

## In(ter)dependent lives

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This article suggests it is important to confront independence, one of the key concepts of our time, with empirical analysis of how this is actually practised by individuals in their everyday life. Within social politics, the cash-for-care system is seen as a notable tool of independence because people receive cash instead of care in order to employ their own care workers. Using a cross-national case study of cash-for-care for disabled people in the UK and Norway the present article points at two different social political interpretations of independence and suggests that neither of them lead to independence in terms of control and that assistance without care is impossible. A narrative analysis rather reveals that the cultural narrative about independence can be in disharmony with disabled people's personal narratives about limited control and care and that this should lead to a replacement of the idea of independence with the praxis of interdependence.

**Keywords:** independence; interdependence; cash-for-care; disabled people

### Introduction

It is the basic assumption of this article that there is what Fraser and Gordon (1994, 6) have called an 'inescapable fact of human interdependence'. The concern here is with interdependence between individuals receiving welfare services and their care workers as well as with the users' dependence on the institutional providers of the services. But this is generally ignored for one or two reasons. Within the new social politics directed at disabled people, this is ignored because of an ideological individualism, having the slogan of more individual choice (Spandler 2004). Within the disability movement it is disregarded because disabled people fear that this will veil the major difference between interdependence of non-disabled people and the forced dependence of disabled people (Kittay 1999; cited in Shakespeare 2006, 146). Instead, the idea of independence or independent living is highly promoted. But why is this idea of independence so highly promoted? One general reason might be found in the genealogy of dependence outlined by Fraser and Gordon (1994). They point out a semantic shift from dependency as normal in preindustrial times to constructing dependency as a deviant and stigmatized situation in industrial times. This stigmatization is further increased in our current post-industrial times, not least because it adds to the existing registers of dependency (economic dependency, socio-legal and political), a new moral-psychological register pointing at an individual character with a lack of will to be self-supporting. While dependency thus has carried

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much ideological weight because of a long tradition of stigmatization, this has promoted a dichotomy between dependence and independence. From various angles the best way to confront this stigmatized dependency is seen to be the promotion of independence.

In the next part of this article I will start to outline the debate about independence and the different positions taken on it and bring in cash-for-care policies as a central theme. Cash-for-care is a fairly new welfare state arrangement in the USA and European countries, primarily directed towards disabled people (Ungerson and Yeandle 2007). It is a new type of social service, which assumes that people's independence increases when they are given the money to employ their own care workers instead of receiving traditional social care services from the local authority. Using a cross-national case study into the experiences of cash-for-care in every day life in the UK and Norway provides the opportunity to learn about different social political interpretations of independence as well as of individual ways of dealing with this within these different contexts. The present study's data were collected in 2005 and 2006 in two cities, London in the UK and Bergen in Norway, both with relatively high numbers of cash-for-care users. The data consist of personal in-depth interviews with physically disabled people and personal assistants, as well as field observations and interviews with direct payment officers and informal carers (relatives) (Christensen 2006). This article is primarily based on a small sample of 21 disabled people with physical impairments (Norway:  $n=8$ ; UK:  $n=13$ ), from whom comprehensive data in the form of narratives were obtained. The sample was recruited through local authorities and support organizations. These disabled people represented both sexes, they were aged between 23 and 69, and they had different assistance needs and used different ways of organizing their assistance (for an overview, see Christensen (2006)). However, because the concrete way in which cash-for-care is organized depends on structural options as well as a unique life course the article will use two cash-for-care user cases to bring the cash-for-care discussion into real-life contexts. The two cases are constructed primarily on the basis of the 21-person sample and give illustrations of how the particular characteristics of the different cash-for-care systems provide both different options and also limitations for disabled people. The analysis tries to grasp structural political characteristics as well as individual everyday life experiences by using narratives at both the cultural and personal levels. The aim of this discussion is to contribute through the knowledge of practice which may challenge the rather ideological idea about independence.

### **The ideal of independence**

Tom Shakespeare has suggested that traditional welfare models of care are part of a colonization of disability, the lives of both disabled people and older people being colonized by service providers when they are not given a voice in the process of care (Shakespeare 2006, 138). The focus in the traditional model of care is on the incapability of these individuals. They are seen as a burden to society and their dependence is interpreted as helplessness. As earlier outlined by Michael Oliver (1990), this view of dependency has far-reaching consequences in society. On an economic basis, disabled people have been excluded from workforce because of their inabilities. On a political basis, they have been treated only as passive recipients of interventions. And on a social work basis, disabled people traditionally have been offered only residential and day-care facilities because:

Professionals tend to define independence in terms of self-care activities such as washing, dressing, toileting, cooking and eating without assistance. Disabled people, however, define independence differently, seeing it as the ability to be in control of and make decisions about one's life, rather than doing things alone or without help. (Oliver 1990, 91)

The professionals' definition of independence represents the Western meaning of independence as being self-supporting and self-reliant. Consequently, those who are dependent become subordinated and subject to control of others. The disability movement has challenged the colonization of disabled people with two elements: civil rights, which aim to obtain equality with non-disabled people, and independent living, in order to gain control in everyday life. According to one of the early advocates of independent living in the UK, Jenny Morris, the disability movement uses the word independent in a practical and commonsense way to mean simply being able to achieve goals. She states, similarly to Oliver, that the point is that independent people have control over their lives, not that they perform every task themselves: 'Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it' (Brisenden 1989; cited in Morris 1993, 23). Worth noticing is that although the Western meaning of independence is challenged, it is only challenged by another definition of independence, and within this definition the obvious dependence of needing assistance is simply ignored.

One of the most important challenges to this independent living ideal of independence has come from feminists claiming that rather than promoting an ethic of rights as a premise for independent living (see for example the slogan 'rights not charity'), which means advocating for formal rules and abstract principles, one should advocate for an ethic of care (Gilligan 1982; Tronto 1994; Wærness 1984). In contrast to the dominating rights perspective, the ethic of care perspective bases its ethic on the concrete relationships between givers and takers of care and the responsible actions between individuals in these relationships. This means there is no such thing as independence and neither should there be, because dependency is in practice part of all relationships and stimulates the ethic of care, which is the collective commitment amongst people. From this point of view the dichotomy between dependence and independence is false. Disability writers have rejected this feministic view by arguing that the ethic of care represents a romantic notion of care, ignoring the recipients of care and ignoring also the existing condescending treatment of disabled people (Shakespeare 2006, 145). Thus, for example, Clare Ungerson (1997), with her focus on relationships and the importance of including the care worker's perspective into the discussion of independence through cash-for-care, is one of those feminists exposed to this critique. The advantage, however, of this interdependence perspective is that it does not have to ignore any kind of dependence. Although Morris (1993) calls the independent living model's definition of independence 'practical', this is exactly what it is not. This article intends to contribute towards an understanding of this.

Within social politics directed at disabled people, the cash-for-care policy has been promoted as being of major significance in gaining independence by offering more control and choice in everyday life. A body of research supports this view (Andersen et al. 2006; Barnes and Mercer 2006; Blyth and Gardner 2007; Dawson 2000; Stainton and Boyce 2004). However, looking more closely into the meaning of this, it becomes clear that it is about gaining greater control of some concrete

decisions, as, for example, those listed in Dawson's (2000) report and confirmed by the other sources mentioned previously: to be able to employ who one chooses, to determine the hours (but not the amount of hours), to determine the tasks, to gain flexibility in the employment relationships and to decrease the involvement with professional agencies. All this means increasing control of some vital aspects of everyday life, but it does not make disabled people independent of the welfare system providing the cash-for-care, nor the labour supply of care workers, nor the concrete relationships to the care worker. In order to conceptualize this as independence, important aspects of dependency have to be ignored, as can be illustrated by this opinion:

I am sceptical as to whether the independent living model can achieve all that its advocates hope for. Further, I believe not only that dependency is inextricable from human existence, but also that many disabled people have needs which will inevitably generate forms of ongoing dependency which exceed typical time-limited dependencies. (Shakespeare 2006, 136)

Shakespeare's voice reveals a glimmer of doubt in viewing dependency as a dirty word and it rather glimpses a weakness in the possible risk of idealizing independence to the extent that it ignores the needs of disabled people in their daily living. This article is going to contribute to this doubt. However, it will not do this by pointing out the challenges to reaching independence among, for example, people with learning disabilities, as shown by Barron (2001), but by pointing at examples of practice among physically disabled people with intellectual resources. To prepare for the empirical discussion the following section will outline two social political interpretations of independence, starting with a short presentation of the different Norwegian and UK cash-for-care systems, termed Direct Payments in the UK and User-Controlled Personal Assistance (BPA; *brukerstyrt personlig assistanse*) in Norway.

### **Cash-for-care in the UK and Norway**

The first British law making cash-for-care legal was the *Community Care (Direct Payments) Act* of 1996, implemented in local authorities in 1997. However, it was not until 2003 that local authorities were given a duty to introduce direct payments to all individuals assessed as eligible for social services. During this time there were important changes in eligibility, this being extended from the original group of adults up to the age of 65, to, in 2000, older disabled people, and in 2001 also to carers, parents of disabled children and 16 and 17 year olds.

In Norway, BPA was introduced by the Norwegian government as an experiment between 1994 and 1997. In 2000 it was added to *The Social Services Act*, but separated from other traditional social services. It moved from being an experiment to become a permanent arrangement of the municipalities. In 2005 it became 'practical assistance' (*praktisk bistand*) together with the traditional social services like home care and domestic care. This mirrors the development in the UK, but taking place five years later: an extension of the target group from younger people with physical impairments to an inclusion as well of the elderly and those with learning disabilities or mental health problems. In principle, this means that everyone who is eligible for social services – and who is willing and able to manage cash-for-care – can potentially employ their own personal assistants (PAs), possibly with

support. However, younger physically disabled adults (under 65) are still the main target group of these services in both countries.

Research has shown that cash-for-care systems are implemented slowly and in very different ways (Andersen et al. 2006; Riddell et al. 2005). Furthermore, being an alternative to traditional social services like home help services, they are still quantitatively a drop in the ocean. However, cash-for-care policies are currently increasingly being promoted by governments (Ungerson and Yeandle 2007).

### **Two social political interpretations of independence**

The British data from the study on which this article is based indicate that the general procedure for obtaining personal assistance starts with an individual contacting the local authority because they are in need of help. A professional, usually a social worker then visits the person in order to make an assessment, including a recommendation regarding the number of hours' assistance required. The assessment goes to a panel, which considers the number of hours and amount of money suggested. If the person is eligible for a certain number of hours (called a care package) it is then the decision of the person her- or himself whether s/he wants to receive (traditional) social services from the local authority or direct payments. If the person chooses direct payments, this can be organized in a variety of ways. One main dimension for differentiation is whether the local authority chooses to control the process itself, at least to a certain extent, (the 'in-house model') or whether it chooses to externalize all aspects of direct payments as soon as a client has chosen to receive direct payments. Partly because of this option of externalization and partly because the disabled person provided with direct payments can buy whatever support they choose, there are big variations in the British direct payments scheme. In London the main model is one in which the local authority contracts one or several non-profit organizations to support people in establishing routines for direct payments. However, there are variations in the way these organizations work. For example, not all organizations provide the pay-roll work (help with calculating tax, national insurance, pay slips, keeping financial records etc.) that is part of employing PAs. This paperwork seems to be a crucial factor in determining whether someone chooses direct payments, because the majority of people are dependent on help to do this. So if the contracted organization does not provide this the disabled person has to find an accountant or another company to provide this service. If the disabled person provided with a care package chooses to manage all parts of the employment duties him- or herself, the money for the care package will be sent to a bank account opened for this purpose. Alternatively, if they choose to use a support organization, this organization will provide the various types of support in order to fulfil the duties of an employer.

Using here the western language of independence as self-support, social political policy practice in both the UK and Norway can be broken down into three parts. In the first part social service users are still treated as dependent people as it is the local authority that controls assessment and its outcome in both countries. The second part, however, is different in the two countries and pushes the two cash-for-care schemes in different directions. While the choice in the UK between social services and direct payments is made by the disabled person, in Norway this decision is made by the municipality.<sup>1</sup> Currently, in Norway, there are three possibilities as to who should have employer status: the local authority (including 64%), the only existing

support organization outside the local authority in Norway: a cooperative for citizen-controlled personal assistance called ULOBA (including 25%) or the user him or herself (including 9%) (Guldvik 2003). ULOBA is run by disabled people and its policy is directed by its members' votes. Its members are disabled people who have employed their own PAs. This model seems to be increasingly popular and research has shown that disabled people find that it gives them more control than when the local authority is the employer, probably because of this organization's higher awareness and knowledge of disabled people's needs (Guldvik 2003). However, it is still the municipality that controls whether this organization will be the employer and not all Norwegian municipalities have contracted ULOBA yet. Giving disabled people no formal voice, which means no right, in this second part means that the Norwegian interpretation of independence takes a more paternalistic view (Askheim 2005) than that of the UK; the users there are seen as more dependent than users in the UK. This difference becomes clearer by noticing that while the British model implies a direct payment, the Norwegian one still implies a service. The third part relates to the practice of everyday life and here very much depends on how the framework for assistance made in the first part of the process meets the actual needs of the disabled person and whether it is *de facto* possible to make the decisions and choices wanted within the local contexts. However, there is still a difference between the two countries here based on the second part of the process about expecting more self support and more individual capacity to find a useful solution among UK users than among the Norwegian. On a general level this can be related to the two different welfare systems and their different values.

According to a well-known differentiation of welfare regimes, the UK represents a liberal welfare state, while Norway belongs to what is known as the Nordic Social Democratic Welfare states (Esping-Andersen 1999). A characteristic value of the liberal welfare state is that the individual tends to be seen as a rational, competent and well-informed individual who is best placed to identify their own needs. As the free market is seen as the best arena for those individuals they then become customers of the services of the welfare state. In contrast, the Nordic Social Democratic welfare state is characterized by paternalism, implying that the individual is not always the best person to identify their own needs (Askheim 2005). Services should therefore be publicly financed and universally implemented. The political differences between the two regimes can be demonstrated, for example, by the fact that while the UK has externalized its cash-for-care services to a high degree and has opened up for privatization within this field, Norway has not. In the few critical assessments of cash-for-care systems this is discussed as an issue about inequality risk (see Spandler 2004, 197). In Norway, this is not an issue as the only externalization consists so far of the cooperative ULOBA.

In the following sections the two cases of Marie and John will be presented.

### **Marie**

Marie is a Norwegian 24-year-old woman living in Bergen. She is a wheelchair user due to physical impairments and needs personal and social help every day. She has been disabled since early childhood and has a basic education. Marie asked a municipality office to help her find work, but when she was offered only sheltered work (adapted to disabled people), which she found stigmatizing, she refused; therefore she now gets disability benefits. Marie doesn't have a boyfriend but hopes to

find one soon. Her mother lives in Bergen and she also has friends there as well as in other parts of Norway. Marie has been allocated 65 hours a week from the municipality. She has four permanent PAs and several supply assistants. All of them are Norwegian. Because she lives in serviced housing, she also gets daily home nursing services in the morning when she gets up and at the night when she goes to bed, but these services are not included in the 65 hours so Marie therefore actually gets a combination of traditional social services and cash-for-care. Marie is the manager of her assistants. She makes the decisions about their daily work for her. But the employment aspect lies with ULOBA. ULOBA receives the money from the municipality Bergen and they pay Marie's assistants. ULOBA also supports Marie when she needs to employ new assistants, but *she* has to make all decisions about whom to choose herself. In order to be a supervisor for her assistants, Marie has learnt about this role at a course arranged by ULOBA. In general, she is very satisfied with her daily life regarding personal assistance and won't go back to the municipality's own social services which she had before. However, she fears that the municipality will cut back her 65 hours.

### **John**

John is 50. He is British and lives in London. He is also a wheelchair user due to physical impairments but spent most of his life being able bodied. John is a professional with an academic background. He has worked full-time for many years and had been married for many years when he was suddenly severely injured by an accident and became dependent on help for almost everything. He gradually improved with physiotherapy but is still a wheelchair user and relies on help for a large number of personal care and domestic tasks. After the accident, his wife became his main carer, arranged through traditional social services from the local authority. But his wife couldn't handle this new carer role for her husband. They also gradually lost most of their earlier social contacts. She then chose to leave him and since then John has lived alone. In this new situation John has been allocated 60 hours a week by the local authority. However, in contrast to the decision made by the local authority, John thinks he actually needs help 24/7. However, when the council refused to change his care package, John decided to solve the problem himself. He searched the internet for a woman who was willing to live in with him as his personal assistant (a live-in carer), and he found a woman from an African country. She was willing to leave her children and family and go to London to earn money for her family. Thus, John has got a care worker, who is available 24/7 and he pays her a wage as well as providing accommodation and food. John did not need to learn about the employer duties and he does everything on his own apart from the paperwork, for which he uses a local accountant. Occasionally, John still does some academic work and wants to visit friends. Therefore, he wants his PA to be able to drive. However, because his live-in carer is unstable (she sometimes drinks too much, he thinks) he is reluctant to put her on his car insurance. John has a lot of interests and he likes his own company. But he also feels lonely from time to time, which is related to his current relationship with his carer. He will probably look for another live-in carer soon because he isn't very satisfied with the current one and has enough experience to know that a relationship with a PA can be better.

### Why choose cash-for-care?

John explained his choice this way:

I used agency people, I found that that was very unsatisfactory because they needed to keep coming back and forwards and at that time I didn't have any problems with my health...

Agency people come from traditional services and John, from the perspective of his current arrangement with direct payments, explains his view on the difference:

... the difference is that the carer who comes from the agency is not paid by me at all, the agency is paid by the council direct. That means I have no control over who it is or what it is. As it happened, it was the same guy that came for a month and I knew exactly what to expect to one another. He was an excellent carer and I would be happy to recommend him to anybody ... the fact that he was late occasionally was just one of those things ...

Although at this time John rarely worked for pay (including going to meetings) he found it unsatisfactory not to know when to expect the carer to arrive. Thus, it was only because of good luck that the male carer turned out to be a good carer and that the same person was able to come for a month. However, this situation was only practicable to the point where it could meet John's needs:

I got in the position where I needed somebody to come in or be here frequently, so I therefore decided, that the only sensible way to deal with it was to employ my own live-in carer; and worse, the council don't seem to accept the fact that I need a live-in carer, the fact of the matter is that I do.

Thus, there were two reasons why John decided to become the employer himself. One was his dissatisfaction with the services from the agency. Another was that he thought he needed a carer who was available (although not working all the time) 24/7. As mentioned earlier, disabled people often use a support organization when they choose direct payments. John did not choose this because it would have tied him to the exact number of hours he had been allotted by the council. Therefore, he solved this by taking over the employer role himself, although he paid an accountant to do the pay-roll work. However, as mentioned earlier, many disabled people *using* a support organization also need to obtain this paperwork service from another source. In summary, John was able to use the direct payments money in order to meet his needs because he had the capacity to find a useful solution.

Listening to Marie, she said:

I started to have home nursing services, home help and night staff [to call if necessary]. On average I had three different people within my home every day. In a way I still have this, I still have night staff and home nursing services, but the difference is that I now have one person in the middle, who can do almost everything while the two others still have their prescribed tasks ... [the one] can join me when I want to go out, fix my hair, give me a shower – a personal assistant can do most things. I haven't yet met an assistant who can't do things ... it is so wonderful in a way. Then you don't need to think, ok she is a home nurse, she is only here to take me up from bed, or he is night staff, so he only puts me to bed ... this is the biggest difference [between BPA and traditional services]. Also, I started feeling more normal than I did before, because now I can say to my friends that I just take with me an assistant, and then we can go to a café.

In common with John, and also with the rest of the sample, Marie's dissatisfaction with traditional social services encouraged her to use personal assistance. In her situation specifically, she pointed to the disadvantages of having different tasks done



by different people, while this was not an issue for John. The other common factor, also mirroring the whole sample, was that both felt closer to the life they wanted to live. Related to their different life courses and ages it is vital to John to feel safe with a carer always available and to Marie to be able to act like other young people her age.

Dissatisfaction with social services and coming closer to the life one wants to live are findings also confirmed by the afore-mentioned studies pointing at the advantages of cash-for-care and some of them have gone so far as to call this 'success' (like, for example, Dawson (2000)). However, in order here to diversify the implicit ideal of an independent life included in this, the next section will introduce the tool of different narratives to explore this further.

### **Cultural and personal narratives**

Mills (1959) has called attention to the deep and basic connection between social history and personal identity. This means that any individual history is continuously related to the general history of society. Considering this point in the context of the stories of disabled people who have gained experiences with cash-for-care, it seems useful to discuss how the implementation of the cash-for-care schemes is seen from the perspective of the disabled person him- or herself, but without missing the perspective of power being top-down. Within narrative theory, where narratives are interpreted as stories constructed by individuals through a combination of personal identity and social history, a distinction is made between cultural narratives and personal narratives (Gergen 1999). When a narrative is 'cultural', it is well known as a social dominating story about a specific phenomenon, i.e., it functions as a master narrative. So when disabled people tell their story about cash-for-care, the major story about cash-for-care is somehow included in the individual story. The 'personal' narrative then is the story of the individual. Some might argue that if the structures are so deeply embedded it will not be possible to grasp the pure individual story. However, I would argue that this personal narrative is crucial in order to understand how the person relates to the master narrative. Furthermore, it would not otherwise be possible to contrast personal narratives with cultural narratives, which means viewing individuals as active interpreters of their social circumstances.

### **The cultural narrative about disability challenged**

From the body of literature written by dominating social disability writers (Shakespeare 2006; Barnes and Mercer 2006; Oliver 1990) the conclusion must be drawn that in our times the historically established hegemonic cultural narrative about disability is a narrative about dependent and helpless individuals. Among disability writers this is called the medical model. The movement that began to challenge this model is the Independent Living Movement (ILM) started in California in the 1960s. From an early stage, the disability movement regarded *personal assistance* to manage daily living as playing a key role towards independent lives. ILM claims that impairments are only impairments in society as long as society treats those impairments as barriers to participation in social activities. Within this discourse, independence primarily requires the social barriers to be removed. This is known as 'the big idea' for understanding disability or the social model of disability (Oliver 1990). Although this one-sided understanding has been criticized by some academic disability writers (see Thomas 2006), because it tends to ignore the body

and emotional parts of disability, it still has a challenging function towards the hegemonic medical model narrative. While the disability movement has played a significant role in the development of cash-for-care systems, there is also a broader development termed 'user involvement' (as part of a community care focus) within health and social care services (Cowden and Singh 2007) harmonizing with this idea of empowering the user. Cowden and Singh's critical exploration of this makes it clear that user involvement has become the new 'mantra', but not necessarily because these services actually reflect the interests of the users. It can also be seen as a further commodification of basic individual needs and welfare. This explains the context in which 'independence' social politics can be defended by liberal as well as democratic values. The reactions against the medical model and the 'mantra' about user involvement has promoted the Western idea of independence as 'self support', which can be seen here as the current cultural narrative challenging the hegemonic one. One of the informants in the current study expresses this when he says:

... the language that I use is the language that most of the people don't and there is a whole stigma about personal assistance beside, that actually society tells us that we need to be self determined, we need to be physically complete, and if we aren't then somehow we are invalid and people absorb that process and therefore when it comes to them needing personal assistance it becomes really problematic ...

In the next section, two implications of this new cultural narrative about being 'complete' (independent): *being in control* and *no need for care* will be challenged by personal narratives found in the current study that contrast with them. The personal narratives aim to reveal examples of interdependence practice within the process starting with a basic dependence on the providers of social services.

### **A personal narrative about limited control**

It has been seen that one of the most central arguments of how users get control through cash-for-care is that services are replaced by money. But what kind of control does this give people in practice? John elaborates on this:

... the direct payments is not my money, it is a payment that the council make to me. I have to account to the council for the money I spend out of the direct payments. It's calculated on the basis of the numbers of hours that the carer works for me based on the care plan and I have to pay the carer income tax and national insurance contributions to the tax man, and anything that's left over theoretically goes back to the council. The money in the account does not belong to me, that belongs to the council ...

Another issue John points to, concerning the money, is that he often does not get it in time. Consequently, he risks conflict with his carer:

... if your carer is working for a month for you and wants payment, it would be perhaps sensible if the local authority would bring forward the payment day a little more than they do, so as to make sure that you can pay the carer immediately instead of having to go almost a week in to a following month before you can afford to pay her ... if I can't pay the girl until the week after, that is stupid. It happens, because I still get the tax payments sitting in the account waiting to be expended, there is probably enough money in the account to cover it anyway, but that is by chance, it's not by choice and it puts you under unnecessary pressure, especially if the carer happens to be somebody who is anxious to have some money ...

John is also aware of future problems due to the status he thinks social services have:

Government funds are reduced from time to time, but it has always been a fact in this country . . . that if a local authority is short of cash, the first budget that it would hold, would be the social services budget, so this means that people like me are directly in the firing line . . .

Thus, when elaborating on the practice of handling these direct payments, several uncertain aspects of it become visible. Also, as mentioned earlier, John pays an accountant to tell him how much tax etc. to pay his care worker. The reason why Marie expressed these kinds of problems to a lesser extent is that ULOBA is doing this work for her. However, this also means that she does not control this money fully herself either.

Another issue, which addresses the question of control, is the issue of being in control of who the PAs are when receiving direct payments. John is satisfied with his PA to a certain extent, but not with his relationship with her. She does most of the tasks he wants her to do, but they don't seem to get on together very well. When I asked him if he wanted his PA to stay with him, this became very clear:

. . . the fact of matter is that you get used to have somebody who knows what you want, but equally there are drawbacks to the situation because effectively you are living with the person and you've got to be satisfied that such a situation is tolerable to you, it isn't always. I've made a couple of bad choices in the people I had working for me, who didn't stay very long. I've also had one or two really excellent girls.

Marie expressed a similar kind of uncertainty related to this choice of PAs:

I have tried to find people who I have something in common with. Not necessarily interests, but where I've got the feeling of harmonising chemistry. Because that's what I think is the most important as we are going to be so close to each other during the day that the chemistry should harmonise . . . but I've made some small mistakes . . .

The present study's sample reveals that while some are able to find PAs they really get on with, they all have experiences with 'mistakes' too. Other research has shown the significance of having the option of choosing the person wanted (see Stainton and Boyce 2004, 449). But what is important here is that, although the money is there to use for employment this does not ensure that the disabled person is able to find the right PAs. Access to advice from support organizations can make a difference, but does not necessarily do so either. Furthermore, disabled people have different capabilities for carrying out the employer role. In John's and Marie's cases, for example, many working years as an academic give John capital for being an employer, while Marie has no such experiences at all and has had to learn from scratch:

If I had known at that time [when she first asked for personal assistance] all I know today, I would have waited to apply . . . I think we get terribly little training as managers in solving conflicts and in how to be a good manager to people from whom we are receiving help . . . ULOBA has a course for managers, but I think it fails to follow up things later. We can talk to ULOBA about different things and they help us solving them, but how much does it help when the people we are talking to don't know us? . . . I miss having a person to talk to without breaking the need for confidentiality.

Although ULOBA is a competent disability cooperative there are still challenges to being an employer. Although cash-for-care is organized more simply and with more

preparation in Norway compared with the UK, the daily practice of the system still depends very much on the resources of the individual. Considering the uncertain aspects in the practice of managing money and choosing PAs means that the personal narrative found here is a narrative about limited control.

### **A personal narrative about care**

In one of the support organizations in London, the PAs are asked to wear a T-shirt with the text: 'Why care when you can PA!' indicating a separation between care and assistance. As mentioned earlier, the rejection of care is another implication of the cultural narrative of independence. Using Ungerson's conceptualization of caring as a combination of *caring about* and *caring for* (Ungerson 1983), this can be explained by saying that the part that is rejected is the 'caring about' dimension. This means PAs are expected to do 'caring for' tasks but not to be involved emotionally with the person cared for (see also Watson et al. (2004)). In terms of the concepts of dependence and independence, this simply means that while dependence is linked with care, independence is linked with assistance. Thus, the assumption within the cultural narrative is that if the care worker is emotionally involved, it will promote treatment of the recipient as a dependent (helpless) person. In contrast, the current study indicates that it is not possible to exclude the emotional aspect, but it is not possible to control it either.

For example, as already mentioned, John is not satisfied with his current care worker:

I had a young Australian girl . . . the big difference between her and the others that I'd had was that she was somebody who had had two years experience in . . . [the diagnosis he has] she knew all the complications plus she was a very nice girl anyway and had a lovely personality . . . we went out in the weekend, she took me to a London park and we had a walk around the park, it was lovely . . . it can get quite lonely, so it's nice if you've got a girl working for you, who is your live-in carer, who is also pleasant to be with and talk to about things other than purely getting me up in the morning and putting me to bed at night.

John expressed a common finding in the British part of the sample: that it is a wish to be able to enjoy the company of the PAs who are doing the tasks necessary to meet their specific needs due to health and life situation. Thus, the emotional part (caring about) seems to be as crucial as the practical part (caring for). Also, the emotional part does not seem to imply treating the disabled person as a dependent person. Rather, this emotional part, including such things as engaging in each other's life and communicating together, gives the option of a dialogue in which both parts participate fully. In the Norwegian case, this is even more obvious as the findings indicate less emotional involvement but without the option of excluding it altogether. This can be exemplified by Marie:

. . . personal assistants are working for me, my friends are my friends . . . They [PAs] can't replace friends, and you should not initiate a friendship with them . . . in a way it becomes friendship too but it is still something else. That friendship has started on wrong premises . . . it becomes purchased and paid friendship. It maybe sounds quite cold but it has to function that way.

Marie also believes that she has the right to ask the PAs to do what she wants because they are paid:

I've always kept a close eye on the things I want to do, and I'm still doing it, but I try to get rid of it, that I should do things they will find pleasant too, instead of thinking, it's you Marie who's is going to live your life . . . they have to follow me . . . as a disabled person I feel it is very easy to be deeply grateful to other people for taking you out or go for a five minutes walk. It's stupid. Now I don't have to, as they actually get paid.

Marie expressed a common finding among the Norwegian part of the sample (although she is one of the youngest in the sample): that although it is important to have PAs emotionally involved it is important too to keep some distance in order to maintain control. And viewing them as paid friends helps because it makes them more equal. ULOBA is supporting this policy:

ULOBA tells us not to relate to the assistant as a psychologist, the assistant is only a helper . . . ok, you don't need to use the assistant as psychologist, but as a matter of fact she is there a great part of the day . . .

It is a central characteristic of cash-for-care compared with traditional services that it individualizes the relationship between the disabled persons and their PAs. So while it is not surprising to find personal narratives about the need for a combination of caring for and caring about in order to get the relationship working – although with the differences pointed at here between different systems – it is surprising that the cultural narrative about independence has so strongly rejected caring (about). Practice reveals that the relationship can only work if it includes some kind of dialogue with a flexible practice of giving and taking. The study suggests that the personal narratives about care challenge the cultural narrative about non-care.

## **Conclusion**

Looking into the day-to-day practice and experiences of disabled people who are using cash-for-care – although within different welfare contexts – it becomes obvious that to conceptualize this as 'independence', for example, in terms of being in control of the money and the choice of PAs or not needing any emotional support, is very problematic. The day-to-day life experiences with cash-for-care rather reveal a practice of interdependence, because the specific ways in which the relationships with the PAs work are crucial, the negotiations with the local authorities, support organizations (whether non-profit or profit-based) and accountants are crucial, and furthermore the recruitment and choice of PAs depends on the labour market for PAs. As pointed out by the few critical investigations of cash-for-care, PA work is low-status work, low-paid and often with insecure working conditions (Spandler 2004; Ungerson 1997). This can be crucial to the ideas for extending these cash-for-care systems in the future.

The lesson to be learned from the present study's different welfare contexts is that in the end the daily challenges for disabled people are very similar. However, the different, more liberal, way the UK cash-for-care system is organized will potentially demand more individually tailored solutions and will bring in more variation than is yet the case in Norway.

## **Note**

1. A legislative amendment is currently being prepared by the Norwegian government and it is likely that in the future this decision will be transferred to the disabled person.

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