulation, such as one in which people with mild intellectual disabilities gave their own assessment of the accessibility of municipal social services.(37)

It is also worth mentioning that research shows that it is far from easy for inspectors to maintain the reflexive character of regulation. Rutz and colleagues studied reflexive regulation practices addressing care and support for children growing up in poverty.(36) To arrive at a judgement, inspectors redefined the problem as one of cooperation between the involved parties, and in this way the focus shifted back to a defined risk and a vertical regulatory relationship with a specific addressee, in this case the municipality.(38)

## Towards reflexive regulation

Person-centred care requires reflexive regulation, as I said earlier. Reflexive regulation is a mode of regulation that encourages actors to be open and creative, and to engage in self-observation and self-criticism.(39, 40) It implies the ability to examine yourself, to direct your focus inward and reflect about your own assumptions, actions, policies, systems and processes.(39) Reflexive regulation can be especially helpful with complex issues, which are associated with uncertainty about standards and where different perspectives play a role.(27, 36)

In reflexive regulation, cooperation is called for between all relevant parties; it takes place in interaction between the different actors who play or could play a role in achieving a particular goal.(41, 42) In short, there is a network of actors. *Who can tell?* – Lots of people, in fact. Reflexive regulation does not adhere to the boundaries of sectors, but cuts across them. Suppose the focus is on making meaningful activities more accessible to people with dementia, even if their mental or physical capacities are declining. In that case, it is not just parties from the care sector that are relevant, but also actors from the local voluntary sector, and in addition – let's not forget – non-human factors such as public space, transport or technological resources. In short, in a form of self-regulation, all parties that play a role in achieving an improvement goal enter into a conversation with each other, coordinate with each other and determine who and what is needed in order to get there.

As well as being interactive, reflexive regulation is also a learning process. It constantly sets in motion new cycles of cooperation, consultation, experimentation and adaptation. This requires constant flexibility from all the actors involved, because the learning is not just obvious learning – for example, learning how to improve the accessibility of activities for people with dementia. Reflexive learning also involves 'higher order learning', which considers how (to stay with the same example) it may have come about that people with dementia do not continue to participate sufficiently in activities.(43) What does this say about assumptions, policies, systems and processes, and how can these things be adapted?(39, 44)

Reflexive regulation should be seen as an alternative form of regulation, not as a total replacement of the current compliance regulation. Ultimately, the purpose of regulation – the regulatory object(45) – determines which regulatory strategy is best suited to creating the intended value to society.(46) If we are assessing whether care professionals have the correct qualifications or whether medication is being stored correctly, reflexive regulation is not the right form. If we are dealing with person-centred care, for example for people with serious psychiatric problems, this has a high level of complexity, involving multiple actors and so-called open standards that are dynamic and changeable. Reflexive regulation can be of significant added value in such a context.

# The potential of narrative approaches for reflexive regulation

Some promising narrative approaches are currently being applied in long-term care that have the potential to shape reflexive regulation. These include the 'Presence approach', 'Ask us!' (developed at this university), 'Connecting conversations', 'Images of quality', the 'Lust for life approach' and 'The story as a quality instrument'.(47-52)

The power of narrative approaches lies in the fact that they map out the diverse experiences of different actors and enable reflection on them from different perspectives, such as those of clients, relatives, care workers and care managers. This can give rise to better mutual understanding.(53) It also does justice to the complexity of care and service provision, which may involve conflicting values, changes over time, and institutional constraints.(54)

Because the people entrusted to our care have been lost sight of, we as a society must find a way to listen to these people in order to prevent 'epistemic injustice'.(55) It is therefore important for the inspectorate to ensure that all actors really listen to the client and translate what he or she has to say into the right support. This requires regulators to put away their checklists. As we have already seen, checklists are more about nonparticipation.(32) It requires regulators to let go of their own structures that could stand in the way of an actor's epistemic contribution.(56) As a result, the regulator is no longer primarily the 'dark force that imposes rules', but the driver of reflection.

In reflexive regulation, narrative approaches can help to make the perspective of those whose voices are easily drowned out – clients, relatives and care workers – better heard. Narrative approaches can help to empower clients, relatives, and care workers to actually say what they, and they alone, know, and by doing so to change the interactions within the network. This is especially important if we want to improve the functioning of people with a decline in capacity.

However, we must not be naive. It would be an illusion to think that power relations can be eliminated with the use of narrative approaches. Just take the inspectorate itself: the legislators have given it enforcement powers. As a regulator, how do you ensure that all actors, including clients and care workers, feel invited to have their say? It is very important for inspectors to remain aware of their power at all times and for it not to hinder dialogue.

The use of narrative approaches in long-term care is often mentioned in the same breath as narrative accountability. This is understandable in itself. In her study, Jerak Zuiderent shows how accountability is inextricably linked with day-to-day care practice and arises in interaction.(57) She distinguishes between accountability that is independent of the context and is the same for everyone, for example where performance indicators are used(58), and accountability that is associated with a specific situation and a specific person. She indicates the importance of the latter in her study, and the 'narrative work' of prioritising and specifying what matters most to whom and what'.(57)

Narrative approaches have so far been used mainly to achieve better coordination of care and support between clients, relatives and care workers, and at a team level. Different perspectives on the quality of care are gathered in order to reflect collectively on improvements that are needed. At organisational level or at regulatory level, however, the use of narrative approaches to improve the quality of care and accountability has as yet received little attention in research and practice.

It therefore remains to be seen how narrative approaches can contribute to the quality of person-centred long-term care and the associated external accountability and regulation, and research is required in this area.(59) I would point out that the regulators cannot be present in all places and at all times, and that the main thing is therefore to encourage narrative approaches within long-term care, as well as in the context of accountability.

## Programme for the chair

The development and implementation of reflexive regulation based on narrative approaches are therefore central to the research programme associated with my chair. The RUN programme – RUN stands for Reflexive Regulation Using Narrative Methods – is partly financed by a 1.2-million-euro grant from the Netherlands Organisation for Scientific Research (NWO), within the framework of the Dutch Research Agenda.(60, 61) One of its deliverables will be a toolkit for regulatory practice to improve dialogue and accountability with a view to better functioning of clients, based on narrative approaches, through networks of involved actors.

In order to produce such a toolkit, there are still some questions that we need to answer with this research. For example, what does reflexive regulation mean for the role of the regulator? In reflexive regulation, the regulator no longer assesses the actor who is subject to regulation: instead, the actors within a network assess each other, and the regulator's role is primarily to support this process and drive

it forward. Are actors always willing and able to reflect on their own actions and adjust them where necessary? Might actors not take advantage of the latitude they have acquired to undermine the regulator's influence? Are inspectors able to let go of their primary stance as assessors and enter into dialogue? And do the other actors also perceive that this is the case? Research shows that inspectors who are willing to enter into dialogue are perceived as 'prescriptive' despite their good intentions.(62) Conversely, positive comments are often seen as confirmation – which then leads to stagnation within an organisation. When and how is the regulator compelled to let go of the reflexive role and switch to an enforcement role? We will consider all these questions in our research.

In addition, there are various research projects associated with my chair which aim to systematically embed the perspective of clients and care workers in regulation. For example, research is being conducted into the recognition and appreciation of care workers and how the IGJ as a regulator can use this knowledge to encourage employee retention in the care sector. An earlier project revealed the extent to which expectations regarding recognition and appreciation of care workers differ depending on who you ask: care managers or the care workers themselves.(63)

After this address, it will be clear that research is not separate from regulatory practice. As Paul Robben, the first endowed professor on behalf of the IGJ at Erasmus University Rotterdam, pointed out in his inaugural lecture, the gap between scientific research into regulation and regulatory practice is not easy to bridge.(64) This is why, following on from the Academic Collaborative Centre (AWT), we have organised both the generation of knowledge and its implementation even more closely to and in conjunction with regulatory practice. For example, inspectors who wish to do so are given the opportunity to conduct research to help answer questions. In this way we hope to contribute to the further development and substantiation of the IGJ's regulatory practice.

## Final words

Ladies and gentlemen, the government has been called upon to restore a human scale to the tasks entrusted to it. Society's insistence on the human scale calls for a shift in the practice of regulation. The human dimension is complex, far from straightforward to measure and emphatically not something that can be captured in checklists.

In the first part of this address, I described what the World Health Organization's *Healthy Ageing* policy framework teaches us about person-centred long-term care. Long-term care includes activities undertaken by others to ensure that people suffering from, or at risk of, a significant ongoing loss of intrinsic capacity can maintain a level of functioning consistent with their basic rights, fundamental freedoms and human dignity. It is about how to ensure that people can function as well as possible over time in interaction with their environment. Long-term care is therefore by definition person-centred.

The second part of this address argued that reflexive regulation of person-centred long-term care for these vulnerable people is a promising approach and needs to be further developed and implemented through research. Narrative approaches will be used in this context. In this form of regulation, it is no longer the regulator that assesses: instead, the actors assess one another.

My chair will be largely devoted to the development and implementation of reflexive regulation. I am well aware that this is an ambitious goal. At the same time, my ambition is of a piece with what I have worked on in my career so far, namely the care of vulnerable people, and I also hope that I have made this clear in this address.

## Acknowledgements

At the end of my address, I would like to add a few more personal words.

I am grateful to the Management of the Health and Youth Care Inspectorate for establishing the Chair of *Regulation of person-centred and integrated long-term care*. Thank you for the trust you have placed in me.

I feel very welcome at the Health Care Governance Department of Erasmus School of Health Policy & Management (ESHPM) under the inspiring leadership of Roland Bal. The personal attention between colleagues is very special. Without you and my colleagues Hester van de Bovenkamp and Iris Wallenburg, I could never have made such a smooth transition from geropsychology to regulation of person-centred and integrated long-term care. I look forward to further shaping the research associated with my chair in the coming years, together with you and many other colleagues and partners.

I also wish to mention my colleague Ian Leistikow: you had already been a professor at ESHPM working for the IGJ for several years when I was appointed to my chair there. I could not have asked for a better colleague: you have always been kind enough to answer my questions about regulation, and then listen patiently to my cocksure responses. I have learnt a great deal from you.

I have also learnt a lot from the knowledge and skills of other experts in regulation. These include my fellow professors of regulation in our peer review group, as well as many colleagues at the IGJ: I would specifically like to mention my colleagues in my own Knowledge Team and my other colleagues from the Risk Detection and Development Department.

An important task of my chair is supervising PhD students. In recent years I have done this at Vrije Universiteit Amsterdam, including in the context of my chair in geropsychology.<sup>(65)</sup> I will continue to do this with great pleasure in the Health Care Governance Department of this university.

International collaboration is of great importance for scientific research and practice. I therefore wish to thank my colleagues from the International Psychogeriatric Association (IPA), of which I am President-elect, and look forward to chair the upcoming Lancet Commission on Long-term Care for Older Persons, together with my colleague Kiran Rabheru. I am also grateful to Optentia, North-West University (NWU), Vanderbijlpark, South Africa, where I have been appointed as extraordinary professor, and especially to my colleagues Jaco Hoffman and Ian Rothman. In the coming years I hope to share some of my expertise and knowledge in the field of regulation with people there, and to gain experience and knowledge myself that will help me to reflect critically on regulation in the Netherlands.

Engaging in science is not possible without practice in creativity. I am therefore happy that music has been played today to symbolise that.

Anyone who has read my book *Zorgen van een mantelzorger* (Care and worries of a caregiver) knows that, after a number of difficult years, my parents are no longer alive.<sup>(66)</sup> On a day like today, the loss feels particularly great. But those difficult years with them have only increased my motivation to help ensure that the human perspective is taken into account in care and regulation.

Finally, I consider myself lucky to have Marcel Barnard. Those who know him are aware of his fondness for rituals, provided they are performed well and with dignity. In my previous address, in South Africa, it turned out at the last moment that he was expected to accompany the procession in a borrowed gown.<sup>(67)</sup> To his dismay, however, he did not have a tie with him. I am glad to be able to give you a second chance today, and that you are here – in your very own gown, complete with bands!

And that brings me to the end of my address, 'Who can tell?'

To use the traditional closing phrase (at the risk of sounding slightly 'Potty'):

I have spoken.

# Literature

1. Tjeenk Willink H. Kan de overheid crises aan? Amsterdam: Promotheus; 2021.
2. Kleinherenbrink A. De constructie van de wereld. De filosofie van Bruno Latour. Amsterdam: Boom; 2022.
3. Latour B. The pasteurization of France. Cambridge, Massachusetts: Harvard University Press; 1993.
4. ZIN. Kader passende zorg. Diemen: Zorginstituut Nederland; 2022 [cited 2022 05-09]. Available from: <https://www.zorginstituutnederland.nl/publicaties/adviezen/2022/06/28/kader-passende-zorg>.
5. WHO. World report on ageing and health. Geneva: World Health Organization; 2015 [cited 2022 13-07]. Available from: <https://apps.who.int/iris/handle/10665/186463>.
6. Beard JR, Officer A, de Carvalho IA, Sadana R, Pot AM, Michel JP, et al. The World report on ageing and health: a policy framework for healthy ageing. *Lancet*. 2016;387(10033):2145-54.
7. WHO. Sixty-ninth World Health Assembly 2016 [cited 2022 05-09]. Available from: [https://apps.who.int/gb/ebwha/pdf\\_files/WHA69-REC1/A69\\_2016\\_REC1-en.pdf#page=85](https://apps.who.int/gb/ebwha/pdf_files/WHA69-REC1/A69_2016_REC1-en.pdf#page=85).
8. WHO. UN Decade of Healthy Ageing [Internet] [cited 2022 05-09]. Available from: <https://www.who.int/initiatives/decade-of-healthy-ageing#:~:text=The%20United%20Nations%20Decade%20of,improve%20the%20lives%20of%20older>.
9. Beard JR, Jotheeswaran AT, Cesari M, Araujo de Carvalho I. The structure and predictive value of intrinsic capacity in a longitudinal study of ageing. *BMJ Open*. 2019;9(11):e026119.
10. Beard JR, Si Y, Liu Z, Chenoweth L, Hanewald K. Intrinsic Capacity: Validation of a New WHO Concept for Healthy Aging in a Longitudinal Chinese Study. *J Gerontol A Biol Sci Med Sci*. 2022;77(1):94-100.
11. Pot AM, Briggs AM, Beard JR. The Sustainable Development Agenda Needs to Include Long-term Care. *J Am Med Dir Assoc*. 2018;19(9):725-7.
12. Dahler-Larsen P. Quality. From Plato to performance. Cham, Switzerland: Palgrave Macmillan; 2019.
13. Grit K. Toezicht houden zonder normen. In: Bal R, Leistikow I, Stoopendaal A, editors. *Toezicht in Turbulente Tijden Liber amicorum*. Rotterdam: iBMG Erasmus Universiteit Rotterdam; 2017.
14. Latour B. On actor-network theory. *Soziale Welt*. 1996;47(4):369-81.
15. Sparrow MK. The regulatory craft. Controlling risks, solving problems, and managing compliance. Washington DC: Brookings Institute Press; 2000.
16. Sparrow MK. Fundamentals of regulatory design: Independently published; 2020.
17. IGJ. Hoe werkt ons toezicht? [cited 2022 13-07]. Available from: <https://www.igj.nl/onderwerpen/hoewerkt-ons-toezicht>.
18. Ayers I, Braithwaite J. Responsive regulation. Transcending the deregulation debate. New York: Oxford University Press; 1992.
19. Braithwaite J, Makkai T, Braithwaite V. Regulating aged care. Ritualism and the new pyramid. Cheltenham: Edward Elgar Publishing; 2009.
20. Leistikow I. The Proof of the pudding. De waarde van overheidstoezicht op kwaliteit en veiligheid van de gezondheidszorg [Inaugural lecture]. Rotterdam: Erasmus University Rotterdam; 2018.
21. Rijksoverheid. Wet kwaliteit, klachten en geschillen zorg (Wkkgz) 2016 [cited 2022 13-07]. Available from: <https://www.rijksoverheid.nl/onderwerpen/kwaliteit-van-de-zorg/wet-kwaliteit-klachten-en-geschillen-zorg>.
22. ZIN. Toetsingskader kwaliteitsstandaarden en meetinstrumenten. Versie 3.0 [cited 2022 05-09]. Available from: <https://www.zorginzicht.nl/binaries/content/assets/zorginzicht/algemeen-ondersteuning/toetsingskader-kwaliteitsstandaarden-en-meetinstrumenten-versie-3.0.pdf>.
23. RVS. Blijk van vertrouwen. Anders verantwoord voor goede zorg. Den Haag: Raad Volksgezondheid & Samenleving; 2019.
24. Gilad S. It runs in the family: Meta-regulation and its siblings. *Regulation & Governance*. 2010;4(4):485-506.
25. Palimetakis F, Woutersen K, Pot AM. The relationship between the quality of care in long-term care homes from the perspectives of care users and the healthcare inspectorate. under review.
26. Halfman W, Bal R. After impact: success of scientific advice to public policy. In: Halfman W, editor. *States of nature - Nature and fish stock reports for policy*. The Hague: RMNO; 2008.
27. Scott C. Reflexive Governance, regulation and meta-regulation: Control or learning? In: De Schutter O, Lenoble J, editors. *Redefining the public interest in a pluralistic world*. Oxford: Hart Publishing; 2010.
28. Grit K, Chrifou R, Stalenhoef H, Braspenning J. Bouwstenen voor toezicht op netwerkzorg. Spreken over het functioneren van samenwerkende organisaties. Rotterdam: Erasmus Universiteit Rotterdam; 2022 [cited 2022 05-09]. Available from: <https://www.eur.nl/eshpm/media/2022-03-volledig-rapport-bouwstenen-voor-toezicht-op-netwerkzorg?download=1>.
29. Sabel CF, Zeitlin J. Experimentalist governance In: Levi-Faur D, editor. *Oxford Handbook of Governance*. Oxford: Oxford University Press; 2012.
30. Wiig S, Aase K, Bal R. Reflexive Spaces: Leveraging Resilience Into Healthcare Regulation and Management. *J Patient Saf*. 2021;17(8):e1681-e4.
31. Wiig S, Rutz S, Boyd A, Churrua K, Kleefstra S, Haraldseid-Driftland C, et al. What methods are used to promote patient and family involvement in healthcare regulation? A multiple case study across four countries. *BMC Health Serv Res*. 2020;20(1):616.
32. Arnstein SR. A Ladder of Citizen Participation. *Journal of the American Planning Association*. 2019;85(1):24-34.
33. Verkaik R, Friele R, Francke AL. Evaluatie van een nieuwe vorm van cliëntgericht toezicht: het Short Observational Framework for Inspection (SOFI). Utrecht: Nivel; 2015 [cited 2022 05-09]. Available from: <https://www.nivel.nl/sites/default/files/bestanden/Rapport-IGZ-inspectie-via-SOFI.pdf>.
34. Adams SA, Paul KT, Ketelaars C, Robben P. The use of mystery guests by the Dutch Health Inspectorate: Results of a pilot study in long-term intramural elderly care. *Health Policy*. 2015;119(6):821-30.
35. de Graaff MB, Stoopendaal A, Leistikow I. Transforming clients into experts-by-experience: A pilot in client participation in Dutch long-term elderly care homes inspectorate supervision. *Health Policy*. 2019;123(3):275-80.

36. Rutz S. Practicing reflexive regulation [Thesis]. Rotterdam: Erasmus University Rotterdam; 2017.
37. Frederiks BJM, Tingen A, Dashorst L. De waarde van de inzet van ervaringsdeskundigen met een licht verstandelijke beperking in het Toezicht op het Sociaal Domein. Amsterdam: Amsterdam UMC; 2019.
38. Rutz S, van de Bovenkamp H, Buitendijk S, Robben P, de Bont A. Inspectors' responses to adolescents' assessment of quality of care: a case study on involving adolescents in inspections. *BMC Health Serv Res.* 2018;18(1):226.
39. Hendriks CM, Grin J. Contextualizing reflexive governance: the politics of Dutch transitions to sustainability. *Journal of Environmental Policy & Planning.* 2007;9(3-4):333-50.
40. McNutt K, Rayner J. Is learning without teaching possible? The productive tension between network governance and reflexivity. *Journal of Environmental Policy & Planning.* 2014;20(6):769-80.
41. WRR. Toezien op publieke belangen. Naar een verruimd perspectief op rijkstoezicht. Amsterdam: Amsterdam University Press; 2013.
42. Grit KJ, van Oijen JCF. Toezicht op het medisch-wetenschappelijk onderzoek met mensen: het in kaart brengen van een multi-centered speelveld. Rotterdam: iBMG, Erasmus Universiteit Rotterdam; 2015.
43. Grit K. Review literatuur reflexief toezicht. Rotterdam: HCG, ESHPM; unpublished.
44. Schön DA, Rein M. Frame Reflection: Toward the Resolution of Intractable Policy Controversies. New York: BasicBooks; 1994.
45. de Kam D. Through the Regulator's Eyes. On the effects of making quality and safety of care inspectable [Thesis]. Rotterdam: Erasmus University Rotterdam; 2020.
46. Leistikow IP, Pot AM, Bal R. Value Driven Regulation and the role of inspections. Commentary to: Hovlid E, Husabo G, Teig IL, Halvorsen K, Frich JC. Contextual factors of external inspections and mechanisms for improvement in healthcare organizations: A realist evaluation. *Soc Sci Med* 2022 Apr;298:114872. *Soc Sci Med.* 2022;308:115170.
47. Baart A. Een theorie van de presentie (3e druk). Utrecht: Boom Lemma Uitgevers; 2004.
48. Heerings M, van de Bovenkamp H, Cardol M, Bal R. Ask us! Adjusting experience-based codesign to be responsive to people with intellectual disabilities, serious mental illness or older persons receiving support with independent living. *Health Expect.* 2022.
49. Sion K, Verbeek H, de Vries E, Zwakhalen S, Odekerken-Schroder G, Schols J, et al. The Feasibility of Connecting Conversations: A Narrative Method to Assess Experienced Quality of Care in Nursing Homes from the Resident's Perspective. *Int J Environ Res Public Health.* 2020;17(14).
50. Reinders H. Kwaliteit als ervaring. Antwerpen: Gompel & Svacina Bvba 2019.
51. Roman B, Waterschoot K, Luijckx K. Het verhaal als kwaliteitsinstrument. Een toepassing van narratief onderzoek voor de ouderenzorg Tilburg: Tranzo, Tilburg University; 2018 [cited 2022 05-09]. Available from: <https://www.tilburguniversity.edu/sites/default/files/download/Rapport%20Het%20verhaal%20DEF.pdf>.
52. Leyden Academy on Vitality and Ageing. Langer leefplezier ervaren: Handreiking voor een narratief kwaliteitskader verpleeghuiszorg 2019 [Available from: <https://leefplezierinzorg.nl/wp-content/uploads/2022/03/Handreiking-Leefplezierplan-voor-de-zorg.pdf>].
53. Dryzek J, Pickering J. Deliberation as a Catalyst for Reflexive Environmental Governance. *Ecological Economics.* 2017;131:353-60.
54. Heerings M, van de Bovenkamp H, Cardol M, Bal R. Tinkering as Collective Practice: A Qualitative Study on Handling Ethical Tensions in Supporting People with Intellectual or Psychiatric Disabilities. *Ethics and Social Welfare.* 2021;16(1):36-53.
55. Fricker M. Epistemic Injustice: Power and the Ethics of knowing New York: Oxford University Press; 2007.
56. Kok J, de Kam D, Leistikow I, Grit K, Bal R. Epistemic Injustice in Incident Investigations: A Qualitative Study. *Health Care Anal.* 2022.
57. Jerak-Zuiderent S. Accountability from Somewhere and for Someone: Relating with Care. *Science as Culture.* 2015;24(4):412-35.
58. Poldrugovac M, Pot AM, Klazinga NS, Kringos DS. Use of long-term care performance indicators by regulatory oversight organizations in 10 high income countries. submitted.
59. Ubels GM. Narrative accountability and quality awareness: Learning about (re) presenting narrative care. *J Aging Stud.* 2015;34:190-8.
60. van Erp J, van der Steen M. Wetenschapagenda Toezicht. Utrecht: USBO advies, Universiteit Utrecht; 2018.
61. ESHPM. Het verhaal als basis voor toezicht [Internet] [cited 2022 13-07]. Available from: <https://www.eur.nl/eshpm/onderzoek/het-eigen-verhaal-als-basis-voor-toezicht>.
62. Kasdorp A, Schakel L. Ambiguous signaling in regulatory conversations how miscommunication and hierarchy hamper voluntary regulatee cooperation. *Administration & Society.* 2021;54(5):903-38.
63. IGJ. Stroomversnelling voor krappe arbeidsmarkt in verpleeghuiszorg – uitgebreide rapportage. Utrecht: Inspectie Gezondheidszorg en Jeugd; 2020 [cited 2022 13-07]. Available from: <https://www.igj.nl/publicaties/rapporten/2020/12/10/stroomversnelling-voor-krappe-arbeidsmarkt-in-verpleeghuiszorg-%E2%80%93-uitgebreide-rapportage>.
64. Robben PBM. Toezicht in een glazen huis [Inaugural lecture]. Rotterdam: Marketing & Communicatie ESHPM; 2010.
65. Pot AM. Ouderenpsychologie: de grijsheid voorbij [Inaugural lecture]. *Psychologie en Gezondheid.* 2009;37(2):65-74.
66. Pot AM. Zorgen van een mantelzorger. Een dozijn dagelijkse dilemma's. Utrecht: KokBoekencentrum; 2020.
67. Pot AM. Person-centred care and support for people with dementia and their carers [Inaugural address]. 2019 [cited 2022 13-07]. Available from: <https://www.youtube.com/watch?v=MUD9B8uSXUI>.









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The government has been called upon to restore a human scale to the tasks entrusted to it. Regulating long-term care is key to this, since it is the care of vulnerable people that shines the light most clearly on what it means to be human. Society's insistence on the human scale calls for a shift in the practice of regulation. Person-centred care cannot be judged on the basis of a checklist which asks whether people prefer peanut butter or chocolate sprinkles on their bread. It is infinitely more complex. It is about how to ensure that people can function as well as possible over time in interaction with their environment. And who can judge that better than the people themselves and those who support them? They can tell.

In this address, Anne Margriet Pot considers the importance of reflexive regulation of person-centred long-term care.

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