Dignity of dependence: welfare state reform and the struggle for respect
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Chapter 3

Welfare state retrenchment and shifting notions of customary care

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Abstract
Choice over home care has become an important pillar in the provision of publicly financed long-term care for people of all ages. In many European welfare states, cash-for-care schemes give care recipients greater choice over home care arrangements by allowing them to pay for care provided by acquaintances, friends and even family members. Paying for such informal care, however, is increasingly contested due to growing care needs, rising costs and the perceived need to tighten access to publicly funded care. Citizens in paid care-giving roles are thus pressured to continue their care unpaid or re-divide their care-giving responsibilities with lay ‘citizen-carers’. On the basis of a Dutch case study, this article examines how paid family care-givers experience this call for greater self-sufficiency in providing care. An analysis of 25 interviews and 21 letters of complaint revealed that care-givers felt trapped between their desire to derive social status from paid work and their inability to reject or re-divide previously paid care responsibilities. In a society where all citizens are expected to work, care-givers feel that their previously paid care-giving is devalued from a public to a private matter, despite the government’s attempts to reframe care as an act of good citizenship.

Introduction
Choice has become a cherished ideal in publicly financed long-term care (LTC) for people with disabilities or chronic illnesses who want to receive care at home. The ideal became popular in many European welfare states in the 1990s in response to criticisms of professional dominance and lack of client control over care arrangements. Market principles were introduced to encourage the greater involvement of private care providers alongside public home care organisations (Pavolini & Ranci 2008). This was followed by the introduction of cash-for-care schemes to facilitate personalised care at home. With cash-for-care, citizens can shop around and purchase care from professionals, freelancers, friends, neighbours and in some countries even family members (Ungerson 2004; Ungerson & Yeandle 2007; Arksey & Kemp 2008). Cash-for-care thus enabled payment for previously unpaid care, a process that has been termed the ‘commodification of care’ (Ungerson 1997a). ‘Services-led’ welfare states embraced cash-for-care as an effective strategy to contain costs through reduced
overheads and the expectation that paid informal care-givers would provide additional unpaid care (Ungerson & Yeandle 2007; Da Roit 2012). The introduction of cash-for-care was generally seen as a way to empower the recipients of long-term care; as ‘citizen-consumers’, they could now purchase care at home that suited their ‘independent’ lifestyles (Clarke 2006).

Cash-for-care schemes and their ideal of expanding choice have received mixed evaluations from an ethic of care perspective that stresses the interdependence of care relationships (e.g. Tronto 1993; Sevenhuijsen 2003; Barnes 2012). On the one hand, disabled and chronically ill persons and/or their representatives are given greater choice over their care relationships and can exit from those marked by obligation, the burden of gratitude or lack of flexibility (Rummery 2007; Moran et al. 2012). On the other hand, the cash payments or vouchers that facilitate cash-for-care have been criticised for the individualistic values they embody. The aim to expand choice suggests that care is a commodity like any other; it neglects the relational nature of care while privileging the interests of care-recipients over care-givers (Ungerson 1997b, 2002; Mol 2008; Lloyd 2010). From a feminist perspective, there has been broad discussion on the gendered implications of cash-for-care, given that care-givers are most often female. While (female) care-givers can profit from payment for previously unpaid care, wages have generally been set low, thereby ‘trapping’ women in underpaid and underregulated employment (Ungerson 1997b, 2007; Rummery 2009). Critics also worry that cash-for-care schemes privatise risk by making individuals responsible for maximising efficiency and by reframing care as an individual rather than a collective good (Ferguson 2007; Newman et al. 2008; Newman 2011; Barnes 2011a).

The threat of constrained choice or compulsion becomes evident in the current context of increased cuts to publicly funded care and its attendant emphasis on ‘active citizenship’. In European countries with cash-for-care schemes such as Finland, the Netherlands, the UK and Germany, there is a growing focus on citizens’ private care-giving responsibilities with only limited support from the state (Johansson & Hvinden 2005; Newman & Tonkens 2011). This demand for ‘active citizenship in LTC’ partly overlaps with the discourse on ‘choice’: it reaffirms the ideal of flexible, individually tailored care at home rather than standardised home or institutional care. Nevertheless, the active citizenship discourse in LTC rejects the importance of choice in care
relationships by prescribing that people are best cared for by their fellow citizens, acting out of sheer good will or out of mutual obligation (Barnes 2011b). It is also believed that greater civic engagement in long-term care will contribute to greater social cohesion and the integration of disabled and ill citizens into mainstream society (Newman et al. 2008).

Depending on how policies are enacted in specific contexts, relying on citizens’ ‘active solidarity’ can be emancipatory and inclusionary or disciplining and exclusionary for care-givers and receivers (Trappenburg 2009; Newman & Tonkens 2011). The ‘active citizenship’ agenda resembles a communitarian ideology, praised by feminist care ethicists for endowing care with public value but criticised for their impact on women’s positions in society (Waerness 1987; Kittay 2001). The discursive construct of the ‘citizen-carer’ is presented as gender-neutral. But due to the gendered reality of care-giving, it is likely that especially women will feel pressured to shoulder (more) unpaid responsibilities on top of regular paid employment (Barnes 2011b; Newman 2011).

The choice and active citizenship discourses view informal care differently. In the former discourse, informal care can be transformed into wage labour (albeit without full employee rights) on the basis of ‘individual’ choice; the latter discourse envisions a greater role for private care-giving on the basis of reciprocity (Barnes 2011b; Newman 2011). This article employs a feminist ethic of care perspective to interrogate these competing discourses as they pertain to changing Dutch LTC policies useful as it foregrounds the societal recognition of care-giving and the social rights of care-givers (Tronto 1993; Knijn & Kremer 1997; Lister 1997, 2002; Kittay 1999; Sevenhuijsen 2003). The Netherlands is a particularly interesting case as encouraging citizens to organise care at the neighbourhood level without seeking state support in the form of home care or cash payments breaks sharply with previous policy (Tonkens 2011). To examine the lived consequences of the reforms, I focus on the experiences of paid informal care-givers confronted by the contradictory demands of ‘choice’ and ‘active citizenship’. The conclusion critiques the current Dutch LTC policy that relies on ‘citizen-supporters’.
Dutch long-term care reform: ensuring care, now and later?

The Netherlands is internationally renowned for its generous LTC program (i.e. for elderly and disabled persons of all ages for periods longer than three months). Compared to other countries, care for the elderly and the disabled in the Netherlands is largely arranged outside the family; scholars have depicted the Dutch system as a ‘services-led welfare model’ (Pavolini & Ranci 2008; Da Roit 2012). Since 1986, there has been a special collective fund, codified in the Exceptional Medical Expenses Act (AWBZ), to pay for LTC needs that are not covered by private health insurance. The AWBZ initially only covered institutional care; for the disabled and the elderly, the choice was either to move to an institution or to be cared for by relatives at home. But over time, calls for client empowerment led to the growing popularity of care at home. Until then a family obligation, home care now also came to be covered by the AWBZ.

Public coverage of long-term home care required rethinking the boundaries of care within families. If a housewife and mother of two children becomes ill, is she entitled to home care or do we expect the working husband to assume these tasks? What can be expected from children as members of the household? These debates on public/private care responsibilities resulted in a protocol on the boundaries of public/private care in the 1990s (LVIO 2003), which was further developed by the CIZ, the new ‘independent’ needs assessment centre. The document restricts ‘customary’ care (i.e. care to be exchanged between members of the same household) to domestic care, temporary personal care, temporary support with daily living (up to a period of three months), and long-term care that does not significantly differ from care usually exchanged between ‘healthy’ household members. When there are pressing reasons why one cannot perform these ‘customary’ care tasks for a disabled or ill household member (e.g. ill health or employment), the CIZ can make exceptions to the rule.

The guidelines for ‘customary’ care allowed setting boundaries to care-giving within families: for what was deemed beyond ‘customary’, families could request professional help. With the introduction of cash-for-care in the late 1990s, these boundaries gained a new dimension. Now care-dependent individuals could hire household members to provide ‘non-customary’ family care in return for pay. When requesting a ‘personal budget’, only voluntary non-customary family care could be deducted from the assessed need (and budget). In principle, all ‘non-
customary’ family care became eligible for payment a model of ‘fully commodified’ informal care (Ungerson 2004).

Between 1998 and 2008, the number of people with personal budgets grew from less than 20,000 to almost 160,000 (Sadiraj et al. 2011). Half of them employed at least one relative; 37 per cent employed professional (most often freelance) care-givers while 14 per cent paid their friends for providing care (Van den Wijngaart & Ramakers 2004). Four out of five paid family care-givers are women. On average they are 45 years old, married or co-habiting, and relatively highly educated. They provide eight hours of paid care and 14 hours of unpaid care each week (Ramakers & Van den Wijngaart 2005). Many family care-givers view payment via the personal budget with salaries ranging from 12 to 45 euros per hour as recognition of their work and compensation for their reduced or possible earnings from regular employment (Ramakers & Van den Wijngaart 2005; Grootegoed et al. 2010). Although the relationship between care in kind and cash-for-care remains uncertain, the fact that 44 per cent of budget holders did not previously receive care and one-third would not request care in kind if the personal budget were discontinued suggests that informal care has indeed been commodified (Sadiraj et al. 2011).

Recent reforms to LTC policy in the Netherlands encourage citizens to assume greater responsibilities for informal care without payment. In Ensuring Care, Now and Later, the Ministry of Health (2008) outlines the need for reforming AWBZ legislation. The Dutch LTC system, it claims, has become too generous, covering care that does not warrant public financing and which puts citizens at the risk of ‘unnecessary medicalisation’. In particular, it singles out one area covered by AWBZ legislation: support with daily living in cases of disability or chronic illness, consisting of accompanied hospital visits, help with one’s administration, learning to cope with one’s disability, and participation in social activities to remain engaged in mainstream society. As the Ministry of Health (VWS 2008, p. 2) puts it:

‘In recent years, the AWBZ has unintentionally grown and now offers too much latitude for claimants . . . There has been a large growth in supportive guidance since 2003, such as assistance with homework and leisure activities for young people with problems. Is this long-term care and should it be part of the AWBZ?’
The Ministry of Health argues that we need to rethink what long-term ‘care’ really is, and gives examples to suggest that supporting people with disabilities to participate in social and school activities does not qualify. The personal budget allows care-dependent persons to not only use but choose the services they receive. But precisely the popularity of the personal budget is what is driving the Ministry of Health (VWS 2008) to regain control over how public finances are spent:

'The unprecedented growth of the personal budget, without demonstrable substitution of care in kind, is due to the broad wording of the AWBZ. Growth in itself does not have to be negative. But extreme growth without an accompanying drop in care in kind, combined with signs of the unintended use of resources, calls for critical reflection. . . . Indeed, there is a lot of unintended use of these functions . . . We want to separate ‘unintended’ from intended use.'

The proposed reforms make clear that ‘unintended’ use refers to people with relatively ‘mild’ care needs who receive support to live independently and remain socially active. Stricter eligibility criteria here are applied to future applicants as well as to current recipients of publicly financed LTC. Between 2009 and 2010, 60,000 people lost their entitlements entirely, while even more had their entitlements reduced (CIZ and HHM 2008). Aside from stricter eligibility criteria, a user-pay principle has been introduced to discourage future growth. The elderly and people with psychiatric problems and cognitive disabilities were disproportionately affected by the reforms. So were the holders of personal budgets: 34 per cent had their budgets for support with daily living reduced, which was the case for 21 per cent of people who received care in kind (Schellingerhout & Ramakers 2011). Payment for informal care was reduced by greater deductions of existing informal care from the assessed care need and through the obligation of co-resident family members to provide one hour of ‘non-customary’ care each day on top of customary care.

While the reforms suggest that choice has become secondary in LTC, the policy document presents choice as a core value. The Ministry of Health (2008, p. 8) explains its future vision:
'Clients need to be able to choose how and from whom they receive care … Clients must be able to choose how they want to live.'

Though choice over care arrangements remains high on the agenda, it is now only considered vital for people with ‘intensive’ rather than ‘support’ needs; the latter are no longer considered welfare ‘clients’. The policy report suggests that ‘support’ can be exchanged informally without compromising the wishes of care-givers and recipients alike. It moreover assumes that all citizens are willing and able to contribute to the exchange of ‘support’ as ‘citizen-supporters’ under the 2007 Social Support Act.

The Social Support Act transfers the responsibility of helping citizens overcome ‘mild’ disabilities in their self-reliance and social participation to the municipalities. But in contrast to AWBZ legislation, individuals do not derive LTC rights from the Social Support Act; the latter merely states that municipalities should facilitate the exchange of support between citizens based on the belief that all citizens will benefit from the enhanced exchange of informal support (Tonkens 2011). The Ministry of Health states in For Each Other: Informal Care and Voluntarism (VWS 2007, p. 1):

‘Apart from the intrinsic value of informal care, volunteers and informal care-givers exemplify ‘active citizenship’. Participation in broader social networks and mutual support have a broader positive effect. They contribute to stronger social cohesion, a stable society and democracy.’

This key policy text not only emphasises the societal value of existing informal care; it also sets out a strategy for encouraging citizen-supporters. First, care-giving and employment are presented as compatible: employers can develop flexible work arrangements for informal care-givers while the long-term unemployed receiving social assistance can gain ‘work’ experience through voluntary care-giving. Second, the government aims to recruit citizen-supporters from among ‘inactive’ citizens (e.g. immigrants and the retired elderly) who would benefit from greater social involvement and relieve overburdened informal care-givers of (part of) their duties (VWS 2007).

While the ‘choice’ and ‘active citizenship’ policy agendas for home care in the Netherlands and the position of informal care within them are contradictory,
the distinction between ‘care’ and ‘support’ provides a rhetorical tool to gloss over the tensions, suggesting that the Dutch welfare state is rejecting neither its care responsibilities nor the right to freedom of choice. To evaluate the inconsistencies between the discourses of ‘choice’ and ‘active citizenship’ in current welfare restructuring, we turn to the lived experiences of those most affected by the reforms: family care-givers supporting their co-resident disabled or elderly kin with daily living who face cuts to their personal budgets.

Methods and approach

To gain insight into the lived experiences of paid family care-givers who face restricted choice and mounting informal care obligations, we combined two data sets. First, we interviewed paid family care-givers; they were selected from a client-oriented study, wherein 45 clients and care-givers were interviewed about the consequences of reduced support with daily living (due to the 2009_2010 reform of the AWBZ discussed above). Affected clients were purposefully selected to form a sample that included a range of ages and physical, psychiatric and/or cognitive disabilities; all had had their entitlements at least halved (for sampling details see Grootegoed & Van Dijk 2012; Grootegoed et al. 2013). Eighteen cases involved a personal budget; in 15 of these, the budget was at least partially spent on payment for care by family members, who also served as spokesmen for the client. We interviewed these primary paid family care-giver, most often a woman: respectively the mother (13), wife (1) and nephew (1) of the care-dependent person.2 All care-givers had requested a personal budget and managed its administration for the care-dependent person. As the official representative of the budget holder, they were often also in charge of its spending (12 cases). The budget was usually spent on a combination of family care and care by freelancers or friends. Only in five cases did the family care-giver receive the entire payment. The female care-givers were aged between 35 and 58; their average age was 48.3 Most earned an income through the personal budget, supplementing that of their partner (only two women were divorced). Six also held part-time jobs. Respondents had received payments through the personal budget for between 4 and 12 years; the reductions in payment (65% on average) ranged between ca. 100 and 700 euros per month. None of the affected family care-givers filed a complaint against the cuts on behalf of or together with
the budget holder.

In the in-depth interviews, we asked respondents how they came to request a personal budget, how they made their decisions on how to spend it, and how payment through the budget impacted upon other life decisions such as pursuing regular employment. Further questions addressed how respondents viewed the framing of ‘non-customary’ family care as an obligation rather than a choice, and its consequences for the quality of their care-giving.

To supplement the accounts of people who had ‘accepted’ their mounting care-giving responsibilities, we analysed the complaint letters of personal budget holders who had appealed against the reduction to their entitlements. When care-recipients or their official representatives disagreed with their re-assessment under the new rules, they could appeal to the authorities (the CIZ) and request a new assessment. With the help of the Dutch personal budget organisation Per Saldo, we retrieved 60 letters of complaint that were written with its support in 2010. Only a small minority (1 in 10) that made use of this opportunity (see Grootegoed et al. 2013).

In 21 of these cases the letter was written by a co-resident, family care-giver (16 mothers, 4 fathers and 1 wife) that acted as the client’s representative, and who (partially) spent the budget on payment for family care. We reviewed these letters of complaint and held 10 telephone interviews with their authors.

To analyse their accounts, we made use of the qualitative data and research software AtlasTi. We compared different motivations for requesting a personal budget, care-givers’ payment from it, their experience of choice and its recent restrictions, recognition for family care, attitudes towards mounting obligations versus perceived care responsibilities and ideals, and expectations of the Social Support Act and its ideal of active citizenship.

Routes to payment for care

The 25 interview respondents reported different motivations for requesting a personal budget; most centred on the needs of the care-dependent person. The main motivation was to enable their relative to live as ‘normally’ as possible with their disability or illness. This was followed by the lack of adequate, flexible formal care; the care-dependent person’s unwillingness to accept non-family care; and the possibility to pay for informal care (cf. Ramakers & Van den
The route to payment for family care proved a lengthy process for most respondents. They had to first find out that the personal budget existed and that it allowed payment for family care. It was also difficult for care-givers, especially those caring for young children, to distinguish ‘customary’ from ‘non-customary’ care. A part-time working single mother explains how she eventually became a paid care-giver for her 26-year-old autistic son:

'I only found out about his autism when he was 14, very late. I had always suspected that something was amiss. But no one could find out what it was. Only when I read about autism did I realise: that is my son. I asked for a diagnosis and it was confirmed. Then I went to the care authorities to ask for professional support in parenting him. I had questions as a parent, how to deal with such a child. I did not ask for professional care as a replacement for mine, because he never accepted any other care than mine. So I didn’t think about that. And you are not going to ask for financial assistance if you don’t know that it’s possible. Nobody told me, I found out later, and only by chance.'

Care-givers who requested the personal budget reported that even though home care was explicitly promoted by the care authorities, payment for family care was not. They usually found out through paid family care-givers in their private networks people who had already faced the public taboo of ‘mingling love and money’ (Folbre & Nelson 2000; Kunkel et al. 2004; Folbre 2012).

For most care-givers, caring for a disabled or chronically ill child or partner evolved from their previous responsibilities as housewives who were not earning incomes or incomes that were secondary to that of their partners (Ramakers & Van den Wijngaart 2005). Nevertheless, payment via the personal budget addressed the tension between paid work and family care, especially as care-givers realised over time that their care exceeded what was considered ‘customary’. A mother of a 21-year-old daughter with a cognitive disability explains:

'Well, some time ago we had financial problems, so I had to work. I worked as a teacher for 10 hours per week. But for my daughter, this was disastrous
because I wasn’t available at fixed times. And then I heard about the option to use a personal budget. So we could financially make it with that. That felt like recognition, that you have a child in need of care.'

Both the freedom of choice offered by the personal budget and the emphasis on providing care at home confirmed the ‘public value’ of care-giving (White & Tronto 2004), which could be seen as ‘work’ with economic value. Many family care-givers thus made important life decisions based on the personal budget, from reducing working hours to making financial investments such as buying a house.

From choice to obligation

The shift in policy from offering financial compensation for non-customary family care to demanding greater self-reliance had a significant impact on families caring for disabled or ill relatives. Apart from the reduced family income, the sudden lack of recognition for the public value of their care work greatly impacted upon care-givers. As a woman who reduced her working hours to care for her 56-year-old husband with a cognitive disability states:

'I don’t think the government can say: now you have the choice [to care], and within three months, you no longer have it. It should not matter for the government who performs the care. The fact is that my husband needs care, and someone has to do it. That it is me doing the care-giving doesn’t mean that the government can abuse my personal commitment and oblige me to perform more [non-customary] care unpaid because they need to organise their finances. They also expect me to be economically independent and provide unpaid care that used to be generously subsidised. It is a dilemma.'

Especially in situations where the care-giver was the only adult in the household who could provide the care, there was no perception of choice. Having internalised the ideal of choice, the obligation to perform the same care unpaid was met with feelings of anger. Though paid family care-givers never confused payment with their intrinsic motivations to care, they now felt that their personal commitment was being abused. A mother of a 21-year-old chronically
ill daughter stated in the wake of the cuts:

'Recognition of my care-giving has gone. Though of course it is not normal that you always have to be there for your 21 year old child. I think in the end those personal budgets were created to have informal care-givers take care of their dependents for longer, which of course is cheaper. And then when you choose to do so, and have adjusted your life to it, they take the money away."

The re-framing of paid family care as citizen support was heavily contested in the written complaints. Arguments resisting extended family obligations included the impossibility of combining regular paid work with care-giving, health concerns among care-givers, the risk of becoming overburdened, as well as their care work being taken for granted. Respondents noted that the CIZ re-assessed available informal care as 'voluntary' even when it was not. One mother, a budget holder for her 17-year-old son with multiple disabilities, states in her written complaint:

'Your [the Needs Assessment Centre's] only task is to define whether or not he [the disabled son] can claim care. You should not interfere with how the money is spent. Informal care, even that of the family, is not enforceable care. I would like to know why you think it is enforceable. The care is performed as paid employee and not as volunteer."

Some care-givers redefined the boundaries for themselves. The parents of a daughter with multiple disabilities state their boundaries for 'voluntary' care very clearly in their written complaint:

'We want to express that we are only willing to provide up to four days a week of care-giving."

Though care-givers defended their private boundaries in their written complaints, the often posed threat of institutionalisation was fictive; all interviewed care-givers stated that they would do anything to prevent institutionalisation. A mother of a 27-year-old cognitively and physically
disabled daughter explains:

'People say to me, why don’t you bring her to an institution? But we want to keep her at home for as long as possible. I am certain that if she goes to an institution she will stop working and participating in no time. There won’t be anyone who coordinates her life to the extent that I do.'

Despite the growing constraints on choice, the home care ideal persists in the accounts of respondents. Though many had to contend with additional burdens, they felt obliged to buffer welfare reform rather than act upon their perceived responsibilities and their desire to receive recognition from paid employment.

**The search for citizen support**

The experience of care-giving as all-embracing and incompatible with having a paid job is not alleviated by the care-sharing ideals of the Social Support Act. Respondents tended to see the involvement of volunteers as a dream-like scenario given the contradictory policy goals of encouraging people to be both gainfully employed and ‘citizen-supporters’. A mother caring for a 27-year-old daughter with a chronic illness and cognitive disability explains:

'I would love to work if I could.. but caring takes all my time. They [the care authorities] said that neighbours could assist, that volunteers could contribute. I don’t understand what they are up to, because everyone works, when would they have the time to do something for someone else? The government wants everyone to work and everyone to care for each other, I just think that they [the government] want to achieve the impossible, so then why should you?'

Respondents repeatedly stated that citizens today just live for themselves. They saw the vision of citizens caring for each other as a ‘fairytale’. Were it ever to come true, it would take years. Respondents were also highly sceptical of the ability, flexibility and motivations of citizen-supporters. As a mother of a 14-year-old son who cannot speak or walk due to a rare chronic illness states:
I think it [involving care volunteers] is scary. You don’t know to whom you are opening your doors. Are they all being screened? I am always a bit suspicious. You put your child completely in their hands. He is obviously very vulnerable and the way we have organised it with the personal budget is very familiar.’

Family care-givers reported feeling irreplaceable because they did not know how to entrust volunteers with care for their kind without the trust derived from a contractual agreement or intimate social bond. They felt that ‘opening up their homes’ to relative strangers not only breached their ideas of privacy but also put their disabled or chronically ill relatives at risk of low-quality care, abuse or malevolent intentions. Also, actively seeking for trustworthy volunteers adds up to the burden of care-givers.

In sum, family care-givers felt trapped between the cuts to cash-for-care, their new care obligations, and their own care ideals. Wanting to be a good parent or partner and acting upon the belief that it is best to keep a care-dependent relative at home makes it almost impossible to reject reframing non-customary, paid informal care as something one ‘ought to do’ (Finch & Mason 1993). Having once taken on the responsibility of arranging for personalised care, family care-givers were now trapped and relatively ‘easy’ objects of welfare reform as the government knows that families, in the end, will provide.

Towards a caring society?

Being able to stay at home for as long as possible is considered a core value for people of all ages with long-term care needs. But care at home assumes the involvement of informal care-givers. In response, many services-led European welfare states have developed policies to subsidise informal care through ‘cash-for-care’ (Daly 1997). With cash-for-care, individuals can choose between different kinds of home care providers: (semi-)professionals, friends, neighbours or even close relatives, thereby placing monetary value on informal care (Ungerson 1997a). More recently, against the backdrop of ageing populations and economic crises, several European welfare states have adopted policies to encourage all (working) citizens to contribute to a caring society as lay ‘citizen-carers’ (Barnes 2011b; Newman & Tonkens 2011).
Examining this policy shift from a feminist ethic of care perspective in the Netherlands where the demand for more unpaid, informal care breaks sharply with the previous emphasis on informal care as a choice, I found that choice remains an important ideal for ‘care’ but no longer for ‘support’. This linguistic distinction increasingly informs the re-division of public and private responsibilities in Dutch LTC reform. ‘Support’ for disabled and chronically ill persons in their daily living and social participation so it is argued can be provided by fellow citizens, i.e. family members, friends, neighbours and community members, with limited state support. Between 2009 and 2010, access to publicly financed care was reduced not only for future applicants but for existing clients with relatively mild 'support' needs for ‘independent’ living. Clients with personal budgets faced the most drastic cuts as they had often used them for purposes now deemed ‘unintended’. Many (female) care-givers who had previously been paid via these budgets now found themselves in an impossible moral dilemma: to give in to the re-privatisation of LTC or to contend with lower-quality care for their loved ones.

The interviewed co-resident family care-givers felt trapped under the new policies reducing payments for care and choice over care arrangements. While cash-for-care previously softened the tensions between care and work (Williams 2001), they now felt that their personal commitment was being abused as they felt obliged to continue to care at home without pay. Though many family caregivers suffered sharp declines in income, their anger is not ‘just about the money’: the real insult is the lack of recognition of the societal value of their care at home (often believed to be better than available professional care). Not only was their care no longer considered worthy of payment; it was also no longer perceived as ‘care’ but as ‘support’ that can be naturally exchanged between citizens under the newly enforced Social Support Act (2007).

The Social Support Act emphasises the ‘pleasure of altruism’ by underlining the many positive social effects of citizens informally exchanging care (alongside pursuing paid employment). While policies attempt to recognise the public value of care, care-givers perceive the ideal of the caring citizen to be misleading: so long as paid employment remains the primary route to full-fledged membership in society, people will lack the time and motivation to provide care to relative strangers. The active citizenship ideal also forgets that care is embedded in relations of trust. Trust the ‘oil in the wheel of care’ (Sevenhuijsen 2004) is
necessary before informal care-sharing outside peoples’ private networks can become a reality. To model citizens as ‘citizen-carers’ (Barnes 2011b), or in the Dutch case as ‘citizen supporters’, does nothing to develop trusting partnerships between overburdened informal care-givers and volunteers. Policy ambitions to extend home care responsibilities to relative strangers without a contractual agreement clashes with families’ aim to protect the ‘safe haven’ at home for their disabled and ill relatives. Already ‘active’ informal care-givers saddled by additional obligations thus feel trapped in a partial form of citizenship with responsibilities but without rights.

The ‘active citizenship’ ideal draws on a romantic vision of people’s intrinsic motivations to care for each other without extrinsic reward (Folbre 2012). But in our time when most women work outside the home and care is exchanged on the market, very few citizens will be willing to assume unpaid care tasks beyond the private network. Policies that place new care-giving demands on citizens without shortening the paid working day are Janus-faced (Newman & Tonkens 2011). While they present care as a ‘public’ good, they wreak havoc on the private lives of those who care at home. So long as the citizen-carer does not enjoy equal status with the citizen-worker, those who care at home will suffer inferior status, lower incomes and fewer social rights (Tronto 1993; Knijn & Kremer 1997; Kittay 1999; Lister 2002). Instead of bridging the gulf between the status of work and care, framing care as a responsibility of citizenship but without a freedom of choice risks further widening it.

Notes

1 Sixty to seventy per cent of long-term care responsibilities are shouldered by women in Western welfare states.
2 People in the Netherlands usually do not live in inter-generational households.
3 The average age of paid informal care-givers in the Netherlands is 45 years (Ramakers & Van den Wijngaart 2005).
4 Lodging an appeal does not involve costs.
5 2009 was a transition year when re-assessments took place. For most, the care assessment was reduced or terminated as of January 2010.
References


CIZ (Centrum Indicatiestelling Zorg) and HHM (2008) *Onderzoek effecten pakketmaatregelen AWBZ*, HHM, Driebergen/ Enschede.


Shifting notions of customary care


