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

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Abstract

In most welfare states, home care for elderly and disabled persons relies on a combination of private and public responsibilities, with gatekeepers adjudicating access to publicly funded care. Unlike other governments, the Dutch government has codified an explicit 'customary care principle' that defines the 'normal daily care that partners, parents, co-resident children or other household members are supposed to offer each other' (CIZ, 2013a) to calculate entitlements to publicly funded care. But the norms set by the Dutch government do not always mirror what citizens consider normal. Using national statistics and interviews with family care-givers, care recipients and assessors, we find that while the norm of customary care can sometimes protect citizens from taking on too

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much responsibility, it has an enforcing element for many others who do not agree with its norms. We discuss the implications of this coercive element for principles of equality, particularly in times of austerity.

Key words

austerity, equality, family care norms, home care, welfare rationing

Introduction

Sometimes I have difficulty with the share of informal care people must deliver ... But I cannot take that into account. I can say that I understand that it is difficult, that it is quite a load, but it does not change anything. It is what is expected of you.

The gatekeeper assessing disabled and elderly people's eligibility for house-keeping support in the above quote is alluding to the Dutch government's latest norm for 'customary care'. This norm defines the 'normal daily care that partners, parents, co-resident children or other household members are supposed to offer each other' (CIZ, 2013a: 13). Customary care, in other words, is not eligible for public funding.

The extension of the right to publicly funded care to care that takes place within private homes has necessitated new rules for what can legitimately be expected from families (Kane, 1995). In the face of ageing societies and budget cuts, governments in many 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. Newman and Tonkens, 2011). Cuts to publicly financed care in many European countries are leading to mounting private care responsibilities (Rostgaard et al., 2011). Governments are trying to make informal care more attractive to citizens by making it easier to combine care-giving and paid work (e.g. the Netherlands), through cash-for-care schemes for care-givers (e.g. UK, Ireland), through personal budgets for care recipients (e.g. Germany, Austria), and through moral exhortation (e.g. UK, the Netherlands). With the exception of Denmark, the availability of informal care is taken into account when assessing needs (Rostgaard et al., 2011). But only in the Netherlands has the government codified the involvement of informal care-givers with a norm for customary care that goes beyond legal family obligations (i.e. parent–child and marital bonds).

This article examines the institutionalised norms for informal home care in the Netherlands and the recently developed concept of customary care which defines care responsibilities within households. We first review why a norm for customary care was considered necessary and how it has evolved over

time. We then examine the extent to which customary care is indeed customary: whether it mirrors what citizens consider 'normal' and whether it serves to protect families from being overburdened, or instead forces them to take on more responsibilities. Finally, we examine the implications of the latest norm for care-giving practices.

The transformation of a concept

The norm of customary care was first introduced in the 1990s in the context of defining access to the Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten*, AWBZ), which covers long-term care for elderly and disabled persons. When the AWBZ was first introduced 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, by the late 1990s, care recipients could also receive a monetary allowance instead of services in kind, allowing them to purchase care on the market. The introduction of this *personal* budget (paid for by *public* funds) further blurred the division between private and public responsibilities as household members could now receive payment for providing care that was previously publicly arranged (Pijl and Ramakers, 2007).

The concept of customary care emerged in a period when public sector accountability, transparency, control and quality management were high on the agenda (Duyvendak et al., 2006). Rather than being assessed by 'biased' home care providers, care recipients' needs, policy-makers claimed, could now be assessed objectively by specialised gatekeepers (Peeters and Francke, 2007). Between 1996 and 2005, the Dutch government developed a standardised assessment of home care needs that promised to be 'independent [of stakeholders], objective, uniform and integral' (Peeters and Francke, 2007: 21), implemented by trained gatekeepers working for regional assessment boards (*Regionale indicatieorganen*, RIO) and, later, for the national assessment centre (*Centrum indicatiestelling zorg*, CIZ). The norm of customary care was originally intended to strengthen the client's position in the assessment trajectory. Van Ogtrop, project leader of the expert team that developed the norm, stated:

We aimed for uniformity and equal rights. Everyone should get the same care. Do assessors think the same in Amsterdam and Roermond? Do we think the same in Protestant and Muslim environments? Regardless of cultural, gender and age differences, everyone should be entitled to the same care. (Morée et al., 2007: 19)

The norm reached deeply into the private sphere. For example, men were expected to provide as much care as women, even when this contradicted the traditional male breadwinner model which remains the reality for many Dutch families (Morée et al., 2007). The norm was envisioned to have two effects on care-giving patterns. On the one hand, customary care would set limits to the duties of relatives who might be at risk of overburdening themselves. The norm was thus supposed to have a *protective* effect by confirming that informal care-giving beyond what was deemed customary would be a free choice:

When a care dependent person receives [non-customary] informal care, it should always be based on free choice. Such care should not be taken for granted, and it should be investigated whether the care-giving does not overburden the care-giver. (LVIO, 2003: 22)

On the other hand, the notion of customary care was meant to have an *enforcing* effect by addressing gender and other differences in care-giving behaviour and by expecting all citizens to live up to the same norm. But given the absence of sanctions in cases of non-compliance, its coercive element is limited to defining the boundaries of publicly financed care. Customary care thus relies on the normative expectation that all families will provide a certain amount of care.

The balance between the protective and coercive sides of the customary care norm has changed over time. At the outset, the norm was only used as a guideline for regional assessment boards to assess families' care-giving capacities:

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.

The introduction of strict rules codifying customary care in 2005 led to turmoil and numerous complaints to the care assessment authority, especially

from households that lost their entitlement to publicly arranged housekeeping (WIG, 2013). Client and informal care organisations as well as left-wing 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 institutionalised the norm.

What was initially a guideline for care assessors has become a behavioural norm for all Dutch citizens (Marseille, 2005; Struijs, 2006). Since 2007, the concept of customary care infuses the new Social Support Act (*Wet maatschappelijke ondersteuning*, Wmo), under which local authorities have greater responsibilities for financing and organising care. The Social Support Act particularly encourages citizens to take on private care responsibilities. Since 2011, customary care has also been codified in national AWBZ legislation on citizens’ rights and duties (Bza, 2011).

The term customary care suggests care that is ‘normal’, ‘usual’ and ‘generally accepted’ (CIZ, 2013a). The assumption of shared ideas and practices gives the concept a sense of legitimacy, while the Dutch government claims it simply mirrors the responsibilities already ‘naturally’ felt between most 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 – becomes truly puzzling when one examines changing definitions over time. The government needed 801 words to describe customary care in 2007, whereas it took 2,432 words to do so in 2013. Defining ‘normal’ is a complex affair.

Defining normalcy

Policy white papers describe customary care 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 point 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 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 that ‘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 provide 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’ (CIZ, 2013a: 13). 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 recognised 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 dependant has an *intimate, emotional* bond and shares a joint, sustainable household’ (CIZ, 2005: 8, italics added).

The government thus assumes household members maintain caring relationships, albeit with varying degrees of intensity. Table 1 shows that care duties are most extensive in the parent-child relationship, followed by partnerships, and then between other household members (including adult children). The child-parent relationship, however, is considered less intimate than the parent-child relationship; children aren’t obliged to care for their parents to the extent that parents must care for their children. While the authorities prescribe these differences based on assumptions of intimacy, anticipated strategic behavior may also play a role in setting the customary care norm; adults can game the rules by maintaining separate living addresses (Morée et al., 2007).

Table 1. What counts as customary care?

	<i>AWBZ (Exceptional Medical Expenses Act)</i>	<i>Nursing^b</i>	<i>Daily support^c</i>	<i>Protected living environment^d</i>	<i>Wmo (Social Support Act)</i>
	<i>Personal care^a</i>				<i>Housekeeping^e</i>
By partners	1 – yes; all personal care 2 – no	1&2 – no	1 – yes; all daily support 2 – yes; all <i>customary^f</i> daily support	1&2 – no	1&2 – yes; all housekeeping
By parents (of children up to 17 years old)	1 – yes; all personal care 2 – yes; all <i>customary</i> personal care plus one non-customary hour per day	1 – yes; all nursing care, provided that tasks can be learnt by a parent within a short period of time 2 – yes; all <i>customary</i> nursing plus one non-customary hour per day	1 – yes; all daily support 2 – yes; all <i>customary</i> daily support ^g plus one non-customary hour per day	1&2 – yes; fully responsible for protected living environment	1&2 – yes; all housekeeping

(Continued)

Table 1. (Continued)

	<i>AWBZ (Exceptional Medical Expenses Act)</i>	<i>Nursing^b</i>	<i>Daily support^c</i>	<i>Protected living environment^d</i>	<i>Wmo (Social Support Act)</i>
	<i>Personal care^e</i>				<i>Housekeeping^e</i>
By other household members (including children)	1&2 – no	1&2 – no	1 – yes; all daily support, except for children 2 – yes; all <i>customary</i> daily support, except for children	1&2 – no	1&2 – yes; all housekeeping, except for children ^h

1 – Short-term, i.e. prospect of recovery, less than 3 months.

2 – Long-term, i.e. chronic care needs, more than 3 months.

^aMainly showering, feeding, dressing.

^bMainly wound care, medication, medical instructions.

^cSupport 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.

^dParents must provide a protected living environment for their children until the age of 17, i.e. at home, with physical and social security and an appropriate educational environment.

^eMainly cleaning and meal preparation; all housekeeping should be (re)distributed among household members; variation between municipalities.

^fTime guidelines for what is 'customary' are based on the time needed for these care tasks for a healthy person.

^gFor example assistance with after-school activities and personal development.

^hFor household members up until the age of 23, housekeeping responsibilities are specified by age.

Interestingly, the government itself questions the emotional tie adage by defining cases where care recipients can or cannot 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: 60). 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!

The Dutch authorities are outspoken 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’ (CIZ, 2005: 9, italics added). 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 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 how much care-giving is considered customary:

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 existing differences between households into account is considered the best way to guarantee the equal right to care – even when these individual or sociocultural differences affect care-giving. In such cases, the only option for those who do not yet provide customary care according to the government's standards is short-term publicly financed support for household members to *learn* the customary care tasks they are expected to perform. The acknowledgement of sociocultural diversity ('this is a multiform society') is not translated into differentiated norms for different groups to secure comparable care provision for all. Government policy thus de facto ignores that society is multiform. And it is by denying these differences – or declaring them irrelevant – that the idea of a normal standard can survive. But are 'equal rights to care' thereby guaranteed? Is equal treatment of unequal cases fair (cf. Taylor, 1994; Young, 1990)?

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 of care for a 'healthy' child – was legitimised by the idea that all (healthy and ill) children have 'natural variations' in the amount of care and attention they require.

Although client organisations protested against this extension of customary care, it was nonetheless implemented (CIZ, 2013a: 59). 'Belangenbehartiger.nl', a non-profit law firm advocating civil rights, mounted a legal challenge, arguing that this broadening of the concept unjustly restricts access to public care as it is motivated by political (and primarily financial) considerations rather than being based on scientific or medical grounds (Belangenbehartiger, 2013). More importantly, Belangenbehartiger.nl, 2013 argued that the customary care norm was changed within internal CIZ guidelines and not in national legislation, which protects citizens' 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)

The CIZ appealed against 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. In the end, the court decided that the CIZ had unjustly applied the one-hour margin to all families, emphasising its duty to investigate what counts as customary care for each child. As of 2014, the one-hour margin has been rescinded (CRvB, 2014).

Another important extension of 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.

There are thus limits to how far the authorities can stretch the concept of customary care. As it is now part of national legislation protecting citizens’ access to the AWBZ, legislators can 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.

Changing ideas of what is customary

Despite the legal difficulties of entrenching the customary care norm in national AWBZ legislation, the Dutch government has been actively promoting the norm through the 2007 Social Support Act. The Social Support Act devolved many of the responsibilities for the care of the chronically ill in national AWBZ legislation to the municipalities. Unlike the AWBZ, the Social Support Act entails fewer rights-based entitlements to care and emphasises personal responsibility:

Personal responsibility ... also includes appealing to family and friends – one’s own social network – before one knocks at the local authority’s door for help. Indeed, it is quite normal for people to do something for their partner, family member or close friend if one cannot participate in society entirely on one’s own. The government wants to break the automatism of residents turning to the government with each and every request for help. (VWS, 2014: 20)

More recently, under the aegis of the Social Support Act, local governments have introduced a twin concept to customary care: ‘customary help’ (VWS,

2014). Although in current policy documents ‘customary help’ and ‘customary care’ refer to the same norms, the term ‘help’ can (and probably will) be stretched to a broader range of activities, including support for elderly parents living outside the household (Raad van State, 2013). The term customary ‘help’ also de-medicalises customary care, suggesting that professional care is unnecessary (Grootegoed, 2013a).

Municipalities differ in their interpretations of what counts as customary care. Although 85% of municipalities use the national customary care appendix to formulate their policies, research shows that they differ in how they make use of this appendix (De Klerk et al., 2010a). For example, most municipalities peg the minimum age of a child’s first housekeeping responsibilities at five, while others put 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).

Municipal policies reveal how customary care 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 its meaning, 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. First, we used survey findings from national statistics compiled by the Netherlands Demographic Interdisciplinary Institute (NIDI) and the Netherlands Institute for Social Research (SCP) to determine how far the norm of customary care mirrors what citizens consider ‘normal’ care. Second, we interviewed care-givers and care recipients subjected to the implementation of the latest norm to see how they experienced it. Our data here derive from interviews with clients and/or their co-resident family members whose care needs at home were (re-)assessed by the CIZ (under AWBZ legislation) or by the municipality (under the Social Support Act). From a wider PhD project sample of 45 clients and their representatives

re-assessed for the AWBZ in 2009–2010 (Grootegoed, 2013b), we selected 20 respondents who experienced mounting informal care responsibilities due to cuts in support for daily living and the – then still valid – one-hour margin of customary care for disabled children. To study the new, local implementation of the norm (under the Social Support Act), we interviewed four clients and seven (female) care assessors involved in (re-)assessments for housekeeping support by the Municipality of Amsterdam in 2013. Additionally, we observed four assessments conducted over the telephone, again for housekeeping support. In all cases, clients had at least one healthy adult household member who could provide customary care. In the interviews, we asked care recipients, co-resident family members and assessors how they understood and experienced the government's norms for customary care. Overall, these empirical data yield a picture of whether, where, and to what extent the government's ideas of customary care mirror popular beliefs or impose new norms upon citizens.

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). In contrast to the government's concept of customary care, these figures suggest that care-giving is not tied to the home. Nevertheless, care-givers 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 takes co-resident family members time to find out that some of their care-giving is considered 'non-customary' and is eligible for public funding. A mother of a 17-year-old cognitively disabled son reflected on her first encounter with the assessment authority in 2005:

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.

Owing to the widely accepted norm to care for one's co-resident children – disabled or not – the care assessor in fact had to convince the mother she was doing more than what was deemed 'customary'. Physical proximity as a regulating principle for customary care also counts for care recipients; for example, the majority of clients with moderate to severe disabilities considered it normal that non-disabled household members (77%) or non-disabled adult children who live with their disabled parents (64%) contribute to household tasks ($N = 673$) (Marangos et al., 2008: 23).

The relevance of the norm to care for family members one lives with, however, is declining alongside this type of physical proximity in Dutch households. The percentage of people sharing households is shrinking: 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 further from 2.3 in 2006 to 2.1 in 2050 (CBS, 2007). In the Dutch case, the absence of household members may at times be an adverse effect of the customary care concept itself. Following its introduction 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 eligibility for publicly financed care (Morée et al., 2007; Wolffensperger et al., 2004).

The decline 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 that they would like to have their elderly parents living with or very close to them (Dykstra and Fokkema, 2007: 125).

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 (De Klerk et al., 2010a). Bodily care (i.e. personal care, nursing) most often takes place in the parent-child relationship (De Klerk et al., 2010a). It seems that the more intimate the care need becomes, the fewer people consider it a 'normal' family task. 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' (Dykstra and Fokkema, 2007; Timmermans, 2003).

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 people are not obliged to perform care tasks for family members they do not like (Dykstra and Fokkema, 2007) – a significant divergence from the government's norm that urges citizens to provide customary care even in times of dispute. Family care-givers who feel pressured to provide care admit such emotional tensions can create difficulties. A mother of a 21-year-old daughter with multiple disabilities (chronic illness, autism) stated:

Well, she is not an easy child. That is for sure. If you yourself are not well, then it [i.e. caring] can be quite difficult. Because honestly, that does happen ... Once I was furious [about an incident with a nurse]. And then Sophie [her daughter] bears the brunt because I am angry and frustrated that she had caused it.

The extent to which the government's concept of 'customary' is mirrored by citizens' feelings and practices is thus questionable: citizens only feel responsible and/or able to provide care in good times, while government policies oblige them to become care-givers in both good and bad times.

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 responsibility for care-giving 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 stated:

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 often 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 declined housekeeping support said that enforcing the customary care norm (which deviates from her own) upon her husband creates internal 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.

Ideas about what is 'customary' does vary among citizens. For example, people with religious backgrounds tend to maintain stronger feelings of obligation towards their parents than non-religious citizens. And compared to norms for 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 (Dykstra and Fokkema, 2007).

High expectations

For citizens with higher expectations of publicly financed care than what is now offered, the (new) policy guidelines came as a surprise. Care assessors were trained to deal with the expectations of disappointed citizens – by explaining that there is a standard, applicable also to those who disagree with it. An 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.' Though there is no such thing as an 'average citizen' in a 'multiform society', care assessors use the vocabulary of customary care to make it sound self-evident. Another care assessor of housekeeping needs told the 23-year-old 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!'

The more limited access to publicly financed care is thus based on the expectation that citizens will assume their 'customary' roles. But in practice, relatives who are supposed to provide customary care may not do so. A third care assessor clearly stated that such scenarios are not her responsibility:

Very simply put, the municipality has set these rules and we [the assessors] just assume that customary care is provided. I am not going to judge if they [the relatives] have enough time to do it. Because it is not my task. I also say to people that I am not going to decide how they should resolve it [customary care tasks], only that they should resolve it.

Does the norm-enforcing element within customary care lead to new care-giving practices? As access to public care becomes more difficult, are citizens now providing customary care as envisioned by the government? Have the new norms encouraged the equal participation of all potential care-givers? A longitudinal study on the provision of informal care between 1975 and

2011 by the Netherlands Institute for Social Research (SCP) shows that government expectations have not created a more equal division of care-giving labour over time. Over the course of more than three decades, the amount of informal care provided by different societal groups (e.g. by age, gender, educational level) has hardly changed (Cloïn et al., 2013; Mensink et al., 2013). Differences between societal groups persist over time, including after the more rigid implementation of the customary care norm since 2005 (Cloïn et al., 2013; Mensink et al., 2013). For example, women provide more informal care than men; 60% of all informal care-givers are women, a percentage that has remained fairly stable over the course of 35 years (De Boer and De Klerk, 2013; Mensink et al., 2013). People with lower educational levels consistently provided more informal care than people with middle and higher educational levels between 1975 and 2011 (Mensink et al., 2013). And up until the age of 65, the older one is, the more informal care one will provide (Mensink et al., 2013).

The consistent averages in time spent on informal care moreover hide another inequality in care-giving that has developed over the past decade: a smaller number of people are providing informal care, but those who do spend more time than before (Cloïn et al., 2013). This intensification of responsibilities among certain care-givers suggests that what is supposedly customary care is increasingly becoming the task of a specific group of citizens. The apparently gender-neutral concept of customary care is in effect disguising the reality that it is especially (poor) women who are buffering this transformation in social citizenship, usually at the cost of their economic independence and/or by risking impoverishment (e.g. Lister, 1990).

The Dutch government is apparently convinced that its norm of customary care mirrors what citizens already do and think. After the assessment, there is no investigation to confirm the actual provision of customary care; the government simply assumes citizen compliance. We have seen that individual and sociocultural differences are ignored, based on the assumption that this is the best way to guarantee equal rights to care for all Dutch citizens. Nevertheless, ignoring individual and cultural differences does not undo their actual influence. With the more stringent implementation of the norm and its 'equal' treatment of unequal cases, the risk is that needs will go unmet as public care is withdrawn and informal care is not provided. The new norm may also have perverse effects on private decision-making, e.g. not living together to maintain access to publicly funded care (Morée et al., 2007). That neither national nor local authorities have studied these risks shows how the concept of customary care has shifted from its ambition to achieve equality among all citizens to a tool to define what care the government is *not* responsible for – a useful tool in times of austerity.

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 expected to be exchanged between household members and what is beyond customary and therefore 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 permanently changing guidelines and legal definitions indicate top-down norm-enforcement rather than a description thereof. Were the suggestion of 'generally accepted standards' true, a 2,432 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 customary 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 of customary care, at times widening the gap between the official norm and citizens' interpretations of what is considered 'normal' care to give and receive. While the government maintains a one-size-fits-all approach to ensure (in its view) the equal treatment of all citizens, the same government is undermining the very idea of equality through the Social Support Act which gives municipalities more authority over care arrangements. While variation at the *individual* level is not allowed as it is said to undermine equal access to care among citizens, *local* variation in the customary care norm is the result of deliberate policy.

The very idea of the notion of customary care reflecting what is customary in society is highly questionable. By setting elaborate guidelines, the government hopes that all citizens will participate equally in informal care-giving, thus giving credence to its claim that all citizens have equal access to (additional) public care. But as we have seen, citizens fail to live up to the government's expectations and the unequal distribution of informal care-giving among different societal groups remains. Amongst family carers that do live up to the encroaching notion of customary care there is little protest as their care-giving hinges on the belief that 'it is normal to do so'. Nor does the Dutch government seem terribly concerned about these uneven outcomes. All of this suggests that the norm of customary care has transformed over time from its aim to protect citizens to a tool for policy-makers to cut budgets in times of austerity.

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