Disabled and elderly citizens’ perceptions and experiences of voluntarism as an alternative to publically financed care in the Netherlands

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What is known about this topic
• Governments of retrenching welfare states place high hopes on community-based voluntarism.
• Although the emphasis on inclusive citizenship can be empowering for people with disabilities, it risks downplaying their actual impairments.

What this paper adds
• Identifies different forms of (mis)recognition in voluntary care, including one’s needs, autonomy and abilities.
• Broadens our thinking on the bases of recognition for people with chronic care needs.

Abstract
Many European welfare states are replacing comprehensive welfare schemes with selective and conditional entitlements. Such changes affect 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 show that although disabled and elderly citizens are often hesitant to open their doors to volunteers, they do experiment with voluntarism to reduce their social isolation, both by receiving voluntary care and by engaging in volunteer work themselves. However, the turn to voluntarism does not always prompt recognition of the needs of vulnerable citizens. This study signals how disappointing and sometimes demeaning experiences with volunteers can increase feeling of misrecognition. We conclude that the virtues of voluntarism may be overstated by policy makers and that the bases of recognition should be reconsidered as welfare states implement reform.

Keywords: care needs, recognition, social participation, voluntarism, welfare state retrenchment

Introduction
Welfare states are currently under great pressure to reform their care policies (Newman & Tonkens 2011, Ferguson & Lavette 2014, León 2014), affecting the balance between the redistribution of public goods and the recognition of citizens’ needs for care (Fraser 2003, Honneth 2003). In earlier decades, growing economies enabled the redistribution of premiums and taxpayers’ money to provide publicly financed care, recognising care recipients as full-fledged citizens with legitimate needs. However, as the pie for redistribution ceases to grow, even generous welfare states are rationing entitlements and reserving publicly financed care for those with the most urgent needs (Pierson 1996, Cox 1997, 1998, Rostgaard et al. 2011). Following the receding redistributive services in retrenching welfare states, governments expect and encourage community-based voluntary organisations to play a larger role in care provision, especially for people with less critical care needs (Dahlberg 2006, Hanlon et al. 2007, Eliasoph 2011, Muehlebach 2012).

Most research on the turn to voluntarism is very positive about volunteering: it seeks to identify the (potential) contribution of volunteers and emphasises how volunteering adds to clients’ well-being and quality of life (Faulkner & Davies 2005, Morris et al. 2012, 2015, Overgaard 2015). However, such studies approach volunteering with a positive bias, often...
overlooking problematic aspects of volunteering, such as continuity or quality of care (Eliasoph 2011). From the perspective of disabled and elderly persons, the turn to voluntarism contains mixed promises. On the one hand, the voluntary ‘third’ sector is potentially more responsive to people’s ‘true needs’ than governments or markets are (Etzioni 1993, 2014, Milligan & Conradson 2006). Voluntary care is said to approximate the ‘warm’ social relations provided by friends, family and neighbours, in contrast to the ‘cold’, distant relations between clients and care-giving professionals in advanced welfare states (Eliasoph 2011, Muehlebach 2012, Verhoeven & Tonkens 2013). The discourse of participation and inclusive citizenship is believed to replace stigmatising patient identities with empowering civic identities (Beckett 2006, Duyvendak & Nederland 2007, Newman & Tonkens 2011). Disabled and elderly persons can receive care from fellow citizens as social equals while being recognised for their own contributions to community life (see, e.g. Seyfang 2003). Through expansion of the role of the third sector in society, the ‘caring capacity’ of the community – its capacity to treat members equally with respect – can flourish (Corbett & Walker 2012).

On the other hand, the increased importance of voluntary organisations 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 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, Muehlebach 2012). Moreover, voluntary projects are often centred on (short-lived) supply rather than on the (long-term) needs of older and disabled persons, thus challenging the quality of voluntary care (Eliasoph 2011). Emphasis on the civic identities of disabled and elderly persons in turn risks downplaying their actual impairments, thereby delegitimising their care needs (Barnes 1992, Hughes & Paterson 1997, Danemark & Gellerstedt 2004).

These potential drawbacks of voluntarism may interfere with disabled and older persons’ need to be recognised as full-fledged citizens. Honneth (1995, 2003) distinguishes between three types of recognition. First, affective recognition of one’s need for mutual loving care instils self-confidence. Second, legal recognition of one’s autonomy regards people as ‘bearers of equal rights and duties’, adding to self-respect. Third, social recognition of one’s unique, socially valuable abilities contributes to self-esteem (Honneth 2003, pp. 139–143). Recognition is a vital human need because it shapes one’s identity; non-recognition or misrecognition can inflict serious harm (Taylor 1992). To be misrecognised in one’s needs, autonomy and/or abilities is to be excluded from a ‘parity of participation’ – ‘social arrangements that permit all (adult) members of society to interact with one another as peers’ (Fraser 2003, p. 36).

In this article, we explore beyond the theory by examining how mildly disabled and elderly persons who previously received publicly financed care perceive and experience this shift towards voluntarism. Do they feel that their needs, autonomy and abilities are being adequately recognised under the new policies?

**Another Dutch miracle?**

We focus our research on the Netherlands, where the government increasingly reserves publicly financed care for citizens with severe care needs (VWS (Dutch Ministry of Health, Welfare and Sport) 2008, 2014). Combined with the renewed interest in community life, the Dutch care reform agenda presents the voluntary sector as an alternative avenue for recognising and fulfilling ‘mild’ care needs (VWS 2007, Newman & Tonkens 2011). The 2007 Social Support Act (Wet Maatschappelijke Ondersteuning) posited that society should reassume ‘ownership’ of the well-being of its vulnerable members (Newman & Tonkens 2011, cf. Peeters 2013). Since then, the right to long-term care has increasingly been restricted to citizens with the most severe needs, while many of the responsibilities for people with ‘mild’ needs have been devolved to municipalities (Grootegoed 2013). ‘Mild needs’ do not necessarily correspond to ‘mild’ impairments: one can be severely injured but nonetheless labelled as having mild needs (e.g. because of a high degree of self-sufficiency). Mild needs also refer to the type of care that is requested: bodily care needs are considered severe more often than social and domestic care needs are (Grootegoed 2013). While the former remain fixed rights under the new core Long-Term Care Act (enacted in 2015), the latter are increasingly regarded as a private responsibility (VWS 2014).

For social and domestic care, the Social Support Act provides a framework for municipalities to pursue their own family care, community life and volunteering programmes. The underlying premise of this act is that voluntary care is superior to professional care in promoting the social inclusion of disabled and elderly persons, as the former is community-based, diverse, inclusive and intrinsically motivated (VWS 2013). Some municipalities even establish targets for the type and number of volunteers they wish to recruit. Although the Dutch government explicitly
states that voluntary care should not replace professional care, volunteers confront increasing and more complex demands under regimes of austerity (VWS 2013). While local authorities celebrate voluntarism – showering volunteers with symbolic gestures such as prizes and dinner parties (Grootegoed 2013) – less attention has been devoted to how recipients of such gestures can derive confidence, respect and esteem from this turn to voluntarism.

An exploratory repeated-interview study

To examine how the turn to voluntarism supports the (mis)recognition of (mildly) disabled and elderly citizens, we interviewed long-term care recipients confronted with reductions in their entitlements to home care resulting from recent reforms and expected to turn to informal care, including care provided by volunteers. We focused on the effects of one particular measure – the ‘AWBZ pakketmaatregel’, enacted in 2009–2010 – which discontinued support for social participation and reduced support for daily living among people with relatively ‘mild’ care needs. This reform did not apply only to future applicants; out of approximately 225,000 existing recipients with various physical, cognitive and physical disabilities, 60,000 lost their entitlements entirely while many others saw their entitlements reduced (CIZ & HHM 2008).

We invited five municipal governments in different parts of the Netherlands to participate in the study and requested the names, ages and telephone numbers of citizens who consented to transfer their information from the national needs assessment centre to the local authority. In a sixth Dutch municipality, we asked professional home-care providers to approach respondents on our behalf. Our selection procedure probably led to an under-representation of people who felt they no longer needed care (e.g. because of improved health) and/or who had avoided care (e.g. because of self-neglect). We aimed for a variety of impairments and care needs by selecting on the basis of age: 1/3 elderly (65+), 1/3 middle-aged (25–65) and 1/3 young persons (10–25). We excluded those who did not use their previous entitlements (most commonly because of changed care needs or dissatisfaction with care quality) and people whose entitlements were reduced by less than half (to exclude cuts with very little impact). We selected 120 persons in total (20 per municipality), 84 of whom either did not belong to the target population or could not be reached (after three attempts during both day and night hours) via a fixed telephone line. Participation was based on informed consent. Only six persons were unwilling to participate in the study (e.g. they did not want to discuss their psychiatric history or had no time). Ethics approval for the study was given by the city councils.

Composition of interview sample

The final sample (see also Table 1) consisted of 30 affected individuals (16 men, 14 women) with disabilities related to old age (9), cognitive disability (8), psychiatric needs (7) and physical constraints or chronic illness (6). Six had multiple disabilities, and we listed them according to the disability that was their primary grounds for requesting publicly financed care. Their ages ranged from 10 to 91. In the case of a young child, one of the parents served as the spokesperson.

We interviewed our respondents twice: first, shortly after the implementation of the ‘AWBZ pakketmaatregel’ (during the first half of 2010) and, subsequently, 1 year later (during 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 this case, we interviewed the daughter). All interviews were held at the respondents’ private homes and lasted approximately 1.5 hours. In the second round, 10 of the remaining 26 respondents did not agree to a second face-to-face interview (because of a lack of energy or a perceived lack of relevance to their situation). In these cases, telephone interviews were held.

Table 1 Main sample characteristics

<table>
<thead>
<tr>
<th>Primary reason for needing support for daily living</th>
<th>Number of respondents</th>
<th>Age variation</th>
<th>Gender balance</th>
<th>Average disentitlement (weekly hours and % of previous entitlement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Old age</td>
<td>9</td>
<td>69, 74, 80, 82, 84, 85, 88, 91, 91</td>
<td>Four men and five women</td>
<td>12 hours; 100%</td>
</tr>
<tr>
<td>Cognitive disability</td>
<td>8</td>
<td>22, 27, 28, 36, 38, 51, 62, 76</td>
<td>Three men and five women</td>
<td>8 hours; 80%</td>
</tr>
<tr>
<td>Psychiatric needs</td>
<td>7</td>
<td>15, 37, 43, 48, 50, 50, 61</td>
<td>Five men and two women</td>
<td>8 hours; 90%</td>
</tr>
<tr>
<td>Physical constraint/chronic illness</td>
<td>6</td>
<td>10, 21, 22, 32, 51, 58</td>
<td>Two men and four women</td>
<td>8 hours; 90%</td>
</tr>
</tbody>
</table>

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Interview structure and data analysis

The interviews consisted of two types of questions. We first asked our respondents about their own experiences seeking alternative, informal care arrangements – including from volunteers – following the cuts to publicly funded care. We then enquired about their views on hypothetical situations through the use of ‘vignettes’ (cf. Grootegoed & Van Dijk 2012, Grootegoed 2013). Vignettes comprise storylines presented to respondents to determine, for example, what they find reasonable, desirable or fair and on what grounds. The hypothetical situations are representative of respondents’ everyday experiences – they pertain to real life. However, the details and context are created by the researchers to facilitate the comparison of answers. The idea behind the use of vignettes is to elicit contextualised interpretations of a focal behaviour (Schirmer et al. 2013). In designing the vignettes, we chose ‘generic yet realistic social situations which all participants could be assumed to comprehend’, which were as ‘simple and concise as possible’ yet provided ‘sufficient context to minimise the likelihood that participants invent overly idiosyncratic contextualisations’ (Schirmer et al. 2013, p. 62).

In this study, we based our vignette on the fictional character Jesse (age 12), who has a mild cognitive disability and has difficulty interacting with peers. Thus, he receives support for social participation. However, because of budget cuts, he has lost this support, and his parents must find an alternative; ultimately, they find a 19-year-old student. In three stages, we invited the respondents to give their opinions on (i) the replacement of professional care with voluntary care, (ii) the reliability of volunteers and (iii) the desired social bond between a volunteer and a care recipient. The vignette also helped us to understand how respondents – often without past or present experience with volunteers – felt about voluntarism in principle.

In the first round of interviews, we asked our respondents why they had requested care, what the (partial) loss of publicly funded care meant to them, and whether and how they had sought alternative care arrangements. We also discussed the above-mentioned vignette. In the second round of interviews, we repeated open questions from the first interview round and asked respondents about the reform’s long-term effects on their daily activities and social participation.

Using the qualitative data analysis software AtlasTi, we first examined their perceptions and expectations of welfare state reform in general and of voluntarism in particular. We deductively examined their accounts of voluntarism, which (elicited by the vignette) revolved around the themes of trust, durability, expertise, choice and personal compatibility.

We then reviewed respondents’ newly acquired experience with voluntarism, including how they felt it affected the recognition of their needs, autonomy and abilities (Honneth 2003), and we explored the possible consequences of a lack of recognition.

Expectations of the turn to voluntarism

Most respondents had heard about the upcoming cuts on the news or via their private networks; their general belief was that the ideal of (re)turning to informal care was desirable but unrealistic. It was desirable because they felt that caring for one another should become ‘normal’ rather than a secluded activity in society. However, it was unrealistic because they did not believe that in a capitalist society, volunteers would be able and/or willing to substitute for the reduced availability of publicly financed care. The respondents often criticised the rampant individualism of contemporary society and depicted community life as a ‘cold shower’ rather than a ‘warm bath’ (Verhoeven & Tonkens 2013). The following explanation was offered by a mother of a physically disabled 10-year-old boy whose support for daily activities was reduced:

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.

In both interview rounds, many respondents reported that they had low expectations for volunteers. Although they felt that volunteers could play a valuable role in simple recreation for people with minor problems, such as ‘working on a puzzle with elderly people’, they did not believe that volunteers could address their persisting and multiple care needs (cf. Grootegoed & Van Dijk 2012). In particular, people with psychiatric disorders and/or rare disabilities/illnesses doubted that volunteers would be able to understand the disabling impact of their impairment(s). This belief prevented them from turning to volunteers for even simple support. A 60-year-old woman with a manic-depressive disorder whose weekly support for daily living was terminated explained as follows:

You could argue that a social volunteer can also help me with financial records, 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.

In responding to the vignette, many informants noted the lack of expertise among volunteers, making them unsuitable replacements for care professionals. A 91-year-old woman reasoned as follows:

No, a 19-year-old student, is way too busy with himself. He cannot support a 12-year-old disabled boy. Moreover, as a student, he still has to learn and cannot care for a disabled boy. He may have good intentions as a volunteer, but he himself is a student.

The belief that untrained volunteers would be 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 teen-aged daughter with a physical and cognitive disability told us the following:

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 a strong family bond or professional expertise to persist through difficulties, the respondents expected that volunteers would be unable to cope in demanding situations. The respondents also feared a lack of ‘control’ over care relations when relying on community-based volunteers. A 21-year-old chronically ill woman responded to the hypothetical case where there is no ‘click’ between the care recipient and the volunteer:

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 discussing the vignette, we asked how much loyalty can be expected from a volunteer if he or she wishes to quit. Almost no one believed that the volunteer could be forced to stay: volunteering can end at any time, they argued. The respondents felt that the turn to voluntarism made them dependent on the benevolence of others and deprived them of the autonomy to choose between different care providers (Collopy 1988). A mother of a 15-year-old autistic boy whose personal budget was halved argued as follows:

The main difference is that he cannot choose on whom he depends. Now he depends on ‘society’. Money is power and offers independence, which was made possible by the AWBZ [Long-Term Care Act]. Now he just has to accept what comes his way.

Such reliance on volunteers rather than publicly financed care was accompanied by a fear of greater dependence (cf. Grootegoed & Van Dijk 2012). Our elderly and disabled respondents feared having little control over their care arrangements: whom they would meet and the durability of such relationships. Relationships with volunteers, in their view, lacked the necessary close personal or deep trust of familial and professional care relations (Linders 2010).

Experiences with voluntarism as another route to recognition

Despite the low expectations of voluntarism, 10 of our respondents had made contact with volunteers via buddy schemes, community centres and/or churches following the cuts, primarily to enhance their social participation. They had generally heard about these organisations through personal networks or through a municipal contact person, suggesting that turning to volunteers ‘privileges’ those who already have more community contacts.

Recognition of one’s needs

Among these 10 respondents, the experiences they reported (in the second interview) were aligned with their expectations (in the first interview). The care provided by the volunteers was deemed inferior to the care previously provided by professionals. Two respondents had accepted the invitation of their municipality to join an alternative day care run by volunteers. The (previously quoted) 91-year-old woman reported the following:

I just do not like it [the new day care]. Because those two ladies who work there are volunteers. They do what they can. But I just miss certain things …. In [the old day care], the day was much longer. We drank coffee, played sports, then we threw balls. We moved, moved, moved. We even did games outside, jeu de boules. There was always something to do. It was much more enjoyable there.

Despite the perceived poor quality of the volunteer-run day care, the elderly woman felt she could not complain because of its voluntary nature. Several respondents with ‘hidden’ disabilities also expressed anxieties about the misrecognition of their needs in the volunteer-run day care and their hesitation to open up to volunteers. A 37-year-old woman with borderline personality disorder and attention deficit hyperactivity disorder explained as follows:

When someone responds to my [atypical] behaviours, I do explain it [my disorder]. Especially when I sense that they accept me as I am. There are only a few who do so … particularly people who have a special background, for
example, because they work in the care sector or have been through similar things, or just a nice person with a very humane attitude.

In the case of a 48-year-old man with a psychotic disorder who had previously received 2 hours of publicly financed individual support per week, he had to turn to pastoral workers, who blamed him for not ‘overcoming’ his impairment:

> It’s been 2 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.

Compared with professional care workers, the volunteers were regarded as less able to meet the respondents’ needs. Similarly, they considered the (often part-time and less generously funded) voluntary-run day care to be inferior to the professional full-day care they had previously received.

Such misrecognition of one’s needs can have far-reaching consequences for how people experience their place in society (Honneth 2003, Danermark & Gellerstedt 2004). Some of our disabled and elderly respondents had abandoned hope of attaining recognition as full-fledged citizens with legitimate needs. With the necessary ‘emotion work’ (Hochschild 2003), they told themselves that it was ‘normal’ for them to be less engaged in society. Another 91-year-old woman whose access to day care was cut explained 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 … 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.

In particular, citizens who already lacked self-confidence would rather refrain from engaging in community life than engage in a continuous struggle to have their needs recognised.

**Recognition of one’s autonomy**

The respondents struggled to rely on the volunteers without feeling dependent. Not only was it difficult to find someone (one person was told to personally distribute flyers in her neighbourhood to find a volunteer), there was also no guarantee of an enduring relation once a volunteer was found. A 61-year-old man with autism had lost his weekly professional support after the cutbacks and was seeking a volunteer.

After one and a half years, he was enthusiastic to have found his new ‘buddy’ with help from the municipality. However, he soon saw the volunteer give up:

> 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 the man organise his book collection (read: mess). However, the man did not allow it because he was more interested in being recognised for his hobby and talking about his books.

Disabled and elderly persons often feel that they are not granted the same autonomy as non-disabled persons in defining the care relationship (Collopy 1988), as neediness and autonomy are frequently polarised (Tronto 1993). Such misrecognition can also increase fears of social interaction, as one 32-year-old woman with a physical and 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 … I also feel that I am different from others, so I first want to address that.

As many of our disabled and elderly informants had expected, their experiences with voluntarism created a feeling of one-sided rather than shared dependence (cf. Tronto 1993).

**Recognition of one’s abilities**

Some of our respondents did view voluntarism as a route to recognition, but in a different way than we expected: by becoming active volunteers themselves and having their abilities recognised. Volunteering provided a way to become actively engaged in society, often as an alternative to employment. However, in their attempts to become volunteers, our respondents encountered an institutional divide between disabled and non-disabled citizens; voluntary organisations often categorised them as ‘needy’ rather than as able to contribute themselves. The (previously quoted) 61-year-old man with autism wished to volunteer but was rejected. His municipal contact person sought an explanation:

> I asked the volunteer organisation, but they said that they employ volunteers for 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.

Given the pressure on voluntary organisations to buffer the cuts to publicly financed care, municipalities select ‘strong’ volunteers (Van Bochove et al. 2013),
thereby devaluing disabled and elderly citizens’ possible contributions to community life. This institutional tendency decreases their access to self-esteem derived from being ‘active citizens’.

For our respondents who managed to become volunteers without the help of voluntary organisations (three in elderly care and one on a client board), being helpful in the community was a reaffirming experience. In the first interview, a 58-year-old woman with physical and psychiatric disabilities described how much she missed the discontinued day care:

R: It is a loss. You are thrown back into loneliness; you are in a place where you do not want to be.
I: What kind of place is that?
R: A place of loneliness, being alone. Normally, I have 2 days a week where I am somewhere else, but that is no longer the case.

In the second interview, the woman no longer missed her previous day care; at that time, she was a volunteer for the elderly people. By focusing on her strengths, she was able to seek a positive identity:

Well, you just have to start somewhere. Just by taking a course, maybe doing voluntary work. I now follow a computer course at the community centre, and I can help the elderly people in my care flat with their Internet, and ordering online groceries for them, things I am good at, where I can help them. Now, I could not care less about the [lost] day care.

In contrast to the disappointing and sometimes demeaning experiences of receiving care from volunteers, participation as volunteers, insofar as it was possible, enhanced their self-esteem.

Discussion and conclusion

The current study draws on interviews with a small sample of disabled and elderly persons facing welfare state retrenchment and the turn to voluntarism in the Netherlands. Firm conclusions cannot be drawn from this study. First, although the sample included persons with various types of disabilities and illnesses, it is too small to represent the full breadth of chronic care needs; hence, further research with a larger sample is needed. Second, our study focused on the transition from professional to informal voluntary care. We did not compare the experiences of our respondents (who were largely forced to seek alternative support in the voluntary sector) with the presumably more positive experiences of people who initially welcomed the turn to voluntarism; comparative research is therefore needed. Third, we gained insight only into the perspectives of care recipients, not the interactive process leading to (mis)recognition, which would require interviewing both care recipients and volunteers and/or participant observations.

Despite the current study’s limitations, it highlights the need for further research on the struggle for recognition as prospects for redistribution recede in retrenching welfare states (Fraser 1995). Recognition contributes to self-confidence, self-respect and self-esteem, whereas the consequences of misrecognition are often severe (Taylor 1992, Honneth 2003, Lind et al. 2014). We therefore enquired whether, how and under what circumstances the replacement of entitlements to publicly financed care with voluntary care affects the recognition of people with (mild) chronic care needs. Our interviews with disabled and elderly persons revealed their widespread scepticism about relying on voluntarism to have their needs and autonomy recognised; most of our respondents feared losing control over the type, content and duration of the social bonds ‘created’. Those who nevertheless sought contact with volunteers often reported disappointing and sometimes demeaning experiences—especially compared with the recognition that they had previously received from their entitlement to professional (day)care. The volunteers were insufficiently trained; similar to distant relatives, they often misunderstood the nature of the disability, affecting the autonomy granted to the care recipient.

We found that recognition (of one’s abilities) is most likely when disabled persons can effectively position themselves as full citizens within reciprocal relationships—for example, when they become volunteers themselves (cf. Linders 2010, Bredewold et al. 2013). However, enrolling as volunteers proved difficult; voluntary organisations facing budget cuts tend to select ‘strong’ volunteers, disregarding the fact that people have both disabilities and abilities. In effect, this tendency blocks disabled and elderly citizens’ pursuit of self-esteem through contributing to community life. Governments must therefore ensure that volunteering does not become an exclusive activity and reconsider what disabled and elderly citizens need to achieve confidence, respectability and esteem on equal footing with non-disabled citizens.

Strategies for increasing the likelihood of recognition of the needs and abilities of disabled and elderly citizens depend on the types of misrecognition (Fraser 2003, p. 45). First, when people with disabilities feel that their needs are not recognised, local authorities can invest in (further) training for volunteers. Alternatively, more time and care could be invested in the
matching of volunteers and care recipients to increase the likelihood of developing a ‘loving bond’ akin to a close family bond. Affective recognition can be based on both personal bonds and the loving labour of care professionals (Hochschild 2003).

Second, when the problem is misrecognition based on a lack of respect, local governments can strive to represent disability (and its resulting care needs) as a human experience that befalls us all (Rorty 1989, Tronto 1993, Nussbaum 2001). Volunteers should be trained to treat the autonomy of care recipients as equal to their own. Third, when the problem is misrecognition based on lack of esteem (or social recognition), public authorities should recognise people’s courage and endurance in living with their disabilities (e.g. which occurs in disability sports). Moreover, disabled and elderly persons’ willingness to 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 effort 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. Especially in times of welfare state retrenchment, when previously established avenues to the recognition of (mild) care needs are being closed, we must ensure new avenues for disabled and elderly citizens to participate in society as equals while actively fighting misrecognition.

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