Dignity of dependence: welfare state reform and the struggle for respect
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Chapter 2

Norm-setting for informal care: the concept of 'customary care'

Submitted as
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What is customary about customary care? How Dutch welfare policy defines what citizens have to consider 'normal' care at home
Abstract

In most welfare states, home care for elderly and disabled persons relies on a combination of private and public responsibilities, with national gatekeepers adjudicating access to publicly funded care. Whereas most countries do not set explicit norms for how much informal care can be expected from citizens, the Dutch government uses a ‘customary care principle’ to distinguish care that is eligible for public funding from ‘normal’ informal care that is not. But the norms set by the Dutch government do not always mirror what citizens consider normal. On the basis of national statistics, interviews with family care-givers, care recipients and assessors, we find that citizens disagree with the government on care-giving outside loving relationships and that which comes at the expense of education or employment. We conclude that while the norm of customary care can in some cases protect citizens from taking on too much responsibility, it has a coercive element for many others who do not agree with its norms.

Introduction

A housewife with two teenage children falls chronically ill and needs help with domestic care. Do we expect the working husband to step in? Can he reject this task and rely on publicly financed home care? How much help can be expected from the co-resident children?

These and other dilemmas of welfare rationing derive from the growing demand for home care and the emphasis on ‘independent living’, which have blurred the boundaries between public and private care responsibilities (Kane, 1995). Many welfare states have extended the right to care to that which takes place within people’s homes, necessitating new rules for what can legitimately be expected from families. How much care-giving can ‘normally’ be expected from citizens and how can this be rationed in the allocation of care?

Systems of allocating care and the place of informal care within them vary greatly between countries. In ‘informal care-led’ welfare states such as Italy and the UK where informal care is the norm (Pavolini and Ranci, 2008), the allocation of care depends on the scarce public services available rather than the expressed needs of disabled and ill citizens (Klein et al., 1996; Rummery and Glendinning, 1999). In ‘services-led’ welfare states such as Denmark and the Netherlands, universal access to publicly financed care for disabled and ill
What is customary about customary care

citizens is a legal right. But as welfare states face ageing societies and financial constraints, such unlimited welfare is increasingly seen as untenable (Thorslund and Bergmark, 1997; Pierson, 2002; Clarke and Newman, 2012). In response, governments in many services-led welfare states are encouraging citizens to consider long-term home care as a ‘normal’ part of domestic life – much as it was before the advent of the welfare state (e.g. Anderson and Parent, 2000; Player and Pollock, 2001; Newman and Tonkens, 2011).

In most European countries, explicit family care duties are reserved for parents of underage children while informal care responsibilities beyond the parent-child bond are subject to assessment by municipal employees or home care providers (Rostgaard et al., 2011). In the Netherlands, norms for informal home care are set at the national level. A ‘generally accepted standard’ was introduced in the 1990s which later became known as ‘customary care’: ‘the normal daily care that partners, parents, co-resident children or other household members are supposed to offer each other’ (CIZ, 2013a). The concept, which codifies what kind of care can legitimately be expected from household members, is used by gatekeepers to assess home care needs.

The concept of customary care emerged in a period when public sector accountability, transparency, control and quality management were priorities in many European welfare states (Duyvendak et al., 2006; Vabø, 2012). Rather than being assessed by ‘biased’ home care providers, care recipients, it was claimed, could now be assessed objectively by specialized gatekeepers (Peeters and Francke, 2007). Between 1996 and 2005, the Dutch government developed a standardized assessment of home care needs that was ‘objective, integral, uniform and independent’ (of stakeholders) (ibid.), implemented by trained gatekeepers working for regional assessment boards (Regionale indicatieorganen, RIO) and later the national assessment centre (Centrum indicatiestelling zorg, CIZ). While such bureaucratic and managerial gatekeeping is common in Europe (Rummetry and Glendinning, 1999), the Netherlands is unique in its formulation of a specific set of informal home care tasks that are deemed ‘customary’.

This article examines the institutionalized norms for informal home care in the Netherlands and the recently developed concept of ‘customary care’ which defines care responsibilities within the household. First, we review why this concept was considered necessary and how it has evolved over time, especially in
the current context of cuts to publicly financed welfare and the encouragement of citizen self-sufficiency. Second, we investigate the extent to which customary care is indeed customary: whether it mirrors what citizens consider ‘normal’ and whether it serves to protect families from – or in fact forces them to – take on too much responsibility.

The paradoxical need for a concept of ‘customary care’

‘Customary care’ suggests care that is ‘normal’, ‘usual’ and ‘generally accepted’ (CIZ 2013a). The assumption of shared ideas and practices gives the concept its legitimacy; the Dutch government claims that the concept simply mirrors the responsibilities that are already ‘naturally’ felt between household members. But the debate on how to define customary care – a concept that, since it is said to be based on generally accepted standards, should not cause confusion in the first place – becomes more curious when one examines changing definitions over time. The government needed 801 words to describe customary care in 2007, whereas it took 2432 words to do so in 2013. Why has defining what is customary become such a complex affair?

When the Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten, AWBZ) covering long-term care for elderly and disabled persons was first enacted in 1968, there was no contestation over the responsibilities of public institutional care and private home care. But two policy shifts subsequently blurred the boundaries. First, care at home became an explicit policy goal in the 1980s: ‘Citizens should live independently in their own environment for as long as possible’ (WVC, 1983:11). Care responsibilities at home could now be both publicly financed and privately met. Second, and especially since the 1990s, clients have been treated as the active ‘consumers’ rather than the passive recipients of care. Since the ‘modernization’ of the AWBZ in 2003, people with long-term care needs can request various types of home care from nursing and personal care to help with daily tasks and domestic aid. By then, care recipients could also receive a monetary allowance instead of services in kind, empowering them to purchase care on the market. The introduction of the personal budget (paid for by public funds) further blurred the divide between private and public responsibilities as household members could
now receive payment for providing care that was previously publicly arranged (Ungerson and Yeandle, 2007; Le Bihan, 2011).

What kind of care at home should be paid for? This became an urgent question, and not only for reasons of public finance. While family members in some households considered it their responsibility to care for their disabled kin, in other households it was considered the responsibility of professionals. In trying to address gender and other differences in care-giving behaviour, the notion of customary care aimed to protect individuals and families from taking on too heavy a burden. The first protocol for customary care allowed regional assessment boards (RIOs) to take into account individual and social differences in care-giving:

'It [customary care] depends on various factors like the lifestyle and the division of tasks within the client system, the strength and values of household members and the like. What is an excessive effort for one person, is an obvious concern for another... The assessor will need to make a good estimate of the capacity-care load ratio of the client system.' (BIO, 1997: 32-33)

Although guidelines were developed for distinguishing customary from non-customary care, the former was not yet an obligation (Morée et al., 2007). This changed when the regional assessment boards were replaced by the current national care assessment centre, the CIZ (2005). The CIZ more strictly enacted the ministry of Health’s policy that ‘it is unjust when citizens receive publicly financed care that according to generally accepted standards should be performed by their social environment’ (CIZ, 2013a: 56). Disabled and ill persons could no longer request publicly financed home care when such care was deemed ‘customary’—defined as the ‘normal, daily care that partners, parents, co-resident children or other household members are supposed to offer each other’ (CIZ 2013a).

Client and informal care organizations struggled with the new norm. While they feared that individual and social differences would be overlooked in the rationing of publicly financed care, the new norm also allowed clients and their relatives to set clear boundaries to their home care responsibilities. It confirmed that informal care beyond what was deemed customary would be exchanged on
free will: ‘When a care dependent person receives [non-customary] informal care, it should always be based on free choice. Mantelzorg [i.e. non-customary informal care] should not be taken for granted, but it should be investigated whether the care-giving does not overburden the care-giver’ (LVIO, 2003: 22). This protective aspect of ‘customary care’ led to client and informal care organizations accepting the concept (Morée et al., 2007). Nevertheless, the introduction of strict rules codifying customary care in 2005 led to turmoil and numerous complaints to the care assessment authority, especially from households which lost their entitlement to publicly arranged house-keeping (WIG, 2013). Client and informal care organizations as well as leftist political parties found the rules too rigid for context-specific cases and doubted it was possible to define what care was ‘customary’ or ‘normal’ for all people – thereby calling into question the very idea of ‘customary’ as such (VWS, 2005; Wolffensperger et al., 2004). Critics also considered the norm of customary care as a sign of government mistrust of citizens too easily requesting public aid (Morée et al., 2007).

But the government, increasingly convinced of the need for cost-containment, further institutionalized the norm of customary care. Initially a guideline for care assessors, it turned into a behavioural norm for each and every citizen (Marseille, 2005; Struijs, 2006). Since 2011, customary care has become part of national AWBZ legislation on citizens’ rights to care (Bza, 2011), serving to define what is ‘normal’ and (de)legitimizing requests for public funding.

The content of ‘customary care’

Defining normalcy
In policy white papers, customary care is described as care that ‘everyone needs (bathing, eating, etc.) but also the care that replaces these “normal” needs due to permanent health problems’ (CIZ, 2013a: 58). As a baseline for time spent on customary care, gatekeepers compare the time needed for a care task for a disabled or ill person with that for a healthy person, for which the frequency and average time spent (in minutes) are determined by the care assessment authority (CIZ, 2013a). Substantial differences in the ‘normal’ time needed to perform these tasks points to ‘non-customary care’.
Customary care responsibilities vary between household members depending on their relationship to the care recipient. A distinction is also made between short and long-term care needs. In short-term care situations – generally a period of up to three months, when recovery is expected – all care tasks within the assigned types of care responsibilities are considered customary. But in long-term care situations – i.e. chronic disorders where care needs (are expected to) exceed three months – customary care consists of only those care tasks which ‘should be performed by the members of the household, based on generally accepted standards’ (CIZ, 2013a: 57). Exceptions include cases where patients are terminally ill or when household members are incapable of performing the assigned tasks (e.g. due to ill health).

*Regulating principles of customary care: physical and social proximity*

Under the current definition of customary care, two criteria define whether or not people are obliged to provide care for each other. First, people must live under the same roof: there must be *physical proximity*. But not all people sharing an address are obliged to care for each other. *Household members* only include persons with whom one shares a sustainable and joint household (CIZ, 2013a: 13): ‘If two people share their main residence in the same house and they show care for each other by means of a contribution to the costs of the household or in other ways’ (ibid.). Hence the second criterion is *social proximity*. But what does this concretely entail? Is it just about *doing* things together (e.g. running a household, paying the bills) or is it about having *feelings* for each other as well? Is emotional attachment a part of social proximity?

The Dutch government’s norm for customary care centres on care exchange in legally recognized relationships: marriage, cohabitation agreements, shared parenthood and other formal agreements of mutual responsibility for a household. But the government also assumes that people in caring relationships share something ‘intimate’ following from the adage: ‘the more intimate the relation, the more care they should exchange’ (CIZ, 2013a: 57). In the case of *adult partners* this intimacy is linked to an *emotional* bond: a ‘partner’ is defined as ‘the adult with whom the care dependent has an *intimate, emotional* bond and shares a joint, sustainable household’ [italics added] (CIZ, 2005: 8).
The government thus assumes household members maintain caring relationships, albeit with varying degrees of intensity. Table 2.1 shows that care duties are most extensive in the parent-child relation, followed by partnerships, and then between other household members (including adult children). The child-parent relationship is considered less intimate; children aren’t obliged to care for their parents to the extent that parents must care for children. While the authorities prescribe these differences based on assumptions of intimacy (Durnová, 2013), countering strategic behaviour – the household separation of adults gaming the rules of customary care – may also play a role (Morée et al., 2007).

Interestingly, the government itself questions the emotional tie adage by defining cases where care recipients can refuse the help of household partners. For the personal care partners are expected to provide each other in cases of short-term need (generally up to three months), the rule is that they should do so even when ‘partners have a dispute’ (CIZ, 2013a). Here the government ignores the basic rule of existing intimate ties and – at least for short-term care – obliges partners to care for each other even when the relationship is strained. But children aged 12 and above (the legal age to make decisions regarding physical integrity) can refuse intimate personal care or nursing from parents. Hence emotional ties – or the lack thereof – matter, but mostly for people in dependent positions or unequal relationships.

Care comes first!

Authorities in the Netherlands have outspoken ideas about how customary care responsibilities trump other activities, in particular paid work, education and all other forms of social participation. ‘By definition having a normal job or being at school can be combined with giving customary care’ [italics added] (CIZ, 2005: 9). The government has set the following priorities:

‘Customary care has priority over the social activities of household members.’ (CIZ, 2005: 9)

‘When (imminent) overload is caused by social activities outside customary personal care, whether or not combined with a full-time school or work week, the performance of customary personal care has priority over those
**Table 2.1 What counts as customary care?**

<table>
<thead>
<tr>
<th>AWBZ</th>
<th>nursing</th>
<th>daily support</th>
<th>living environment</th>
<th>Wmo</th>
</tr>
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<tbody>
<tr>
<td><strong>by partners</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 - yes; all personal care</td>
<td>1&amp;2 - no</td>
<td>1 - yes; all daily support</td>
<td>1&amp;2 - no</td>
<td></td>
</tr>
<tr>
<td>2 - no</td>
<td></td>
<td>2 - yes; all customary (f) daily support</td>
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<td></td>
</tr>
<tr>
<td><strong>by parents</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(of children up to 17 years old)</td>
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</tr>
<tr>
<td>1 - yes; all personal care</td>
<td>1 - yes; all nursing care, provided that tasks can be learnt by a parent within a short period of time</td>
<td>1 - yes; all daily support</td>
<td>1&amp;2 - yes; fully responsible for living environment</td>
<td></td>
</tr>
<tr>
<td>2 - yes; all customary personal care plus one non-customary hour per day</td>
<td>2 - yes; all customary daily support (g) plus one non-customary hour per day</td>
<td>2 - yes; all customary daily support</td>
<td>1&amp;2 - yes; all house-keeping</td>
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<tr>
<td>1&amp;2 - no</td>
<td></td>
<td>1&amp;2 - no</td>
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<tr>
<td>1&amp;2 - no</td>
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<td></td>
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<tr>
<td><strong>by other household members</strong> (incl. children)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1&amp;2 - no</td>
<td></td>
<td>1 - yes; all daily support, except for children</td>
<td>1&amp;2 - no</td>
<td></td>
</tr>
<tr>
<td>1&amp;2 - no</td>
<td></td>
<td>2 - yes; all customary daily support, except for children</td>
<td></td>
<td></td>
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<tr>
<td>a) mainly showering, feeding, dressing</td>
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<td></td>
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<tr>
<td>b) mainly wound care, medication, medical instructions</td>
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<tr>
<td>c) support with daily living; mainly support with social participation, household-related tasks other than cleaning; informing one’s private network on how to deal with care needs</td>
<td></td>
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<tr>
<td>d) creation of protected living environment, i.e. at home</td>
<td></td>
<td></td>
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<tr>
<td>e) mainly cleaning and meal preparation; all house-keeping should be (re)distributed among household members; local variations exist between municipalities</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>f) time guidelines for what is ‘customary’ are based on the time needed for these care tasks for a healthy person</td>
<td></td>
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<tr>
<td>g) e.g. assistance with after-school activities and personal development</td>
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<td></td>
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<tr>
<td>h) for household members up until the age of 23, house-keeping responsibilities are specified by age</td>
<td></td>
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</tbody>
</table>
social activities.’ (Bza, 2013)

‘When overload is caused by too many hours of employment or stress at work, the solution should primarily lie in fewer hours of employment or a way of reducing tensions at work.’ (CIZ, 2013a: 66)

These rules show that customary care has priority over public activities including employment, even when it means care-givers have to work less to avoid burnout (implying reduced income and the risk of poverty).

**Ignoring individual and sociocultural diversity**

In the new guidelines, sociocultural and individual characteristics (except age) play no role in defining expected customary care:

‘With the inventory of possibilities of customary care, no differentiation should be made based on gender, religion, culture, the way of income generation or personal opinions on the performance of household tasks. This is a multiform society, in which every citizen has equal rights to care.’ (CIZ, 2005: 9)

The passage above deserves close reading. Not taking differences into account is considered the best way to guarantee the equal right to care – even when individual or sociocultural differences affect care-giving. In such cases, the only option is short-term publicly financed support for household members to learn the customary care tasks they are expected to perform. However, the very acknowledgement of sociocultural diversity (‘this is a multiform society’) calls into question the existence of ‘generally accepted’ ideas and practices: what is customary in a multiform society? It is by denying these differences, or declaring them irrelevant, that the idea of a normal standard – as well as (the illusion of) equal access to care – can survive.
Changes and variations in the concept of 'customary care'

*Extending customary care*

Since the introduction of the concept of customary care, several changes have extended the care responsibilities of family members. A significant change in 2009 concerned the parent-child relationship: parents were now obliged to perform one hour a day of previously ‘non-customary’ care for their children and view this as ‘customary’. Only care that exceeds this new threshold is considered eligible for public funding. The introduction of the one-hour margin – rather than the previous baseline for a ‘healthy’ child – was legitimized by the idea that all (healthy and ill) children have ‘natural variations’ in the amount of care and attention they require.¹

Although client organisations protested against this extension to customary care, it was implemented nonetheless (CIZ, 2013a: 59). ‘Belangenbehartiger.nl’, an advocacy organisation for people with disabilities, mounted a legal challenge, arguing that this broadening of the concept unjustly restricts access to public care as it is motivated by politics rather than being based on scientific or medical grounds (Belangenbehartiger, 2013). More importantly, Belangenbehartiger.nl argued that the customary care norm was changed within internal CIZ guidelines and not in national legislation, which protects citizen’s access to the AWBZ. The court ruled in May 2013:

‘By not assessing seven hours a week of non-customary care, access to care is restricted. For that, there is no juridical ground… and it therefore conflicts with Article 6 of the AWBZ [i.e. national legislation on the rights of the insured].’ (CRvB 2013)

Although the court found against the CIZ’s broadening of the customary care rule, the CIZ appealed the decision, arguing that customary care can also entail care that is not standard for healthy children but is common among children with chronic conditions: ‘For children with a chronic impairment, it is common that parents give the necessary care, which can be more than on average needed for healthy children of the same age’ (CIZ 2013b: 1). The CIZ further argued that the one hour-rule was not meant to limit the right to care, but to further interpret ‘customary care’ (CIZ 2013c) – namely, to differentiate between
customary and non-customary care for healthy and chronically ill or disabled children. Although the appeal is pending, it is likely that the CIZ will be able to out-argue Belangenbehartiger.

Another important extension to customary care in 2012 introduced the obligation of parents to guarantee a protected living environment for their (disabled) children, thereby raising the threshold for demanding institutional care. As this extension does not directly restrict access to public care, it has not been challenged legally.

**Changing ideas of what is customary**

For now, the Dutch authorities have limited the responsibilities of informal care-giving to people who live under the same roof, share a household, and are emotionally attached to each other. (Adult) children who no longer live at home have no customary care obligations. Whether this will change in the near future – given recent policy reforms to create ‘caring communities’ – remains to be seen.

The Social Support Act (*Wet maatschappelijke ondersteuning*, Wmo), enacted in 2007, aims to make informal care-giving an integral part of the provision of welfare in the Netherlands. While reducing access to publicly financed home care, it encourages both care recipients and their private networks to take on more care tasks ‘voluntarily’ as part of ‘communities of care’. Current Dutch policies combine austerity with moral exhortation to encourage the informal exchange of care between citizens (Kampen *et al.*, 2013). Some local policymakers already assume that neighbours will provide care for each other. Other initiatives urge children to live with, or close to, their care-dependent parents (e.g. by building multi-generational homes, giving care-givers priority on waiting lists for public housing, or by providing mobile ‘care-giving chalets’ that can be placed in parents’ gardens). Whether a new definition of customary care will develop due to these new forms of ‘living apart together’ remains to be seen.

There are, however, signs that customary care will be stretched again in the near future, including the recent call by the Association of Dutch Municipalities (VNG) to develop legal instruments² to realize the Social Support Act’s ambition of greater informal care responsibilities in both citizens’ homes and neighbourhoods (VNG, 2013).
The Social Support Act devolved many of the responsibilities for the care of the chronically ill in national AWBZ legislation to the municipalities. Support for house-keeping is one example. This has since led to municipalities invoking ‘customary care’ in their own policies to define private and public responsibilities. Although 85% of municipalities use the national customary care appendix to formulate their policies (De Klerk et al., 2010a), research shows that they differ in how they make use of this appendix (ibid.). For example, most municipalities peg the minimum age of a child’s first responsibilities in house-keeping at five, while other have it at age eight (e.g. Gemeente Zaltbommel, 2012). Research in the UK has shown the tension between universal welfare rights and regional differentiation in similar processes of social welfare devolution. While supporters of devolution argue that regional welfare organisations can more accurately serve the needs of their clientele (and would therefore be more just), opponents warn that ‘territorial justice’ is undermined when regional policies give different rights to citizens – with the risk of weakening solidarity across the polity as a whole (Chaney, 2013).

The use of ‘customary care’ in municipal policies once again shows how the concept is being used not only to describe the ideas and practices of ‘normal’ care-giving among household members, but to define care that the government explicitly does not consider a public responsibility. The fact that ‘customary’ is no longer exclusively defined at the national level also introduces local variations to the meaning of ‘customary’, potentially undermining any national claims to what is ‘generally accepted’ and ‘normal’.

What care do citizens consider ‘customary’?

Methods
We now turn to what we know about Dutch citizens’ perceptions of ‘customary care’. We combine survey findings with our own interview data on care-givers and recipients’ perceptions of the boundaries of customary care. The survey data come from national statistics compiled by the Netherlands Demographic Interdisciplinary Institute (NIDI) and the Netherlands Institute for Social Research (SCP). The interview data derive from our interviews with clients and/or their co-resident family members whose care needs at home were recently assessed. From an existing sample of 45 clients and their representatives
who were re-assessed by the CIZ for assistance with daily living in 2009-2010 as provided by the AWBZ, we selected 20 respondents to whom the customary care norm applied. We also purposefully selected four clients and seven care assessors who had been involved in assessments for house-keeping support in 2013, as carried out by municipalities under the Social Support Act. Additionally, we observed four assessments by telephone for requested house-keeping support. In all cases, clients had at least one adult healthy household member who could provide ‘customary care’.

In the interviews, we asked care recipients, co-resident family members and assessors how they understood the government’s norms for customary care and their reasons for agreeing or disagreeing with them. Overall, these empirical data give us a picture of whether, where, and to what extent the government’s ideas on ‘customary care’ mirror – as the government claims – people’s own beliefs and experiences in daily life.

Customary care: care that is customary?
Informal care-giving is common in the Netherlands. In 2008, 1.4 million people were providing intensive informal care (i.e. for more than eight hours per week). Of these, 1.1 million persons (about 7% of the Dutch population) were providing long-term care (i.e. for periods over three months). More citizens are prepared to provide short-term care: in caring for the elderly, 53% of the Dutch population expressed willingness to provide short-term care, in contrast to 36% for long-term care (De Klerk et al., 2010b). Care was usually provided to non-household members: elderly parents (in law) were the largest group of informal care recipients (40%), followed by friends, acquaintances and other relatives (30%). The remaining 30% of cases involved caring for co-resident family members (partners and children) (Oudijk et al., 2010). Unlike the government’s concept of customary care, these figures suggest that care norms are not tied to the home.

Most informal care-givers reported providing emotional support, supervision and accompaniment on outdoor visits to their close relatives – more often than domestic care, help with administration, personal care or nursing (Klerk et al., 2010a). It seems that the more intimate the care need becomes, the fewer people consider it a ‘normal’ family task. Personal care and nursing most often take place in the parent-child relation (ibid.). The motives to care also point to the
affective bond: for most informal care-givers, feelings of affection are the most important reason for providing care, followed by ideas about ‘the proper thing to do’ (Timmermans, 2003; Dykstra and Fokkema, 2007).

Social proximity thus appears as an accurate regulating principle for customary care: the majority (83-92%) of the Dutch population would perform care tasks because they care about their family. However, more than half of the population thought one is not obliged to perform care tasks for family members one does not like (Dykstra and Fokkema, 2007) – a significant divergence from the government’s norm. The extent to which the government’s concept of ‘customary’ is mirrored by citizens’ feelings and practices is thus questionable: citizens only feel responsible to provide care in good times, while government policies oblige them to become care-givers in good times and bad.

Physical proximity as a regulating principle for customary care was supported by the majority of clients with moderate to severe disabilities, who considered it normal that non-handicapped household members (77%) or non-handicapped adult children who live with their disabled parents (64%) contribute to household tasks \([N=673]\) (Marangos et al., 2008: 23). Care-givers also found it normal to care for household members: more than 90% of those caring for a partner or child found their responsibilities to be self-evident \([N=931]\) (Timmermans, 2003: 45). It thus took co-resident family members time to find out that some of their care-giving was considered ‘non-customary’ and was thus eligible for public funding. A mother of a cognitively disabled son stated:

‘Many things are normal for me. It is only when you talk to other people that you realize it is not normal. And also, the woman from the CIZ told me: ‘you have to think that normally, a 13-year old boy can do this all by himself. And now, you have to do it for him’. Like, I prepare his clothing, brush his teeth, and check his toileting. These kinds of things.’

Due to the deeply embedded norm to care for one’s children – disabled or not – the care assessor had to convince the mother she was doing more than what was deemed ‘customary’.

Despite the perceived norm to care for family members one lives with, this type of physical proximity within households is declining in Dutch society. The percentage of people sharing a household is declining – the number of single-
person households increased by half a million between 2000 and 2012 (CBS, 2012) – while the average number of people sharing a household is expected to decrease even further from 2.3 in 2006 to 2.1 in 2050 (CBS, 2007). This trend is typical for Western societies and is often presented as a new social risk (Hancock, 2002). In the Dutch case, the absence of household members is sometimes even an adverse effect of the customary care concept itself. Following the introduction of ‘customary care’ in the assessing of entitlements, care-giver advocacy groups have warned of ‘undesired developments’ – of adult children refusing to take in their elderly parents and adult children leaving the household to secure their eligibility for publicly financed care (Wolffensperger et al., 2004).

The decrease in the average number of household members – and therefore in the amount of customary care provided by them – has led the government to consider initiatives such as encouraging multi-generational homes. But this seems to go against the preferences of Dutch citizens, who show little interest in creating new multi-generational households with adult family members. Between 0 and 1% of respondents would like to live in with their children or ask one of their children to live in when they are old and incapable of living on their own [N=7800] (Dykstra and Fokkema, 2007: 125). We see a similar reluctance among care-giving (adult) children. Only between 9 and 11% of respondents stated they would like to have their elderly parents living with or very close to them (ibid.).

From the government’s perspective, care-giving responsibilities at home have priority over social activities and employment. This valuation of care-giving over work clashes with the views of citizens, whose feelings of care responsibility are weakest when significant costs such as disturbance of working life and loss of income are involved (Dykstra and Fokkema, 2007). Among care recipients we see a similar reluctance to ask for help from busy household members: 82% of those with moderate to severe disabilities thought more professional care should be arranged when household members have demanding work or school obligations (Marangos et al., 2008). Our interviewees also felt squeezed between their ‘customary’ care needs and the busy lives of household members. A 59-year-old woman with physical disabilities:

‘My [23-year old] daughter works and goes to school. She works at different theatre productions here and there, therefore she is very busy and often not
at home…. She works very hard in the evenings and at night. I don’t see when she could do the household tasks! … Of course, she helps sometimes, with vacuum cleaning or something like that. But you cannot expect her to keep the whole household running.'

People with ‘customary’ care needs do not want to demand care from co-resident family members if this means they will have to give up their daily activities. A 33-year old woman with a chronic illness who was rejected housekeeping support said that enforcing the customary care norm (which deviates from her own) upon her husband creates internal moral conflict:

'I really wanted to receive outside housekeeping support, because I do not want to burden my husband…. When my husband gets home from work at midnight, I hear him cleaning up in the kitchen or some other housekeeping, and that really makes me feel guilty.'

For citizens who had higher expectations of publicly financed care than what is currently offered, the (new) policy guidelines come as a surprise. Care assessors have been trained to deal with the expectations of disappointed citizens – by conveying that there is a standard, applicable also to those who disagree with it. A (female) assessor of housekeeping support stated:

'Customary care, is care that is customary, which is the custom, actually. Because that is what it is; it is the habit, what is generally accepted as just. By the average citizen.'

As there is no such thing as an ‘average citizen’ in reality, care assessors use the vocabulary of customary care to make it sound self-evident. A (female) care assessor of housekeeping needs told a daughter of an ill mother who requested support:

'Now you live in with your mother, you say, you are now busy with your job, but you should help your mother in the household. Because it is customary care!'
Ideas about what is ‘customary’ vary considerably among citizens. For example, people with religious backgrounds tend to maintain stronger feelings of obligation towards their parents than non-religious citizens (Dykstra and Fokkema, 2007). And compared to native Dutch people, norms for greater involvement in care-giving were found among all immigrant groups, with the most demanding care norms found among Muslim immigrant groups. Just as changing policies have challenged the norms of citizens with previously more limited conceptions of customary care, they might also have the consequence of narrowing these norms for people with broader notions of customary care. For example, second-generation immigrants have higher expectations of public support with home care needs than first-generation immigrants (ibid.).

For citizens who have adjusted their care-giving to the government’s norms and requested public support for ‘non-customary’ care, the recent broadening of what is considered ‘customary’ has come as a surprise. Clients (and their representatives) who were re-assessed for their care needs for support with daily living in 2009-2010 now faced new rules for children living at home. A mother of a 15-year-old autistic boy related how the previously ‘non-customary’ nature of her autistic son’s care needs was re-assessed:

‘Now they [gatekeepers] attribute a lot of things to his puberty. Because well, if he doesn’t want to wear clean underwear, then they say that it is something normal adolescents also resist. But the difference is that I have to force him ten times to make him do it, and if I don’t then I am certain he doesn’t . . . I understand that he is older now, and is expected to be able to do more for himself, but if you look at all the extra work and costs we have as a family I think it [the more extensive customary care norm] is not justified.’

In earlier assessments, parents had learnt not to overburden themselves with ‘non-customary’ care tasks and to request public support instead (see also Grootegoed, 2013). But the recent extensions and stricter application of the customary care norm tell them otherwise. Even though these shifts clearly stem from policy changes and do not correspond to changes in clients’ situations, care assessors still present ‘customary care’ as a concept that derives its legitimacy from mirroring social reality.
There are, however, boundaries to how far the authorities can stretch the concept. As customary care is now part of national legislation which protects citizens’ access to the AWBZ, legislators can now oppose government attempts to stretch the norm. Amendments to the customary care norm that restrict access to care cannot be made by the CIZ in its internal guidelines without changing national legislation. For example, the obligation for parents to count one hour of previously non-customary care for disabled and ill children per day as customary was the subject of a legal challenge in 2013. The court found against the new measure, reasoning that non-customary care cannot be enforced. Depending on the outcome of the CIZ’s pending appeal, the measure may yet be reversed.7

Conclusion

The Dutch government has set clear boundaries between public and private responsibilities for long-term care at home. Its norm for ‘customary care’ informs citizens how much care is normally exchanged between household members, and what is beyond customary and eligible for public funding. Although the government – by using words such as ‘usual daily care’ and ‘generally accepted standards’ – presents customary care as a ‘mirroring’ concept that reflects a norm ‘out there’, its changing guidelines and legal definitions indicate top-down norm-enforcement rather than a description thereof. Were the suggestion of ‘generally accepted standards’ true, a 2432 word description of customary care would be unnecessary to address problems of interpretation. Our empirical data indeed suggest that the idea of normalcy contained in the notion often diverges from the opinions and sentiments of citizens.

With its agenda to further roll back public responsibilities for long-term care, the Dutch government is extending and more strictly applying its norm for customary care. But the gap between the norm and the diverse interpretations citizens have about the care they consider normal to give or receive may widen with its further enforcement – especially as citizens have learnt that care beyond what is deemed customary is ‘voluntary’ and eligible for public support.

The very idea of customary care as reflecting what is customary in society is highly questionable. By setting extensive guidelines, the government directs citizens to conform to (new) standards of normalcy, under the dictum of equality. But notions of ‘customary care’ may indeed be difficult for many
citizens to oppose, precisely because their care-giving hinges on the belief that ‘it is normal to do so’. In the long run, we can expect changes to citizens’ beliefs about what is normal.

Finally, the principle of equality becomes highly questionable under the recently enacted Social Support Act which gives municipalities more authority over care arrangements. While the customary care norm can be applied differently in local settings – presented as a ‘tailored approach’ – variation at the individual level is not allowed and said to undermine equal access to care among citizens. This local variation of the customary care norm may ultimately undermine the legitimisation of the norm altogether.

Notes

1 No ‘natural’ variation of care needs is assumed for adult household members.
2 These legal instruments do not conflict with ‘the right to care’ as the Wmo (as opposed to the collective AWBZ insurance) is a framework law that does not operate on the basis of uniform, fixed care rights.
3 The current plans consist of a further devolution of AWBZ responsibilities to municipalities: in 2015 personal care and help with daily tasks will also be incorporated into the Social Support Act.
4 Despite the intent of the Social Support Act to encourage informal care, almost no municipalities have extended the non-customary care norm in the rationing of housekeeping support. Variations have instead involved a loosening of the customary care norm (15% in 2007 and 13% in 2008 of all 443 Dutch municipalities) (De Klerk et al., 2010a: 88).
5 This interview was held in 2009 when the measure was just enacted, i.e. before it was appealed in court in 2013.
6 The research was conducted in 2009 when the measure to expand the customary rule for parents of co-resident children with one hour of non-customary care per day was still in effect.
7 The government is planning to devolve further responsibilities for long-term care to municipalities and stretch the customary care norm from 60 to 90 minutes per day. How this can be legally achieved remains unknown. It partly depends on the outcome of the CIZ’s appeal of the court’s decision on the extension of care for children and the legal precedent it creates. If the government adjusts national legislation on access to care as a right, further trials can be avoided.
What is customary about customary care

References


Belangenbehartiger (2013) VWS legt uitspraak van hoogste rechter naast zich neer.


CIZ, Centrum Indicatiestelling Zorg (2013c) Herziene beschikking op bezwaar van een cliënt [02-036374], 16 May 2013.

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