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Dealing with new social care frontiers:

**How welfare state reform is perceived and enacted upon by mildly disabled
people and their networks**

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Introduction

In 2007, the Dutch government launched the Social Support Act (SSA; *Wet maatschappelijke ondersteuning – WMO* in Dutch). The WMO marks a major revision of the whole area of social services and in particular social care as it replaces the former Welfare Act and Act on Facilities for the Disabled of 1994 and parts of the Exceptional Medical Expenses Act for care and support for frail elderly and people with disabilities (AWBZ) of 1968. Apart from cost reduction, the main aims of the WMO are to promote participation and tailor-made services. The ideal is to promote participation of all citizens in society, regardless of their disabilities or health, and to do so by way of devolution of services from the national to the local level, in order to ensure individually targeted services.

We base our findings on 30 in-depth interviews with frail elderly and people with physical, psychiatric or cognitive disabilities who are affected by the welfare state transformation from protection to participation as embodied in the WMO. Specifically, we focus on two groups: those who are faced with reductions in their entitlements to individual guidance with daily activities in and outside the home and people who loose access to daycare facilities.

From equal rights to tailor-made services

The WMO replaces the Welfare Act and Act on Facilities for the Disabled of 1994, and replaces parts of the AWBZ (Exceptional Medical Expenses Act), the law on health and social care of 1968. Legal rights to social care services were firmly installed with the AWBZ. Welfare services such as support from social workers were not included, but these became subsidised from the 1950s onwards, with the Welfare Act as its legal framework (devoid of individual rights). The Act on Facilities for the Disabled provided for practical services, such as a supplying a wheelchair to a physically disabled person. The legal framework of the AWBZ was the main framework for social care - the broad range of care and support services for vulnerable groups such as the elderly and people with disabilities.

Figure 1: Changes in the legal framework for social care in The Netherlands

	1940s	1950-2000	2000s
Cure	Health-fund law, 1941: Entitlement to cure for low income (high income: private insurance)		Health-insurance law (ZVW), 2005: Universal entitlement to cure for all Dutch citizens
(Long-term) care	Pillarized non-profit organisations	AWBZ, 1968: Universal entitlement to social care	AWBZ continued but restricted
Support (welfare)	- (charity, subsidised by government)	Welfare Act (Welzijnswet), 1994, Act on Facilities for the Disabled (WVG), 1994; no individual entitlements to social care (devolution of services to the local government)	WMO, 2007; Combination of parts of AWBZ, Welfare Act and WVG; no individual entitlements to social care

In the AWBZ, individual entitlements to social care were firmly rooted. The WMO has a much weaker legal framework virtually without individual rights to services. While the AWBZ phrases individual legal entitlements, the WMO describes ‘areas of achievement’ for local governments in which they must prove to be active, without guaranteeing services to individual clients (Ossewaarde 2007). What clients do or do not receive depends on the money available and on the local priorities in allocating that money. The decrease of social care rights is supposed to contribute to cost reduction.

Cost reduction is argued to be necessary for the future sustainability of long-term care. All over Europe, the sustainability of long-term care schemes is under pressure. The ageing trend results in a growing demand for care and increased welfare spending. Currently, the economic crisis also resorts effects on governance strategies to reduce care costs (Jordan 2010). The introduction of user-pay systems, quasi-markets, fixed ceilings of welfare benefits (instead of open-ended entitlements) and more limited eligibility criteria are all attempts to sustain universal long-term care schemes (Glendinning & Moran 2009).

Apart from cost reduction, the WMO also has ideological aims. In the current economic crisis, financial considerations threaten to overshadow the ideological underpinnings of the WMO. Citizens, social care professionals and even local and state politicians more frequently refer to the WMO as an instrument for welfare retrenchment. Nevertheless, the ideals behind the WMO are too ambitious to wipe away. The core ideal of the WMO is to promote participation of all citizens in society. Not care but participation should be the central aim of social services. As the Ministry of Health phrased it: *'The aim of the Social Support Act is participation of all citizens to all facets of the society, whether or not with help from friends, family or acquaintances'* (Ministry of Health, Welfare and Sport, website visited July 2009). Participation can entail a move towards more network aid as a substitute for rights-reduction: informal care and volunteering is valued over public aid, implying a new social contract (Knijn 2007; Ossewaarde 2007; Gilbert 2009). To promote participation thus has a double meaning: it means to promote clients to participate in society but also to promote carers and volunteers in care and support for patients where paid care disappeared or will disappear in the near future. The ideal of participation in the WMO primarily implies a communitarian idea of citizenship of taking responsibility for social care in your family and your community, both as a family member and as a member of the local community and civic organisations.

The second ideological underpinning of the WMO is devolution (i.e. decentralized authority) of services from the national to the local level. In line with a broad transition in thinking about welfare and social policy in Europe more general, the idea is to no longer develop top-down services, but rather to seek partnerships with all parties involved and form bottom-up alternatives, thereby creating a multi-level governance (Newman et al. 2004). Support needs are supposed to be best fulfilled at the local level as local authorities are closer to citizens, service providers and voluntary and community organizations and to have better knowledge of their needs than central government. Decentralized social care allows for greater diversification of standards, meaning that not only the type but also the quality of

services can vary per municipality (Greer 2010). The responsibility for the quality of social care is dispersed among all local stakeholders, including citizens. They are supposed to act as governance partners rather than as claimants of welfare rights.

Participation and tailor-made social care services: the case of guidance

The aim of our study is to analyze how the two core ideals of the WMO, participation and tailor-made services, work out in practice. As this is a too broad question to study in one research project, we selected one particular measure that took place recently in the context of the move from the AWBZ towards the WMO: the move of some entitlements for 'guidance' to the WMO. This move pertains to 120.000 frail elderly and people with mild psychiatric, cognitive and/or physical disabilities (CIZ & HHM 2008).

Since 2005 both the demand for and volume of guidance service use under the AWBZ has increased sharply. Indications including guidance increased with 20-30 per cent yearly until 2007. Additionally, the volume of guidance use also increased. In one client group that used activating guidance in combination with other AWBZ-care, the average volume increased from 9,4 hours in 2005 to 18,5 hours in the first half of 2008. Possible explanations for this vast increase are sought in the enhanced familiarity with and broadening grounds for entitlement to guidance (CIZ & HHM 2008). Guidance consisted of daycare or personal support, focusing at support with daily tasks in and around the home and/or social participation. Guidance entailed a wide range of activities such as making social contacts, organizing a household, emotional support or shopping. Apart from receiving the guidance in kind, disabled persons could also choose to contract caregivers privately, with the use of a personal care budget (PGB), which gives even greater flexibility for its usage. The endless variety of guidance use made it difficult to control for its legitimate usage and reasons of the growing popularity.

In 2008 it was decided that people who use guidance in overcoming difficulty with daily tasks due to a mild disability better suit the WMO. People with moderate or severe disabilities are not struck by the measure; their rights under the AWBZ remain the same. The severity of a disability is tested on five fields: social life, mobility and transport, problem behavior, psychic functioning and memory- and orientation disorders. For each field, it is defined which disabilities are considered mild, moderate and severe. When it is not necessary to take over tasks of the disabled, and he/she can depend on network or local aid structures in

overcoming difficulties, a person is called ‘mildly’ disabled (CIZ 2010). People with a mild disability exchange their care rights (AWBZ) for favors under the Social Support Act (WMO).

Of the 230,000 eligible prior to the measurements, 120,000 have been confronted with reduced entitlements to guidance, of which 60,000 persons have become entirely ineligible for the function guidance as of January 2010 (CIZ & HHM 2008). By limiting access to the AWBZ, these people are expected to be freed from one-sided dependencies and activated in their social participation: *‘The measurements [i.e. restricted access to AWBZ] can prevent people from becoming dependent on heavy and individual help trajectories, isolating people from society rather than activating them and bonding with fellow citizens’* (Jet Bussemaker, state secretary of the Ministry of Health, Welfare and Sports 2008).

The goal to activate mildly disabled persons and their network by reducing public aid marks a clear shift from protective policies. It raises questions of whether mildly disabled persons are capable of, and willing to find alternatives for public aid. In this study, we analyze how mildly disabled persons, with decreased access to social care services as indicated above, give meaning to and deal with the reform on basis of their needs and beliefs. We particularly look at how the two core aims of the law we indicated above, work out for them: does their reduced entitlement indeed lead to increased participation and if so, how, and how do they experience this? And secondly: does it indeed lead to more tailor-made services as devolution to the local level promised?

Methods

This study makes use of qualitative data, gathered between January and July 2010. In total, we performed 30 in-depth interviews in six Dutch cities, with persons with a mild physical, psychiatric or cognitive disability. In eight cases it was essential to interview an informal or formal caregiver, as a complement (5) or substitution (3) for the disabled person’s own account. The cities involved are Amersfoort, Dordrecht, Haarlem, Utrecht, Rotterdam, and Zwolle. With 600,000 inhabitants, Rotterdam is the second city of the Netherlands; the other five cities are of moderate size according to Dutch standards and house between 100,000 and 200,000 inhabitants.

In all except for Dordrecht, we selected respondents from the lists municipalities received from the AWBZ-care indication organ (CIZ). These lists contain information about the people who have reduced entitlements to guidance, including name, address, age and indication loss. We selected cases on basis of differential ages and a minimum of 50 percent

indication loss. A differential age is the best predictor to find a maximum variety of disabilities. The criterion for minimal 50 per cent indication loss is included to increase the likelihood that the measurements have impact and alternative arrangements are sought. We did not opt for selection of only full indication loss, as we intend to compare people with varying institutional interfaces (i.e. people who still have partial access to the AWBZ and those who do not).

After sending a letter to the targeted respondents, we phoned them when their telephone number was available in the telephone book. Many people of a relatively young age (18-45) were not registered in the telephone book and could therefore not be reached. Only three people who were unregistered contacted us on basis of the letter. During the telephone call, four people denied cooperation, of which mostly people with a psychiatric background. The information on indication loss was not always accurate. It happened quite often that during the telephone call, it appeared that there was no indication loss or less than anticipated. In Dordrecht we used a different selection method. There, the municipality did not demand for the client information, as they find that is in contradiction with the WMO-ideal to approach citizens on basis of their previous care indications (i.e. the AWBZ regime). Therefore, we selected cases in cooperation with three regional care providers for people with a cognitive disability or old age.

We interviewed 30 respondents, - 16 women and 14 men- , aged between 10 and 91. Most of the respondents suffered from old age (9), followed by psychiatric (6), cognitive (5), physical (4) and multiple disabilities (6). The guidance received prior to the measurements ranged from 2 to 28 hours per week. The largest indications were given for daycare. More than half of the cases lost the entire access to guidance, amongst which mostly elderly with daycare. In appendix 1 we present a full overview of the characteristics (age, sex, disability, indication loss, and network) of the selected respondents.

Results

We now present our first results (of an ongoing longitudinal study) of how the mildly disabled persons we selected give meaning to and react to the changes indicated above, in terms of social participation and tailor-made services. The disabled and/or their network can seek private solutions for the unwanted guidance loss or reduction. In this way, the degree of social participation prior to the measurements can be maintained or even advanced. Taking action requires activation of the disabled persons or their network. We therefore speak of ‘activation’

when it implies that *mildly disabled people or their network develop (new) activities to enhance the participation of the client in society in reaction to the measurements* - as opposed to de-activation, which we define as *the extent to which mildly disabled people withdraw from society in reaction to these measurements*. We focus on three factors that can explain varying activating and de-activating pathways of the mildly disabled: their disability, their embeddings in an institutional and/or private network, and their norms and values regarding social care.

During the interviews we asked respondents what functioned as an alternative to the guidance loss. One third of the 30 respondents did not undertake action or worked on their participation without help from third persons. For another third the informal network (family, friends or voluntary sector) buffers the previous guidance. Besides self and network reliance, one third of the respondents did not come loose from their institutional reliance, either by: receiving a new indication for guidance after objecting to the reform (2), a (growing) demand for mental health care (3) or because the care professionals continues the guidance unpaid (5). These varying pathways cannot fully be explained by the disability type – as the different disabilities occur in each of the three groups. We therefore grouped the respondents' networks as dominantly private or institutional and related that to the alternative they seek: self-reliance, network reliance or professional reliance.

Interestingly, there has been no shift from people with a predominantly institutional network towards a greater reliance on the private network. Another remarkable finding is that eight people with a private network opted for more self reliance – which cannot merely be explained from the strength of the network: both weak and strong networks are included. Then, there are also six people who opted for alternative professional solutions while primarily having a private network. These contrasts need further explanation: why do these mechanisms occur, how does it relate to the disabled person's norms and values, and how do the alternative solutions translate into activation or de-activation? We analyze these mechanisms for the three areas: self-reliance, network reliance and professional reliance. We will evaluate what the care responsibility shifts imply for the disabled person's social participation and whether or not more tailor-made services are found in a local setting.

Self-reliance

Reliance on oneself after guidance loss occurs at both ends of the spectrum of activation: those, who activate themselves, and those, who withdraw from mainstream society. Still they do have in common that they no longer ask for institutional or private guidance.

Activation

Looking at those persons who ‘activated’ themselves we primarily see people who have little social contacts – yet are in the midst of their lives. They have used guidance to learn how to cope with a disability or live independently, run a household and make social contacts. Now that the guidance is stopped, they see it as an ‘opportunity’ to take the final steps to participate in mainstream society. A woman with a stable psychiatric disorder (who went to daycare in a mental health care institution) says: *‘In that period [when the daycare was stopped], I was already looking for a paid job with the help of a job coach. They told me that was the reason why my daycare was cut off. So when I heard about that I took on the first job I could get.’* If the daycare was not discontinued, she says that she would have stayed in her safe environment. Now, she takes the insecurities of her ‘new life’ as they come. She considers exchanging the prior institutional environment for the real world as a form of empowerment: *‘Financially, I gain nothing [from taking on a job to substitute the daycare loss], but psychologically it is healthier. You no longer sit there, waiting what they [government] will decide about you now. I can now take care of myself. (...) I also want to work on my private life; get a grip on my work, and that is how I see my future’* (R24). To her, requesting additional aid from the private network to substitute guidance loss is not an option: she wants to do it herself now instead of leaning on other people’s shoulders. Moreover, she sees informal care as a form of injustice (as the care needs are unequally distributed in society).

Besides taking control over one’s own life, mildly disabled persons see the necessity to cover for the guidance loss to uphold and advance social activities. A woman (33) who suffered from brain injury receives fewer hours of individual guidance. She finds that she needs to invest in her social life as it makes her forget about her disability: *‘When you are busy with something outside yourself, or someone visits you, like (...) [the care professional] or a relative then I forget about it [disability].* To her what matters most is that just someone is there for her. Still she finds that though her family is helpful she wants to keep them at a certain distance: *‘My father always drives me around whenever I want. On the one hand that is nice but on the other hand it is not. I mean, I am 32 years old now and I do not want to be... I am becoming a mollycoddle. I loose part of my independence. And I do not want to bother them with my problems.’* Now that the guidance is reduced, she aims at a church club and volunteer work to develop more of her own activities: *‘Now I am going to do*

volunteer work in an elderly home. I think it is nice to be meaningful for society, yes I think that is great. Only I cannot take much, I easily get tired' (R14). Here, the guidance loss has forced her to think about meaningful alternatives she can undertake on her own.

Interestingly, there are also respondents who accept the guidance loss or reduction as a positive prospect, whereas their professional caregivers foresee risks. A mother with a cognitive disorder receives pedagogical help in raising her son. She says that she can manage on her own, yet reports that her professional help disagrees: *'I already wanted to reduce the help I get [prior to the measurements], because it is going better now. Actually, I want to do it [raising her son] on my own. But she [professional aid] won't let me. Till she finds that my son listens to me, and all goes well, then maybe she will finally let go of us' (R22).* As the mother thinks she can handle the responsibility for her son, she also does not see the need to cover for the reduced guidance in the private sphere. Besides, she herself is an informal caretaker of her mother, who is ill, which to her is an extra argument why she is on the 'caring side' rather than needing help herself.

Middle aged disabled persons can be activated in the domains of (volunteer) work and social contacts by the guidance loss. The persons who buffered the loss themselves were however already oriented at reducing their dependence on public aid – the guidance loss being the encouragement rather than the motive. Additionally, the disabled persons that became activated by the reform refuse to see informal care as an alternative option to the guidance; while some occasional help might come in handy, no one accepts it as a structural solution to the guidance loss, undermining their autonomy.

De-activation

At the other end of the spectrum, there are persons who feel left in the dark by the guidance loss and incapable of covering for the lack of support and daily contacts. A typical case is that of an elder person who can no longer visit daycare, but has not developed social contacts outside the daycare. Though they have children, a lacking proximity and availability of their offspring impedes care requests (and offers). Especially the combination of both decreasing public aid with limited or absent family aid leads to intense feelings of loneliness. Elderly who went to daycare prior to the measurements experience being cut off from their social network. An older woman (91) reports: *'I went to this daycare for many years. We [elderly] were all really connected to each other and to the group leader. I had many friends there; we played games with each other, we read the newspaper, and so on. Now they [government] force us to sit behind the geraniums' (R19).*

What many de-activated elderly call 'sitting behind the geraniums' seems to have a negative impact on the quality of life of the elderly. A 91-year old woman who used to go to daycare explains: *'Outside that [daycare] I have nothing. I went there for seven years. I needed it for some*

distraction after my husband died. And now I am 91, and all of a sudden I do not need it anymore? I find that so strange. (...) I went there one day per week, for some recreation, we did games and handicrafts. I used to dress up nicely for that occasion, but now I do not do that anymore, it does not matter, nobody sees me. I just sit home all day. The days last and last. I look at the clock and think: is it still half past 2?' (R18). In her opinion, the family has no responsibility in covering for the daycare loss; in fact she finds the mere suggestion a sign of poverty: 'I think it is absurd that in a welfare state like The Netherlands you become reliant on your family when you are 65. I think that is more like a Third World country system. There, when you become old, you have to rely on your family. You need to ensure you have many children to secure your old age' (R18).

When asking further, most elderly however admit that they are hesitant about asking their children to come more often because they have a 'life of their own'. Only one woman has asked her daughters to visit her more often now that the daycare is gone. Yet, even in this case, it does not lead to more family aid. The 80-year old woman reports: *'I would like to see my daughters more often. And I also told my daughters that I need their support. But they think of me as someone who can still do many things independently.'* Now that her daycare has ended, she decides to entertain herself, thereby limiting her contact with the outside world: *'I watch a lot of television, in the morning I do gym and then I watch the Olympics. So yes, that is what I do now. I do not go outside every day, only with good weather; with snow or rain I am too afraid to fall'* (R5).

Limited energy and mobility hampers the elderly in developing new contacts and activities, and their feeling of being a 'burden' to their children – often their only contacts aside from the daycare – limits their requests. The elderly experience the reform both as unfair and unnecessary rather than as a challenge to start something new. They argue that if the reform would only be applied to future applicants and not to them, it would have cost the government little, due to their limited life expectancy. Due to their limited energy, they do not object to the reform, but learn to live with it.

Network reliance

Social activation does not only entail the formation of new bonds or undertaking of new activities. According to the WMO-ideal, it also involves enhanced reliance on the private network in the need for guidance – as opposed to reliance on professional caretakers. Family, friends, acquaintances, neighbors, volunteers are all expected to contribute to disabled and older people's care need. We review cases wherein informal care can be seen as a 'shock absorber for welfare reform' as they take over the guidance tasks that were previously performed by professionals or for payment (Tonkens & Van Daalen, submitted).

Though the quality of the network varies per respondent, not one respondent is completely isolated from friends and family. There is however a clear contrast between elderly and younger people and their network reliance. While the elderly do not increase their network dependence in reaction to entitlement loss (and rely on themselves; see ‘self reliance’) it is the first step taken in families in which a younger disabled person is still part of the household. A mother of two autistic children, of whom one with reduced guidance says: *‘On the one hand, I am happy about their reduced professional aid, because I want them to become more independent, but on the other hand, the reality is that I need to do more for them. And that has its limits too’* (R16).

That these limits can easily be reached becomes clear from stories of overburdened family caregivers who try to seek alternatives for their role as buffer, for example by looking out for volunteers. The mother of the 10-year old physically disabled explains: *‘My child has a physical disability and therefore he is really isolated. First, a student used to come [guidance] and play with him and that did him well and it also relieved me. He [son] cannot play outside alone, so now he misses out on social contact with his peers. I want to find an individual supporter for my son in my neighborhood, a volunteer [to substitute for the guidance loss]. Well, you can forget it these days. The mentality is not like that. My neighbors already put on a face like ‘don’t’ ask me anything’* (R11). Despite the negative experiences in her neighborhood the mother does spread flyers in search for a volunteer. It has not yet resorted effects and in fact, she complains that caring for her son fulltime while also seeking for a volunteer strains her even more.

The demand for more family responsibility can be unrealistic when taking the context into account. A mother who takes care of her daughter, but experiences greater burden due to the loss of guidance says: *‘They [indication organ CIZ] just assume the family can take up these tasks [guidance for the 22-year old cognitively and physically disabled daughter] without asking whether that is actually possible. And I mean, already one of our daughters died of the same illness, my husband develops dementia, and I have a hernia and my knees are worn. So it is pretty hard and not all that self-evident’* (R21).

Apart from the limitations to what the family can do, the disabled person can also feel uncomfortable with the increased tasks their relatives take up. A 21-year old woman, living with her brother and parents, is physically disabled and cannot go outside on her own. She always needs to be accompanied by someone (brother, parent, friend), whom she used to pay via the personal care budget she receives on basis of her indication for guidance. She explains that her network still accompanies her, but now does so unpaid. Though it has no direct consequences for her daily life, she does foresee future problems, as she wishes to advance her independence to be able to live independently one day: *‘I want to be able to compensate them [informal caretakers]. Especially when I will [later] live on my own. They [relatives, friends] will certainly do it*

without the money, but it is just for my feeling. That you are not so dependent' (R9). Being able to compensate her network for their efforts in aiding her reduces the barrier to express requests.

In short, from the interviews with the informal caretakers it becomes clear that they find their limits concerning giving support were already reached prior to the measurements. They do however cover for guidance loss while looking out for other structural solutions in the voluntary sector. (Parents of) disabled youngsters do worry about their path to individual living; now that they still live at home, they can manage reduced public aid, yet they do hope to be able to live independent of their family one day – and then, more individual support is needed.

Professional reliance

In one third of the cases, it became clear that the reform has *not* lead to reduced public aid. This has varying backgrounds – but they have in common that the disabled person or a key person in their network countered the guidance loss by asking for (other) professional aid.

In two cases, informal caretakers have played a crucial role in objecting to the reform and regaining the full indication for guidance. The bureaucratic competencies and perseverance of these informal caretakers (sibling and parent) was crucial in successfully objecting to the reform. As a man with a physical disability explains: *'Over the past half year I have battled heavily to get a new indication. I did not accept it. My eldest brother is my contact person and he works in health care himself. Therefore he understands these mechanisms and institutions. He managed to arrange a personal meeting with a CIZ-associate [usually, indications are arranged during a telephone call and on basis of a standard questionnaire]. There I could tell my full story. At first she explained me that the rules changed and I did not stand a chance. But at the end of the conversation I sensed a shift in her opinion and she finally gave in. Now I have my full indication again for the maximum period of five years! So I thought yes, that's in the pocket! You just have to be on it and not be put off like so many unassertive people do, like elderly or people who do not have a network' (R2).*

In the second case, a mother managed to reclaim the indication for guidance for her cognitively disabled daughter. She explains that her mentality is not to give up, and is motivated to do so because she perceives the reform as unjust, and has learnt from earlier experiences that 'talking helps'. She says: *'When I received the letter [in which one is informed about the reduced indication] I became really angry. So I immediately called the complaints line. Ok, not immediately, because I have learnt first to think and then to act, but on the phone they asked me: "did you not know that the rules have changed? There is just no money available." And then I said well, then I will send my daughter to an intramural institution, because all people with her disability type have an indication for 24-hour stay. Do you think that there is money for that?! And then he [CIZ-associate] told me that I could decide to object to the*

guidance loss. *[Goes on explaining how she regained the indication] I do the talking, because I am good at that. You just have to be so alert, and sell yourself. I am sure there are many people that cannot do that' (R27).*

These two persons managed to reclaim guidance for their relatives. Their actions cannot merely be explained from holding strong professional care ideals, as both relatives performed care tasks themselves. They also find informal care important, but they see objecting to the measurements as an activity they do for their disabled relative out of compassion.

Compassion is not restricted to the informal network. Care providers, who gave individual support or organize daycare, try not to let go of clients who they think are at risk of isolation and carelessness. They feel responsible for the wellbeing of their clients, and some have developed close bonds with them through time. Care providers still visit the clients, either by taking time off from other clients, by letting them come to daycare unpaid, or visit them in their spare time. Also, care providers have attempted to object to the guidance loss.

There was also one situation wherein both the older person and care provider profited from allowing continued daycare participation unpaid. The man (74) who is still in good health explains that he used to aid other elderly during the daycare – and on basis of that can still go to it: *'I used to push a wheelchair or help someone put on a jacket [during daycare] and so did others. Now all the healthy ones can no longer come [to daycare] and they [personnel] are stuck with all the needy. I can still go to daycare in return for my help. They call me when they need me. That can differ from null to five times per week. For example when someone from the personnel is ill, and they are short of helpers. So in fact I am a volunteer, a care provider. Probably, it saves them some money' (R23).* Surely, it is uncertain how long such a situation can last. If the care provider did not make this offer, the man reports he would have sought some volunteer work elsewhere, and would in strict sense be 'activated' by the reform.

Professional aid was also sought without the interference of the care providers. In three cases, people with a psychiatric disability requested more mental health care (ZVW). There, they could find a substitute for the guidance they used under the AWBZ: talking to someone about daily troubles. Their poor social network is part of the explanation why they seek institutional aid, but also their preference contributes to it. A man with a psychiatric disorder, who covered for the loss by requesting more mental health care explains that he prefers professional over informal care: *'No, I would not like them [sister and brother] to help me. They have a job and family of their own. If they support me in addition [to their own daily tasks] I would feel really guilty about it and that causes stress. I do not feel guilty asking for some help occasionally. But the guidance and domestic aid is needed structural, at a fixed moment every week. I rather have some professional do it, because they adjust to my pace and they also know what I can and cannot do with my disorder' (R30).*

Understanding for a disability is an important factor in preferring professional over private aid, as mentioned by many people with an *invisible* disability. They often report having to ‘defend’ themselves against social expectations: Why don’t you work? Why do you react so slowly? Why do you sleep till late? – All questions that are not asked by a professional who knows what a disability entails. A woman with brain injury even tells how glad she is that her father has recently gotten the same injury; maybe now, her family will finally have a better understanding for her situation.

Tailor-made services

We also analyze the degree to which services and forms of participation are more tailor-made than before. Concerning tailor-made services we will particularly examine the role of local institutions. The WMO has a responsibility in compensating people’s incapacities to participate, but as we will see, local institutions cannot provide for the wide range of care needs previously covered under the AWBZ. As a woman (37) with a borderline disorder reports, going to a local institution for aid was of no value to her: *‘I went to MEE [regional institute that is charged with the responsibility to aid disabled persons with guidance loss] for help. It is the first thing I did after having heard about the entitlement loss. But with my borderline disorder they could not serve me as they only help people with autism. They said they did not have the capacity for my disorder. Now, there I was ... I asked it twice, also with someone accompanying me, like, can you help me? I thought it was really strange they did not want to help me [to buffer the loss of therapeutic horseback riding]’ (R25).*

Besides deficient expertise of certain disabilities, the target-oriented local services supply for a limited range of disabilities. For specific disability types, it proves particularly difficult to find tailor-made services. The mother of the 10-year old son with spasm explains: *‘So much has been arranged for cognitively disabled children, but he [son] doesn’t have that, and when he has to engage in activities with cognitively disabled children all the time I think that is not good for his development. For young children with a physical disability there are no arrangements. And when I ask for options at a regular sports club, they tell me they cannot account for his disability’ (R11).* Local services are not targeted at the individual but rather grouped around common disability types, such as the elderly and cognitively disabled, while overlooking others.

Where an alternative to the guidance is offered, such as with daycare for elderly, daycare is less attuned to respondents’ personal needs (not more, as the idea of tailor-made services promises). An elder woman (91) who used to go to daycare for a full day, with all sorts of activities and professional guidance, says: *‘Yes, they offered me an alternative for the daycare. And I went there, but it is rather disappointing. We come in at 10, drink coffee, play one game, have lunch, and*

then the busses are ready again. Also, there are usually only two or three other elderly and no one shows up regularly. The group leaders are volunteers and they try their hardest so I do not want to complain about the quality to them, you see' (R18). The quality of alternative services is rated lower than the previous guidance. And even when a suitable alternative is found, practical barriers are overlooked. An older woman was helped with finding a reading mate to cover for the daycare loss: 'Well I went to MEE [institution for the disabled] and said that I could no longer share my interests with someone [as she did during daycare]. So they put me in contact with another old woman. Sometimes we visit each other and talk about books, and lend each other some new ones. That is really nice, only she lives at the far end of town, then I need to take public transport, and I do not trust myself with that, so I do not think it will last' (R19). Even though the social contact seems perfectly suited for the older woman, her limited mobility and long distance to the contact is perceived as a barrier, being overlooked at the time of match-making.

The capacity and expertise at the local level to arrange for tailor-made services is frequently questioned by the disabled and older persons. A man recalls speaking to the local authorities about his guidance loss. He feels as if he is not being taken seriously: 'They make me feel like I am a number. And I have the feeling I need to convince them all the time that I have a disability. They also do not understand what happens to a person like me when you take away guidance. They just think I should learn to do it myself' (R30). The man, who suffered from psychoses, says he needs stability in order to prevent relapse. He explains that he did not face this type of ignorance when guidance was still arranged at the national level, and has a negative perception of the local authorities.

Negative perceptions of the possibilities for local aid are influenced by the acknowledgement that finances are not available at the local level. Local authorities receive only a fraction of the finances that were available under the AWBZ for guidance of mildly disabled persons. An old woman (91) recognizes the lack of financial resources and says: 'They [MEE/institution for the disabled] do not have any means to help you. They have the task to assign you to existing situations. Between brackets, it should not cost any money. That is the bottom-line. They said to me that I could go to a volunteer organization or a coffee corner. But I am not interested in new things; I cannot deal with that anymore. And I am not the type of person to go and present myself. There [daycare] I had a steady environment, with people I know' (R18). The woman is not asked what her needs and desires are; rather, they present her the 'cheapest' options.

The negative perception of the local authorities and their ability to provide for tailor-made services results from taking the AWBZ as their frame of reference. Also, not many people are familiar with the WMO-ideals. Some people know it because that is where they receive their domestic aid: 'I heard of the WMO, but I am not sure what they want with it. Probably it means they will do more cuts. Recently I asked for more domestic aid [at the municipality], because I need one

hour extra, and instead of granting an extra hour, they reduced my domestic aid with one hour' (R21). The woman does not know why that is, but thinks that if her domestic aid is being cut off, the WMO potential in aiding her in other domains will be limited.

From the above examples, it becomes clear that the ideal of 'partnership' between local authorities and their (disabled) citizens has not yet been reached. Disabled persons feel that they are not taken seriously and their requests are not closely examined, but dealt with in an administrative manner, while keeping the costs as low as possible by relying on informal care and existing public services.

The conclusion must be that the aim of more tailor made services is not met. The barriers between services for specifically targeted groups that hampered participation before are still in operation. The services are also cheaper with more help from volunteers which so far does not lead to a better fit between the persons' needs and the service offered. And the local service organizations are not (yet) familiar with the exact needs of people with disabilities.

Conclusion

In this study, we looked at the significance of welfare retrenchment for people who are pursuing an independent life, with a mild disability. According to the new categorical distinction of mild, moderate and severe disabilities in the Dutch care law (AWBZ), having a mild disability is no longer a legitimate entitlement to public social care. Individual support or daycare services (also: guidance) for mildly disabled persons is (partly) discontinued as of 2010. Mildly disabled persons now fall under the responsibility of the local authorities. On basis of the Social Support Act (WMO) of 2007, local authorities have augmented responsibilities in realizing participation of, and tailor-made services for (mildly) disabled citizens.

We interviewed 30 mildly disabled persons with different disabilities who lost (part) of their previous care rights due to the devolution of social care services to the local authorities. We asked them how they perceive their new classification as ‘mildly disabled’ and what routes they take in seeking for a substitution for the personal support or daycare loss. Three pathways can be distinguished: a (further) reliance on oneself, the private network or professional aid.

Disabled persons who rely on themselves in reaction to the reform are both activated and de-activated in their participation. *Activated*, in cases where new activities are developed in reaction to the guidance loss. Being independent of both professional aid and informal care is highly important to them, as they aim to develop themselves in the midst of their lives. They were already oriented at reducing their reliance on public aid prior to the measurements. *De-activated*, when no new activities are developed, yet no aid is requested from the network or (local) institutions either. This mainly concerns the frail elderly, who have little energy to develop new activities and are reluctant of requesting their children to visit them more often.

The private network is mainly a structural solution for families with a disabled child. They take up the previous publicly financed tasks – yet do fear of becoming overburdened, and seek for additional support, such as volunteers. Disabled adolescents mainly worry about their future possibilities for independent living. They fear having to choose between staying with their family and going to an intramural institution when they become older.

Covering for guidance loss with (additional) professional aid can be considered as an ‘undesired outcome’ of the measurements. When looking more closely, three routes occur that are not necessarily undesirable. A first route taken is that of objecting to the reform. In two cases relatives successfully reclaimed the previous guidance for their disabled kin. They

report that both their assertiveness and bureaucratic competencies explained their ‘success’ and consider fighting for the rights of their disabled kin as an act of love (cf. Tonkens et al. 2008). The second route consists of daycare providers who cling on to their clients and find creative ways to cover for the lack of payment for their efforts. The third route consists of people with psychiatric disabilities who find their way to the mental health care sector, where they can find substitution for the personal support they previously received. They explain that professional aid is needed to uphold stability in their life. Informal care is not an alternative, as their informal network does not understand the daily consequences of their *invisible* disability. A professional caretaker is not prejudiced about what a person should be able to do him/herself and adjusts oneself to the expectations of the client.

Concerning the tailor-made services, there has not been one case wherein the local authorities provides they key solution in resolving care needs due to the guidance loss. It can be that the disabled persons do not approach local authorities in the right manner due to their lacking knowledge about the WMO. Still, their negative perceptions of the municipality are often based on real-life experiences, inhibiting further requests. The timing of this study can certainly contribute to the lacking support for mildly disabled persons; most municipalities were not well-prepared for the needs of persons who previously used AWBZ-care. At this moment, the local authorities are still developing their support schemes for this target group – although, as we learnt from this study, ‘target groups’ do not ensure tailor-made services. Therefore, it might be better to organize local support around categories of participation rather than disability types. Connecting disabled people on basis of shared interests and domain-specific challenges can ultimately contribute to the WMO-ideal of social inclusion and ‘participation for all’.

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Appendix I: Overview of the 30 respondents

X	Gender	Age	Disability	Guidance before reform (hours per week)	Guidance after reform (hours per week)	Other professional care*	Informal care network
1	V	84	OLD AGE	16	0	WMO (D)	WEAK
2	M	51	PHYSICAL	2	0	AWBZ (N, P)	STRONG
3	M	43	PSYCHIATRIC	14	0	ZVW (T)	WEAK
4	M	50	PSYCHIATRIC	2	1	-	WEAK
5	V	80	OLD AGE	16	0	ZVW (F), WMO (D)	WEAK
6	M	88	OLD AGE	8	0	-	STRONG
7	M	51	PHYSICAL + COGNITIVE	2	0 (→ 2)	WMO (D), ZVW (T)	STRONG
8	M	82	OLD AGE	16	0	WMO (D), AWBZ (P)	STRONG
9	V	21 ^I	PHYSICAL	4	1	AWBZ (P, S), ZVW (T)	STRONG
10	V	85	OLD AGE	16	0	AWBZ (P, N) WMO (D)	WEAK
11	M	10 ^I	PHYSICAL	6	0	AWBZ (P)	STRONG
12	V	22 ^I	PHYSICAL + COGNITIVE	16	2	AWBZ (P), ZVW (F)	STRONG
13	M	69	OLD AGE	7	0	WMO (D)	STRONG
14	V	33	PHYSICAL + COGNITIVE	7	2	ZVW (T)	STRONG
15	M	76 ^I	COGNITIVE	2	0	AWBZ (P), WMO (D)	STRONG
16	M	15 ^I	PSYCHIATRIC	7	4	ZVW (T)	STRONG
17	V	36 ^I	COGNITIVE	7	2	-	STRONG
18	V	91 ^I	OLD AGE	8	0	AWBZ (P), WMO (D)	WEAK
19	V	91	OLD AGE	16	0	WMO (D)	WEAK
20	V	28 ^F	COGNITIVE	7	0	-	WEAK
21	V	58	PHYSICAL + PSYCHIATRIC	16	0	AWBZ (P), WMO (D), ZVW (T)	WEAK
22	V	38	COGNITIVE	13	7	WMO (D)	WEAK
23	M	74	OLD AGE	16	0	WMO (D)	WEAK
24	V	50	PSYCHIATRIC	26	1	ZVW (T)	STRONG
25	V	37	PSYCHIATRIC	6	0	ZVW (T)	WEAK
26	V ^I	22	COGNITIVE	10	4	-	STRONG
27	V ^I	27	PHYSICAL + COGNITIVE	10	4 (→ 10)	-	STRONG
28	M ^I	62	PHYSICAL +	28	0	AWBZ (P),	STRONG

			COGNITIVE			WMO (D)	
29	M	61	PSYCHIATRIC	2	0	ZVW (T), WMO (D)	WEAK
30	M	48	PSYCHIATRIC	2	0	ZVW (T), WMO (D)	STRONG

*AWBZ (Exceptional Medical Expenses Act), P=Personal care, N=Nursing, S=Stay / WMO (Social Support Act), D=Domestic aid / ZVW (Health Insurance Fund), T= (psychological) Therapy, F=Fysiotherapy