Dignity of dependence: welfare state reform and the struggle for respect
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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, *government* (through direct control) is to be replaced by *governance* (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 years³ 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 recommodification 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). 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, 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). The rhetoric suggests a cozy 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.ergotherapeuten.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 caregivers 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). 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’. 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 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 caregivers 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 caregivers 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 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 responsibilities11 (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 workload, 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’ 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 caregivers (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), 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)

'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)

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’ 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). 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’ 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 Etzioni 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’ \([\text{Begeleiding}]\) 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 caregiving. 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 elicited 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).
Introduction

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.
Introduction

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.
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’.
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.
13. Wmo-raden.
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/herindicatiehuishoudelijkverzorging.
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).

Dutch: ‘Het is niet meer van deze tijd dat je als inwoner van dit land maar hoeft te kijken en de één of andere overheidsinstantie lost jouw probleem op.’

Dutch: ‘Het centraal stellen van de client vooronderstelt het serieus nemen van de client als mondig burger, die zelf verantwoordelijkheid neemt voor zijn of haar eigen situatie. Primair betekent dat: zo lang mogelijk op eigen benen staan en zorgrafhankelijkheid zo lang mogelijk voorkomen.’

Though long-term care in the Netherlands is a typical example of ‘defamilisation’ (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).

Dutch: zorgzame samenleving.

References


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


Introduction


