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

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Publication date
2013

Document Version
Final published version

Citation for published version (APA):
Grootegoed, E. M. (2013). *Dignity of dependence: welfare state reform and the struggle for respect*.

Dignity of Dependence

Welfare State Reform and the Struggle for Respect

Ellen Grootegoed

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Cover illustration: 'My soul is somewhere' (2011) by Laura Di Fazio

Editor: Takeo David Hymans
Layout: Anton Grootegoed
Printed: GVO| P&L

The studies described in this thesis were financially supported by Platform 31, the Dutch ministry of Health, Welfare and Sport (VWS) and the municipalities of Amersfoort, Amsterdam, Dordrecht, Eindhoven, Haarlem, Leeuwarden, Rotterdam, Utrecht, Zaanstad and Zwolle.

Dignity of Dependence

Welfare State Reform and the Struggle for Respect

Waardigheid van afhankelijkheid:

de strijd om respect in een activerende verzorgingsstaat

(met een samenvatting in het Nederlands)

ACADEMISCH PROEFSCHRIFT
ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. D.C. van den Boom
ten overstaan van een door het college voor promoties ingestelde commissie,
in het openbaar te verdedigen in de Aula der Universiteit
op woensdag 18 december 2013, te 15:00 uur

door

Ellen Maria Grootegoed

geboren te Barendrecht

Promotiecommissie

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Chapter 1

Introduction

The crisis of the welfare state

Since the 1990s, European welfare states have undergone major transformations that signal the surrender of public responsibility – transformations that may together signal the end to the welfare state as we know it. Previously significant variation between social-democratic, liberal and corporatist welfare state regimes (Esping-Andersen 1990) have narrowed due to reforms to contain costs (Pierson 1996). As the provision of services in a 'post-industrial society' replaces the post-war era's industrial production of goods, different welfare state regimes face similar social risks (Taylor-Gooby 2004) posed by flexible labour markets, low-skilled labour, and strained work-life balance due to increased female labour participation. Many countries also have ageing populations and growing dependency ratios (Cohen 2003), while the increasingly globalized economic order and financial crisis have fuelled the perceived necessity of reform (Clarke 2010).

These socio-economic challenges in mature welfare states have led to political debate on the limits of public responsibility and the introduction of more selective welfare programs (Gilbert 2004). Paul Pierson (1996) a decade ago described these reforms as pathways to welfare state 'retrenchment'. In contrast to the post-war era of welfare state expansion through broad social programs and extensive social rights, retrenchment entails the off-loading of collective responsibilities (ibid.). The call for major reform has been touted as the end of the golden age of welfare, or even of the welfare state itself. If true, this would mean that the welfare state was a very brief stage in the history of some Western countries rather than a permanent feature of developed economies (Baldock 2007).

Retrenchment parallels the turn towards 'active' welfare states. The European Union's Lisbon summit in 2000 introduced a strategy to reduce unemployment by 'activating' citizens, both men and women – policies that marked a turning point for many European countries. Social welfare was no longer to be unconditionally consumed (Trubek & Mosher 2001; Borghi & Van Berkel 2007); in return for social benefits, unemployed citizens were now expected to foster their employability through volunteer work or training programs (McQuaid & Lindsay 2005). Prompted by changes in social assistance, citizens in welfare states were discouraged to 'passively' consume rights and to assume responsibilities as 'active' citizens (Hvinden & Johansson 2007).

This transformation has been described in numerous ways: 'as moving from Keynesian welfare to Schumpeterian workfare state,[1] social rights to social obligation, passive to active social policy and – for those who favour more evocative metaphors – safety net to trampolines' (Gilbert 2004: 10). The idea of the 'active' welfare state is that, in contrast to 'passive' welfare states that 'only' spread safety nets once undesirable outcomes have occurred, reformed welfare states invest in the self-sufficiency of their citizens (Vandenbroucke 2002). The transformation has translated into new modes of governing, typified by the well-known metaphor of a government that is 'steering, and not rowing' (Osborne & Gaebler 1992). According to the new model, govern*ment* (through direct control) is to be replaced by govern*ance* (by encouraging and coordinating public-private partnerships) (Rummery 2006). Encouraging such responsible, 'active' citizenship is said to reconcile economic and societal interests, and is also known as the 'Third Way' – a synthesis between left and right-wing ideologies (Giddens 1998; Jordan 2010).

The new governance style and emphasis on 'active' citizenship also inform current care policies as welfare states respond to growing demands, strained resources, and a skewed 'dependency ratio' arising from the demographic explosion of the elderly.[2] Declining fertility rates, increased longevity and the ageing of the baby boom generation lead to a sharp increase of the average age of the population in the next 40 years (Cohen 2003; De Hollander et al. 2006). Especially the 'oldest old' (ca. 80 years[3] and above) are more likely to have higher levels of disability (Bravell 2007), while at the same time severe shortages of care labour supply are signalled (Stone & Wiener 2001). Policy-makers who must deal with these pressures increasingly view care as problematic (Daly & Lewis 2000). Hochschild (1995) even speaks of a 'global care crisis' as the need for (affordable) care fuels migration chains wherein care workers migrate from developing to developed countries. Rising public spending and the anticipated future growth of care needs are thus encouraging many national governments to engage 'active' citizens in responding to the (growing) care gap (Newman & Tonkens 2011).

Pierson (2001) argues that retrenching welfare states can pursue (combinations of) three different strategies: cost containment, recalibration and recommodification. 'Recalibration' implies bringing welfare state programs in line with contemporary goals and demands for social provision. 'Recommodification' reverses previous measures that distanced citizens from the labour market, while 'cost containment' prioritises cutbacks and control over public spending. Disaggregating these three dimensions, Pierson argues, enables us to better understand the political processes that make up welfare state reform. For example, in the field of care, 'cost containment is *the* issue in most countries, though flanked in some cases by efforts at modernization. Only rarely will re-commodification provide the primary lens for analysing the character of reform in these core welfare state sectors' (Pierson 2001: 427). This is in contrast to labour market reform where recommodification and recalibration are primary strategies.

Though retrenchment strategies vary across sectors, they centre on the contentious question 'who shall be eligible?' (Gilbert 2004). The adjudication of need is a political question; according to Fraser (1989), 'needs-talk' is an idiom through which 'political conflicts are played out and through which inequalities are symbolically elaborated and challenged' (Fraser 1989: 162). From this perspective, shifting private and public responsibility for certain 'needs' defines the boundaries between the political, economic, and domestic or personal spheres of life (Fraser 1989: 162). Given current economic and demographic trends, care needs are increasingly framed as a responsibility of the domestic and personal sphere. In terms of citizenship, it implies a shift from universal to selective social rights (Gilbert 2004) and an emphasis on individual responsibility (Dwyer 2006; Newman, Glendinning & Hughes 2008; Newman & Tonkens 2011).

Many European countries – including states such as Sweden, Finland and the Netherlands which have maintained comprehensive public long-term care schemes – are increasingly reserving publically funded care for their 'neediest' citizens (Rostgaard et al. 2011). To achieve a 'just' redistribution of scarce resources, recent policies have aimed to distinguish between levels of need. First, *monetary* barriers provide financial disincentives for gatekeepers to distribute and for citizens to request public services. It builds on the premise that when people are made more responsible for (co-)financing public care, they will distinguish between urgent and less urgent needs. Examples of such measures include budget capping, positioning users as consumers in a care market, and demanding income or means-based co-payments from service users ('user-pay principles'). For example, in Sweden the maximum income-based user fee for social care is around €180 per month. For those only needing a few hours of care each week, it is often cheaper to privately purchase services. This is especially true for housekeeping support as the government introduced a tax deduction for domestic services in 2007 (Meagher & Szebehely 2010; Rostgaard & Szebehely 2012).

Second, *medical* barriers provide a health-related logic to reserve access to people with the most pressing needs. England introduced a system of risk assessment in 2003 that distinguishes between low, moderate, substantial or critical risk (were the client not helped within the next six months). In the critical category, the client's life is in danger; in the lower categories, a client's *social and domestic* life is at risk (Brand, Green & Statham 2010). In practice, cash-strapped local authorities reserve care for people with substantial or critical needs (Rostgaard et al. 2011).[4] Such categorization shows how medical needs are prioritized over social and emotional needs for publicly financed care (Vabø 2011a). Especially social care – when understood as a form of welfare entailing both cash and services to assist the elderly, chronically ill and disabled persons with daily living in and outside the home or institution (Daly & Lewis 2000) – is being cut through medical barriers to redistribution.

Third, *moral* barriers raise the threshold for accessing public care by reserving it for people for whom informal care (i.e. care that is not provided for pay and/or on the basis of a profession) is unavailable or impossible. Informal care often cannot be legally obliged; it is therefore mediated by negotiation between citizens and assessment authorities. For example, informal care in Finland is viewed as part of an integrated approach to home care. A needs assessment determines how much informal care is available and/or possible; municipalities then enter agreements with clients and their care-givers. In return for their participation, informal care-givers are entitled to an allowance, respite care and other services,[5] though there are signs that not all informal care-givers receive the desired support due to financial restrictions (Kröger & Leinonen 2011). Moral barriers prioritize (investment in) informal care over publicly financed care in the assessment of 'public' care needs.

The selective interpretation of care needs is often accompanied by the devolution of responsibilities from national to provincial and/or local authorities

(Rostgaard et al. 2011). The belief here is that local authorities are best able to adjudicate the needs of vulnerable citizens as their physical proximity allows for integrated care provision tailored to individual needs. Local variation in service levels is allowed or even encouraged, creating a multitude of local welfare cultures (Trydegård & Thorslund 2001; Cochrane 2004). Rather than enjoying uniform rights, citizens negotiate care that is necessary in a given context (Cox 1998). For example, the Dutch national government devolved many responsibilities for care to municipalities in 2007 and 2009-2010. In their gatekeeping procedures, many municipalities do not speak of assessments but rather of 'kitchen table conversations' (Peters 2012).[6] The rhetoric suggests a cosy atmosphere in which municipal representatives visit needy citizens in their homes.

Given the expressed need for reform, citizens are increasingly expected to assume more responsibility for finding solutions for their own care needs. It is therefore likely that the negotiation of needs is marked by selective barriers to the use of public care. To respond to increasing demand and reduced resources for home care, several municipalities in Norway have introduced a new service that provides 'help-to-self-help' rather than help itself (Vabø 2011b). 'Everyday rehabilitation' trains disabled and elderly people to master important daily life activities without (extensive) public care (www.ergotherapeutene.org). In other words, citizens are summoned to embrace private responsibility and 'self-sufficiency' and to reduce their dependence on the welfare state (Newman & Tonkens 2011).

Welfare state reform and emotions

The encouragement of self-sufficiency has numerous consequences for care-givers and recipients. Disabled and elderly persons who are considered less needy can be denied access to services and must seek alternative arrangements. But reforming care is not only about changing rules, rights and duties; it also entails an 'emotional reform' that tells citizens what they are worth and how they should feel about private versus public care (see also Tonkens et al. 2013).

Arlie Hochschild's work on the sociology of emotions is particularly useful for studying welfare state retrenchment as emotional reform. Hochschild approaches emotive experiences from the perspective of symbolic interactionism, which sees the creation of meaning as a process of social interaction (see Wallace & Wolf 1999).[7] The Thomas Theorem states that it is unimportant whether an interpretation is correct or not because 'if men define situations as real they are real in their consequences'.[8] Subjective meanings or definitions of a situation are thus important objects of study as they inform people's behaviour, while the subjective meanings ascribed to any given situation include an emotional element (ibid.). Hochschild's work on family, gender, capitalism and globalization centres on emotions[9] and feelings, which she sees as open-ended and inherently social. Hochschild claims that we experience feelings in tandem with 'social guidelines that direct how we want to try to feel' ('feeling rules') (2003: 97). From this perspective, emotions are products of social interactions that define the proper extent, direction and duration of feelings (ibid.).

Welfare state reform that aims to off-load public long-term care responsibilities reworks existing norms and feeling rules regarding the 'right way to depend' (Hochschild 2003, 2013). First and foremost, citizens should avoid welfare dependency for as long as possible. Whereas using publicly financed care was previously perceived as a valid and honourable route to (both decisional and executional) autonomy from one's family and friends, there is now more emphasis on the dishonour of depending on the welfare state (Fraser & Gordon 1994; Sennett 2003; Newman & Tonkens 2011). People who use(d) extensive home care provisions for purposes now deemed 'unintended' are now seen as 'welfare queens' who shamelessly claim public money (Gustafson 2009).

Second, many European governments present 'active' citizenship as the new 'honour code' that leads to respect in society. Depending on one's private network is no longer seen as undermining the autonomy of care recipients, but cherished for its empowering, inclusive and social nature. In the Netherlands, people who take on (more) informal care responsibilities are lauded as 'the cement of society' (Plemper et al. 2006), engendering pride in their altruistic, public-spirited acts and 'knightly behaviour' (Le Grand 1997).

Welfare state reform thus not only entails changing *care rights* but '*feeling rights*' (Hochschild 2003). Is one entitled to feel angry about cuts to publicly provided care? If so, to whom can it be expressed, with what intensity, and for how long? Should one feel (more) grateful for the public care that remains available? How do people deal with differences between what they *want* to feel and what they are *expected* to feel? People in need of care and their relatives may have to perform 'emotional labour' to bring their thinking and feelings about the 'right' person or institution to turn to in line with changing norms (Hochschild 2003, 2013). Emotional labour goes further than 'impression management' where people try to *appear* to feel in a certain way; it requires 'deep acting' where people try to change the feeling itself (Hochschild 2003: 94-95). Especially care-givers and recipients may be forced to perform emotional labour to be recognized as full citizens worthy of respect (Fraser 1995; Honneth 1995; Tonkens et al. 2013). To appreciate the full impact of welfare state reform, we need to study not only its financial and practical dimensions, but also its emotional subtext that constitutes identity, recognition and (changing) moral worth.

Focus on the Netherlands

The central ambition of this thesis is to examine how long-term care recipients and family care-givers facing cuts to publicly financed care cope with the demands of active citizenship. As the reform agenda demands both behavioural and emotional change, I examine people's care seeking strategies as well as their subjective experiences of reform. The study focuses on one affluent welfare state because I assume this is where citizens most strongly perceive *rights* to public care; given the collective principles underlying generous welfare support, it was believed that strong welfare states would withstand the full impact of retrenchment (Cox 1997). From this perspective, the Netherlands can be seen as a radical case. The Dutch welfare state – a hybrid with both social-democratic and corporatist elements (Esping-Andersen 1999) – is characterized by a high degree of universalism combined with policies centred on the male breadwinner model (Lewis 1992). Especially in long-term care, the Dutch welfare state is renowned for its generosity for people of all ages (Pavolini & Ranci 2008). Together with Sweden, the Netherlands[10] provides the most comprehensive long-term care in Europe in both coverage and spending (ibid.). The current reform agenda therefore breaks more sharply with previous policy than in less generous welfare states where informal care already played a central role.

The Netherlands is also an interesting case because cutbacks not only affect future recipients; current recipients see their entitlements reduced by stricter eligibility criteria. The question is how these citizens, who have long benefited from generous entitlements, cope with changing demands on their self-sufficiency. Under what conditions are they willing and/or able to accept the new honour code and change their care seeking strategies? What emotional labour do they have to perform to overcome dissonance between their own feelings and the new feeling rules concerning dependence on public and private care? To answer such questions, we need to see how the redefinition of dependence affects current care recipients who, next to moral (what is right) and pragmatic (what is possible) also have historical (what was possible) 'frames of reference' (Hochschild 2003; Tonkens 2012).

The focus on the Netherlands as a 'radical case' is not to say that the lived experiences of Dutch citizens who face reduced care rights are incomparable to those in less generous welfare states. In countries where rights to care have always been limited, the turn to informal care may not be a revolutionary development. Nevertheless, governments may employ comparable policy rhetoric and appeals to responsible citizenship that delegitimize dependence on the state, thereby demanding similar emotional reform.

Dutch long-term care reform: two sides, one story

As the boundaries between public and private care responsibilities in the Netherlands have always been contested, it is difficult to pinpoint when 'active' citizenship first became a policy goal. Nevertheless, 2007 was a turning point for several reasons. First, the Social Support Act (*Wet maatschappelijke ondersteuning*, Wmo) set a trend of devolution. Local authorities now became responsible for aspects of care that were previously arranged under the national Exceptional Medical Expenses Act (AWBZ, enacted in 1968), which covered all long-term care needs at home and in institutions. Since 2007, 'housekeeping support' (2007), 'support with daily living' for people with mild disabilities (2009-2010), and care and support for people with psychosocial needs (2009) are municipal responsibilities[11] (in addition to existing social welfare responsibilities, see also Tonkens 2011). The underlying idea is that local governments are better equipped to serve citizens' needs as they can consider the individual context of cases (Cox 1998). The idea that care is best organised at the lowest feasible level is also known as the 'subsidiarity principle' (Esping-Andersen 1990; Vischer 2001).

Second, the local, tailored approach implies a new type of gatekeeping: not a standardized assessment of one's needs but a negotiation of one's (lack of) self-sufficiency. It criticizes standardized assessments as 'impersonal' and 'a-contextual' (Cox 1998). Equal access to services is no longer the primary goal; it is equal outcomes that count in the Wmo (Van der Hoff 2011). Local governments must ensure that all citizens can participate in society, assisting them to find tailored solutions to concrete 'participation barriers'. Responding to unique and changing individual needs is termed 'creative justice' by Foster (1983), in contrast to 'proportional justice' where achieving fairness between individuals is of primary importance (see also Vabø 2011a).

Finally, citizens are no longer approached as 'welfare users' but as 'welfare agents' who must work with governments rather than demand services from them (Newman et al. 2004). Citizens are expected to collaborate with local authorities and embrace what policy-makers call citizen 'self-sufficiency'[11] to manage one's care needs without (extensive) public care. In local communities, citizens with care needs and/or their representatives are invited to participate in 'Wmo boards'[12] to voice their opinions and help develop local programs to enhance the self-sufficiency of 'vulnerable'[14] citizens (Sok et al. 2011).

By allowing local variation in service levels, the Social Support Act (also 'Participation Act') breaks with the protective and rights-based scheme for long-term care codified in the Exceptional Medical Expenses Act (also 'Care Act'). The reform agenda, embraced by a broad political spectrum, relies on two lines of argument that are used interchangeably to appeal to different audiences: the logic of financial reform and the logic of moral reform.

For money: the financial reform logic

Cost containment has always been a major thrust in the reform of Dutch long-term care. The debate on the AWBZ centres on the tension between guaranteeing access to quality care and the financial sustainability of public services. While cost containment strategies first sought to protect long-term care for all citizens, the more recent logic of financial reform is informed by new ideas about public-private responsibilities (Da Roit 2012).

When cost containment first became a policy objective in the late 1970s and 80s, reforms centred on deinstitutionalization. The AWBZ was broadened to cover a range of home care services, which were believed to be less expensive than residential care (Da Roit 2012). At the time, residential care was also provided to people with relatively mild needs; home care was expected to reduce overhead costs. The strategy was perceived as a double gain as it allowed people with disabilities to stay in their communities while the government could safeguard the financial sustainability of comprehensive entitlements. The substitution of institutional by home care indeed contained costs in the period 1985-2005 (SER 2008: 70). Cost containment strategies altered in the 90s when the AWBZ was 'modernized' to meet the increased claim for 'demand-oriented' care (VWS 1999, 2001). The need to regulate AWBZ spending centred on maximising citizen's benefits of the collective scheme:

> 'Everything increases: the spending, the care needs, the waiting lists, the work load, the rules, and the overhead. People in need of care (and their fellows) however experience a decrease of monetary funds and also that the available funds are not well-spent.' (VWS 1999: 12)

To counter 'ineffective' spending, market incentives were introduced in the 1990s to reduce the dominance of professionals in setting care standards, to increase competition between care providers, and to make care recipients more responsible for the quality of care they received. The 'modernization' agenda encouraged care recipients to see themselves as 'consumers' of care in a 'care market' (VWS 1999). To enable citizens to purchase the specific care they needed, the government introduced AWBZ 'care functions' that could be purchased separately from different providers. Instead of a standard home care package from a single provider, citizens following an assessment by the care assessment centre (CIZ) could now request domestic aid, personal care, nursing, (temporary) stay, treatment, and support with independent living from different providers. This, it was believed, would lead to more client-oriented assessments less dependent on the (self-interested) offers of care providers. The modernization agenda also advanced the 'Taylorisation'[15] of care (Knijn 2001): entitlements to care were now given per hour, with care providers having to account for the number of minutes performed per task. With the introduction of market principles in the AWBZ, care was increasingly viewed not as an investment in society but as a societal *cost* to be privatised (Knijn 2004). The early 1990s witnessed the first measures to reduce access: the introduction of co-payments to discourage potential clients from requesting publically funded care. This was followed in the late 1990s with the introduction of the personal budget (PGB), which allowed care recipients to privately purchase care at home rather than receiving care in kind. It was believed that clients would more efficiently purchase care with a personal budget and negotiate lower rates with their care-givers (Da Roit 2012).

But attempts to control spending on long-term care by relying on market incentives did not have the desired results, with care recipients consuming more care each year for the same disability or illness (SER 2008). Nor did user-pay principles have any immediate tangible effect (Da Roit 2012). After remaining steady for years, expenditure on the AWBZ rose from 3.5% of GDP in 2001 to 4% in 2003, largely due to the broadening of home care services and pent-up demand due to the reduction of budget capping and waiting lists (Eggink, Pommer & Woittiez 2008). The personal budget scheme proved highly popular, with spending rising 24% annually between 2003 and 2009, as opposed to 6% for care in kind (Sadiraj et al. 2011). While evidence suggests that care purchased with a personal budget is 25 per cent cheaper than care in kind (Kaaij & Huijsman 2008), the personal budget not only substituted care in kind; it also stimulated new (home) care demands (Sadiraj et al. 2011). One study found that 47% of personal budget holders would not have requested care in kind if the personal budget did not exist; it allowed payment for informal care and/or for care that was unavailable in kind (Ramakers et al. 2008: 117). Previously unpaid care thus received a price tag on the market (the 'commodification' of care) (Ungerson 1997; Knijn 2004). The personal budget was also popular due to the flexibility it afforded, allowing clients to avoid residential care (Ramakers et al. 2008: 118). The Ministry of Health estimated that without changes in policy, the costs of the personal budget would increase by €1.6 billion between 2007 and 2011, claiming two-thirds of the available growth budget for long-term care (SER 2008: 55). Although the personal budget may have disproportionately contributed to rising public expenditures, it currently accounts for only 10% of overall spending on the AWBZ (Sadiraj et al. 2011).[16]

The struggle for cost containment intensified in the 2000s when annual AWBZ spending rose from €18 billion in 2002 to €23.5 billion in 2010 (CBS 2012). The welfare state, it was claimed, had exceeded its financial limits. The agenda of cost *containment* through modernisation was now replaced with one of cost *reduction* by cutting back (current and future) entitlements. The government stated in a recent policy document:

> 'Also internationally we walk out of step. In the Netherlands, a relatively large proportion of long-term care is publicly funded. Together with Sweden, Netherlands is a frontrunner. Spending on long-term care is now 2.5 times as high as the average of all OECD countries... With unchanged policies in the Netherlands in the coming decades, the share relative to GDP will double. Such growth leads to greater crowding out of other government spending.' (VWS 2013a: 3)

The generosity of public long-term care is no longer seen as a source of national pride (RVZ 2005) but as untenable in the context of an ageing society and economic crisis (VWS 2008a). It is no longer reasoned that reform is needed to uphold *existing* entitlements; cutbacks are necessary to protect a 'core AWBZ' to 'ensure care, now and later' (ibid.). Such cutbacks generally distinguish between 'care' and 'support'. While the first involves bodily care (washing, getting dressed, going to the toilet), support or help are the terms increasingly used to describe social care, or cash and services to assist elderly, chronically ill and disabled persons with their daily living (shopping, going to the hospital, handling the mail) (Daly and Lewis 2000). These latter forms of care are increasingly deemed a misuse of public money, as becomes clear from the 2009-2010 cuts for support with daily living and social participation (VWS 2008a) and the more recent cuts to housekeeping support.[16]

The need to cut entitlements is not as self-evident as it seems. Though costs have grown and monthly premiums have risen to €320 for people with average incomes (VWS 2008b), there are no signs that citizens are unwilling to pay these premiums, as has been argued by the government (ibid.). There thus seems to be a disconnect between the retrenchment agenda and the continued support for protective schemes among the Dutch electorate. While politicians from left to right claim that the country needs to reduce public spending on care, voters continue to support affordable, quality health care for all (Prodemos 2012; Vabø 2012). Nevertheless, the current agenda to encourage self-sufficiency may undermine the collective solidarity needed to uphold public long-term care.

Knijn (2003) points to the ‘risk of individualization’ – of citizens withdrawing their support for public care as they become less likely to benefit from it.

Given the lack of popular support for retrenchment, one may ask why there is so much political agreement on the matter, especially as political scientists have warned of its effects for the popularity of the ruling parties (Pierson 1996). To reduce this threat, the politics of retrenchment is marked by blame avoidance (Weaver 1986; Pierson 1996). Whereas extending social programs previously enjoyed popular support, there is little credit to be claimed for reforms that have direct costs for citizens without any immediate benefits. The government thus seeks as broad a consensus as possible, framing retrenchment as a collective effort to ‘save the welfare state’ (Pierson 1996: 177). Others argue that the negative effects of retrenchment on the popularity of political parties has not been proven, and that especially (liberal and religious) parties that already supported reduced state intervention can claim some credit for the cuts in social policy (Giger & Nelson 2010; Mortensen 2013). Be that as it may, opportunities to claim credit for retrenchment remain limited when the electorate perceives inequity in sacrifice (Clarke & Newman 2012). For example, elderly people facing cuts to their pensions point to bankers’ bonuses that remain intact despite the billions of euros in public money spent on the recovery of the banking sector. Such discrepancies are not easily accepted by the public, whose consent is not assured and/or may be passive (ibid.). Green-Pedersen (2007) argues that retrenchment can be more radically pursued in countries with coalition governments; when centrist parties are committed to retrenchment, other parties which wish to govern have to accept the framing of reform as an economic necessity. Parties can thus only influence the retrenchment agenda if they accept the need for it in the first place.

Above all, the need for retrenchment is presented as hard-nosed economics. The key claim of economists is that ‘strategies of fiscal constraint can, counter-intuitively, produce expansionary effects in national economies’ (Clarke and Newman 2012: 301). But there has only been equivocal evidence for this claim, suggesting a combination of ‘hard-nosed economics’ with normative and ‘magical thinking’ (ibid.). For example, and contrary to other non-governmental statistical bureaus, experts in the Dutch Ministry of Health believe that the substitution of residential care with home care will continue to be an effective cost containment strategy in the years to come: ‘The reasoning here is that the average home care user is on average less costly than the average user of residential care' (SER 2008: 201). But this expectation remains doubtful as it is likely that further deinstitutionalisation will affect the most severely disabled persons (ibid.) for whom care at home is likely to be more expensive than residential care. The policy becomes even more dubious when combined with cuts to home care as it is unlikely that severely disabled persons will suffice with a few home care visits per week.

All of this shows that the government is banking on changing public/private responsibilities for long-term care. The question is thus not how further deinstitutionalisation will render economic gains, but on whose account? In other words, on which 'hidden' care resources (Daatland 1997) does the government implicitly rely when combining a process of deinstitutionalisation with cuts to home care? On informal care-giving? On private funding? If the government is relying on informal care, possibly at the expense of paid work, how will this affect GDP? It seems that the government particularly expects (partially) unemployed citizens to step in, otherwise there is no guarantee that retrenchment, especially when considering the costs of reform, will reduce welfare spending in the long run (Jordan 2011).

While economic necessity is presented as a reason for reform in its own right, it is combined with a normative appeal to citizens to view 'social care' as a private responsibility – as 'help' or 'support' that does not require payment. As such, the government's struggle to contain costs has shifted from measures aimed at safeguarding universal care rights to new strategies that provide more selective entitlements. While previous and current Dutch cabinets (led respectively by the Christian Democrats and Liberals) have framed these measures as necessary to preserve the AWBZ for 'current and future generations', they have in effect altered the system, which no longer serves all citizens with chronic care needs. In the next section, the normative principles underlying the Dutch care reform agenda are more closely examined.

For love: the normative reform logic

The Dutch care reform agenda increasingly reserves access to public care for those who 'really need it' (VWS 2008a, 2013). The rhetoric suggests that the state has gone 'too far' in assuming responsibilities for care at home, with negative consequences for both care recipients and society at large. Since the 1980s, there has been growing criticism of the dominance of professionals in the lives of care recipients (Duyvendak 1999; Knijn 2004) – for creating dependency rather than relieving it, and for being 'paternalistic' (Achterhuis 1979). But whereas the government first aimed to reduce the effects of professional dominance by giving clients more voice and choice over their own care arrangements (VWS 2001),[18] the current agenda goes further by suggesting that dependence on the welfare state is in itself undesirable. Interestingly, it is no longer only the professional who is to blame for creating dependence, but the citizen who too 'passively' consumes rights to care without pursuing private solutions (Wilken & Dankers 2012):

> 'It is outdated for inhabitant of this country to depend on public authorities to solve their problems.' (Spies 2012)[19]
>
> 'Focusing on the client presupposes that we take them seriously as assertive citizens who take responsibility for their situation. Primarily it means to stay self-sufficient as long as possible and avoid dependence on [public] care for as long as possible.' (VWS 1999: 16)[20]

Whereas extensive rights to care were previously seen as the core of full citizenship for ill and disabled people (Oudenampsen & Steketee 2000; Tonkens 2011), it is now increasingly seen as a hurdle to their autonomy (Kampen et al. 2013). Self-sufficiency, however, is not an end in itself; the government believes that encouraging 'active' citizenship and reduced dependence on public care will contribute to the ability of disabled and elderly persons to manage their own lives (Tonkens 2011: 62).

The meaning of autonomy has thus changed: one no longer becomes independent by relying on the government, but by relying on one's private network (Bos, Wekker & Duyvendak 2013). But instead of downplaying the importance of autonomy, the current reform agenda makes use of slogans such as 'personal strength' (*eigen kracht*), 'self-empowerment' (*zelfredzaamheid*) and 'self-control' (*zelfregie*) which present independence as a necessary condition for living a worthy life and participate on a par with others in social life (Sennett 2003).

The Dutch government further argues that extensive public care has 'crowded out' private initiatives and 'active' solidarity (Trappenburg 2009). This argument stems from a debate over welfare which centres on the 'crowding out hypothesis'[21] which states that increased government intervention will reduce the availability and willingness of families and volunteers to provide care and welfare (Van Oorschot & Arts 2005). Although this criticism was already heard in the early days of the AWBZ, it became prominent in the 1980s when the Christian Democrats emphasized the need for a 'caring society' (Da Roit 2012).[22] According to the then Minister of Health Brinkman, families too easily outsourced care to professionals, in the process undermining the bonds of society. His ideas were criticized by care professionals as well as feminists who considered the appeal to provide more unpaid care as an exploitation of women (Kwekkeboom 1990). While the debate on public-private care responsibilities fell silent with the fall of the cabinet in 1989 (Kwekkeboom 2010), it re-emerged in the 1990s with the increased popularity of home care (Da Roit 2012). New assessment procedures now led to the creation of a norm for 'customary care' (*Gebruikelijke zorg*) to distinguish the 'normal' informal care which household members are supposed to offer each other from care that is eligible for public funding (Morée et al. 2007).

It was not until 2003-2005 that the Dutch government, again headed by the Christian Democrats, called for a more fundamental restructuring of private-public boundaries in long-term care. Inspired by American sociologists such as Robert Putnam and Amitai Etionizi who criticized the lack of community spirit and the need for its revival (Etzioni 1993; Putnam 2000), communitarian ideas now entered the Dutch policy field (Timmermans & Kwekkeboom 2008). Although the government recognizes the contributions of the (750,000 out of 16 million) Dutch citizens who already provide care that is both intensive (i.e. more than 8 hours per week) and long-term (i.e. more than 3 months) (Timmermans 2003), it believes civil society must be revitalized. The Ministry of Health stated in a key policy text:

> 'Volunteers and care-givers contribute significantly to the self-reliance and participation of others. And they contribute to mutual involvement and social cohesion in our society. Voluntary work and lay care-giving offer citizens the opportunity to meet each other and establish contact…. 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.' (VWS 2007b: 1)

This vision glosses over the possible negative effects of relying on informal care, such as abusive relationships and the overburdening of lay care-givers. Eliasoph (2011) refers to the government's rose-coloured reading of civic engagement as a 'mantra'; through repetition, it sticks in people's minds. The Dutch government's 'community spirit mantra' is moreover contrasted to *professional* and *paid* cares, which increasingly receive negative associations: cold, impersonal, bureaucratic, and even inhuman (cf. Hochschild 1995).

Informal care as opposed to professionalism

The community spirit mantra changes how professional care is viewed. Whereas responsive, professional home care was previously seen as a means towards equal participation in society, the community spirit mantra emphasizes the risk of unnecessary medicalization and exclusion from social life when citizens rely (too much) on professional (home) care:

> 'Value is also attached to the avoidance of unnecessary medicalization, because this can cause unintended stigmatization. It may happen that young people are at risk of becoming too dependent on the AWBZ. That is not desirable and not necessary. So we have to prevent this.' (VWS 2008a: 1)

> 'The care and support of and with that, daily life, is too often unnecessarily taken over – albeit with good intentions – by professionals (medicalization), causing people to be made too dependent on care.' (VWS 2013a: 2)

The community spirit mantra dictates that fewer people should enter professional care trajectories and that professionals must learn how to disengage from clients' lives and instead focus on their self-sufficiency. A brochure on 'Welfare 2.0' instructs professionals on how to approach their clients:

> 'Once the care request of the citizen is clear, you [i.e. the professional] ask yourself who does what. What can citizens do for themselves, or with help from their immediate social environment? What can be the role of social networks in the district or neighbourhood? How can volunteers be deployed? What can neighbours and family mean for individual care requests? In other words, what do the professionals do and what do the citizens do? The self-sufficiency of the citizen, his network, the street and district is ignored too quickly. Taking on the problems [as professionals] is mostly counter-productive for self-management.' (VWS 2010:18)

From this perspective, professionals can do more harm than good when they take over the problems of their clients (cf. Achterhuis 1979). While social care professionals have been trained to assist persons in need, they are now told to do as little as possible. Their new function is to bridge their clients' care needs and private care arrangements, in effect to build 'networks' around their clients. This 'social network strategy':

> 'builds on the client's self-resolving power and that of his environment. The power to take decisions, make plans, and carry them out together. In the lives of clients, professional carers are but passants. They therefore do no offer real continuity. Family and friends are often connected for much longer and are closer to the client.' (www.meeplus.nl/mee/sociale-netwerk-strategieen)

Critics argue that the government's reliance on 'active' solidarity may generate new inequalities; because care needs are unevenly distributed amongst families and deprived and privileged neighbourhoods, some citizens can more easily ignore the hardships of fellow citizens than others (Trappenburg 2009).

Informal care as opposed to payment

The altruism of volunteers and lay care-givers who provide unpaid care is furthermore contrasted to the 'commodification of care' (Ungerson & Yeandle 2007; Knijn 2004; Hochschild 2003, 2012). The mingling of 'love and money' within care is tied to one of the leading socio-economic developments of the past decades: the increased participation of women in the labour market. Since the explosion of the service economy in the 1980s, markets have discovered the added value of tailored services (Vandermerwe & Rada 1988). A service implies 'personalized labor, immateriality, information, and greater human satisfaction, and fundamentally different modes of production, movement, and organization than in the industrial age' (Walker 1985: 46). This 'personalized' labour derives its added value from being responsive to personal needs, embodying the 'care' and 'intimacy' previously associated with the private sphere – what Hochschild (2003) has referred to as the 'commercialization of intimate life'. Not only did women enter these service jobs; their presence in the home as care-givers was no longer guaranteed, further fuelling the development of paid child care and long-term care services (Knijn 2007).

Critics suggest that outsourcing family tasks to the market 'jeopardize(s) the quality of family life and family solidarity' (Esping-Andersen 2009: 104). This claim, however, is not supported by empirical evidence (Folbre 2012). Nevertheless, politicians suggest that public money should not be spent on care that can take place without pay, exchanged for reasons based on a higher morality. In Dutch policy rhetoric, the benevolence of family, friends and volunteers is considered 'invaluable', while questioning the implications of care-giving for one's chances on the job market is inappropriate:

> 'Everyone should participate. The time is over when voluntarism was viewed as bread robbery and that it was debated whether or not people who received unemployment benefits could perform it. It is about commitment and solidarity with groups in our society which need extra support and attention.' (VWS 2007a)

Complaining about decreased payments for care has become morally questionable. Informal care exchanged within private networks or performed by volunteers is considered altruistic, warm, loving and more durable than care that is contractual and/or motivated by payment. The key idea is that people in need of social care are better off relying on care that is altruistic and public-spirited rather than care that is directed by self-interested or 'knavish' motives (Le Grand 1997). This will eventually also lead to a better and more cohesive society.

In sum, the Dutch care reform agenda combines an economic logic with a moral appeal, constituting an ‘alchemic combination of virtuous necessity’ (Clarke & Newman 2012: 312). It summons citizens to reduce their dependence on public long-term care by relying on their private networks. State support is no longer considered a legitimate way to avoid dependence on one’s family and friends, thereby reversing the previously understood meaning of autonomy. In retrospect, citizen reliance on public long-term care is viewed as a moral failure (Bos, Wekker & Duyvendak 2013). Like being unemployed and receiving benefits, dependence on public services is increasingly seen as a moral hazard, a ‘post-industrial pathology’ (Fraser & Gordon 1994; Van Oorschot 1998).

Research questions

The present thesis examines how care-givers and recipients deal with the recent shifting normative logics on the ‘right way to depend’. This translates into a number of questions concerning citizens who are involved in home care situations, as care recipients or family care-givers. The focus of these questions is on how they experience and cope with cuts to publicly financed care and the new demands of individual responsibility and 'active' solidarity.

a) What norms does the Dutch government set for the care responsibilities of family members? How have these shifted over time? To what extent does this mirror citizens' family care norms?
b) How are the values of choice in long-term care and 'active' citizenship reconciled in Dutch care policy? And how do family care-givers, which are confronted with mounting informal and unpaid care tasks, in retrospect reflect on their choice for a personal budget?
c) How do care recipients cope with retrenchment? Do they search for alternative means to receive the care they need? Is their coping based on practical, moral or emotional considerations? If they do find alternatives, what shifts in responsibility are involved? How are these negotiated?
d) How do care recipients experience the increased emphasis on community-based voluntarism in social care? Do they believe in a 'participation society'? How do their ideas and experiments with social voluntarism evolve over time, and in which ways does it affect their self-esteem and self-respect?

e) How do care recipients who disagree on the cuts contest the reform? How can we explain individual decisions in the use of the right to make an appeal? What role do emotions play in their arguments?

The investigated measures

To address the above questions, this study focuses on two retrenchment measures: 1) reduced access to care for 'mildly' disabled persons and 2) reduced access to care for people with co-resident relatives. These measures present citizens with respectively a tightened medical and moral barrier to access to care, and these two types of barriers are highly interlinked in the rhetoric of 'active' citizenship, in the context of the Social Support Act (Wmo). The monetary barrier is decoupled from the Wmo-rhetoric of active citizenship; therefore we did not include a monetary barrier in the study. We expect that a monetary barrier also requires emotional reforms but of a different type; co-payments also discourage users to access publicly financed care, but it does not consider them undeserving.

First, the ‘AWBZ-pakketmaatregel’ (2009-2010) increased the threshold for the care function ‘support with daily living’ [*Begeleiding*] for people with relatively *mild* disabilities. This care function aids people with disabilities to overcome barriers in activities of daily living and social participation. Since January 2010 (2009 was a transition year), only people who are re-assessed as having moderate to severe disabilities are eligible for support with daily living. These categories are primarily based on medical indicators (i.e. bodily dysfunction, memory loss) and applied to all types of disability (Bza 2013). The threshold - as with other AWBZ-functions - however also entails a distinction between impairment and disability. A person with a high level of bodily care needs can experience few *disabilities* when it comes to activities of daily living, e.g. due to available public facilities or available informal care. The measure can thus also be described as affecting people with relatively *mild* care needs. Moreover, care that is oriented at social participation is no longer considered a ground for publicly financed support with daily living; it is integrated in the Wmo.

In the policy rhetoric, the measure was defended with the statement that the AWBZ ought to be preserved for people that ‘really need it’ (VWS 2008a, 2013)

– thereby suggesting that those clients that were re-assessed as having mild care needs - and therefore no longer eligible for support with daily living - did not *really* need the previously received care. It was also suggested that the care received by mildly disabled recipients had adverse effects, putting them at risk of 'unnecessary medicalization' and 'isolation' (ibid.). Finally, as local authorities acquired more responsibilities towards these mild care needs under the local Wmo, affected clients were encouraged to assume more private responsibility for their care needs, as contributing to their 'self-sufficiency' (*zelfredzaamheid*). In short, clients affected by the 'AWBZ pakketmaatregel' were expected to alternate their norms and feelings about the right way to depend, i.e. to rely on self-care and/or turn to the private network.

Second, the customary care norm is tightened since 2009, in particular for parents of young children (*1-uurs aftrek*). This reduces access to AWBZ care for the care functions personal care, nursing, and support with daily living. Before this measure was enacted, parents of children could request an assessment of long-term care needs that were more extensive than those of healthy children of the same age. Since 2009, parents are asked to perform one hour of 'non-customary care' per day, which is no longer considered eligible for public funding (although this measure is currently juridically debated) (CrvB 2013). In the Wmo, the customary care norm also applies to the request for housekeeping support (mainly cleaning).

In the policy rhetoric, the extension to customary care is presented as customary, i.e. the '*normal* daily care that partners, parents, co-resident children or other household members are supposed to offer each other' (CIZ 2013). In other words, families ought to broaden their ideas about what care should be performed within the family (though this is legally debated, see Chapter 2). This normative logic is intensified by the policy rhetoric of 'active' citizenship (Wmo) wherein citizens are encouraged to care for each other on the basis of 'active' solidarity, and without or with limited use of the AWBZ (care in kind or the personal budget). It tells citizens that they ought to care more for the akin, especially within the private home, and experience this as an act of 'active' citizenship. In the proposed policy amendment of the Wmo in 2015, a new word is created to contribute to this moral barrier to access publicly financed care in the local context (Wmo): customary help (*gebruikelijke hulp*) (VWS 2013b).

Methods and approach

To investigate the impact of the medical and moral barriers to access to publicly financed care, we chose for a qualitative research design. In order to not only capture the effects of the measures on daily life but also to investigate citizen's attitudes, experiences and feelings, in-depth interviews provided the most equipped method. In in-depth interviews, attention can be given to complex feelings, and contextual factors can be taken into account.

Reform 1: AWBZ Pakketmaatregel

To examine client's experiences with the 'AWBZ pakketmaatregel', we made a combination of survey and interview data. First, we sought information on the consequences of reduced care via a telephone survey, held amongst 500 affected clients in cooperation with the municipality of Rotterdam in 2010 (see also Van Dijk & Hoekstra 2011). In 53 per cent of the cases, the representative (usually a relative) answered the close-ended questions. It proved that a majority of respondents either experienced (45%) or foresaw problems in the near future (15%). The most frequently mentioned problems were: reduced psychological well-being (80%), increased dependence on the private network (79%), less social contact (71%) and less time spent outdoors (69%) (n=298).

Second, to investigate these problems of clients, we purposefully included 30 clients in the study who made use of their entitlements for a minimal period of six months, and whose current entitlements were at least halved, despite their conviction they needed this care. The interview sample developed through time, from 30 to 45 respondents. In the selection of the latter 15 respondents, we removed the requirement that the respondents expressed difficulties resulting from the cuts. We aimed for a wide variety of care needs but also ensured that the final sample included a large proportion of the most affected client groups: elderly and people with cognitive and psychiatric needs (CIZ & HHM 2008), and recipients of a personal budget (Schellingerhout & Ramakers 2010).

The respondents were primarily approached via the names and addresses that were transferred to the municipality if authorised by the client, which implies that we have no data on those who did not give this permission (except for five respondents who we have been able to contact via care organisations), so that we cannot generalise our results to all affected clients. We expect that people who did not give permission include individuals who do not, or no longer, consider support with daily living necessary due to improved health or access to privately funded care. Furthermore it is important to note, that we conducted the interviews with inhabitants of six cities: Amersfoort, Dordrecht, Haarlem, Rotterdam, Utrecht, and Zwolle. As these research sites are medium-to-large cities, findings might be different for villages. We aimed to contact twenty potential respondents per city and to request their participation (120 persons in total), of whom thirteen denied their cooperation and sixty-two could either not be reached, or did not belong to the target population.

The 45 respondents allowed us to generate a dataset, forming the basis for the first two articles (Chapters 2-3). The last three articles (Chapters 4-6) focus on the 30 respondents that were first included in the present study, to target the client's perspective.

Composition of final sample

The final sample consisted of 45 clients, 22 women and 23 men, aged between 10 to 91 years (with an average age of 49). Respondents had disabilities due to old age (12), psychiatric needs (13), cognitive impairments (11), physical constraints or chronic illness (9). Nine had multiple disabilities, but we enlisted them according to the disability that was their main ground for requesting the AWBZ care. In 18 cases, respondents received (part of) the care as a personal budget. In 18 out of the 45 interviews, a relative (usually a parent, in one case a nephew and one a partner) served as a spokesman for the care recipient. Their levels of education varied from low to high, and their (family) incomes were low to moderate; adult clients mostly received social assistance due to their inability to work.

In-depth interviews

We held a semistructured interview with respondents (see Appendix 1). In the case a spokesmen served as a proxy for clients, we asked the same questions from their recipient's view, but also additional questions on their own views and care-giving. In the interviews we asked respondents 'what the cuts meant for them?'; we did not prime emotive experiences by directly asking specific questions about their emotions. This way, respondents could use their own words to frame their experiences. Though this approach elicitated sufficient insight into emotive experiences, we did experience that women disclosed their feelings more in-depth than men. The client's disability sometimes interfered with the quality of the interview. Not all respondents were able to fully respond to the hypothetical dilemmas posed in the interview; therefore we did not use these as central method in our findings. We approached the first 30 respondents for a second interview, one year after the first interview. We repeated questions from the first interview round and asked respondents to reflect upon the long-term impact of the reform on their wellbeing and social participation.

Reform 2: Shifting 'customary care' norm

To examine clients and caregiver's experiences with the (extended) customary care norm, we started out from the respondents from the final sample (n=45). In 20 cases, clients lived together with healthy, mature relatives, wherein the customary care norm was applicable. In the case of a young disabled or ill child, the extension of customary care with one hour of non-customary care (‘1-uurs aftrek') was also recently applied. To investigate citizen's experience of the tightened customary care norm in the first two articles (Chapters 2-3), we felt we would need a broader range of respondents.

Additional interviews were held with citizens who requested house-keeping support and their assessors in the Wmo. Faced with budget constraints, local gatekeepers have little leeway to make exceptions to the rule; especially given the recent re-assessments aimed at retrenchment (Zorgbelang Nederland 2013). We interviewed clients or their representatives (n=4), care assessors (n=7), and observed care assessments (n=4) of the enactment of the customary care norm in assessing entitlement to housekeeping support. Respondents were selected with the help of the MO-zaak in the city of Amsterdam. In addition we used available, national statistics to evaluate to what extent the customary care norm mirrors the care norms of Dutch citizens. We used this data for the first article (Chapter 2).

To specifically investigate why citizens protested against extended family care norms, we also retrieved complaint letters of co-resident family caregivers (n=21) with the help of the Dutch personal budget organisation Per Saldo. We held 10 telephone interviews to ask further questions about their discontent with the mounting family care tasks, which we used in the second article (Chapter 3).

Structure of this thesis

This thesis contains five articles, presented in Chapters 2-6, that explore the lived experiences of the Dutch care reform agenda. The methods used, globally described above, are outlined in more detail in each of the articles.

The first article, Chapter 2, examines the development of gatekeeping procedures for long-term care as they pertain to the boundaries between formal and informal care. In the Netherlands, the norm of 'customary care' defines the boundary between informal care that is usual and expected to be exchanged between citizens, and 'non-customary' care which is considered more than standard and eligible for public funding. While customary care is presented as something that mirrors prevailing practices, we show that citizens in many ways disagree with the norm. Nevertheless, the Dutch government in the past years has sought to extend the norm of customary care, for example in the parent-child relationship, which increases the tensions with social reality.

The second article, Chapter 3, examines the tensions between choice in long-term care and mounting family care duties, as resulting from the tightened customary care norms and reduced access to care for people with relatively mild disabilities. Choice has been a spearhead in Dutch long-term care policy; allowing for disabled and older care recipients to choose their own care-givers, including co-resident relatives who can be paid for non-customary care. This chapter examines how the policy changes concerning freedom of choice and active citizenship affect paid informal care-givers. It finds that the idea of 'citizen-carers' and citizen-workers serenely co-existing is naive, especially as informal care-givers learn the economic value of their 'non-customary' work.

The third article, Chapter 4, reviews the impact of the reform agenda from the perspective of the disabled and elderly recipients of long-term care. It focuses on the impact of reduced entitlements for people re-assessed as having 'mild' disabilities, and examines their alternative care-seeking strategies. It questions the extent to which disabled and elderly persons turn to their relatives, friends and acquaintances for care – as summoned by the government. We find that many clients resist (further) dependence on their private networks. They would rather hide their care needs from their families than become (more) dependent on them, as they feel this would undermine their autonomy. This is highly paradoxical because if care needs are unmet, citizens may end up becoming less self-reliant than before the reforms.

The fourth article, Chapter 5, focuses on the recognition of the needs of vulnerable citizens, which are increasingly framed as a private responsibility – one which can be met by the voluntary sector. We interrogate the feasibility of ambitions to advance the social inclusion of people with disabilities with recognition measures rather than entitlements to social care in retrenching welfare states. Repeated interviews with disabled and elderly persons, affected by cuts to care, reveal that the turn to voluntarism frequently leads to disappointing and sometimes even demeaning experiences as they feel their needs, autonomy and talents are misrecognized. We conclude that we need to broaden the bases of respect and esteem to arrive at participation parity.

The fifth article, Chapter 6, questions why affected clients and their representatives, despite their deeply felt grievances, do not protest against reductions to their entitlements. It asks what motives and feelings deter them from formally appealing and thus possibly retrieving their lost care, and how these are mediated by social norms. It finds that (fear of) shame is a powerful and de-mobilising emotion: clients and their representatives do not want to risk the shame of being dishonest to themselves, their social environments and the authorities. Rather than being silenced, affected clients are seemingly silencing themselves.

The final chapter, Chapter 7, reflects on the nature of the lived, emotive experiences of the care reform agenda for clients and care-givers. It points to the myth of self-sufficiency and explains why it is so difficult for care-givers and recipients to experience dependence on a par with respect and esteem. It then reflects on our form of governance that intervenes so deeply in the private lives of citizens. Finally, the conclusion points to the importance of vulnerable citizens to depend on others without shame and presents the necessary ingredients for such a shame-free dependence.

Notes

[1] Whereas Keynes sought to generalize norms of mass consumption through welfare rights and new forms of collective consumption, Schumpeter emphasized the importance of self-regulated market innovation and enhancement of the structural competitiveness of open economies; herein social policy is to be subordinated to the demands of labour market flexibility and structural competitiveness.

[2] Old age is the best determinant for predicting the need for care (Folbre 2012).

[3] Depending upon the demographic makeup of the population pyramid in a specific country.

[4] Some councils even want to increase the threshold from sustainable to (super-) critical care needs (Samuel 2011).

[5] As established in the 2005 Act on Support for Informal Care.

[6] Dutch: keukentafelgesprek.

[7] Symbolic interactionism originated in the work of George Herbert Mead and Herbert Blumer. Hochschild mainly builds on the work of Ervin Goffman (1922-1982) and his concept of 'impression management'.

[8] See William I. Thomas (with Dorothy Swaine Thomas), *The Child in America* (New York: Alfred A. Knopf, 1928).

[9] Hochschild uses the terms 'emotion' and 'feeling' interchangeably, although she acknowledges that emotion is a 'bodily cooperation with an image, a thought, a memory – a cooperation of which the individual is usually aware' which implies a state of being overcome that feeling does not (Hochschild 2003: 87).

[10] The Dutch and Swedish care systems are comparable, but with greater emphasis on residential care in the Netherlands (Pavolini & Ranci 2008).

[11] Current government plans include devolving 'personal care', 'temporary stay' and 'support with daily living' for people with moderate to severe disabilities to local authorities in 2015.

[12] Dutch: zelfredzaamheid or eigen kracht.

[13] Wmo-raden.

[14] Dutch: kwetsbare burger.

[15] The term 'Taylorisation' refers to Frederick Winslow Taylor (1856 -1915) who sought to improve industrial efficiency in America. In his 'stopwatch study', he found that labour could be divided into its component parts with a standard time needed for its performance.

[16] As measured in 2008 when 20% of AWBZ recipients used a personal budget alongside or instead of care in kind (Sadiraj et al. 2011).

[17] See for example the Municipality of Rotterdam: www.rotterdam.nl/herindicatiehuishoudelijkeverzorging.

[18] The Dutch Ministry of Health states that the 'current care scheme insufficiently meets the demands of patients and clients. This shortcoming follows from several bottlenecks, such as limited choice, insufficient service integration and lack of fit between offer and demand' and proposes new plans to enable patients and clients to become more actively involved in their care provision (VWS 2001: 6-7).

[19] Dutch: 'Het is niet meer van deze tijd dat je als inwoner van dit land maar hoeft te kikken en de één of andere overheidsinstantie lost jouw probleem op.'

[20] Dutch: 'Het centraal stellen van de client vooronderstelt het serieus nemen van de client als mondige burger, die zelf verantwoordelijkheid neemt voor zijn of haar eigen situatie. Primair betekent dat: zo lang mogelijk op eigen benen staan en zorgafhankelijkheid zo lang mogelijk voorkomen.'

[21] Though long-term care in the Netherlands is a typical example of 'defamilialisation' (Leitner 2003; Bambra 2007) – i.e. welfare state expansion leading to reduced dependence on the family – there is no unequivocal evidence that the state has crowded out the family (Daatland & Lowenstein 2005). There is, however, evidence that the family provides different types of care (Motel-Klingebiel et al 2005; Brandt et al. 2009; Haberkern & Szydlik 2010) such as emotional and practical support (Timmermans 2003).

[22] Dutch: zorgzame samenleving.

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Chapter 2

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

Submitted as
E. Grootegoed, E. van Barneveld and J.W. Duyvendak
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 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 (Rummery 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?

1 - short term, i.e. prospect of recovery, less than 3 months
2 - long term, i.e. chronic care needs, more than 3 months

	AWBZ				Wmo
	personal care [a]	nursing [b]	daily support [c]	living environment [d]	house-keeping [e]
by partners	1 - yes; all personal care 2 - no	1&2 - no	1 - yes; all daily support 2 - yes; all *customary* (f) daily support	1&2 - no	1&2 - yes; all house-keeping
by parents (of children up to 17 years old)	1 - yes; all personal care 2 - yes; all *customary* 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 *customary* nursing plus one non-customary hour per day	1 - yes; all daily support 2 - yes; all *customary* daily support (g) plus one non-customary hour per day	1&2 - yes; fully responsible for living environment	1&2 - yes; all house-keeping
by other household members (incl. children)	1&2 - no	1&2 - no	1 - yes; all daily support, except for children 2 - yes; all *customary* daily support, except for children	1&2 - no	1&2 - yes; all house-keeping, except for children (h)

a) mainly showering, feeding, dressing
b) mainly wound care, medication, medical instructions
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
d) creation of protected living environment, i.e. at home
e) mainly cleaning and meal preparation; all house-keeping should be (re)distributed among household members; local variations exist between municipalities
f) time guidelines for what is 'customary' are based on the time needed for these care tasks for a healthy person
g) e.g. assistance with after-school activities and personal development
h) for household members up until the age of 23, house-keeping responsibilities are specified by age

> 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 policy-makers 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 instruments[2] 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.[3] 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.*).[4] 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.[5] 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.'[6]

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.

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Chapter 3

Welfare state retrenchment and shifting notions of customary care

Published as
E. Grootegoed (2013) Between 'choice' and 'active citizenship': Competing agendas for home care in the Netherlands
Ethics and Social Welfare 7(20): 198-213

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.[1] 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.[4] 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.[5] 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

Wijngaart 2005).

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 care-givers 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.

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Chapter 4

Cuts to publicly financed care and client autonomy

Published as
E. Grootegoed and D. van Dijk (2012) The return of the family?
Welfare state retranchment and client autonomy in long-term care
Journal of Social Policy 41(4): 677-694

Abstract
European welfare states are cutting back their responsibilities for long-term care, emphasizing 'self-reliance' and replacing care as an entitlement of citizenship with targeted services. But we do not know how former long-term care recipients cope with retrenchment and if they are able to negotiate support from their family and friends. Through an analysis of 500 telephone interviews and thirty face-to-face interviews with long-term care recipients facing reduced care rights in the Netherlands, we found that disabled and elderly persons resist increased dependence on their personal networks. Most clients who face reduced access to public long-term care do not seek alternative help despite their perceived need for it, and feel trapped between the policy definition of self-reliance and their own ideals of autonomy.

Introduction

Long-term care (LTC) systems that arrange care for people with chronic care needs face significant economic and demographic pressures in Europe. In particular, the expected growth of the sixty-five-plus age group by 68 per cent to 133 million in 2050 is a pressing issue (Muenz, 2007). Against this background, social policies promoting self-reliance for long-term care needs are becoming the norm. Even countries with extensive LTC systems are restricting access to services by introducing user-pay principles, budget ceilings and tightened eligibility criteria. Instead of relying on public services, citizens are encouraged to find care arrangements within their own networks, in the voluntary sector, or on the market.

This 'surrender of public responsibility' marks a clear break with 'universal' welfare schemes developed in the post-war era to reduce social risks such as family care dependence (Gilbert, 2004). Note that equal access to services was an ideal; in reality, citizens lived under unequal circumstances (Vabø, 2011). The basis of universalism, however, lays in viewing care as a social right, an entitlement of citizenship. In contrast, the current trend towards a less formal conception of care rights, with an emphasis on selective assistance, seeks to entrench individual responsibility (Cox, 1998). While protection of the most vulnerable remains an integral part of public long-term care, it is no longer the default option, but a 'safety net'.

In contrast to the vast literature on welfare state expansion, less is known about the mechanisms of welfare state retrenchment (Pierson, 1996). For instance, we do not know whether tightening access to LTC will reduce state expenditures as citizens may apply for related social services instead (Jordan, 2010). The operational costs of restricting access may also be greater than any savings achieved through reduced use. How LTC recipients themselves cope with retrenchment is also unknown. Do they search for alternative means to receive the care they need? Is their coping based on practical or moral considerations? If they do find alternatives, what shifts in responsibility are involved? How are these negotiated?

This article examines client experiences of welfare state retrenchment in long-term care in the Netherlands. We first outline the policy background of the current cutbacks. Based on a telephone survey of 500 respondents and thirty face-to-face interviews, we then review the different care-seeking strategies of elderly and disabled persons in response to retrenchment of public LTC. As affected individuals mostly turn to their families, we focus on their (re-) negotiations with relatives. In our conclusion, we assess the extent to which recent reforms have led to the return of the family in long-term care, and the attendant effects on care recipients' experiences of autonomy.

Policy background

The Netherlands is known for its extensive rights to care and its services-led dual health care system (Pavolini and Ranci, 2008). In addition to the National Healthcare Insurance (ZVW), there is a comprehensive public scheme to cover non-insurable expenditures related to long-term care. The AWBZ, or the General Exceptional Medical Expenses Act of 1968, covers care functions such as nursing, personal care and support with daily living. The ideal of alleviating the burden on family members was an explicit aim in the allocation of public LTC (VWS, 1966: 16).

Nevertheless, the extent of AWBZ coverage and the development of a universal LTC system was controversial from its inception. The Christian Democratic and Conservative parties pointed to the possible substitution effects of broad LTC services; later on, the Left – inspired by the anti-psychiatry movement of the 1970s – grew critical of institutional settings and professional dominance (Tonkens, 1999). While the AWBZ initially provided institutional care, it was increasingly extended to care at home, thereby moving towards a social model of disability (Barnes, 1998; Oliver, 1996).

AWBZ legislation witnessed thorough-going reforms in the late 1990s and 2000s to create more flexible care markets in response to a growing variety of care needs. The introduction of market principles assumed a greater level of individual responsibility, with recipients of long-term care expected to act as informed, critical and assertive consumers (Mol, 2006). The Ministry of Health (VWS, 1999: 50) expressed the need for clients to be more active in managing their own care needs:

> 'Primarily, we plea for more demand-oriented services in the whole system, with a full position for the (individual) client (no longer a passive subject but an actively engaged player).'

Care providers had previously been contracted to provide comprehensive care. With the introduction of market principles, care was split into several 'care functions' such as nursing and personal care that could be purchased separately, allowing for greater competition between care providers. Such demand-oriented home care allowed for a wider coverage of needs. Moreover, the new Personal Budget (PGB) gave LTC clients the option to privately purchase care on the market. This cash-for-care scheme aimed to both provide greater choice and to contain costs, with privately purchased care estimated to be on average 25 per cent cheaper (Kaaij and Huijsman, 2008). But due to its popularity, the PGB created new care markets, including the monetisation of previously unpaid informal care (Grootegoed *et al.*, 2010; Kremer, 2006).[1]

Between 2000 and 2003, the LTC costs of the public system rose from 3.5 to 4 per cent of GDP (Eggink *et al.*, 2008) – high compared to other European countries and, without reforms, predicted to rise to 8 per cent by 2050 (Comas-Herrera *et al.*, 2006; OECD, 2011). Workers' premiums for the collective LTC system can add up to 340 euros monthly. Even then, user-pay principles, health care funds and state finances are needed to pay the remaining 40 per cent of the costs. According to the Ministry of Health, the AWBZ's unintended expansion has resulted in excessive claims and has made people overly dependent on public aid (VWS, 2008: 5):

> 'By the state taking over too many responsibilities from people, citizen participation has increasingly declined . . . Individual responsibility [for LTC] should be returned [to citizens].'

To create more civic responsibility for long-term care, contain expenditures and combat ‘welfare dependency’, the Dutch government passed the Social Support Act (WMO) in 2007. The WMO promotes ‘self-reliance’ – introducing as a positive term for disabled and elderly people who can manage ‘on their own’ without professional help. But in practice, disabled and elderly people often cannot manage on their own; ‘own’ in their case therefore means their ‘own network’.

The renewed emphasis on informal care is present in other European countries as well, the ‘Big Society’ agenda in the UK perhaps being the most prominent (Alcock, 2010; Kisby, 2010). As with the Big Society, the Dutch government’s underlying assumption in the WMO is that many LTC clients receive care that they do not really need, and that untrained informal care-givers can provide this type of care. The WMO moreover assumes that people have a social network, are able to articulate their care needs and arrange for assistance. The responsibility to arrange for care in one’s own social network is believed to enhance one’s self-reliance. The WMO also suggests that all citizens can support their compatriots with care needs. In practice, however, we know that mostly female relatives perform informal LTC (Boer and Keuzenkamp, 2009).

In sum, we see a clear shift from public to private responsibilities for LTC in the Netherlands, with the previous generous scheme being replaced by targeted services. The message of the 2007 Social Support Act is normative, as it explicitly promotes independence from public services. Hence autonomy is no longer realised by receiving welfare aid or consuming it by choice, but by relying on one’s ‘own strengths’ and that of active citizens (Tonkens, 2011).

Welfare state retrenchment: a case study

Our study of client experiences with the retrenchment of long-term care focuses on the effects of the so-called *AWBZ-pakketmaatregel*. This reform, enacted between 2009 and 2010, entails the tightening of access to one specific AWBZ home care function: practical support for elderly and disabled persons in their daily living. It includes personal aid with shopping, administration, making social contacts, structuring the day and/or group-based activities, such as day-care for the elderly (i.e. not their personal care or nursing).

The *AWBZ-pakketmaatregel* entailed two core changes. First, it discontinued the daily living support for promoting social participation. Second, it categorised disabled and elderly people as having *mild, moderate* or *severe* care needs. These new categories are domain-related, such as mobility, and are assessed independently of the type of disability. Those in the mildest category can no longer count on support with daily living. This resembles retrenchment measures in other European countries, such as in the UK, where critical needs have been prioritised over other needs in the provision of home care (Glendinning and Wilde, 2011) and, more recently, adult day care centres, that offer social and recreational activities for the elderly and disabled in a group setting, have been closed by several city councils.

The new legal divide in the Netherlands not only affects future applicants, but also current clients. After a re-classification of 230,000 legitimate clients, approximately 120,000 had their support with daily living reduced; 60,000 were cut off entirely. The people most frequently affected by the reform included the elderly using day-care, psychiatric patients and persons with cognitive disabilities (in contrast to individuals suffering from chronic illness and physical impairments) (CIZ and HHM, 2008).

Affected clients thus need to switch from public to private care arrangements, while local authorities – under the aforementioned 2007 Social Support Act – have been made responsible for facilitating the social participation of those in need.[2] The WMO is a typical framework law; allowing for a local variation of welfare provision (Trydegard˚ and Thorslund, 2001). To carry out these responsibilities, municipalities receive additional funding from the state, though the decentralisation of LTC encompasses cutbacks.[3] Municipal help related to one's daily activities in and outside the home is generally limited to support with informal care and/or making referrals to the voluntary sector.[4] To ease the transition for elderly and disabled persons, a special foundation (MEE) has received funding to assist people in their search for alternative care.

As the Ministry of Health (VWS, 2010: 1) stated in an evaluation of the reform, its objective was to reduce access to public LTC:

> 'The introduction of the AWBZ measure in 2009 has led to a reduction in the number of people that use support with daily living [i.e. public LTC]. Thus the measure has had the intended effect.'

The AWBZ reform differs markedly from previous reforms as it explicitly replaces the right to care (AWBZ) with care favours that need to be negotiated with local authorities (WMO). We focus on this measure as it combines all the factors by which we define 'retrenchment', namely: (i) tightened LTC eligibility for existing and future clients, (ii) an explicit goal of cost containment and (iii) a strong normative appeal to greater self-reliance. The retrenchment of public services can also imply the marketisation of care. But, in practice, purchasing care on the market is not an option for most AWBZ clients who, on average, have low incomes (Woittiez and Sadiraj, 2010).

Autonomy

The debate on the changing public-private boundaries of long-term care usually focuses on the providers – and not the recipients – of LTC. However, the willingness of persons to *accept* care is of equal importance to the success of any care arrangement (Daatland and Herlofson, 2003). In negotiating personal care arrangements, expectations to receive and felt obligations to provide care have to match (Finch and Mason, 1993). Asking relatives for care when it has not been offered can upset relationships and harm one's reputation. Even in cases where family members do feel responsibility, requesting care can undermine the flexibility of providing aid voluntarily, which Finch and Mason (1993) call the 'donor right'. Although this inequality of power is not necessarily a one-way street as the recipients of care may offer care-givers status or money (Kittay, 1999), accepting long-term care does come with concerns regarding autonomy.

The feeling of being in control over one's life is often considered essential to the quality of life of disabled and elderly people (Bowling, 2007; Boyle, 2008; Rabiee and Glendinning, 2010; Rummery, 2009). Client and patient movements have indeed been central in advancing LTC schemes that enable disabled persons and people with LTC needs to live autonomously. There is, however, an inherent tension between receiving care and preserving autonomy

(Fine and Glendinning, 2005; Tronto, 1993). In the realm of care, autonomy has to be understood as a form of 'relational autonomy' (Mackenzie and Stoljar, 2000; Reindal, 2010; Verkerk, 2001) – the ability to control or influence decisions and express personal choices and values in interactions with the caregiver (Boyle, 2008). The relational autonomy of elderly and disabled people can be severely constrained when they cannot choose the type of care relationship. This is particularly true when they no longer have the means to remunerate informal care and/or opt for professional care. Our study therefore critically examines retrenchment in relation to negotiations of care needs and autonomy.

Methods

We base our findings on a survey conducted in the city of Rotterdam and face-to-face interviews held between January and September 2010 in Rotterdam and five other Dutch cities (Haarlem, Utrecht, Amersfoort, Zwolle and Dordrecht). The latter was part of a larger research project on the Social Support Act (WMO). We received ethical approval for both studies by the city councils; for the personal interviews, we arranged that critical, unresolved care needs would be reported to the responsible local authority with the respondent's consent.

For the survey and interviews we selected people whose entitlement to support for daily living had been reduced by the AWBZ reform and who authorised their names and addresses to be transferred to the municipality (since we have no data on those who did not give this permission, we cannot generalise our results to all affected clients). We expect that people who did not give permission include individuals who do not, or no longer, consider support with daily living necessary due to improved health or access to privately funded care, as well as people who avoid being cared for.

Survey

The Rotterdam survey sought information on the consequences of reduced care, how affected individuals dealt with these consequences, and whether and how they searched for alternative (public or informal) care. Most questions were close-ended, with different answer categories. To reduce non-response, all potential respondents or representatives of clients received a letter announcing and explaining our telephone survey. Of this group (1,461 persons), 1,367 persons were called. We first asked if they had received notification from the authorities that their access to care had been reduced, or that they had noticed that they received less care. Of the respondents, 358 (26 per cent) answered 'no' to both questions, at which point the session ended because they did not fit the selection criteria.[5] There are a number of possible reasons why respondents claimed their care was not reduced while according to our information it was. First, their actual use of care may have differed from what was assigned to them. Respondents were sometimes also confused over which type of care we meant, as many received different types of care. Before asking if they received notification that their access to care had been reduced, clients were asked if they handled their care administration themselves. If a relative or representative helped them, we asked if this person could answer the survey questions. In 53 per cent of the cases, the representative or relative of the client answered the questions. Other non-response reasons were refusal (8 per cent) and technical/non-contact (wrong telephone number or number not in use) (29 per cent). Most respondents said the reason for their refusal was a health problem (45 per cent). As our aim was to conduct 500 survey interviews, no further respondents were approached after the 500th interview.[6]

Face-to-face interviews

We also held thirty in-depth, face-to-face interviews with disabled and elderly persons facing reduced care to see how they now met their care needs. We selected individuals whose entitlements to daily support had been more than halved despite their conviction that they required this care. We aimed for a wide age distribution to capture the variety of care needs. We selected twenty potential respondents per city and requested their participation (120 persons in total), of whom six denied their cooperation and eighty-four could either not be reached or did not belong to the target population. We omitted respondents who did not or no longer perceived their allotment of care as appropriate. When we asked them why this was, the most common replies were that day care did not meet their preferences (it was usually requested by a professional or relative) or they lacked the energy to take part in activities. Regarding individual assistance, the most frequent answer was that the client's health had improved.

The final sample included respondents with problems managing their daily lives due to old age (9), cognitive disability (8), psychiatric need (7) and physical constraints or chronic illness (6).[7] Their ages ranged from ten to ninety-one; in six cases a parent served as a spokesperson.

The interviews were semi-structured and consisted of open-ended questions on the following topics: understanding of the AWBZ reform, its quantitative and qualitative impact, care-seeking strategies and moral values regarding professional, family and voluntary care. At the end of the interview, we posed some hypothetical dilemmas regarding alternative care-seeking strategies. In the analysis, we used a text analysis program (AtlasTi) to code the different (public versus private) care-seeking strategies.

The public route was infrequently taken; one respondent had the financial means to purchase care on the market, and eight people turned to the local authorities for help (which, as we will see, was unsuccessful in most cases). Most respondents considered the private route as the only option. Here we coded their negotiations with family members for signs of resistance or acceptance. But as the first category was predominant, we integrated sub-codes to distinguish the different techniques used, such as 'masking' and 'hinting'. Finally, we analysed the relationship between increased family care and perceived autonomy for half of our respondents for whom this shift took place.

Findings

Prior to the *AWBZ-pakketmaatregel*, survey respondents had received support with daily living on the basis of their physical constraints (24 per cent), needs related to old age (21 per cent), a chronic disease (16 per cent) or psychological problems (13 per cent). They had received care and support to help them engage in daytime social activities other than work or education (42 per cent), to do their financial or other administration (42 per cent), to go for a walk/outside (39 per cent), to visit government agencies (37 per cent), to plan their week (29 per cent) and/or to find and maintain social contacts (20 per cent).

We asked survey respondents if they had experienced problems due to reduced care. This was the case for 45 per cent of our respondents, while 15 per cent anticipated problems in the future. One-third (34 per cent) stated that they neither experienced nor expected any problems. Of the rest, 3 per cent said they had experienced problems in the past and 3 per cent answered they did not (yet) know. The most frequently mentioned problems are listed in Table 4.1.

Table 4.1 The most frequently mentioned problems

expected or experienced problems	percentage (n = 298)
reduced psychological well-being	80
increased dependence on personal network	79
less social contact	71
less time spent outdoors	69
health problems	63
administrative problems	50

We asked clients if they had searched for alternative care. Surprisingly, only 20 per cent of survey respondents said they had done so. However, there was a discrepancy between searching for and actually receiving alternative care. Of all respondents, 15 per cent reported receiving care that partially replaced the lost care and 24 per cent received care that fully replaced it. Alternative care was most often (54 per cent) provided by family members. Although 39 per cent of our survey respondents had found alternative sources of care, half of these respondents (51 per cent) stated that they were still in need of additional care. Most survey respondents (61 per cent) reported not receiving any alternative care. Of these clients, 62 per cent stated that they needed it.

Of the small group that searched for alternative care (eighty-five respondents), the majority sought help from their families, followed by professional organisations and then voluntary organisations. The MEE foundation, designated to mediate between affected clients and the local authorities, was only mentioned nine times. Only two respondents sought direct contact with the municipal central service point. One third of those who did not search for alternative care stated that they did not need it; a quarter claimed that they did not know how and where to search for it. But as we will see below, it was not only a lack of information but also low expectations which made respondents less inclined to turn to the municipal authorities for help.

Turning to the local authorities

In the in-depth interviews, we asked respondents about their understanding and expectations of the reform and its institutional changes. Interview respondents understood the intentions behind the reform, i.e. that long-term care has become a private responsibility. Most were highly sceptical of the Social Support Act (WMO) – installed to 'buffer' LTC retrenchment – and considered going to the local authorities as a 'dead end'. Respondents, moreover, doubted the ability of the available publicly financed alternatives to meet their (perceived) needs. A ninety-one-year-old woman explained why she had not approached the MEE Foundation:

> 'I know that I could request MEE to seek for alternatives, but they cannot do anything for you. They just give advice, but they do not have financial resources to support you. They can only provide you with free care.'

By 'free care', she is referring to voluntary care. Although interview respondents appreciated the altruism of volunteers, most rejected voluntary care as a valid alternative. In some cases, their needs were considered too complex for volunteers. Most considered the lack of a long-term contractual commitment a problem. As a fifty-year-old woman with psychiatric disorders stated:

> 'Voluntary care is an informal agreement, so it lasts until one of the parties decides to end it. If the volunteer decides to opt out, you just have to accept that. You can never rely on it.'

Voluntary care does not deliver the safety of 'being in control' over one's own care arrangement. Affected clients regarded voluntary care as 'an extra' rather than a substitution for public care, as it cannot provide the solid basis for living 'independently'.

Our interviewees showed a general distrust of the local authorities. Their 'needs' were no longer recognised at the national level (within the AWBZ) and they expected that at the municipal level they would similarly not be eligible for public funds (through the Social Support Act). A parent of two autistic children (aged twelve and fifteen, who had previously received help with daily planning) stated:

> 'Under the new rules, they [AWBZ authorities] reason that the problems my children are having are unrelated to their autistic syndromes but are part of their 'puberty', as they have become teenagers. And that all parents have difficult teenagers, so it is our parental task to deal with it. I cannot see why they would reason differently under the Social Support Act.'

For the few interviewees who did turn to the municipality for help, the initial contact proved particularly meaningful. When this was unsatisfactory, our interviewees renounced approaching the municipality again. Disappointment was fuelled by unmet expectations, which were fed by municipal brochures, magazines and websites inviting citizens with special needs to participate in the community. As a mother of a ten year-old disabled boy recalled:

> 'I've read the Social Support Act flyers and they all talk about 'participation for all', but when I called them [the local authorities] to arrange a weekly sports activity for my disabled son, they told me they don't have anything that is suitable for him.'

Receiving 'no' for an answer informs people that they have to 'manage on their own'. Nevertheless, interviewees felt that they had the right to express their disappointment over the lack of local alternatives. This was true for both respondents who realised that their needs are no longer 'recognised' at any level of government, and those who expected municipal aid to make up for their lost care.

Turning to the family

The survey revealed that people who do search for alternative care often turn to their families. Simultaneously, they experience the increased dependence on their personal networks as a problem. How do these people renegotiate care-giving and receiving with relatives? In the following section, we first examine our interview respondents' normative beliefs regarding the limits of family care. We then reflect on the different strategies used to 'manage' needs in relation to family care boundaries. Finally, we relate shifting family responsibilities to care recipients' perceptions of autonomy.

We asked people to define their ideas about the limits of family care by responding to fictional storylines in which people had lost their support for daily activities. One storyline, that of a middle-aged man (Tim, forty-two), was particularly meaningful as it exemplified the boundaries of 'acceptable' family involvement. The storyline goes as follows: 'Tim has a psychiatric disorder. He cannot do his own finances and was supported in his administration [i.e. personal affairs] for many years. Due to the AWBZ reform, he no longer receives public aid. Tim can choose to do three things: object to the decision, ask a relative for help, or try to do it himself. What do you think Tim should do?' The majority of interviewees said that Tim, out of self-respect, should try to do it himself first – despite the storyline framing it beyond his abilities. A fifty-year-old woman with a psychiatric disorder argued:

> 'Yes, you should first try to do it yourself, just endure and if you do not succeed right away, then maybe you will the second time. And, if not, then you can ask a relative.'

Asking relatives for help was only legitimate once he had tried to substitute the lost public aid himself. In other words, affected clients first need to 'prove' to others that help is necessary. Even when the grounds for asking for help were sound, a process of negotiation followed. A thirty-seven-year-old interviewee with a psychiatric disorder ventured:

> 'I do not think you should force your relatives to do it [the finances], I mean, if you decide on it with mutual consent than it is different, but, in this case, his family may think it goes far beyond their responsibilities.'

The discomfort involved in turning down a request for help is considered a form of enforcement. This is considered unacceptable, even if the situation is created by an external factor, in this case reduced access to public aid.

In the fictional case, where the parent offers administrative help, Tim struggles to accept the offer. He fears it might harm his relationship with his parent. Again, the majority considered this a valid doubt, showing a clear preference for a more distanced care relationship with relatives. A fifty-one-year-old interviewee with a cognitive disability stated:

> 'Yes, I can see myself in this situation. Because it is his father, and I think that my father would become overly involved, and then I would feel very controlled. I think that if an outsider performs the job, it is different, more neutral. With all due respect for the father, I do not think I would want that.'

Letting a relative do one's administration was viewed as particularly threatening as family members can gain (too) much control over one's life. Interviewees thus wished for 'intimacy at a distance': if relatives could gain control over non-care related decisions, our interviewees preferred to maintain greater distance.

We found that affected clients did not consider welfare state retrenchment a legitimate reason to place greater demands on their families, though some clearly desired their families to help. In the interviews, we found different mechanisms to conceal and display the message of need, which we refer to as *masking* and *hinting*.

Masking need

None of the affected clients regarded it as the family's duty to solve the care gap resulting from the AWBZ reform. Some interviewees felt inhibited to inform their relatives about their reduced care. As an eighty-five-year-old man explained:

> 'I didn't tell my relatives that I lost the care. Why should I? I mean, they will only start worrying about me. And I don't want that. Besides, I don't think it is my children's responsibility to substitute public care.'

By not telling one's relatives, relatives cannot enquire whether help is needed. In fact, this is the goal. While this may seem contradictory – especially given that most affected clients perceived a need for care – it protects them from having to negotiate new boundaries and expectations with their relatives.

Another way to mask the need for care is to pretend that all is well despite the lost care. This strategy occurs most frequently among adults and the elderly living alone. An eighty-eight-year-old woman told us about her reduced social contacts and time spent outdoors, but when asked how she reports this to her relatives she stated:

> 'My children ask me how I am getting on [since the day-care loss], and then I tell them I am just fine, but inside I feel devastated.'

Again, the purpose is to show to her relatives that no help is needed – or rather expected – from them.

Though our interviewees experienced problems, this did not automatically mean that they conveyed a message of need to their relatives. This partly stems from their resistance to greater reliance on the family. They also wanted their relatives to be able to offer care on their own volition – that is, to help without the feeling of obligation, as will become clear below.

Hinting at need

In principle, some of our interviewees welcomed (more) family care. To convey a message of need, they used subtle hinting techniques so as not to offend their relatives and to uphold their self-reliant image. These could consist of general complaints about the cutbacks to care and the gaps that arise from it. An eighty-four-year-old woman who wanted her children to do more for her tried to convey her message of need subtly:

> 'I would like my children to visit me more often now. I do ask for it, or, at least, I tell them something needs to be done, so that they can offer to do it, and see me at the same time. But they do not always get it, and, as you see, my lamp is still not working.'

The woman points out that a broken lamp needs to be repaired by 'someone', whereas what she really values is increased social contact with her children. Clearly, relatives do not always understand or act upon subtle hints. Our interviewees did not blame their relatives for this, tracing their lack of response to their busy lives with children and careers.

Another strategy was to not discuss the new needs for care. Accepting additional family care is less problematic if renegotiation is not required. As a twenty-two-year-old woman with a chronic illness stated:

> 'Well, we do not really talk about it [the reform], I mean, my mother just does more for me now, it is the only solution we see for now. And she does not complain about it. For me, now I think it is all right, but I am aware that it makes me more dependent on my parents.'

The young woman is aware of the extra burden for her mother, but because care is taken over as a natural thing and her mother 'does not complain', it does not result in a moral conflict. This natural way of taking over lost care mostly occurs in families where the exchange of care is to be expected from past conduct. The Matthew principle therefore applies: those affected clients who already received a lot of family care prior to the reform will receive even more when public services are cut back. Other factors such as residential proximity and age can also predict why, in some cases, care is taken over as a 'natural thing'. But it is most likely that retrenchment of public long-term care will increase women's unpaid labour, as women typically have more time and inclination to care (Waerness, 1984).

Renegotiating family care and perceived autonomy

Accepting help from relatives affects perceptions of autonomy and dependency among recipients of care. Our interviewees often stressed what they could still do themselves, rather then pointing to what they could not do. The far-reaching involvement of relatives in one's affairs was considered intimidating. As a thirty-two-year-old woman with a physical disability explained:

> 'Well, I think I lost part of my independence now that my family takes on more responsibility for me. I am 32 years old, and I am like a mollycoddle to both my parents. I don't want to be like that. To me, to be autonomous, means I can be at home by myself, and not bothering others with my problems.'

Interview respondents did not consider expressing care requests to professionals as ‘bothering others’. As they are not part of one’s inner social circle, professional care-givers pose lesser threats to one’s autonomy; with them one can discuss needs in a more business-like manner. With relatives, control over care-giving is more complicated and embedded within existing social relationships. A thirty-six-year-old woman with a cognitive disability explained:

> 'Well, my family now comes in at times that fit them well, or have available, they do not understand that with my disability, structure and rest is very important. My previous professional carer tried to assist me in renegotiating the familial assistance, but they still do not understand my needs, and I find it hard to tell them, because they will think of me as being ungrateful.'

This shows that feelings of gratitude are more complicated in informal care relations. Moreover, interview respondents often stated that their relatives do not fully understand the nature of their disability, disorder or chronic illness. These findings support the notion of a ‘request scruple’ that people with care needs have *vis-a`-vis* members of their private networks (Linders, 2010). Interview respondents who faced greater dependence on family members resisted entanglement with the burden of gratitude.

Conclusion: the autonomy trap

Based on a survey of 500 affected clients in Rotterdam and thirty in-depth interviews in six Dutch cities, this article examined client experiences of reduced access to publicly funded long-term care, focusing on a recent reform of the AWBZ (General Exceptional Medical Expenses Act).

Of our survey respondents, 60 per cent were experiencing or anticipating problems due to reduced access to care. The most frequently mentioned problems were reduced psychological well-being and increased dependence on private networks. The latter is striking in light of the Social Support Act’s stated intent: to encourage self-reliance. Our findings suggest that accepting (more) informal care reduces the sense of autonomy of people with care needs. Due to conflicting public and private definitions of autonomy, clients face an *autonomy trap*. If trying to remain autonomous means not asking for the care one needs to buffer reduced public aid, one ends up becoming less self-reliant than before the reforms.

The survey found most respondents stating that they have unfulfilled care needs. Yet, most of them do not search for alternative care. Of the survey respondents who had found an alternative to (partially) substitute the reduced public care, this care was most often provided by relatives. Very few survey and interview respondents turned to the local authorities for help. The interviews revealed widespread scepticism of what they had to offer: referrals to 'free' (i.e. voluntary) care rather than individually tailored professional care. As interview respondents did not consider voluntary care an adequate solution, the only option left was to turn to the family.

The face-to-face interviews revealed that most affected clients resist (further) family involvement in their care. Here the normative belief that relatives should not be responsible for substituting public aid was an important inhibiting factor. Rather than asking relatives for help directly, many of our interview respondents employed strategies to hint at their needs more subtly. They did this to respect their relatives' right to offer care freely. Some of our interview respondents consciously concealed their needs from their relatives, or portrayed themselves as capable of covering for the loss of public care on their own, a strategy called 'acting as if' (Finch and Mason, 1993). Their normative beliefs meant that they considered direct requests of help threatening to their autonomy and reputation, as well as disrespectful to family members, on whom most did not want to structurally depend. Nor did the severity of care needs change the desire to limit dependence on family care.

When (more) care was given by relatives (which happened in half of the survey and interview cases), our respondents reported feeling less autonomous. The ability to reciprocate gifts (of care) clearly matters here. People with disabilities and the elderly often feel that they have nothing to offer in return or do not have the resources to do this. This can cause a burden of gratitude towards their (mostly female) relatives, which is experienced to a much lesser extent under publicly financed care (Galvin, 2004).

We did find a difference between seeking and finding alternative care arrangements. While only 20 per cent of all survey respondents said they searched for alternative care, 24 per cent were receiving care that fully replaced the previous publicly financed care. In such cases, greater informal care responsibilities may have been negotiated without the respondents' knowledge. Future research is thus needed to examine negotiations on family care responsibilities using a network perspective. Our findings are, moreover, based on a snapshot in time; longer-term studies are needed to understand the longer-term effects of LTC retrenchment on affected clients' well-being and social participation. We found that, in particular, the elderly and young disabled adults experienced the reform as a threat to their quality of life. The elderly whose day-care was discontinued experienced severe social and/or emotional loneliness, in two cases to the extent that they no longer wished to live. Young disabled or chronically ill adults living in the parental home saw their increased dependence on family caretakers as preventing them from achieving a more independent future. These signs of decreased quality of life require further study to inform future LTC policy-making.

Autonomy clearly mattered to our interview and survey respondents. The difficulty of maintaining an 'autonomous identity' lies in the mixed messages people receive from social policy. Recent policy posits 'self-reliance' as the ideal – attained by refraining from claiming publicly financed care. The use of this term, however, reflects an imaginary gap between the individual and society that neglects people's interdependency (Elias, 1987).

For people with care needs, an autonomous identity means not being overly dependent on one's own social network. In contrast to the policy definition of self-reliance, our survey and interview respondents viewed state support as a means to remain autonomous. The 'return of the family' in long-term care is thus resisted by disabled and elderly persons, who carefully ration or filter requests for care to their family and friends. The most problematic aspect of this filtering of needs is that they can become invisible. Affected individuals may be able to hide their problems for a long time. However, challenges may grow in severity over time, creating insurmountable obstacles to their participation in society. Based on these findings, we can conclude that making people more autonomous, self-reliant or engaged in society is not attained by reducing state obligations to provide care to its citizens. A more thorough and uniform recalibration of the welfare state is needed to establish citizen–state partnerships that bridge people's experiences and policy ideas of 'what counts' as autonomy.

Notes

[1] The Dutch government has therefore decided to end the PGB scheme for 90 per cent of its 128,000 current users (i.e. 20 per cent of all LTC clients) to prevent its further growth.

[2] The WMO does not guarantee individual social rights. Under the scheme, local authorities have a 'compensation duty' to help people with care needs to overcome hurdles to their social participation.

[3] By decentralising LTC oriented at daily life activities and social participation, the Dutch government aims to make a clearer distinction between physical care (personal care, nursing) and social care (support with daily living) at home.

[4] Aside from the political idea that informal care enhances one's self-reliance, local authorities are limited in their capacity to provide for professional care arrangements as they also face drastic cutbacks.

[5] The interviewers were trained in how to ask questions. To reduce the non-response bias, respondents were contacted both during the day and in the evenings. If necessary, a translator was present.

[6] This meant that 6 per cent of the sample was not contacted due to time limitations.

[7] Six respondents had multiple disabilities which were listed for the disability that was their main ground for requesting AWBZ care.

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Chapter 5

Community-based voluntarism and the struggle for recognition

Submitted as
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Community as a warm bath? How disabled and elderly citizens perceive and experience the 'spirit of community' in a retrenching welfare state

Abstract

Many European welfare states are replacing comprehensive welfare schemes with selective and conditional entitlements. This threatens the recognition of vulnerable citizens' needs, which are increasingly framed as private responsibilities to be met by the voluntary sector. Repeated interviews with 30 clients affected by cutbacks to publicly financed (day)care in the Netherlands showed that while disabled and elderly citizens are often hesitant to open their doors to volunteers, they experiment with voluntarism to reduce their social isolation, both by receiving voluntary care and by partaking in volunteer work themselves. But the turn to voluntarism frequently leads to disappointing and sometimes even demeaning experiences as vulnerable citizens feel their needs, autonomy and talents are misrecognized. Our findings show that the virtues of voluntarism are often over-stated by policymakers and that a fundamental rethinking of the bases of recognition is required.

Introduction

Welfare states are currently under great pressure to reform their care policies. In former decades, growing economies allowed the redistribution of premium and taxpayers' money to provide social care, thereby recognizing care recipients as full-fledged citizens with legitimate needs. But as the pie for redistribution ceases to grow, even hitherto generous welfare states are rationing entitlements, reserving publicly funded care for those with the most urgent needs (Pierson 1996; Cox 1997, 1998; Rostgaard et al. 2011).

Retrenching welfare states place high hopes on voluntary, community-based organizations taking over care for disabled and elderly persons (Gilbert 2004). This 'voluntary turn' is informed by claims that communities are more responsive than states or markets to people's 'true needs' (Etzioni 1993; Milligan & Conradson 2006). In contrast to the 'cold', distanced relations between clients and care professionals, voluntary care is said to approximate the 'warm' social relations provided by friends, family and neighbours (Verhoeven & Tonkens 2013). But how do disabled and elderly persons who previously received publicly financed care experience this shift towards voluntarism?

In thinking about social policy and social justice, 'the center of gravity has shifted from redistribution to recognition' (Fraser 2003: 89). Struggles for recognition dominate the political arena, particularly as prospects for redistribution recede in retrenching welfare states (Fraser 1995).[1] Honneth (1995, 2003) distinguishes between three kinds of recognition. First, *affective* recognition through mutual loving care gives people self-confidence (Honneth 2003: 139). Second, *legal* recognition of people as 'bearers of equal rights and duties and as owing the same autonomy as all other members of society' contributes to their self-respect (ibid: 142). Third, *social* recognition of one's unique, socially valuable abilities creates self-esteem (ibid: 143). Recognition is a vital human need as it shapes one's identity; non-recognition or misrecognition can inflict serious harm (Taylor 1992). When care-dependent persons are seen as inferior, 'every appearance in the public world means risking insult, ridicule, and embarrassment' (Wendell 1996: 65). To be misrecognized is to be excluded from 'parity of participation' – from 'social arrangements that permit all (adult) members of society to interact with one another as peers' (Fraser 2003: 36).

The turn to voluntarism contains mixed promises for the recognition of disabled and elderly persons as full citizens. On the one hand, the participative discourse replaces stigmatizing *patient* identities with empowering *civic* ones (Shakespeare 1993; Oliver 1996; Beckett 2006; Nederland & Duyvendak 2007). Disabled and elderly persons can receive care from their fellow citizens while being recognized for their own contributions to community life (see e.g. Seyfang 2003). On the other hand, the emphasis on the civic identities of disabled and elderly persons risks downplaying their actual impairments, thereby delegitimizing their care needs (Barnes 1992; Hughes & Paterson 1997; Danermark & Gellerstedt 2004). There is also no guarantee that community-based voluntarism advances social integration between disabled and non-disabled citizens as voluntarism operates through both inclusive and exclusive mechanisms (Gilbert 2004; Tonkens & Newman 2011; Eliasoph 2011).[2] Furthermore, the increased importance of voluntary organizations in retrenching welfare states places a premium on the third sector's efficiency, accountability and complementarity with public services (Dahlberg 2006; Hanlon et al. 2007). Growing state control over voluntarism[3] may thus ultimately undermine its informal structure and responsiveness to citizen rather than government demands (Gilbert 2004; Dahlberg 2006; Hanlon et al. 2007; Jager-Vreugdenhil 2012).

The virtues of voluntarism

The Dutch government's recent embrace of the 'participation society'[4] where citizens assume more family and community care responsibilities exemplifies the sharp break from years of welfare state expansion when policies aimed to 'free' citizens from the social control of communities (Cox 1998). The 2007 Social Support Act (*Wet Maatschappelijke Ondersteuning,* Wmo) posited that society should reassume 'ownership' of the well-being of it vulnerable members (Barnett 2003). Since then, the right to long-term care has been increasingly restricted to citizens with the most severe needs, while many of the responsibilities for people with relatively 'mild' needs have been devolved to municipalities. The Wmo is a framework law that enables municipalities to pursue their own programs.[5] These generally centre on family care, community life and voluntarism, which is lauded as intrinsically motivated, diverse and inclusive (VWS 2013b). Some municipalities even set targets for the type and number of volunteers they wish to recruit:[6]

> 'In the government's vision on long-term support and care, the work of volunteers and carers is becoming even more important…. By strengthening social cohesion and supporting volunteers, municipalities can further expand the already large potential of informal care.' (VWS 2013b: 11)

The Wmo and its aim to revitalize the 'spirit of community' (Etzioni 1993) is based on two premises. First, voluntary care is superior to professional care in promoting the social inclusion of disabled and elderly persons (VWS 2013b):

> 'The purpose of the Wmo is to promote citizen participation and tailored support for people who need it… volunteers will ensure that others who need some extra help can also participate.' (www.invoeringwmo.nl/onderwerpen/vrijwilligersbeleid)

Though the government explicitly states that voluntary care is not meant to replace professional care, it hopes volunteers will help alleviate the unevenly distributed and mounting family care obligations[7] that result from reduced access to publicly financed care (ibid.).

Second, people with disabilities can enhance their social participation by *becoming* volunteers themselves. The new government adage is to 'begin with what people (still) *can* do rather than what they cannot do' (VWS 2013b: 4). In practice, this can mean that disabled citizens who request support from the local authorities are asked to do something in return.[8] A physically disabled person who receives help with transport, for example, may be asked to read to school children. According to the Municipality of Amsterdam:

> 'When recruiting volunteers…, there is special attention for residents who are on welfare and who cannot easily get a job. But there is also attention for the elderly. They possess much knowledge and experience. Participation is a way for them to keep active, and to prevent loneliness and isolation.' (Gemeente Amsterdam 2012)

Under the Wmo, community-based voluntarism is thus both a *means* and an *end* (see also Jager-Vreugdenhil 2012: 221). Its participative discourse presents 'participation for all' as the key to greater social cohesion and a remedy for the misrecognition of disabled and elderly persons' knowledge and experience (VWS 2007).

A longitudinal study

To examine how citizens have experienced the turn to voluntarism, we interviewed long-term care recipients who faced cuts to their entitlements due to recent reforms. We focused on one particular measure – the 'AWBZ pakketmaatregel' enacted in 2009-2010 – which discontinued support with social participation and reduced[9] support with daily living for people with relatively 'mild' care needs. The reform not only affected future applicants; out of approximately 225,000 existing clients with various physical, cognitive and physical disabilities, 60,000 lost their entitlements entirely while even more had their entitlements reduced (CIZ & HHM 2008).

We purposefully selected 30 affected individuals with disabilities related to old age (9), cognitive disability (8), psychiatric need (7), and physical constraint or chronic illness (6) from six Dutch cities, whose files had been transferred from the national needs assessment centre to local care authorities upon consent.[10] We selected clients whose previous entitlements were at least halved, despite their conviction they required this care. We omitted clients who did not make active use of their entitlements.[11] Their ages ranged from 10 to 91.[12] In the case of a young child, one of the parents served as the spokesperson.

We interviewed our respondents twice: shortly after the implementation of the 'AWBZ pakketmaatregel' (in the first half of 2010) and one year later (in the first half of 2011). Four respondents could not be interviewed in the second round: one was unreachable, two did not want to participate, and one was deceased. In the case of the deceased individual, we interviewed the daughter. Of the remaining 26 respondents, 10 interviews were held by phone as these respondents did not agree on a second face-to-face interview. Reasons for this were a lack of energy and perceived lack of relevance for their personal situation. In the first round of interviews we asked why care was requested, what the (partial) loss of publicly funded care meant, and about their search for alternative care arrangements. As not all care recipients had experience with volunteers, we posed a hypothetical dilemma regarding voluntary care to elicit their normative views. In a fictive storyline, respondents were invited to give their opinions on: (1) the replacement of professional with voluntary care; (2) a volunteer's dilemma between continuing his volunteering and accepting paid work; and (3) the lack of personal click between the volunteer and the care recipient. In the second round of interviews, we repeated questions from the first round and asked about the reform's long-term effects on respondents' daily activities and social participation.

With the use of the qualitative data analysis software AtlasTi, we reviewed the problems respondents experienced after the (partial) loss of their entitlements and how it affected their struggle for recognition. We then coded respondent's attitudes towards the 'participation society' in general and voluntarism in particular, according to the themes of trust, durability, expertise, flexibility, and personal click.[13] We analysed respondent's (changing) attitudes and experiences with voluntarism in the second interview round by deductively differentiating between three types of (mis)recognition (Honneth 2003): of one's needs, one's autonomy and one's abilities. As few respondents had durable, positive experiences with volunteers, we also examined the consequences of missed recognition for individual respondents.

Results

The cuts negatively affected our respondents' psychological well-being, social contacts and ability to participate in activities outside their homes (see also Grootegoed & Van Dijk 2012). A majority also perceived increased dependence on their private networks as problematic, even if they did not rely on relatives to buffer the lost (day)care (ibid). The first round of interviews revealed that reduced entitlements led to unanswered needs and ate into self-respect (Sennett 2003). A 91 year-old woman whose access to day-care was discontinued stated that the cutbacks confronted her with her 'value' to society:

> 'I do feel sad at times that I am alone. Just because of the fact that when you are 91, you are excluded from society. That is how I experience it. That when someone from the municipality comes to measure my curb and asks whether I use my walker to go into the garden, then says: you don't get a ramp because you never go into the garden.'

The cuts deeply affected disabled and elderly persons, whose lives were already marked by the struggle for recognition. Most respondents did not believe that greater reliance on community-based voluntarism could relieve their need for recognition. Rather than viewing community life as a 'warm bath', respondents talked of it as a 'cold shower' (Verhoeven & Tonkens 2013). As a mother of a physically disabled 10-year old boy explained:

> 'So you have to rely on your private network now or on volunteers. Well, in this society? People are only occupied with themselves, at work or in their private life. And now I need to… find a volunteer for him? Well, you can forget about it these days… you cannot just reverse the social system, it can take years before people are available again, and think like they used to in the 1970s.'

But even if volunteers were readily available, respondents remained sceptical of the underlying social bond. Many mentioned that a personal 'click' was needed:

> 'Even if a volunteer is found, you just have to wait and see if there is a click. We have experienced it with the care purchased via the personal budget that someone came, and it was just really drama.' [Mother of two autistic children]

Respondents feared having less ‘control’ over care relations when relying on community-based volunteers. A 21-year old chronically ill woman reacted to the hypothetical case where there is no ‘click’ between the care recipient (a 12-year old disabled boy) and the volunteer (a 19-year old student):

> 'Yes, well if it doesn’t click with a paid care-giver you can easily request another person. But if it is a volunteer, that is much more difficult.'

In the hypothetical dilemma, we asked how much loyalty can be expected from a volunteer if he or she wishes to quit. Almost no one said the volunteer could be forced to stay, as it is in the nature of volunteering that the agreement can be ended at any time. This insecurity was seen as harmful to care recipients. A 91-year old woman with physical disabilities whose day-care was discontinued argued about the fictive case:

> 'Yes, you cannot count on volunteers. They do it voluntarily. Adult volunteers, who live for it, can perhaps persevere, but not a 19 year-old student. The more volunteers, the more destructive it is for the [disabled] boy. He needs a certain peace in his life.'

Respondents felt that the turn to voluntary organisations for care and support made them highly dependent on the benevolence of others, and that they had lost the autonomy to choose between different care providers (Collopy 1988). A mother of a 16-year old autistic boy, whose personal budget was halved, argued:

> 'The main difference is that he cannot choose on whom he is dependent. Now he is dependent on ‘society’. Money is power and offers independence, which was made possible by the AWBZ. Now he just has to accept what comes his way.'

Relying on volunteers was seen as a threat to the autonomy of care recipients; their relationships with volunteers lacked the durability, flexibility and ‘thick trust’ of relations with care professionals and relatives (Linders 2010). A 60-year old woman with a manic-depressive disorder whose weekly support with daily living was stopped told us she would not entrust volunteers with her ‘problems’:

> 'I guess you could argue that a social volunteer can also do my financial administration, but I don’t think so because a social volunteer cannot deal with the related [psychiatric] problems, and also, there is a barrier for me to talk about it, especially to a volunteer, I don’t just tell them that I am developing a manic or depressive episode.'

The belief that volunteers were unable to respond to one’s needs was also rooted in failed attempts to redistribute the burden of care-giving within one’s private network. A mother of a teenaged daughter with a physical and cognitive disability told us:

> 'Disabled persons are not always easy in social relations, especially a person like Esther. Everyone fled after looking after her once or twice. Even relatives, they are pretty useless. They all find her too hard to deal with.'

Lacking the family bond or the professional expertise to endure difficulties, respondents feared that volunteers would stop coming when their extrinsic motivations had run dry.

In short, our respondents felt that the government’s turn to voluntarism was a utopia based on the idealization of the pre-welfare state, community-based exchange of care. But the current prioritisation of work and private life over community made such a turn to a caring society impossible. Even if they were able to find volunteers, respondents remained sceptical about the quality and reliability of their care. While they felt volunteers could come to ‘make a puzzle with the elderly’, they did not seek the help of volunteers to meet their persisting and complex care needs, for which expert[14] assistance was deemed necessary. Their struggle for recognition thus grew more pressing as they experienced the cutbacks to publicly financed care as a misrecognition of their needs.

Positive versus demeaning experiences

Our respondents expressed similar ideas about relying on volunteer care in the second round of interviews. But as the cuts to publicly financed care often targeted support for social participation, and many felt increasingly isolated; some overcame their hesitation and reached out to volunteers over time. Half of our respondents had sought contact with the third sector, including voluntary organisations, buddy schemes, community centres[15] and churches. While municipalities sought to inform vulnerable citizens about local third sector activities,[16] most respondents found out about these organizations through their personal networks, thereby 'privileging' those who already had more contacts in the community.[17] Ultimately, most respondents experienced their encounter with voluntarism as disappointing and sometimes even demeaning – especially in comparison to their earlier 'sheltered' (day)care.[18]

First, there was misrecognition of one's needs. Especially respondents with 'hidden disabilities' felt that volunteers had unrealistic expectations, and felt misjudged when they failed to live up to them. A 48-year old man with a psychotic disorder who had previously received two hours of individual support per week turned to his pastoral workers, but met with misrecognition as they concluded that he was failing to 'overcome' his impairment:

> 'It's been two months since I stopped [seeking guidance from pastoral workers], because they are only really good pastoral workers for people who do not have mental problems. They say if you're depressed, it is your own fault. That is absolutely not true because if you break your leg, it is also not your fault. They see it as a failure of your belief that you are depressed. They have that twist of mind.'

Especially respondents with psychiatric disorders felt that their needs went unrecognised by social volunteers. They felt that there was less understanding for their needs than for people with physical and/or visible disabilities.

Second, there was misrecognition of one's autonomy. A 61-year old man with autism told us he searched for a social volunteer for one and a half years after his weekly individual help was lost due to the cuts. But the man, who was very enthusiastic about his new 'buddy', soon saw the volunteer give up:

> 'I searched for a buddy via the local authorities, and well, he came here once, and he didn't turn up for the second meeting. I heard from the local authorities that he didn't want to come anymore, I really find that disappointing…. '

The municipal contact person explained that the volunteer wanted to help him organize his book collection (read: mess). But the man wanted to be recognized for his hobby and talk about his books. For him, his book collection was a source of esteem; for the volunteer, it was a symptom of his disability that needed fixing, a belief also held by his family:

> 'My family also criticizes me, on how I live. They want to 'help' me in their way. They want to throw all the books away. But I have my own way…. They do not want to talk about the content of the books.'

Especially adults with psychiatric or complex[19] care needs living 'independently' felt that volunteers and relatives failed to grant them autonomy – that their needs were assumed rather than discussed (see also Grootegoed 2012; Grootegoed & Van Dijk 2012).

Third, there was misrecognition of one's abilities, as a lack of recognition of one's needs also undermines access to esteem derived from *overcoming* one's disabilities. This is rooted in the cultural opposition between happiness and disability/ill health. A 21-year old girl with a chronic illness explained that she feels 'the weight of a social obligation to be either healthy or miserable' (Wendell 1996: 63):

> 'It feels very good that I go to university, despite my disability. But well, I do have one of course, and sometimes it is difficult to explain how much that impacts my life and how much it constrains me. I often have to justify myself, how severe my fatigue really is and so on.'

The pressure to justify one's disabilities when claiming recognition for one's abilities undermines disabled and elderly citizens' control over what is being revealed about them (Sennett 2003). Respondents felt especially 'naked' when seeking care and support in the community, needing to explain their impairments to 'defend' their claims for both support and esteem.

In their attempts to become volunteers themselves and have their abilities recognized, our respondents encountered an institutional divide between disabled and non-disabled citizens. Voluntary organizations often categorized them as 'needy' rather than being able to contribute themselves. A 61-year old man with autism wished to volunteer but was rejected. His municipal contact person sought an explanation:

> 'I asked the social volunteer organization, but they said that they employ volunteers <u>for</u> people like him.... They said it would be too difficult because he needs supervision and that is not available there. So it is very crooked; it [the appeal to active citizenship] is only one-sided, as they do not accept people with disabilities as volunteers. But well, that is the structure. And that structure is restrictive.'

Due to the pressure on voluntary organisations to buffer the cuts to publicly financed care, municipalities select 'strong' volunteers (Van Bochove, Verhoeven & Roggeveen 2013), thereby devaluing disabled and elderly citizens' possible contributions to community life. This institutional tendency decreases their access to esteem derived from being 'active citizens'.[20]

For the few respondents who were able to become volunteers themselves, being helpful in the community – becoming persons capable of returning the deed – was a reaffirming experience. In these cases, respondents avoided the restrictive structures of voluntary organizations by becoming active in their own surroundings. A 58-year old woman with physical and psychiatric disabilities no longer missed her previous day-care as she was able to position herself as a 'volunteer' in her seniors' flat. She had learnt that by focusing on her strengths, she could seek a positive identity:

> 'Well, you just have to start somewhere. Just by following a course, maybe doing voluntary work. I now follow a computer course at the community centre, and I can help the elderly in my care flat with their internet, and ordering on-line groceries for them, things I am good at, where I can help them. Now, I could not care less about the [lost] daycare.'

Her initial experience of 'loss' of daycare was replaced by rewarding activities that she managed to pursue independently. Most importantly, her new activities were not a threat to the recognition of her care needs, as (unlike many others) she still received publicly financed care for housekeeping support, personal care at home, and psychiatric therapy.

The consequences of missed recognition

While welfare state retrenchment undermines previously established avenues for the recognition of disabled and elderly persons' care needs, it fails to offer new avenues for recognition. Our findings show that recognition in retrenching welfare states cannot be de-coupled from the redistribution of resources (Fraser 2003). Especially citizens who lack self-confidence due to the non- or misrecognition of their needs would rather refrain from engaging in community life than risking (further) insult. A 33-year old woman with a cognitive disability explained:

> 'I first want to feel safe in society. That I do not think people always talk about me… that they just see me as I am, just like them, and only then that I have a disability. I also feel myself different from others, so I first want to restore that.'

Some of our disabled and elderly respondents had given up on attaining recognition as full-fledged citizens with legitimate needs. With the necessary 'emotional labour' (Hochschild 2003), they told themselves that it was 'normal' for them to be less engaged in society. The 91-year old woman whose access to day-care was cut told us that she now 'accepts' her loneliness as part of old age:

> 'Now I am used to the fact that I can no longer go there [day-care]. I would like to go again, because I have nothing on my hands, I am alone all-day. Yes, care-givers visit me, but to them I never say that I am lonely. I never complain; no one can do anything about it. I just say to myself that it belongs to my age, that I am lonely and go nowhere.'

The ideology of 'active citizenship' tells disabled and elderly persons that they are responsible for achieving their own dignity and respect. While some aimed to ‘repair’ their sense of self before demanding recognition as full-fledged citizens, others ‘accepted’ their inability to participate in society.

Conclusion and discussion

As in many other retrenching welfare states, the government in the Netherlands increasingly reserves publicly financed care for citizens with ‘severe’ care needs (Rostgaard et al. 2011). Combined with the renewed interest in community life, the Dutch care reform agenda presents the voluntary sector as an alternative avenue for the recognition and meeting of ‘mild’ care needs (Dahlberg 2006; Hanlon et al. 2007; Eliasoph 2011). But our interviews with long-term care recipients facing cuts to their (day)care showed that disabled and elderly people do not easily open their doors to unknown volunteers. They fear lack of control over the type, content and duration of the ‘created’ social bond. If they nevertheless do seek contact with volunteers to surmount the ‘participation barriers’ resulting from their reduced entitlements to (day)care, they often experience these contacts as disappointing and sometimes even demeaning – especially when compared to the recognition they previously received from their entitlements to professional (day)care. Most notably, respondents felt that contact with volunteers lacked mutual respect; only in reciprocal relations did disabled persons manage to position themselves as full citizens (Linders 2010; Bredewold, Trappenburg & Tonkens 2013).

In embracing voluntarism as the new route to recognizing the needs of people with (mild) disabilities, local authorities overlook institutional shortcomings that hinder equal access to confidence, respectability and esteem. First, social volunteers are not trained to be neutral towards people with disabilities; respondents often felt misjudged by volunteers who failed to grant them autonomy, sometimes to the extent of being blamed for their own care needs. Second, while the Wmo lauds those who provide care and support to their fellow citizens, people with disabilities who manage to overcome barriers to their participation in society are treated as ‘citizens, like any other’. Citizens with disabilities who take on a civic identity thus cannot achieve recognition for their ‘special’ accomplishments or impairments (Danermark and Gellerstedt 2004). Third, while in theory both disabled and non-disabled citizens are invited to participate in the community, in practice a sharp institutional divide between vulnerable and able-bodied citizens in the selection of volunteers disregards the fact that people have both disabilities *and* abilities. Voluntary organizations that select 'strong' volunteers in effect block disabled and elderly citizens' pursuit of esteem by contributing to community life themselves.

We need to rethink what is required by disabled and elderly citizens to achieve recognition on an equal footing with non-disabled citizens. How to pursue the recognition of their needs and abilities depends on the type of misrecognition (Fraser 2003: 45). First, where people with disabilities feel their needs are not recognised, we need to rethink the bases of 'affective' recognition. While affective recognition can be based, as Honneth argues, on personal bonds, it can also come from the loving labour of care professionals (Hochschild 2003). To support care recipients' self-confidence is a major part of what it means to be a professional care-giver; affective recognition cannot be established by care-givers who are both impersonal and unskilled. The training of volunteers may provide a solution to the experienced lack of affective recognition – but then they can hardly be called volunteers anymore.

Second, where the problem is misrecognition based on lack of respect, we need to broaden the basis of respect to more than just autonomy: we deserve respect on the basis of our shared dependence (Tronto 1993), vulnerability (Nussbaum 2001), and capacity to experience pain and suffer from cruelty (Rorty 1989). Presenting disabling experiences of the body (and resulting care needs) as a shared human experience will reduce their power to threaten self-respect. Still, people with disabilities should not feel pressured to talk about their disabilities if they do not want to as they need to retain control over what is being revealed about them. In other words, volunteers should treat the autonomy of care recipients as equal to their own – even if they violate social norms such as being untidy or unemployed.

Third, where the problem is misrecognition based on lack of esteem (or social recognition), we need to broaden the basis of esteem to include both people's disabilities and abilities. This could happen for example by recognizing people's courage and endurance to live with their disabilities, as happens for example in disability sports. Moreover, disabled and elderly persons' willingness to themselves become volunteers should not be subjected to the increasingly instrumental, outcome-driven orientation of the voluntary sector (Hwang & Powell 2009). 'Vulnerable' volunteers should be invited, supported and valued for what they perceive to be a contribution to community life – even if this requires more manpower.

The parity of participation of people with disabilities can be advanced in 'active' welfare states by investing in skilled, loving care and broadening our notions of respect and esteem. For all citizens to participate on an equal footing, we have to accept the professional as well as personal foundations of affective recognition. We also have to accept our shared fragility and vulnerability and encourage disabled and elderly citizens' pursuit of esteem for both their inabilities and abilities – and to fight misrecognition, especially in times of welfare state retrenchment.

Notes

[1] Other scholars view redistribution (Rawls 1971, 1993; Dworkin 1981) or recognition (e.g. Honneth 2003) as the overarching route to social justice. This article pursues Fraser's idea that redistribution and recognition can be separate routes.

[2] Eliasoph (2011: 180) found that where voluntary projects promised to empower the poor and needy, volunteers developed a 'cool, respectfully distant politeness' at best.

[3] One may even argue that in the process of welfare state retrenchment, voluntarism is presented by governments as an alternative form of redistribution.

[4] Dutch: *participatiesamenleving*.

[5] The Act contains a 'compensation principle' that obliges municipalities to assist citizens with disabilities to overcome barriers to their self-sufficiency and social participation. Concretely, municipalities must compensate barriers to mobility, housekeeping, and participating in social activities (Sijtema 2008). While the provision of support for mobility and housekeeping is standardized, municipalities have discretionary power over social participation: informal care, social voluntarism, public facilities and collective arrangements can all provide 'compensation' while cheaper variants are favoured over individual entitlements to (day)care. Citizens can only demand professional (day)care or a personal budget if they can prove the municipality has not been able to sufficiently compensate their participatory problems in another way. It is thus legally difficult for citizens to make a case against the local authorities. For example, an autistic man's request for a personal budget was rejected. He appealed against the decision but the municipality claimed he could suffice with social volunteers (despite the claimant's argument that for him this was no solution). While such priority setting by municipalities sits uneasily with the legal right to choose one's care arrangements, the sustainability of local budgets is deemed more important than individual choice over care arrangements (VWS 2013a).

[6] See for example the volunteer policy of the Municipality of Utrecht, 2008-2012: www.utrecht.nl/images/DMO/ontwikkeling/PDF/Samenleving/Welzijnsbeleid/Vrijwillige_inzet_voor_elkaar.pdf.

[7] Dutch: *respijtzorg*.

[8] See for example: www.wmowijzerkerkrade.nl/hulp-vragen/voor-wat-hoort-wat.

[9] Entitlements are given on the basis of hours of needed care; these hours were reduced.

[10] We also managed to find five of the respondents via local care providers. Nevertheless, it is likely that people who avoid being cared for and those who could privately pay for the lost care are under-represented.

[11] Reasons for not using the entitlements were often related to improvements or deterioration of one's health.

[12] In six cases a parent served as a spokesperson.

[13] We first posed the interview questions; the hypothetical dilemmas were posed at the end of the interview. The issues of durability and personal click arose from the open questions, independent of the hypothetical dilemmas.

[14] Based on either professionalism or expertise acquired by family care-givers over time.

[15] Community centres are increasingly run by volunteers.

[16] It was made explicit by the national government that the ‘AWBZ pakketmaatregel’ was not a one-to-one transfer of care tasks to municipalities.

[17] Let alone the differences between wealthy and deprived communities.

[18] This finding could be related to the fact that the research took place in cities and not in small villages, and often in deprived neighbourhoods.

[19] i.e. multiple disabilities.

[20] As respondents did not seek direct contact with the municipality, they did not meet gatekeepers who demanded something in return for care.

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Chapter 6

Clients' waiving of their right to appeal against the cuts

Published as
E. Grootegoed, C. Bröer and J.W. Duyvendak (2013) Too ashamed to complain: Cuts to publicly financed care and clients' waiving of their right to appeal *Social Policy and Society* 12(3): 475-486

Abstract
This article examines how Dutch citizens with long-term care needs have used existing legal opportunities to respond to cuts in publicly financed care. Unexpectedly, most did not make use of their right to appeal the reduction or elimination of their previous entitlements, even when this led to marked problems in daily life. Thirty interviews with disabled and elderly persons and their care-givers revealed that specific social norms on how to feel about the cuts inhibited the lodging of appeals. Given the new policy's stated intention of preserving care for the most needy, many affected clients felt they had no right to be angry. Despite their (often objectively warranted) grievances, they did not appeal as breaking with the new moral code would trigger feelings of shame – of not being autonomous, of demanding too much when others are worse off, and of appearing ungrateful.

Introduction

Democratic welfare states allow citizens to express their dissatisfaction with the quality and allocation of healthcare and social services in numerous ways, including through informal complaints, legal procedures against the authorities (for example, the right to appeal), the exercise of individual 'choice' when consuming services (for example, via cash-for-care) and politically via patients' rights organisations. Nevertheless, dissatisfaction in most cases is not expressed in any of these ways. Mulcahy and Tritter (1998), for example, found that only about one in ten dissatisfied healthcare clients lodge formal complaints.

How can we make sense of something that *people do not do*, in this case not making use of the right to appeal against cuts to publicly financed care and waiving the chance to maintain their previous entitlements? The question of non-take up has been raised more generally within legal studies (for example, Briar, 1966; Sarat, 1990), in poverty research (for example, Kerr, 1983; Van Oorschot, 1991, 1995), in social policy studies (for example, Lens and Vorsanger, 2005; Aronson, 2006; Allsop and Jones, 2007; Gulland, 2011) and in social movement studies, upon which we primarily base our approach. Within social movement studies 'failure to act' has been traced to the lack of resources and skills (Verba *et al.*, 1995), a lack of political opportunities (Kriesi *et al.*, 1992; McAdam *et al.*, 2001) or, more precisely, lack of support by those in power

(Lowndes *et al.*, 2006). Mulcahy and Tritter (1998) suggest that not making use of the right to appeal is mostly couched in negative terms, as a failure on the part of dissatisfied clients or on the part of the complaints system as a whole.

As in many other countries, citizens in the Netherlands are encouraged to mobilise their private networks to arrange for long-term care (LTC) before seeking state support (see Glendinning and Moran, 2009; Newman and Tonkens, 2011). Recent policies summoning such 'active citizenship' posit that public goods, such as the provision of care, are best arranged at the lowest feasible level of organisation, such as the family and community (Jordan, 2010: 11). Against the background of an ageing population and economic crisis, the government deems cutbacks to healthcare both desirable and necessary: necessary because LTC costs have ballooned over the past decades, and desirable because the services-led model is said to have disengaged citizens from informal care-giving and alienated disabled and elderly persons from mainstream society. To contain costs and to encourage citizens to take a greater role in informal care-giving, care under the Dutch Social Support Act (Wet Maatschappelijke Ondersteuning, WMO (Sijtema, 2006)) is no longer a legal right of citizenship (c.f. Cox, 1998). Recent legislation restricts access to LTC to the most severely disabled, or in political rhetoric, to those who 'really need it'. The rhetoric furthermore suggests that there are 'welfare queens' receiving excessive care, at times fraudulently (Gustafson, 2011). Implicitly, the rhetoric also suggests that those who are not 'genuinely disabled' should feel guilty about using publicly financed care.

In Europe, welfare state clients reclassified as ineligible for publicly financed care have several avenues to express disagreement. Alongside the right to an individual re-assessment of their needs, many countries guarantee the right to procedural fairness. Most European welfare states recognise the right to appeal against the authority handling individual assessments (Vabø, 2012: 4). In some countries (for example, the UK), care professionals adjudicate such appeals; in other countries (for example, Norway and the Netherlands), there are independent gatekeepers. Although lodging an appeal requires bureaucratic skill, care recipients (and their care-providers) who lack resources can receive aid from client organisations and from their own care providers, with whom they have a shared interest in challenging the cuts.

This article asks why most people newly deemed ineligible for publicly financed long-term care do not appeal. We present a Dutch case study wherein tighter eligibility criteria led to reduced care entitlements for around 120,000 disabled and elderly people.

Retrenchment measures

Our analysis focuses on a recent piece of Dutch legislation, the so-called *Awbz-pakketmaatregel* (hereafter 'the reform'). Enacted between 2009 and 2010, it includes tightened eligibility criteria for personal aid with daily tasks such as shopping, administration, making social contacts, structuring one's day and/or group-based activities, such as day care for the elderly. The tighter criteria apply to both current clients and future applicants. Of the 230,000 persons previously receiving care, 60,000 lost their entitlements entirely and even more had their entitlements reduced (CIZ and HHM, 2008). A survey among 500 affected clients revealed that 45 per cent were already experiencing, and a further 15 per cent foresaw, problems due to the reform, including reduced psychological well-being, less time spent outdoors, having fewer social contacts and increased dependence on their personal networks (Grootegoed and van Dijk, 2012).

Individuals adversely affected by the reform had the right to appeal.[1] After re-assessment by the independent needs assessment centre (CIZ) by means of a telephone survey that categorised one's care needs under the new criteria, affected clients were informed about the decision on their new care entitlements in a letter that also outlined the option to appeal against the CIZ. In the wake of the reform (2009–2010), an estimated additional 10,000 appeals were lodged, that is by less than one in ten affected clients (VWS, 2010). Between one-fifth and one-third of those who appealed had their care reinstated (CIZ representative, January 2011). Although scholars have reported that appeals-making in absolute numbers is on the rise due to the more general trend of consumer empowerment, the limited number of appeals relative to the number of all dissatisfied clients is representative for appeals systems in healthcare settings (Allsop and Jones, 2007).

While welfare state retrenchment usually targets future claimants, the *Awbz-pakketmaatregel* also reduced *existing entitlements*. We therefore surmise that many of those affected believed they had a right to care, which, together with their perceptions of need and opportunities to appeal, would encourage them to protest. The re-assessment of care recipients as ‘undeserving’ can also be seen as a strategic attempt to shame them for having used (excessive) welfare assistance in the past; much as the insult could well be expected to trigger action in response (Jasper, 2006: 42). The question, then, is why such a small fraction of those who reported experiencing problems due to the cutbacks made use of their right to appeal.

Factors inhibiting appeal

Living a life of chronic illness or disability and reliance on long-term care often leads to low self-esteem (Schneiderman *et al.*, 1989) and social stigma (Goffman, 1963; Susman, 1994). While the prospect of stigma may discourage people from turning to welfare in the first place, here we want to address a different question: why people who are already in the system do not defend their existing entitlements in the face of cuts and shifting eligibility criteria.

Reasons for not lodging an appeal can be manifold. Taylor-Gooby and Hastie (2003) found in the UK that people with higher education and income more readily expressed dissatisfaction with falling standards in the National Health Service. Other factors correlated with the expression of dissatisfaction included relatively young age and support for opposition parties. Research based on factor modelling and statistical analysis, assuming more or less rational actors, has produced extensive lists of factors contributing to the non-use of social provisions (for example, Van Oorschot, 1995; SCP, 2006). Here we want to know why people do not feel able or justified to mobilise. Crucially, we need to focus on the intersection of emotion and argument, a line of inquiry that has also been employed by some social movement scholars in studying how and why people (do not) start acting, complaining and protesting. The relationship between emotions and social movements (Goodwin *et al.*, 2001) involves both macro- and micro-level processes. On the macro level, the social production of loyalty and trust serves to ‘cement’ social structures (Flam and King, 2005), while on the micro level, overcoming individual shame or turning anger against the authorities helps mobilise aggrieved individuals.

The approach we follow builds on Hochschild’s work on managing emotions (1979, 2003) and its application in social movement research (Broer¨ and Duyvendak, 2009, 2011). Hochschild argues that people adjust their emotions to what is considered appropriate within specific social situations, referring to the implicit 'feeling rules' and 'framing rules' that govern these situations. 'Feeling rules' are 'guidelines for the assessment of fits and misfits between feeling and situation'; framing rules are 'the rules according to which we ascribe definitions or meanings to situations' (Hochschild, 1979: 566). Applying this framework to the 'right to care' in retrenching welfare states, we would expect from affected citizens a combination of claims to entitlement and attempts to adjust their feelings to the new realities. That is, we expect citizens to 'read' policy changes in ways that foster or inhibit anger, shame, fear, trust and loyalty.

The emotion management perspective has rarely been applied to changing welfare policies (see the introduction to this Themed Section). One study close to our own by Aronson (2006) followed the lives of Canadian women facing home care rationing. In most cases, the (elderly) women were severely hit by cut-backs but did not complain, in many cases not even to the interviewer. But, over time, Aronson was able to observe how these women were silenced and/or silenced themselves, or, to put it more neutrally, how they brought their feelings in line with what they thought was the (new) cultural norm. Non-complaining women often did not want to burden others and were ashamed to display their needs and be seen as complainers; external pressure stifled feelings of unfairness and encouraged feelings of fear and shame. Without making it explicit, Aronson showed how new feeling rules implied in policy enter into management of the self.

The current study focuses on the emotional dynamics of inhibited appeals-making in our era of welfare state retrenchment. In what follows, we ask which feeling and framing rules inform the thoughts and behaviour of people facing cuts to their long-term care in the Netherlands.

Methods

Our findings are based on thirty interviews with affected clients who reported problems after implementation of the reform. The reform was enacted between 2009 and 2010; the research was conducted between January and June 2010. Based on client consent, municipalities received names, addresses, year of birth and the duration and reduction of care entitlements from the CIZ. In order not to exclude people who did not consent to conveying their personal details to the local authorities, we asked care providers to request the participation of clients who matched our selection criteria. We selected forty-five clients of various ages and care needs in six medium- to large-sized Dutch municipalities whose entitlements to care had been more than halved due to the reform. We included individuals with care entitlements of varying duration (minimally six months) and excluded persons whose entitlements would have been re-assessed without the reform. Clients who did not report strains due to the cuts were also excluded.

The final sample consisted of thirty individuals aged ten to ninety-one experiencing problems with self-reliance and social participation due to old age (nine), cognitive disability (eight), psychiatric need (seven) and physical constraint or chronic illness (six). In the case of a young child, a parent served as the spokesperson. For respondents with cognitive disabilities, relatives or care providers were usually present during (part of) the interview. The respondents all lived independently and received care in kind or via a cash-for-care scheme that allows clients to purchase care privately with a personal budget. Despite varying levels of education, respondents' incomes were low to moderate; adult respondents mostly received social assistance due to their inability to work.

The face-to-face interviews were held in people's homes and lasted two to three hours. In the semi-structured questionnaire, we asked for a short history of how the respon-dent entered public long-term care and the impact the reform had on their care arrangements and daily lives. We then asked each respondent how they experienced the re-assessment procedure and whether they had considered appealing the authorities' final decision to cut off (or part of) their care entitlement. For the thematic content analysis of interviews, we used the qualitative data analysis and research software AtlasTi. We first coded respondents as accepting or objecting to the cuts (that is lodging an appeal) under the new rules, and their relative success in retrieving their former entitlement. We deductively examined both traditional, more rational explanations (resources, chance of success), and 'emotional' accounts (reported feeling rules) of why our informants acted as they did. Inductively we constructed types of emotions and feeling rules.

Three ways to manage shame

Of the thirty clients who found the reduction in care problematic, six formally appealed while twenty-four did not. Of the six who appealed, two had their previous entitlements restored. None of the respondents answered the question ‘Did you deliberate over making a formal appeal?’ with a purely rational account of their available resources or chances of success. Interestingly, respondents who did not appeal more often related their acceptance to feeling rules than to rational explanations. We found three types of feeling rules, relating respectively to one’s dignity, to more needy (deserving) citizens and to the authorities. For each, the greatest obstacle to lodging an appeal was the ‘sanctioning’ emotion of shame, or more precisely, the *threat* of feeling shame (see Flam, 2005). Shame, described by Scheff (1988, 2000, 2003) as a ‘bond affect’ that influences all aspects of daily life, evolves from viewing ourselves through the eyes of others. Shame can arise from the disgrace of deeply felt social stigma, but also from the more commonly perceived failure to conform to social norms. We therefore analyze shame in its broadest sense, with references to social stigma, disloyalty and ingratitude as its indicators.

Shame and desire to be autonomous

Lodging an appeal was seen, especially by older people, as an admission of being overly dependent on others. While such fear of ‘losing face’ was likely an issue before the cuts, it had not deterred them from requesting public aid. But now, it kept them from appealing against cuts to their entitlements. An elderly woman (eighty-eight) who decided not to appeal stated:

> 'My care provider advised me to make an appeal, but they are just the new rules. I am not going to beg for care, I want to be helped, but in a normal way, I do not need preferential treatment. I am just like every other person.'

She perceived appealing as synonymous with begging, while her fear of shame centred on not being ‘independent’. It suggests that the threat of shame is greater when requests for care are reviewed on a case-by-case basis rather than by uniform rules. An elderly woman whose day care was discontinued answered:

> *Interviewer: Did you consider making an appeal?*
> 'No, I am not going to beg for it, either I can get it or I cannot. If not, then it stops for me.'
> *Interviewer: What does the reform mean to you in practice?*
> 'That I haven't been outdoors since Christmas . . . [continues talking about how she misses day care]. But I still try to do as much as possible by myself. I may be disabled but I am still partially independent.'

Although the elderly woman struggles with the reform's effects, she maintains her pride by refusing to 'beg' for care. Working on an 'internal reputation' (Jasper, 2006) apparently requires one to accept care only when the terms of its provision are universal. Having to prove that one is an 'exceptional case' is not in line with the shame management of chronically ill or disabled people who desire to be autonomous.

Shame and social comparison

The intention behind the reform of preserving care for the most severely disabled was systematically communicated within the policy field, the care sector and the media. The cuts were presented as necessary, especially in a time of economic crisis. In deciding how to feel about the cuts, respondents made subjective comparisons to people whom they considered 'worse off'. When asked how she feels about her reduced entitlements, a thirty-eight-year old woman with a cognitive disability receiving pedagogical assistance replied:

> 'Well, I am glad that I still receive care, but if they [the government] only care for people who really need it, then I would prefer that others receive more care, and I get less, you see what I mean?'

This reference to 'the hardest hit' often informed how affected clients felt about appealing. As a twenthy-one-year old woman with a chronic illness whose personal budget was halved explained:

> 'Yes, I feel bad about the cuts, not only for myself but also for the many others who lost their care. But at least I still have a personal budget. At the riding school [for the disabled], I heard that there are a lot of people who no

> longer have anything. That is why I say: you will not hear me complain. If I did complain, I think that would be unfair to others. I would feel ashamed to appeal, I seriously mean that. If I hear and see what others have, then I think I cannot complain. If I succeed in retrieving my full budget, then another would get less.'

This argument reproduces the zero-sum logic of the policy. The woman 'feels bad' but does not complain. Threatened by shame when she thinks of those who are worse off, she manages her emotions. A forty-eight-year old man suffering from psychosis even tried to feel grateful as he compared himself to poorer people:

> 'Well, if you see how the poorest people live in Europe, then I think I am reasonably well off. I have food, shelter and a bed. You see, because I see that it can be worse, I think that I should feel grateful for what I have, and that keeps me from appealing against the reform.'

These respondents only compared themselves to people worse off than themselves, not only to the 'hardest hit' but also to people who do not live in welfare states, currently or in the past. In this way, respondents could place their own grievances in perspective and ward off feelings of relative deprivation (Morrison, 1971). Identifying with the most severely disabled persons, we surmise, would undermine their attempt to maintain an autonomous identity.

Shame and demand for gratitude

Social institutions inevitably set norms around disputes as their representatives tell citizens how to address their grievances (Felstiner *et al.*, 1981). The interviews revealed that clients felt trapped between their own perceptions of the problem and the information they received from the CIZ, that is that their care need is no longer (fully) a *public* concern. A mother of two autistic children (aged thirteen and fifteen) whose personal budget was reduced stated:

> 'On the one hand, I can understand it, they [children] also become older and more independent, but when I see how much extra work and related costs their disability creates I think it is very unjust . . . I thought about making an

> appeal, but the CIZ person told me that it is 100 per cent sure that I will not retrieve the previous assessment. The rules have become stricter, and they [CIZ] tell me that it [the problems] is considered part of their puberty now. She [CIZ official] says ‘you have no grounds to stand on’ and so I tell myself that I should just feel grateful for what [care] remains.'

The above passage clearly shows that this mother manages her feelings to try to bring them in line with the new policy. Gratitude towards the authorities is what she thinks she should feel – not anger, indignation or being seen as a person who asks for too much. Appealing was also inhibited by officials emphasising the integrity of the re-assessment procedure. A mother of a twenty-two-year old daughter with a cognitive disability whose personal budget was halved stated:

> 'For a long time, we did not have to worry about finances, but now we do, and we worry about that a lot, and if you do not have a solution, it eats away at you. It also feels unfair that at first you are encouraged [by the government] to use a personal budget to arrange care in a private setting, and when you have done so, they take away the money. I mean, if I would request intramural care for my daughter, she would without a doubt get it.'
>
> *Interviewer: Did you consider making an appeal against the cutbacks?*
>
> 'Well, I might have if I felt that I was mistreated, but how the CIZ spokesperson explained the new rules made me think that she cannot do anything about it. I trusted her, because she seemed a nice person. I had the feeling she understood my problems, so I felt that I had to accept it.'

The former recipient of publicly financed care again downplays her indignation. Instead she reaffirms her trust in the authorities, backed by the construct of a ‘nice person’ who ‘understands’ when she is told that there is no other way. Here client loyalty to the authorities (and the threat of being seen as disloyal) encourages acceptance, while the showing of empathy by authority figures appears as an effective strategy to regain client trust and to cool feelings of anger and frustration (see Goffman, 1952). This finding differs significantly from studies on poverty that have traced clients not claiming their social rights to the degrading treatment of their claims (for example, Corden, 1987).

By adopting the moral frame of reference of the care authorities, respondents' experience of indignation does not develop into anger and/or the use of the right to appeal. The care that is still received is presented by the authorities as a 'gift', to not accept it with gratitude is to undermine the underlying social bond, risking shame (Hochschild, 2003). The respondents' reasoning goes beyond so-called 'shielding stories' (ibid.) that cover up their lack of agency and its attendant dishonour. Rather, indignation is mediated by (a fear of) shame; one has to appreciate the care that is still received, despite being labelled as a relatively 'undeserving' welfare recipient.

In sum, we find that making use of the right to appeal is inhibited by the shame or anticipation of shame that arises when one is no longer able to perceive oneself as a relatively independent person, a sociable peer and good citizen who is loyal to the authorities and their new moral rules.

Dodging shame: pathways to the right to feel angry

A minority of clients who were labeled as having a relatively mild disability and had their care entitlements reduced lodged an appeal. They often experienced the re-assessment as illegitimate. An elderly woman (eighty-two) recounts her experience of a telephone interview and her path to anger:

> 'I was phoned by CIZ for the re-assessment and was asked some general questions about my mobility and so forth. I noticed that the woman on the phone needed to follow a strict procedure, not leaving room for personal specifications, but when I found out I was actually talking to an unskilled call centre employee I became really mad! That was so degrading and inhuman.'

The above passage reverses the reform's attempts to shame and blame; it is the authorities who should feel ashamed, not clients with 'mild' care needs. Such anger over-rides officials' attempts to justify the reform and inhibit protest by cultivating citizen 'loyalty'. Those who appeal believe they are victims of the reform, made necessary by external actors such as the greedy rich or blundering politicians, an attribution not often made by those rejecting the right to appeal. A fifty-eight year old woman with physical and psychiatric problems stated:

> 'My opinion is that we [people with care needs] have to pay for the mistakes of the bankers. They request loans from the government, not us. We have nothing to say about that. We stand offside. But now we have to pay, because we lose our welfare support, and I think that is unfair.'

The woman redefines the situation in a way that circumvents loyalty and shame and that legitimises anger: cuts to public services should not be made on the backs of the innocent in society. Pointing to external villains redirects blame from oneself, thereby evading (the fear of) shame (Jasper, 2006: 51). Scheff (1988) suggests that mostly people with high self-esteem are most capable of evading shame; high self-esteem may also lessen the need to defend an autonomous identity. Still, these people must make peace with the issue of solidarity with fellow citizens. A middle-aged man with a physical disability, who managed to retrieve his care assessment by appealing, was asked by the interviewer how he felt about others unable to do so:

> 'Well, lately I hear about that on the news, about an elderly woman who went to day care for six years, with no friends or relatives left. She can no longer get to day care as of January, and is stuck behind the geraniums. That is terrible! It makes me angry. Because she is not so assertive, she cannot appeal. Well, luckily I am . . . In the end, I made an appeal on advice of my brother. He said to me, you need to ask for a personal hearing; the official needs to see you in person and you should be able to tell your story.'

From this perspective, appealing against the decision of the authorities remains the right thing to do, regardless of whether other (possibly more needy) individuals do so or not. They do not reason as if they are cutting the same cake. When a client's denial of (the fear of) shame is supported by friends and family, when lodging an appeal is not synonymous to begging but the 'proper thing to do', shame can be acknowledged and overruled. In some cases, it becomes the authorities who should feel ashamed.

Conclusion and discussion

Recent reforms of the welfare state have pressured citizens to organise long-term care within their private networks. The current redistribution of care rights builds on the distinction between relatively mild and critical care needs and preserves rights only for 'those who really need it'. To enact this divide, around 230,000 LTC clients in the Netherlands were re-assessed under the stricter criteria of the reformed Exceptional Medical Expenses Act (AWBZ). Sixty thousand people lost their entitlements to care entirely, while even more individuals, most often the elderly and people with psychiatric or cognitive disabilities, had their entitlements reduced (CIZ and HHM, 2008). Many affected individuals reported increased dependence on their private networks, reduced psychological well-being and less time spent outdoors (Grootegoed and van Dijk, 2012). Still, only a minority made use of the readily available opportunity to appeal against the decision of the independent needs assessment centre (the CIZ).

Emotions were central in our respondents' decisions not to appeal; none mentioned that they lacked the ability to do so. Those who did not appeal were, broadly speaking, too ashamed to do so, going to great lengths to avoid the risk of (further) stigmatisation, of depriving other fellow citizens of care, or of showing distrust and disloyalty towards the authorities. In contrast to the common perception that not making use of the right to appeal is a 'failure' on the part of dissatisfied clients (Mulcahy and Tritter, 1998), our findings show that clients resisted appealing so as to manage their reputations and to avoid shame.

The fear of shame follows from seeing oneself in the eyes of others and prompts people to adjust their conduct and emotions accordingly. Older and chronically ill people did not want to risk potential shame by appealing. The shame of social stigma was evident as they did not want to be perceived as 'begging'. They refrained from identifying with people receiving more care as this would imply that they were among the 'most severely disabled'. They would rather become isolated than admit inability to manage their daily lives. Distributed on the basis of the severity of need, claiming the right to care today is a different matter than when these clients entered public care, then seen as a right of citizenship. They thus preserved their dignity by not asking for more than they were judged entitled to by the needs assessment centre.

Affected clients also distanced themselves from other, perhaps needier persons. In this way, they could see themselves as relatively independent and loyal to the authorities. These feelings were not self-evident; they emerged through interactions with the needs assessment centre and through comparison with other affected clients, which inhibited feelings of relative deprivation (Morrison, 1971). During their re-assessments, the needs assessment centre discouraged clients by referring to the slim chance of successful appeal and the reform's aim to preserve care for the genuinely disabled. When clients compared themselves to needier individuals, they actively downplayed their anger, feeling ashamed to claim their rights. At least they had 'a roof over their heads'.

When clients did appeal, they managed their emotions differently. Referring to organisational misconduct and external causes for the reform legitimised their anger, as did a refusal of the logic of the welfare cuts. They were encouraged by family and friends, who assured them that lodging an appeal would not threaten their autonomous identity but would instead empower them. Interestingly, those who chose to appeal were not discouraged by thinking of the plight of others, but felt inclined to fight for their 'own' rights.

Avoiding shame proved a crucial concern for disabled and elderly persons who already felt that they had to defend their dignity. If policy states that only the 'truly needy' deserve publicly financed care, this raises significant emotional hurdles to individuals who, against the evidence, resist identifying themselves as 'truly needy'. Our analysis has shown that the risk of (the eminently social) emotion of shame cannot be battled alone; the new policy norm to feel solidarity with the 'hardest hit' can only be breached when one's family and friends affirm that it is proper to feel angry. Rather than any objective criteria of deservingness, we may say that making use of the right to appeal has more to do with one's ability to take distance from (the fear of) shame.

Note

[1] No financial costs are involved in lodging an appeal against the needs assessment authority. Only when the client disagrees with the outcome can he or she take further legal steps, which involve financial costs.

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Chapter 7

Conclusions

The appeal to 'active' citizenship

European welfare states are in transition due to social, demographic and economic developments that are challenging their sustainability. After a period of welfare state expansion under highly favourable circumstances between the 1950s and 1970s, mature welfare states now face the pressures of growing needs and limited resources (Pierson 1996). In the field of care, three main developments contribute to these 'new' social risks (Taylor-Gooby 2004). First, the increased labour market participation of women has led to the receding of the 'male breadwinner model' and the 'natural' availability of women as family care-givers (Lewis 1992). Second, growing longevity and numbers of the elderly have changed the ratio between the working and non-working populations; the resulting old age dependency ratio puts pressure on public care spending, the supply of care labour, and the intergenerational social contract (Bonoli 2005; Goerres & Tepe 2008). Third, the imperative of economic competitiveness in a globalised market urges governments to adapt their care policies to financial developments such as the recent economic crisis that began in 2007-8 (Taylor-Gooby 2004; Clarke 2010).

To respond to the growing 'care crisis' (Hochschild 1995), many European welfare states are pursuing policies to off-load public responsibilities for long-term care (Newman & Tonkens 2011). Instead of 'passively' consuming rights bestowed by the welfare state, citizens are encouraged to become more self-reliant, either by anticipating their own care needs (e.g. private or individual saving schemes)[1] and/or by seeking private arrangements (e.g. family or community care) (ibid.). The appeal to 'active' citizenship is framed as furthering citizen voice and empowerment; it invites people with disabilities and chronic illnesses to participate in decision-making and to co-create care arrangements in their communities (Newman et al. 2004; Newman & Tonkens 2011). But this participative discourse also assumes that vulnerable citizens can rework their claims for full and equal participation in a reformed welfare state in which citizens enjoy fewer rights.

The reform of long-term care policy affects both the *redistribution* of care and the *recognition* of care needs (Newman & Tonkens 2011). Redistribution in the 'classical, post-war welfare state' as outlined by Keynes and Marshall (1965) entailed the redistribution of resources in the struggle against socio-economic injustice. In many mature welfare states, publicly financed care is increasingly reserved for those who are deemed most in need (Rostgaard et al. 2011). Even generous welfare states such as the Nordic countries and the Netherlands are making access to public long-term care much more selective. Different combinations of monetary (e.g. income), medical (e.g. severity of disability) and moral (e.g. family care norm) barriers restrict care to citizens who cannot assume 'active' responsibilities. Alongside the more stringent logic of 'proportional justice' (Foster 1983) applied to existing long-term care schemes, new policies include programs that are not codified in law or which fall under 'framework' legislation (Cox 1998). Municipalities – to which many of the previously national responsibilities for long-term care have been devolved (Trydegård & Thorslund 2001; Cochrane 2004; Rostgaard et al. 2011) – are thereby free to organise local, 'tailored' care services (also 'creative justice', see Foster 1983) that often focus on providing 'help-to-self-help' (Vabø 2011, 2012). Universal entitlement to collective care insurance built on the idea that 'everyone pays, everyone gains' is now considered a 'passive' form of solidarity (Trappenburg 2009).

In contrast, the recognition of care needs entails identity-related struggles against cultural or symbolic injustice, institutionalized patterns of cultural value that express (dis)respect for citizens and define opportunities for achieving social esteem (Fraser & Honneth 2003). Recognition as respect and esteem is a vital human need as it shapes one's identity; non-recognition or misrecognition can inflict serious harm (Taylor 1992). The struggle for recognition becomes more salient as redistribution recedes (Fraser 1995), while the dichotomy of active/passive citizenship increasingly stigmatizes reliance on public services through its portrayal of a negative 'dependency culture' (Fraser & Gordon 1994; Lister 2001). This means that it is now more difficult for citizens to have their care needs recognized as a *public* responsibility and to derive respect and esteem from depending on public services. Welfare state retrenchment thus entails more than changes to rules, rights and responsibilities; it defines what citizens are worth and how they are supposed to 'feel' about public versus private care arrangements. This thesis therefore not only examined the practical consequences of long-term care reform, but also how citizens experience the new identities that governments seek to bestow on them as part of an 'emotional reform'.

Dutch long-term care reform: from rights to favours

The Dutch care reform agenda is particularly interesting in this broader process of welfare state 'retrenchment' (Pierson 1996, 2001). The Netherlands was often seen as an international leader, upholding one of the most generous and comprehensive long-term care schemes for people of all ages (Pavolini & Ranci 2008). But in the period 2003-2005, the government's care reform agenda broke sharply from previous policy. For the first time in the history of the Dutch welfare state, the government cut back entitlements to publicly financed care, even for current beneficiaries. Incremental amendments to the rights-based Care Act (ABWZ) have reduced access to both services (care in kind) and allowances (cash-for-care or personal budgets), especially for people with relatively mild disabilities. The reasoning is that public care is reserved for those who 'really need it' (VWS 2008, 2013a) – suggesting that too many people had shamelessly been claiming public money.

Citizens with 'less urgent' needs are now subjected to the Social Support Act (Wmo, enacted in 2007). Unlike the national long-term care insurance (AWBZ) with its (increasingly selective yet) fixed care rights, the Wmo is a framework law that allows municipalities to replace *absolute* with *negotiable* claims (Cox 1998a). Municipal representatives now negotiate public/private care responsibilities with citizens during a home visit, or 'kitchen table conversation'.[2] The 'negotiation' is value-laden as publicly financed care is only granted when all private options (e.g. family care, voluntarism, etc.) have been exhausted. In effect, the introduction of the Wmo (also 'Participation Act') marks the Dutch long-term care system's turn to an 'informal care-led' welfare model (Ranci & Pavolini 2008).

The turn to informal care (i.e. care that is not provided for pay and/or by professionals) is not only considered financially necessary but desirable in itself. At the heart of the reform agenda is the belief that citizens have become too dependent on public services: extensive (home and residential) care services have led to the social isolation of citizens with disabilities and the crowding-out of private initiative. To revitalize civic engagement, the Dutch government not only encourages the informal exchange of care but sees this as the way to transform society and repair the 'broken moral economy' (Clarke & Newman 2012). Alongside the supposedly altruistic, loving, warm, and durable nature of informal care, the government's 'community spirit mantra' (cf. Eliasoph 2011) emphasizes the positive effects of informal care exchange for social cohesion and democracy (VWS 2007). The Dutch government thereby presents welfare state retrenchment as a 'virtuous necessity' (Clarke and Newman 2012) and claims credit for enhancing 'active solidarity' among citizens (Trappenburg 2009) while justifying (the social costs of) retrenchment by appealing to the higher goal of 'saving' the collective long-term care scheme for current and future generations (Pierson 1996; VWS 2013a).

Pierson's (2001) differentiation between strategies to reform the welfare state – cost containment, recalibration and recommodification[3] – provides insight into Dutch government strategy. The 'problem' of rising demand and shrinking resources is not addressed by reducing but by enlarging the distance between care-givers and the labour market ('*de*commodification'[4] rather than '*re*commodification'). Citizens are encouraged to provide (more) unpaid care to their relatives, neighbours and communities on the basis of altruism, substituting previously paid services. The premise is that care is either provided 'for love' or 'for money' (Folbre 2012) and that unpaid, informal, 'warm' care is superior to paid, professional care (cf. Hochschild 1995).[5]

To examine how citizens experience the changing norms on the 'right way to depend', we focused on care recipients and their relatives affected by recently tightened medical and moral barriers to access to to publicly financed care. First, the 'AWBZ pakketmaatregel' enacted in 2009-2010 mainly targeted 'social care' (as opposed to medical and bodily care, for which universal rights still remain).[6] Due to this reform, approximately 60,000 people with relatively 'mild' disabilities lost their entitlements to support for daily living (even more had their entitlements reduced) (CIZ & HHM 2008). The lost support consisted of assistance with daily living in and outside the home or institution (e.g. shopping, going to the hospital, handling the mail) and support with social participation (e.g. elderly day-care) – rights that were once considered the 'triumph' of the public recognition of disabled and elderly persons' needs (Newman & Tonkens 2011: 14). Affected clients were encouraged to (re-)turn to their own private networks and/or communities for help – framed as enhancing '*self*-reliance' [7] or one's independence and autonomy vis-à-vis the state. Second, the tightening of the 'customary care' norm (2009) increased the family care responsibilities of household members, which are not eligible for public funding. Affected relatives who are confronted with these mounting care duties are encouraged to view these as an act of 'active' solidarity (Trappenburg 2009) in the context of the Wmo.

Clashing moralities of 'self-sufficiency'

Empirically – based on a survey, the analysis of letters of complaint, and personal interviews with affected clients and their family care-givers – this thesis found that citizens struggle with the new demands of ‘active’ citizenship. Many felt trapped in moral dilemmas regarding their autonomy (among care recipients) and altruism (among care-givers).

The autonomy trap

Disabled and elderly citizens facing shrinking entitlements to care were not attached to their previous rights per se, but to the autonomy these rights gave them to live their ‘own, independent’ lives. Alongside reduced psychological well-being, the survey revealed that most affected clients saw increased dependence on their own private networks as the most problematic effect of the reforms. The personal interviews revealed that disabled and elderly persons do not find the statement ‘I need help’ particularly shameful, so long as the need can be managed. They saw (the previously received) publicly financed care as essential for their autonomy in two ways. First, using professional care allowed them to receive care relatively anonymously and to uphold an image of ‘self-sufficiency’ in the eyes of family members and friends. Second, by using a personal budget to pay for informal care, care recipients felt that they could distinguish between care and social relations, thereby equalizing one-sided dependency. Client understandings of autonomy thus contrasted sharply with that of the participatory discourse, which sees autonomy and independence as self-reliance vis-à-vis the state.

Given the reduced choice between professional/paid and informal care, interviewees experienced the ‘nakedness of shame’ – of ‘losing control over what is being revealed’ about their frailties and to whom (Sennett 2003: 117). Affected clients did not want their kin to ‘buffer’ welfare state reform. When possible, affected clients hid or repressed their (persistent) care needs from their relatives to avoid their (further) involvement. Such masking of need also demands the masking of emotions, of telling family and friends that one is 'just fine' while feeling devastated inside. This 'strategy' to preserve one's autonomy from one's private network often leaves disabled and elderly persons less 'self-reliant' than before the reforms.

The altruism trap

Family care-givers affected by welfare state retrenchment likewise struggle with the new demands of 'active citizenship'. They are expected to provide more care for their co-resident relatives and see this as 'customary'. Most informal care-givers indeed refer to intrinsic motivations to care for their kin: 'it is normal to do so' (Timmermans 2003; Dykstra & Fokkema 2007). But the simultaneous introduction of the 'customary care' norm in assessment procedures and personal budgets in the late 1990s created the possibility for informal care-givers to set boundaries to their unpaid, 'non-customary' care-giving. Approximately 84,000 informal care-givers performed 'non-customary care' in return for pay via the personal budget (Knijn et al. 2009). Under the current reform agenda, payment for informal care via a personal budget is increasingly seen as an 'unintended use of [public] resources' (VWS 2008: 202).

With the cutbacks to the AWBZ and the more demanding 'customary care norm', the care provided by relatives is increasingly reframed as 'support' rather than 'care' and as 'charity' rather than 'work'. In other words, the dichotomy between caring for love and caring for money has been sharpened (Folbre 2012) as the 'community spirit mantra' emphasizes altruistic motives for care-giving. Care-givers affected by the reforms thus feel misrecognized, that their extensive care *work*[8] has been devalued. Some even feel abused for their personal commitment: having taken on 'non-customary care' for their relatives, sometimes at the expense of paid employment, the cutbacks and extension of the customary care norm oblige them to perform the same care without pay. They also feel trapped in their predicament: as they primarily provide care for altruistic motives, they cannot morally reject the continuation of their care-giving when the payment stops (Ramakers & Van den Wijngaart 2005). Family care-givers then have to suppress their feelings of anger and continue providing care as 'love's labour' (Kittay 1999) – leading to grudging consent with the reformed rules.

The helping hand of citizen-carers: a utopia?

Both care recipients and family care-givers thus feel trapped between the new morality of 'active' citizenship and their privately held beliefs about the 'right' way to depend formed during a period of welfare state expansion (Hochschild 2013). But what about the promise of the Wmo to revive the 'spirit of community' (Etzioni 1993) and engage all citizens in the meaningful exchange of care (Jager-Vreugdenhil 2012)? How do care recipients and family care-givers judge the (possible) contributions of their fellow citizens?

This thesis found that they do not experience society to be 'caring'. They instead experience the weight of the reforms landing on their shoulders. Disabled citizens and their families describe the Wmo ideal of a caring society as a utopia given the conflicting demands of the 'workfare state' where *paid* work comes first (Peck 2001). Care recipients perceive voluntary care as an informal agreement on which they cannot rely for their long-term needs. The volunteer may become bored, fed up or disinterested and end the agreement at any time. Over time, disabled and elderly persons did experiment with voluntary support to aid their social participation, but they often felt misrecognized by volunteers who misjudged their (dis)abilities, or when contacts stranded sooner than they had hoped. Relying on volunteers thus often undermined their self-esteem. In the eyes of family care-givers, care-sharing with anonymous volunteers was often perceived as a threat to the safety and well-being of their loved ones. In contrast to the faith they had in care-sharing with professionals, they mistrusted the motives of fellow citizens willing to care 'for free'. And as they watched their neighbours rush back and forth from work, they wondered who would have the devotion and patience to care for their disabled or chronically ill relatives. To safeguard the quality of care, family care-givers did not share their duties with unknown others. As trust is the 'oil in the wheel of care' (Sevenhuijsen 2004), scepticism over voluntary care will likely continue.

The ambiguous success of 'active' citizenship

The current Dutch care reform agenda aims to morally revitalize society. Nevertheless, official evaluations of the reforms rarely consider the subjective experiences of affected citizens, who view mounting informal care dependencies as a moral *dilemma* rather than a moral *revival*. The Minister of Health, Welfare and Sport lauds the successes of the 'AWBZ pakketmaatregel':

> 'The introduction of the AWBZ measure in 2009 has led to fewer people who use support with daily activities. Thus the measure has had the intended effect. Support with daily living is now limited to people with moderate or severe restrictions to their self-reliance. The support with social participation has stopped. Although the effects of the measures for the individual client may be annoying, the Minister notes that great social unrest was absent.' (VWS 2010)

Although the findings of this study are not representative for *all* clients and care-givers affected by the Dutch care reform agenda, they clearly show that the absence of 'great social unrest' cannot be equated with citizen consent. Many care recipients and their families experience social and/or emotional costs that go beyond merely 'annoying', far from leading to 'opportunities to take matters into their own hands and shape their own lives' (VWS 2009: 2). Such a positive framing of the effects of reform not only fails to recognise 'individual' social and emotional costs; it also conceals the factors that inhibit individual and collective protest.

Missing voices in long-term care reform

Individuals whose entitlements to publicly funded care were cut or reduced have the right to appeal against the reassessment. But most interviewed clients did not use this opportunity, not due to practical obstacles but because they did not want to consume services at the expense of those who 'really need it'. Many also felt that using their right to appeal was akin to 'begging' – an act which would undermine their autonomous identity. For these reasons, care recipients and their families were too 'ashamed' to appeal, despite their grievances and the possible inaccuracy of the reassessment (conducted over the telephone). These findings correspond with earlier studies on the de-mobilising effects of (the fear of) shame on protest and complaint (Flam 2005; Aronson 2006). Shame functions as a self-control mechanism; we feel shame when we 'fail to live up to our own and/or internalized societal standards' (Flam 2005: 22). It can be 'triggered in us by others who want to achieve our compliance' (ibid.); it is a sanctioning emotion that inhibits unruly behaviour, thoughts or feelings (Scheff 1988). Given the role of shame in inhibiting complaint, the lodging of an appeal did not necessarily reflect the severity of need, but who was best able to surmount (the fear of) shame. Interviewees also did not return to the local authorities with new care requests as they saw this route as a 'dead end'. Citizens who disagreed with the new rules were thus not only silenced by the care authorities; they also silenced themselves to avoid (the threat of) shame (Aronson 2006; Aronson & Neysmith 1997).

No public demonstrations were held to protest against[9] the 'AWBZ-pakketmaatregel' or tightened customary care norm (except for a legal challenge regarding the extension of the customary care norm, described in Chapter 2). Although public protest against long-term care reform was beyond the scope of this study, the existing literature points to at least two factors that might explain the lack of 'great social unrest'. First, protest is precarious for people who depend on the solidarity underlying collective care schemes as one risks breaching the social contract (Shakespeare 1993). Although the public is generally sympathetic to disabled and chronically ill persons, radicalism will eventually alienate the public support on which they rely (ibid). Second, joining public demonstrations or going on strike is difficult for care-givers: 'in order to assert their power, they must not give care. In so doing, they undermine their own legitimacy and standing as care-givers' (Tronto 1993: 143). Especially those who care for close relatives will not easily display their refusal to perform mounting care tasks in public.

In short, the Dutch government views reforms such as the 'AWBZ-pakketmaatregel' to have been successful in promoting greater citizen self-sufficiency. It points to the 'lack of great social unrest', the 'reduced number of welfare recipients' and the (hypothetical) 'opportunities' for civic engagement offered by welfare state retrenchment. But in practice, affected citizens face moral and emotional hurdles to appealing against the cuts and participating in public protest. In evaluating the success of the Dutch reform agenda, their missing voices cannot be equated with consent.

Deepening inequities of sacrifice

Individual problems resulting from the cuts are framed as shared sacrifices for the greater good – to preserve public care for ‘those who really need it’. But such claims about fairness and shared sacrifice are ‘merely rhetorical’ (Clarke & Newman 2012: 314). The current Dutch reform strategy is leading to a deepening inequity of sacrifice in at least three ways, thereby ‘making the claim that “we are all in this together” implausible’ (ibid.: 314).

First, the increased ‘tailor-made’ approach to care entitlements assumes that responding to needs on a case-by-case basis (cf. ‘creative justice’, see Foster 1983) is more ‘just’ than granting citizens uniform rights. An often-invoked image is that of the ‘unused wheelchair’: why invest resources where they are not needed? By replacing absolute with negotiable claims, care is said to be more tailored to individual needs, while ruling out unjust claims. As citizens no longer have fixed rights under the Wmo, ‘the welfare recipient must persuade officials of the need for assistance’ (Cox 1998: 11). They must be resolute in conveying that their needs cannot be met through private means. It is likely that ‘the brazen fare better than the meek in such a welfare state’ (ibid.). Socio-economic inequalities will thus increase as individuals and groups better equipped to assert their needs claim a larger share of the (shrinking) welfare pie.

The more selective rationing of care entitlements leads to prioritizing medical and bodily over social and domestic care needs. While the former remain fixed rights within the ‘core AWBZ’, the latter are increasingly seen as private responsibilities. Schuyt (2013) argues that this can be seen as a necessary differentiation between ‘needs’ and ‘wants’. If a need is unmet this leads to ‘panic, urgency and often impotence. If a want is unmet, that is tedious and frustrating, but one can adjust one’s wants to that which is available’ (Schuyt 2013: 11). But alongside the finding that social care needs are not easily adapted to the care that is available, the emphasis on safeguarding medical care while jettisoning public responsibility for social care suggests that the latter is ‘less important’.[10] This is a problematic assumption as the boundaries between ‘needs’ and ‘wants’ are in reality diffuse. For example, a 91-year old interviewee whose weekly access to elderly day-care was discontinued felt as if society had ‘written her off’. The loss of day-care deeply affected her quality of life, and ultimately, her will to live. To only focus on safeguarding bodily care can thus have inhumane consequences. A too strict separation of (urgent) medical and (less urgent) social care needs also strengthens the dominance of the medical profession in defining the needs of the vulnerable (Hutschemaekers & Tiemens 2006).

Second, the demand for active solidarity interacts with existing gender, race and class divisions in care work (Trappenburg 2009; Tronto 1993). While the rhetoric asserts that *all* citizens should become active citizen-carers, the reality is that care work is often 'devalued, underpaid, and disproportionally occupied by the relatively powerless in society' (Tronto 1993: 113). The appeal for active citizenship thus does not fall equally upon citizens. 'Those of limited economic means are forced to accept their obligations, while those with extensive resources can purchase exemptions' (Cox 1998: 12). While at first sight this may seem a fair rearrangement of 'active' and 'passive' forms of solidarity, it risks deepening existing socio-economic inequalities. Citizens who take on the bulk of informal care-giving not only face losses of income but are also deprived of certain social rights (e.g. pension rights) without paid employment (Knijn & Kremer 1997). The 'cost of caring' ultimately puts informal care-givers at risk of poverty (ibid.; Folbre 2012). Although the Dutch government has policies to bridge the competing demands of care-giving and paid employment,[11] the rights of citizen-carers are still secondary to those of citizen-workers (Knijn & Kremer 1997; Lister 2002).

In terms of recognition, care as *work* is devalued when care-giving is disguised in society (Tronto 1993). In Western society, where care is typically performed by women and servants, the 'best off members of society often use their positions of superiority to pass caring work off to others' (Tronto 1993: 113). Care work then often becomes invisible, appreciated only for its instrumental value: personal services to a director are more highly valued than caring for *dependents*, i.e. 'those members of society who by normal social standards are unable to care for themselves' (Waerness 1996: 235). The low status of care-giving means that exemption from it becomes a 'privileged irresponsibility' (Tronto 1993). Though the participative discourse praises lay care-givers as the 'new gold' in society who 'exemplify active citizenship' (VWS 2007: 1), this is 'lip service' (Lister 2001: 100). While local authorities 'compliment' informal care-givers with symbolic gestures (prizes, dinner parties, etc.),[12] such gestures are mere palliatives when active citizen-carers come to realize that they are unsupported by fellow citizens who maintain their 'privileged irresponsibility'.

While the Dutch government claims that the reserving of care for those who 'really need it' constitutes equity of sacrifice, in practice the reforms risk deepening existing inequalities between assertive and non-assertive care recipients, higher and lower income groups, and given the gendered nature of care-giving, between men and women. Alongside the socio-economic inequalities resulting from the care reform agenda, reduced recognition for (social) care needs and care as work 'eats into respect' as longing for what one lacks breeds a sense of inferiority (Sennett 2003: 117). Or as Sandel (2010: 261) puts it, social justice is 'not only about the right way to distribute things. It is also about the right way to value things.' Knijn and Kremer (1997: 349) argue that the central question in care reform is 'whether welfare states recognize explicitly citizen's rights to receive or give care'. Under the current care reform agenda, it does neither: care recipients face reduced care rights, while care-givers are saddled with mounting care tasks as 'second-class citizens' (ibid.).

The 'active' welfare state: romantic authoritarianism

Given the moral traps and deepening inequities of sacrifice faced by citizens affected by cuts to publicly financed care, one may question what kind of government is steering our society (Osborne & Gaebler 1992; Denhardt & Denhardt 2000). Over the past years, governments have experimented with new forms of governance considered better able to respond to uncertainty and the 'new' social risks (Beck 1992; Giddens 1999; Taylor-Gooby 2004). The new 'steering rather than rowing' role for government entails replacing top-down 'government' with collaborative 'governance' between the state and its citizens (Rummery 2006; Newman et al. 2004). The participative discourse exemplifies this turn, inviting citizens to act as 'stakeholders in public service provision, participating in consultation exercises, deliberative forums or citizen panels, taking part in governance arrangements, contributing to evaluation exercises and so on' (Newman 2011: 115). But how equal is this 'civic-state partnership' given the moral compass of the Dutch government in reforming long-term care?

This thesis supports the idea that given how informal care norms are currently enforced, collaborative governance is at best 'quasi-democratic'

(Newman 2011). By imposing informal care norms upon citizens without sufficiently examining whether they match citizens' ideas about 'good care', the Dutch government is trying to engineer social bonds that do not in reality exist (Trommel 2009; Schnabel 2012). In doing so, the reformed welfare state, rather than taking a step back, is intervening more deeply into the private sphere – most notably into the sphere of the private home (Duyvendak, Knijn & Kremer 2006). The normative principles underlying the Dutch care reform agenda reveal a turn towards the moral – rather than merely contractual – regulation of society (Jordan 2010),[13] a turn that I argue is both romantic and authoritarian.

Romantic, as the 'community spirit mantra' only sees the positive side of citizens exchanging care: it minimizes unnecessary medicalization, empowers disabled persons to become independent vis-à-vis the state and to participate in society, contributes to social cohesion, a stable society and democracy (VWS 2007). This romantic view is largely based on nostalgia for the society that preceded the welfare state (Jordan 2010). Bracketing the fact that family (Beck-Gernsheim 1988) and church (Sennett 2003; Hoogenboom 2006) would be difficult to 'crowd in' again, the social solidarity underlying the exchange of informal care was not always so rosy. Alongside love and sympathy, there was conflict and relations of unequal power (Tronto 1993: 146).

In many ways, exchanging informal care can be compared to the exchange of 'gifts', constituting an 'economy of gratitude' (Hochschild 2003; Komter 2003). But gift-giving is not always positive. 'Gifts reflect, confirm, distort or hurt identities. The motives of gift-giving range from love and sympathy, uncertainty and fear, power and prestige to self-interest and open hostility' (Komter 2003: 61). When 'love declines and duty takes over' in care relations, the darker sides of social solidarity come to the fore (Wilson 1993: 639; Komter & Vollebergh 2002; Komter 2004). For example, care-givers are likely to subordinate their own needs to those of their charges; they can become 'enraged about their own unmet needs. If they are unable to recognize this rage care-givers are likely to vent their anger on those for whom they care' (Tronto 1993: 143). Care recipients may also lack the ability to express gratitude and resent or resist (growing) dependency, leading to conflict (Komter 2004). Finally, extended informal care duties fall upon *all* families – even those where members are at odds or are in the process of separation (CIZ 2013: 60). Rather than being alert to the possibilities for neglect and abuse that arise from vulnerability, the Dutch government's view of active citizenship idealizes 'altruistic' behaviour (Folbre 2012). A more fundamental discussion of what 'good care' entails in families and communities is lacking.

The pursuit of active citizenship is also marked by authoritarianism as its claims are moralising rather than moral (Muehlebach 2007; Clarke & Newman 2012). The demands placed upon citizens are moreover paternalistic; if citizens are *in*active in the informal exchange of care, this is attributed to a lack of skills, not of willingness. The Dutch government's concept of customary care exemplifies this pedagogic citizenship: it treats citizen resistance against the (extended) customary care norm as an 'educational' affair. For example, a husband who resists taking over the household when his wife falls ill can look forward to cooking lessons (CIZ 2013). To the extent that citizens are inactive in care-giving, they need to 'learn' how to do it. Or as LeGrand (1997) puts is: citizens need to be re-educated in civic virtue, to be converted from self-interested 'knaves' into public spirited altruists or 'knights'. As a matter of principle, citizens cannot reject mounting care responsibilities; that they may do so is not even considered.

The moral authoritarianism of the Dutch authorities can also be seen as instrumental or 'greedy' (Trommel 2009). The government summons citizens to become active in the provision of informal care, but only in ways that contribute to the current political project,[14] in effect making citizens 'executors of government policy' (Schnabel 2012: 329). For example, municipalities often establish targets for the number of social volunteers they aim to 'recruit' within a certain time period. The Municipality of Rotterdam even experimented with contracts where lay care-givers committed themselves to a certain amount of care-giving in exchange for support (Gemeente Rotterdam 2006). The participative discourse thus invites citizens to be *active* but not *activist*, implying strategies that 'open out more of the person to governmental power' (Newman 2007: 7, 2011; Schnabel 2012). From this viewpoint, devolving care responsibilities to the local level not only seeks to advance the provision of tailored care but is a way to more effectively control citizens' care-giving behaviour (Mowbray 2010).

While the government's plea for a caring society seems romantic, the radical enforcement of mounting informal care duties without citizen consent typifies the turn to moral authoritarianism. This thesis has shown that the participative discourse effectively generates ‘disaffected’ consent (see Clarke & Newman 2012). Although citizens do not, or only grudgingly, agree with the care reform agenda, the (threat of) shame of dependence and disloyalty to the new social contract hampers activism. While the absence of ‘great social unrest’ may allow the government to pursue further cutbacks to publicly financed long-term care, there is no guarantee that we are heading towards a ‘caring society’. The shame of dependence in the active citizenship discourse may in fact strengthen citizen resentment and/or resistance against growing care dependencies in the private realm.

The coupling of dependence and shame

In ‘active’ welfare states, dependence is increasingly associated with a lack of self-responsibility and moral failure (Fraser & Gordon 1994; Lister 2001). Dependence has been made to appear shameful to delegitimize the ‘passive’ consumption of welfare benefits, while those ‘identified as dependent are assumed actively to seek to reverse this status’ (Fine & Glendinning 2005: 605; Sennett 2003). While the turn towards ‘active citizenship’ may have pushed the unemployed to enrol in welfare-to-work programs, emphasizing the shame of dependency in the field of care may in fact risk undermining people’s self-reliance vis-à-vis the state.

First, restricting publicly financed care to the most severely disabled citizens increases the (threat of) shame of demanding (too) much from the welfare state. In public discourse, citizens become ‘welfare queens’ if they (still) claim public care for their ‘less urgent’ needs. The discrediting of payment for informal care via the personal budget illustrates how a practice previously considered legitimate has now become shameful. Citizens who fall short of the active citizenship ideal may also be viewed as ‘welfare paupers’ when they turn to the safety net of public care. For example, the prioritization of informal care in local assessment procedures presents applicants with an almost existential dilemma: ‘is there no one in your network who cares for you? There *must* be someone?’ The emphasis on self-responsibility can thus ‘easily lead both to the fear of stigmatization on the part of (potential) claimants, and to stigmatizing and discrediting elements in the practice of administration’ (Van Oorschot 1991: 17). In all likelihood, the appeal to active citizenship not only inhibits requests for public care from citizens who can do without it, but also from those who cannot but think they should.

Second, and perhaps more puzzling, is that the Dutch reform agenda's embrace of informal care emphasizes the need for reduced dependence and promoting 'personal strength' (*eigen kracht*), 'self-empowerment' (*zelfredzaamheid*) and 'self-control' (*zelfregie*). The policy rhetoric presents autonomy as an *absolute* value for being a respectable citizen (Duyvendak 1999; Sennett 2003). As such, it upholds the 'myth of autonomy' (Fineman 2004) wherein *all* dependence is suspect. But the completely independent citizen is 'a virtual, non-existent human being' (Knijn & Kremer 1997: 352). Rather than alleviating dependence on care, the current reform agenda risks increasing the *shame of* depending on care. The shame of dependence also comes back to haunt the private sphere, where it pressures care recipients to uphold an image of their own autonomy in the eyes of their friends, neighbours and even close relatives. Care recipients then feel they must perform deep acting to suppress feelings of dependence and/or resist (extended) informal care altogether. Family care-givers also suffer from this negative image of dependence as it locates care within 'trivial, private and emotional states' thereby ignoring its broader social, moral and political significance (Tronto 1993: 112; Waerness 1996).

The Dutch reform agenda with its call for self-reliance thus emphasizes the shameful side of depending on public services while denying the reality of dependence in the private realm. The key question is what makes it so difficult to accept that dependence is the 'ultimate characteristic of every individual human being?' (Knijn & Kremer 1997: 352; see also Fine and Glendinning 2005; Tronto 1993). Sennett (2003) argues that the shame of dependence is rooted in the 'infantilization thesis': 'liberal thinkers have supposed that dependency, particularly dependence on government, makes adults behave like children'. Independence is equated with adulthood and maturity; dependence with childhood and immaturity. These negative associations of dependence have profoundly shaped modern beliefs about respect and esteem. To move towards a more caring society, the dignity of dependence needs to be affirmed (Tronto 1993; Sennett 2003).

The dignity of dependence

In Western societies – and especially in reformed, 'active' welfare states – the shame of dependence arises from ideals of adulthood and rational self-sovereignty. This coupling of shame and dependence is culture-specific and it is 'useful to keep in mind just how culturally specific' it is (Sennett 2003: 114). The same connection between shame and dependence does not necessarily arise in other cultures. For example, in Japan, the verb *amaeru* denotes a specific kind of relationship, 'to depend and presume upon another's benevolence' (Doi 1986: 121). According to Doi, the author of *The Anatomy of Dependence* (1986), the term equates dependence with 'closeness' and idealizes the parent-child bond as the most valued one in society. When a person becomes an adult, dependence upon another's benevolence does not become shameful. Put differently, 'each moment of surrender creates an immediate connection to people who don't know one other' – it ties people together (Sennett 2003: 115). Shame 'comes to the person who fails to respond, shame comes to the indifferent individual' (Sennett 2003: 115). Doi agrees that the desire to entrust another with one's dependence is not an emotion limited to Japanese culture, though the fact that no exact equivalents to *amaeru* exist in other languages suggests that other societies may find it more difficult to be attentive to the positive emotions and feelings of dependence (Doi 1981, 1986; Milkov 2009).

This cultural comparison suggests that to move towards shame-free dependence, we need to value *interdependence* as a common human trait – one which allows us to 'understand both autonomous and involved elements of human life' (Tronto 1993: 162). But arriving at shame-free dependence will require a fundamental shift in our political and moral thought. First, we need to accept that autonomy only comes after a long period of dependence and that to some extent, we remain dependent on others throughout our lives (ibid.). Second, dependence should not be seen as an immoral state to be surmounted, but valued for its ability to establish ties between people (Knijn & Kremer 1997; Fine & Glendinning 2005).[15] Third, we need to accept that autonomy cannot be understood as the 'capacity to separate from others' or as non-dependence (Sennett 2003: 120; Fine & Glendinning 2005), but at most, as the freedom to choose between one's *spheres of dependence* (cf. decisional autonomy, see Collopy 1988; or relational autonomy, see Mackenzie & Stoljar 2000). Finally, shame-free dependence requires that those who depend on another's benevolence are treated with respect. The 'autonomy' granted to a care recipient should be equal to that of the care-giver: 'to avoid the virtuoso's mastery, the grant must be mutual' – even if we do not understand the other (Sennett 2003: 122). These are all necessary ingredients for dependency to become dignified, in both the public and private realms.

In emphasizing the dignity of dependence – or interdependence – we need to be wary of constructing dichotomies between care and social justice (Tronto 1993; Barnes 2006, 2012) and obscuring the 'underlying unequal relationships of dependence and independence' in policy discourse that uncritically uses the language of interdependence (Lister 1997: 21). Fraser and Gordon (1994: 24) point to an important difference between two kinds of dependence: whereas '*socially necessary*' dependence is rooted in the basic human trait of needing care, '*surplus*' dependence is rooted in fundamental social injustices related to e.g. gender, race and class (see also Tronto 1993). In valuing interdependence, these unequal power relationships within the exchange of care should not be overlooked or justified. Dependence cannot become dignified if interdependence becomes a vehicle for welfare state reform to jettison public care responsibilities while simultaneously deepening structural social inequalities. Moving towards a truly 'caring society' can only succeed if we are really 'all in this together'.

Notes

[1] A typical example was the Dutch life course insurance which encouraged individual savings for care leave, parental leave and retirement (see Knijn 2003).

[2] Dutch: keukentafelgesprek.

[3] Commodification refers to the process in which goods and services that are not yet market 'commodities' become connected to the cash economy (Esping-Andersen 1990).

[4] Or moving back to a situation of 'pre-commodification' (Esping-Andersen 1990).

[5] This is also due to the failure of experiments with the marketisation of care (Newman & Tonkens 2011).

[6] Current government plans also entail placing personal care (e.g. dressing, washing, preparing meals) under the Wmo by 2015, meaning there may no longer be rights to personal care.

[7] Dutch: zelfredzaamheid / eigen kracht.

[8] Referring to the societal value of their care-giving.

[9] Two public demonstrations in The Hague protested against the abolition of the personal budget (23 June 2011) and the cumulative effects of welfare state cutbacks on disabled and elderly persons (19 September 2011).

[10] See e.g. Nico de Boer's statement that 'you have five to twenty per cent of citizens who cannot perform self-control … Caring for them cannot be left to volunteers, because it is too important.' In Zorg&Welzijn, 31 May 2012, www.zorgwelzijn.nl/welzijnswerk/nieuws/2011/5/Nico-de-Boer-Aan-de-welzijnsinstelling-als-supermarkt-komt-een-eind-ZWZ017099W/.

[11] For example, by making existing care leave entitlements and working hours more flexible (VWS 2011).

[12] The latest government plans require municipalities to recognize informal care. They 'will be required to record how the college in their regulation of mayor and aldermen ensures a token of appreciation' (VWS 2013b: 8).

[13] Paralleling the move from formal to moral citizenship (Schinkel 2008).

[14] Cf. A British guide for local authorities promotes teaching skills as contributing to 'effective citizenship' (Newman 2011: 116).

[15] Newly introduced terms such as 'samenkracht' (mutual strength) (VNG 2012) and 'samenredzaamheid' (mutual empowerment) (Murawski 2013) admit to this need of identifying dependence as dignified.

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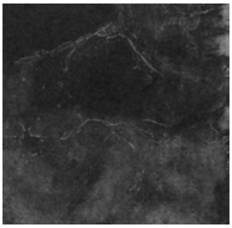
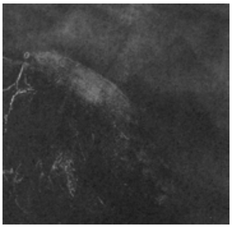
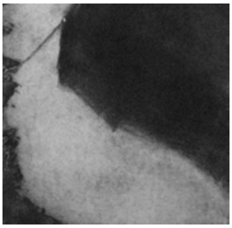
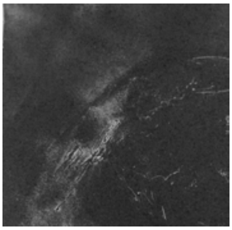
Addendum









Appendix 1 Main questionnaire

Introduction

Getting acquainted
Explain the structure of the interview
Request permission to record the interview

Publicly financed care, situation before AWBZ measure

Reason of the request for support with daily living (AWBZ) in kind and/or in cash
Type of care received, type of care-giver
Goal and use of this care
Availability of other AWBZ-entitlements or other forms of publicly financed care

Publicly financed care, situation after AWBZ measure

Re-assesment trajectory: written or by telephone, by representative or client, lenght of time, notification about outcome
Experience of the re-assessment
Outcome of re-assessment
Meaning of outcome for (dis)continuation of previously publicly financed care
Influence of re-assessment for support with daily living on use of other AWBZ-entitlements (e.g. personal care)

Publicly financed care, knowlegde about the measure

Way of being informed about the (upcoming) measure
Idea of why the measure was enacted
Consideration on making use of the right to appeal
If made an appeal; how was it dealt with and what was the result
Reasons for consent/denial in transfering information from CIZ to the local authorities

Publicly financed care, persisting needs after measure

Meaning of the cuts to entitlements for the client
Effects on wellbeing, capability to run own household, mobility, social contacts, participation in activities outside the home
Preferences/desires regarding activities of daily living

Local Wmo, seeking solutions to persisting needs

Contact and experience with Stichting MEE
Contact with local voluntary organisations, Wmo-loket, social work
Alternative offer by local authorities
Familiarity with and opinion of the Social Support Act
Reasons for/against, and experience with, participation in client boards

Informal care, seeking solutions to persisting needs

Way of informing private network about cuts to their entitlements
Whether or not asked private network to take over the previously received (day)care; from whom (not) and why
Whether or not received offers from private network to take over the previously received (day)care
Contacts with other affected clients
Comparison of personal situation to that of other affected clients
Possible, shared solutions to persisting needs with other affected clients

Informal care, possible request scruple and care ideals

General easiness/difficulty of requesting care from the personal network
Relative easiness/difficulty of requesting care from family, friends, neighbours
Personal preferences regarding care-giving relations
Feelings of indebtedness when receiving care; norms regarding reciprocity

Hypothetical dilemmas

Storyline 1: Lisa, old age

1a) Lisa (80) lives independently in a senior flat. 4 years ago her husband died. She was very depressed and at risk of loneliness. A social worker requested daycare for her. Now she can go there for 3 days per week.

Do you think this is a proper solution to Lisa's problem?

1b) In 2009 Lisa receives a re-assessment for daycare. She tells the assessor that she is very satisfied with the daycare and that her situation has much improved. Now it is decided she is entitled to only one day of daycare per week.

What do you think that this decision means to Lisa?

1c) Lisa notices that a co-resident flat member in a comparable situation has also been affected by the measure, but in her case, daycare was reduced from 3 to 0 days.

How do you think Lisa should feel, now that she learns that her flatmate is affected even more?

Storyline 2: Jan, psychiatric disorder

2a) Jan (42) has a psychiatric disorder. He cannot do his own administration. That is why for years he received individual support. This support has now ended. The care assessment authority judges that he is no longer eligible, because he only has a mild disability.

What do you think that Jan should do?

- i. Make a formal appeal against the measure
- ii. Ask a relative to help him out
- iii. Try to find out to what extent he can manage by himself

2b) His father offers to take over the administration. But Jan finds this difficult, because he feels it undermines his autonomy. He also feels it could change his relationship with his father.

Do you agree on his line of reasoning?

2c) Jan decides to accept his father's offer. After some time the relation with his father becomes tensed, because he interfers with Jan's lifestyle.

Do you think that:

- i. Jan should continue to express gratitude?
- ii. Jan should express his discomfort?

Storyline 3: Jesse, cognitive disability

3a) Jesse (12) has a mild cognitive disability, and finds it hard to interact with peers. That is why he receives individual support in his participation in the scouting club. Due to the cuts this support is now lost, and his parents search for an alternative. They go to a voluntary organisation, where they find a 19-year student who is prepared to support Jesse.

Do you think this is a proper solution?

3b) It is decided that Jess will support Jesse for the whole academic year. Everything goes well. But after 4 months the student receives an offer for a paid partime job which he wants to take on due to financial need. He explains his dilemma to Jesse's parents.

Do you think that Jesse's parents should request the student to stick to the agreement?

3c) The parents decided to offer payment to Jesse for his volunteer work, but nevertheless, he still decides to quit. They find another volunteer for Jesse, but they lack a personal click. The parents give up finding another volunteer and the mother considers to take over the care task herself, at the cost of her work.

Do you think this is a good idea of the mother?

Personal information

Age, marital status, household composition, religion, political affiliation, education, (volunteer)work, social network

Extension interviews with clients' representatives

Involvement in the care situation

Amount and type of care given
Recognition of boundaries to customary/non-customary care
Pathway to requesting publicly financed care
In case of personal budget; reasons, budget administration, way of spending

Personal impact of cuts to publicly financed care

Assumed more care responsibilities or not after reform
Ways/attempts to redivide mounting care responsibilities
Experience of mounting care-giving duties
Consequences for own activities, such as (volunteer)work and free time
Attitude towards increased informal care norm

Samenvatting

Een uitgebreide verzorgingsstaat waarin burgers worden verzorgd van wieg tot graf lijkt verleden tijd. De naoorlogse opbouw en uitbouw van sociale zekerheden worden steeds minder gezien als een toekomstbestendig systeem. Toenemende onzekerheid op de arbeidsmarkt, een vergrijzende bevolking, de stijgende arbeidsparticipatie van vrouwen, een globaliserende economie; allemaal nieuwe sociale risico's die volgens Europese overheden vragen om maatschappelijke en bestuurlijke vernieuwing. Govern*ment* moet plaatsmaken voor govern*ance*, waarin samenwerking tussen publieke en private partijen voorop staat. Zo ook de Nederlandse overheid die haar burgers oproept om meer eigen verantwoordelijkheid te dragen voor werk en inkomen, gezondheid, zorg, welzijn en de wijk. Deze vormen van 'actief' burgerschap zouden burgers minder afhankelijk maken van de overheid, en bovendien bijdragen aan een betere, democratische, zelfsturende samenleving.

Met name in de langdurige zorg betekent dit moreel appèl op burgers een drastische wijziging van voorgaand beleid. Lange tijd stond Nederland internationaal bekend om haar uitgebreide en toegankelijke zorgvoorzieningen voor chronisch zieken en gehandicapten via de in 1968 ingevoerde Algemene Wet Bijzondere Ziektekosten (AWBZ). Deze collectieve zorgverzekering is een vorm van 'passieve' solidariteit: elke werkende burger draagt premies af aan de AWBZ en kan indien nodig een beroep doen op publiek gefinancierde langdurige zorg. In het begin waren de grenzen met de eigen verantwoordelijkheid van burgers helder getrokken: de AWBZ vergoedde zorg in een instelling, terwijl de familie zorgde voor thuiswonende familieleden met een beperking of ziekte. Deze scheidslijnen vervaagden echter met de toenemende 'vermaatschappelijking' van de zorg vanaf de jaren '80, waardoor steeds meer zorg buiten de muren van de instelling wordt verleend. Zorgbehoevenden worden zo in staat gesteld om zo lang mogelijk 'zelfstandig' te wonen en hun plek in de maatschappij te behouden. De stapsgewijze verruiming van AWBZ voor vergoeding van zorg aan huis beantwoordde aan dit ideaal, en het leek ook goedkoper. Een groeiende vraag, stijgende kosten en stagnerende welvaart zetten het AWBZ systeem echter steeds meer onder druk en de roep om hervorming van de AWBZ klinkt steeds luider.

Het (huidige en vorige) kabinet meent dat de publiek gefinancierde zorg beperkt moet bijven tot degenen die het 'echt nodig' hebben. Dat wil zeggen, mensen met een relatief ernstig invaliderende aandoening en die vaak lichaamsgebonden zorg behoeven. Zorg voor mensen met een relatief lichte beperking zou best weer in eigen kring en op eigen kosten kunnen worden opgevangen, op basis van 'actieve' solidariteit: de onderlinge ruil van zorg, zonder of met geringe tussenkomst van de overheid. Met de invoering van de Wet Maatschappelijke Ondersteuning (Wmo) in 2007 hebben Nederlandse gemeenten de taak gekregen om burgers te bewegen tot en te ondersteunen bij deze informele zorg. Voor mensen met een chronische ziekte of beperking betekent de nieuwe aanpak dat zij niet meer als vanzelfsprekend een beroep kunnen doen op collectief gefinancierde, langdurige zorg. Zij dienen allereerst te kijken naar hun eigen mogelijkheden om een zorgvraag te beantwoorden, door zelfhulp of hulp uit het eigen netwerk, alvorens een beroep te doen op de overheid. Volgens de overheid bevordert dit de 'eigen kracht' van mensen met een beperking of chronische ziekte. De AWBZ wordt dus niet alleen gezien als een financieel maar ook als een moreel probleem: burgers doen te weinig voor elkaar en zorgbehoevenden en burgers maken te vaak, te veel of zelfs onnodig gebruik van de publieke zorg, waardoor ze afhankelijk worden van de overheid. De AWBZ moet, zo meent de overheid, alleen nog een vangnet zijn voor degenen die geen of niet afdoende 'eigen kracht' hebben.

De herziening van het langdurige zorgstelsel behelst meer dan een hervorming van regels, rechten en plichten. Burgers worden geconfronteerd met een veranderend denken over afhankelijkheid. Waar zorgbehoevenden eerst - door de publiek gefinancierde AWBZ - in staat werden gesteld zich los te maken van verregaande afhankelijkheid in de privé-sfeer, wordt er nu verwacht dat zij een toenemend beroep op de eigen omgeving zien als een blijk van 'eigen kracht' en 'zelfredzaamheid'. De toenemende selectie aan de poort van de AWBZ betekent dus ook een emotionele hervorming. Immers, burgers moeten opnieuw leren van wie zij welke zorg mogen verwachten, en welke gevoelsnormen daarmee gepaard gaan. Dat geldt indirect ook voor inwonende familie, van wie wordt verlangd dat zij 'bovengebruikelijke' familiezorg weer als 'gebruikelijk' gaan zien. Dit onderzoek naar de betekenis van de hervoming in de langdurige zorg voor burgers gaat daarom niet alleen in op de praktische consequenties van een verminderde toegang tot zorg, maar beziet ook de gevolgen voor de emotiehuishouding van zorgbehoevende en zorggevende burgers. Begrippen als respect, erkenning, eer, trots, schuld en schaamte staan hierin centraal.

Om deze diepere lagen/effecten van beleidshervorming bloot te leggen is kwalitatief onderzoek verricht bij zorgontvangers en hun naasten die te maken hebben met een verminderd recht op de AWBZ. Twee recent genomen maatregelen zijn exemplarisch voor de toegenomen eigen verantwoordelijkheid. Ten eerste, de AWBZ-pakketmaatregel (2009-2010) vermindert de toegang tot dagbesteding en begeleiding bij dagelijkse activiteiten voor mensen met een relatief 'lichte' zorgvraag. Ten tweede, de gebruikelijke zorgnorm, die bepaalt welke zorg verondersteld wordt binnen een huishouden te worden gegeven, is de afgelopen jaren verscherpt, met name door de uitgebreidere zorgplicht van ouders voor kinderen (2009). Voor het onderzoek zijn een survey (n=500) en interviews (n=45) afgenomen bij cliënten met een fysieke, cognitieve of psychische beperking en hun naasten met een verminderde toegang tot de AWBZ als gevolg van deze AWBZ pakketmaatregel. Bij 20 geïnterviewden was ook de gebruikelijke zorgnorm van toepassing. Daarnaast zijn aanvullende interviews gehouden over gebruikelijke zorg bij indieners van bezwaarschriften tegen besluiten over AWBZ indicatiestellingen (n=10) en gebruikers en indicatiestellers van huishoudelijke hulp in de Wmo (n=11).

Uit het onderzoek onder zorgbehoevenden en hun naasten blijkt dat er sprake is van hoge sociale en emotionele kosten als gevolg van de wetswijzigingen. Zo voelen veel zorgbehoevenden die geconfronteerd zijn met een toenemende afhankelijkheid van hun familie, vrienden en kennissen zich verre van 'zelfredzaam'. Ze ervaren juist een toenemend verlies van autonomie, doordat zij geen of minder professionele hulp van buitenaf kunnen inschakelen voor dagelijkse begeleiding of dagbesteding om familie te ontlasten of om de familie er in het geheel buiten te houden. Ook zien ontvangers van het *Persoonsgebonden budget* (PGB) minder mogelijkheden, financieel gezien, om de inzet van het eigen netwerk, en de daaruit voortvloeiende 'negatieve' schuldbalans te compenseren. Zorgbehoevenden zitten tussen twee vuren: enerzijds mogen zij niet meer leunen op de overheid, anderzijds hoeden zij zich voor een toenemende afhankelijkheid van het eigen netwerk. Deze 'autonomieparadox' heeft als pervers effect dat als zorgbehoevenden autonomie nastreven door hun hulpvragen in te slikken, zij uiteindelijk minder ‘zelfredzaam’ zijn dan voorheen.

Zorgverleners die zorgen voor een zorgbehoevend, inwonend familielid met een verminderd recht op zorg, zien zich juist genoodzaakt om de teruggang in zorgrechten op te vangen, vaak ten koste van hun eigen activiteiten, zoals vrije tijd en (vrijwilligers)werk. Familiezorg wordt gekenmerkt door een hoge mate van vanzelfsprekendheid en dat maakt het tot een interessante ‘buffer’ voor een overheid die wil terugtreden. Burgers die al betrokken zijn in een zorgrelatie met een PGB, wordt opgelegd om te blijven zorgen, maar nu als ‘actieve’ burgers, zonder of met minder vergoeding via het PGB. Familiezorgers ervaren deze verschuiving veelal als miskenning van hun zorg als *werk*. Familiezorgers die vastzitten in deze ‘mantelzorgval’ ervaren dat hun altruïsme wordt misbruikt door een overheid die haar financiën op orde moet krijgen. Terwijl familiezorgers worden geroemd vanwege hun altruïsme, groeit de spagaat tussen zorgverlening en betaald werk.

Zorgbehoevenden en zorgverleners zitten klem tussen strijdige noties van autonomie en altruïsme, waar zij alleen maar uit kunnen komen wanneer veel meer burgers bij de zorg betrokken zouden raken. Maar waar is de helpende hand van zorgzame medeburgers in de beoogde participatiesamenleving? Dit onderzoek laat zien dat zorgbehoevenden en familiezorgers weinig vertrouwen hebben in dit overheidsideaal. Zij verwachten niet dat in korte tijd de benodigde cultuuromslag zal plaatsvinden, zeker niet omdat ze ervaren dat iedereen vooral heel druk is met zichzelf, met werk, het eigen gezin en privé-leven. Mocht de cultuuromslag er komen, dan vrezen zij dat deze voor hen in ieder geval te laat komt, en zij vooralsnog tussen wal en schip vallen.

Hoewel veel burgers knelpunten ondervinden als gevolg van de verminderde toegang tot de AWBZ, concludeert de overheid, wat betreft de pakketmaatregel, dat die zijn doel heeft bereikt. Immers, die maatregel heeft geleid tot een verminderde aanspraak op de AWBZ, en grootschalig protest is uitgebleven. Problemen worden gereduceerd tot het individuele niveau; het merendeel van de cliënten profiteert volgens de overheid van nieuwe kansen en mogelijkheden om ‘zelfstandig’ deel te nemen aan de samenleving. Uit deze politieke conclusies blijkt dat de overheid geen of weinig oog heeft voor de sociale en emotionele kosten van de wetswijzigingen zoals die in dit onderzoek naar voren komen.

Ondanks het aanwezige ongenoegen over de hervormingen, maakten maar weinig mensen gebruik van de mogelijkheid tot bezwaar tegen de verminderde toegang tot de AWBZ. De onderzoeksbevindingen wijzen uit dat dit komt omdat de meeste zorgbehoevenden zich zouden schamen als ze bezwaar zouden maken. Dan zouden ze het gevoel hebben te moeten bedelen om zorg, en bovendien riskeren om te worden weggezet als iemand die misbruik maakt van de schaarse publieke middelen - zelfs als het gemis van zorg tot grote problemen leidt. Dit onderzoek laat zien dat de roep om ‘eigen kracht’ maakt dat burgers zich veelal niet uitspreken over hun negatieve gevoelens: zij nemen genoegen met minder en zien het gebrek aan ‘eigen kracht’ steeds meer als eigen probleem. Hierdoor lijkt schaamte ook een rol te spelen in het terugkeren naar overheidssteun, zelfs wanneer dit ‘echt nodig’ is.

De geringe weerstand tegen de wetswijzigingen laat zien hoe verlammend schaamte kan werken, of in bovenstaand geval zelfs de *angst voor* schaamte. Angst voor schaamte ontstaat wanneer mensen zich zien door de ogen van anderen, wat hen vervolgens dwingt om hun gedrag en emoties aan te passen aan de sociale norm. Deze angst is extra dwingend wanneer men zich in een relatief kwetsbare positie bevindt. Hier betreft dat de zorgbehoevenden die al moeten vechten voor respect en waardigheid van hun deels zelfstandige maar ook deels afhankelijke identiteit. De steeds selectievere toegangspoort tot publiek gefinancierde zorg kan er dus toe leiden dat burgers die een gebrek aan 'eigen kracht' niet willen toegeven, soms liever schaamte vermijden en dan niet om de nodige zorg vragen.

Vooralsnog lijkt er in plaats van een toenemende zelfredzaamheid eerder sprake te zijn van een toenemende schaamte voor afhankelijkheid. De nadruk op eigen kracht, zelfredzaamheid, eigen regie en zelfhulp lijkt door zorgbehoevenden te worden opgevat als bevestiging van de noodzaak om ‘zelfstandig’ te zijn, en vooral niet afhankelijk. Dit zelfstandigheidsideaal staat echter haaks op het idee van de ‘participatiesamenleving’ die wederzijdse afhankelijkheid juist veronderstelt. Wil de participatiesamenleving echt een succes worden, dan moeten we de schaamte voor afhankelijkheid voorbij. Afhankelijkheid zou geen negatieve bijklank moeten hebben, in de publieke noch in de privé-sfeer. Afhankelijkheid zou juist waardig moeten zijn; een vorm van burgerkracht voor zowel gever als ontvanger. Juist doordat we als individu kwetsbaar zijn, kunnen er betekenisvolle relaties ontstaan tussen mensen. Alle burgers zijn wederzijds afhankelijk van elkaar, of je dat nu abstraheert tot een collectief zorgverzekeringssysteem of vormgeeft in buurthulpsystemen. Op weg naar een participatiesamenleving moet er wel voor gewaakt worden dat sociale rechtvaardigheid niet in het geding komt. Een te eenzijdige nadruk op de waardigheid van afhankelijkheid, kan afhankelijkheden in de zorg die voortvloeien uit structurele sociale ongelijkheden tussen vrouw en man, arm en rijk, allochtoon en autochtoon, verhullen.

About the author

Ellen Grootegoed (1983) completed an interdisciplinary bachelor at the Utrecht University Honours College, with tracks in Sociology and Psychology (Bachelor of Arts 2005). Then, she specialised in the analysis of social policy, in the master programme Social Policy and Social Interventions at Utrecht University (Master of Science 2007, *cum laude*). In 2007, she started to conduct research in the field of care and welfare policies. Between 2007 and 2009 she worked as a junior researcher/teacher at Utrecht University, Department of Interdisciplinary Social Science, where she worked on the analysis of choice schemes in long-term care, and the combination of care and work. Her PhD trajectory at the University of Amsterdam, Department of Sociology and Anthropology, was performed in the period 2009-2013. In this period she conducted her research on welfare state reform in long-term care, followed a PhD training program, and taught Sociology bachelor students. In October 2013, she started working at the University of Edinburgh, School of Social and Political Science, where she obtained the position of Chrystal Macmillan Research Fellow in Social Policy.

Ellen Grootegoed Dignity of Dependence