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

Grootegoed, E.M.

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (http://dare.uva.nl)
Chapter 5

Community-based voluntarism and the struggle for recognition

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

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

Introduction

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

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

In thinking about social policy and social justice, ‘the center of gravity has shifted from redistribution to recognition’ (Fraser 2003: 89). Struggles for
Community-based voluntarism

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

The turn to voluntarism contains mixed promises for the recognition of disabled and elderly persons as full citizens. On the one hand, the participative discourse replaces stigmatizing patient identities with empowering civic ones (Shakespeare 1993; Oliver 1996; Beckett 2006; Nederland & Duyvendak 2007). Disabled and elderly persons can receive care from their fellow citizens while being recognized for their own contributions to community life (see e.g. Seyfang 2003). On the other hand, the emphasis on the civic identities of disabled and elderly persons risks downplaying their actual impairments, thereby delegitimizing their care needs (Barnes 1992; Hughes & Paterson 1997; Danermark & Gellerstedt 2004). There is also no guarantee that community-based voluntarism advances social integration between disabled and non-disabled citizens as voluntarism operates through both inclusive and exclusive mechanisms (Gilbert 2004; Tonkens & Newman 2011; Eliasoph 2011).² Furthermore, the increased importance of voluntary organizations in retrenching welfare states places a premium on the third sector’s efficiency, accountability and complementarity with public services (Dahlberg 2006; Hanlon et al. 2007). Growing state control over voluntarism³ may thus ultimately undermine its informal structure and responsiveness to citizen rather than government demands (Gilbert 2004; Dahlberg 2006; Hanlon et al. 2007; Jager-Vreugdenhil 2012).
The virtues of voluntarism

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

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

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

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

Though the government explicitly states that voluntary care is not meant to replace professional care, it hopes volunteers will help alleviate the unevenly distributed and mounting family care obligations that result from reduced access to publicly financed care (ibid.).
Second, people with disabilities can enhance their social participation by becoming volunteers themselves. The new government adage is to ‘begin with what people (still) can do rather than what they cannot do’ (VWS 2013b: 4). In practice, this can mean that disabled citizens who request support from the local authorities are asked to do something in return. A physically disabled person who receives help with transport, for example, may be asked to read to school children. According to the Municipality of Amsterdam:

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

(Gemeente Amsterdam 2012)

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

A longitudinal study

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

We purposefully selected 30 affected individuals with disabilities related to old age (9), cognitive disability (8), psychiatric need (7), and physical constraint or chronic illness (6) from six Dutch cities, whose files had been transferred from the national needs assessment centre to local care authorities upon
We selected clients whose previous entitlements were at least halved, despite their conviction they required this care. We omitted clients who did not make active use of their entitlements. 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: shortly after the implementation of the ‘AWBZ pakketmaatregel’ (in the first half of 2010) and one year later (in the first half of 2011). Four respondents could not be interviewed in the second round: one was unreachable, two did not want to participate, and one was deceased. In the case of the deceased individual, we interviewed the daughter. Of the remaining 26 respondents, 10 interviews were held by phone as these respondents did not agree on a second face-to-face interview. Reasons for this were a lack of energy and perceived lack of relevance for their personal situation. In the first round of interviews we asked why care was requested, what the (partial) loss of publicly funded care meant, and about their search for alternative care arrangements. As not all care recipients had experience with volunteers, we posed a hypothetical dilemma regarding voluntary care to elicit their normative views. In a fictive storyline, respondents were invited to give their opinions on: (1) the replacement of professional with voluntary care; (2) a volunteer’s dilemma between continuing his volunteering and accepting paid work; and (3) the lack of personal click between the volunteer and the care recipient. In the second round of interviews, we repeated questions from the first round and asked about the reform’s long-term effects on respondents’ daily activities and social participation.

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

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

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

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

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

But even if volunteers were readily available, respondents remained sceptical of the underlying social bond. Many mentioned that a personal ‘click’ was needed:
'Even if a volunteer is found, you just have to wait and see if there is a click. We have experienced it with the care purchased via the personal budget that someone came, and it was just really drama.' [Mother of two autistic children]

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

‘I asked the social volunteer organization, but they said that they employ volunteers 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. But well, that is the structure. And that structure is restrictive.’

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

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

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

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

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

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

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

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

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

**Conclusion and discussion**

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

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

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

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

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

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

Notes

1 Other scholars view redistribution (Rawls 1971, 1993; Dworkin 1981) or recognition (e.g. Honneth 2003) as the overarching route to social justice. This article pursues Fraser’s idea that redistribution and recognition can be separate routes.
2 Eliasoph (2011: 180) found that where voluntary projects promised to empower the poor and needy, volunteers developed a ‘cool, respectfully distant politeness’ at best.
3 One may even argue that in the process of welfare state retrenchment, voluntarism is presented by governments as an alternative form of redistribution.
4 Dutch: participatiesamenleving.
5 The Act contains a ‘compensation principle’ that obliges municipalities to assist citizens with disabilities to overcome barriers to their self-sufficiency and social participation. Concretely, municipalities must compensate barriers to mobility, housekeeping, and participating in social activities (Sijtema 2008). While the provision of support for mobility and housekeeping is standardized, municipalities have discretionary power over social participation: informal care, social voluntarism, public facilities and collective arrangements can all provide ‘compensation’ while cheaper variants are favoured over individual entitlements to (day)care. Citizens can only demand professional (day)care or a personal budget if they can prove the municipality has not been able to sufficiently compensate their participatory problems in another way. It is thus legally difficult for citizens to make a case against the local authorities. For example, an autistic man’s request for a personal budget was rejected. He appealed against the decision but the municipality claimed he could suffice with social volunteers (despite the claimant’s argument that for him this was no solution). While such priority setting by municipalities sits uneasily with the legal right to choose one’s care arrangements, the sustainability of local budgets is deemed more important than individual choice over care arrangements (VWS 2013a).

Dutch: respijtzorg.

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

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

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

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

In six cases a parent served as a spokesperson.

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

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

Community centres are increasingly run by volunteers.

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

Let alone the differences between wealthy and deprived communities.

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

i.e. multiple disabilities.

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

References


CIZ (Centrum Indicatiestelling Zorg) and HHM (2008) Onderzoek effecten pakketmaatregelen AWBZ. HHM, Driebergen and Enschede.
Community-based voluntarism


