

## Towards solidarity: working relations in personal assistance

Ingrid Guldvik<sup>a\*</sup>, Karen Christensen<sup>b</sup> and Monica Larsson<sup>c</sup>

<sup>a</sup>Faculty of Education and Social Work, Lillehammer University College, Box 952, 2604 Lillehammer, Norway; <sup>b</sup>Department of Sociology, University of Bergen, Bergen, Norway; <sup>c</sup>Department of Social Work, Malmö University, Malmö, Sweden

(Received 20 March 2013; accepted 20 February 2014)

This article explores personal assistance from the assistants' perspectives. Many assistants are satisfied with their work and the possibility to combine the work with other activities on a flexible basis. However, the structural framework of the personal assistance scheme creates risks for the workers who carry out the assistance. These risks are related to strong user control, intimate and personalized relations, part-time work, weakly formalized working conditions and few chances to gain qualifications for future employment opportunities. The gendered labour market is also a structural condition of the scheme. The article focuses on three theoretical working life discussions: flexibility, professionalization and co-determination (between service user and assistant). The article reveals the specific and inverted form these processes are transformed into by the personal assistance scheme and suggests that they create barriers for sustainable working conditions for the assistants as well as options for developing solidarity between service users and assistants.

**Keywords:** personal assistance; care work; employee perspective; flexibility; professionalization; co-determination

### 1. Introduction

Independence has become one of the central values of the Western world during the last part of the twentieth century. Within social services, the welfare scheme of personal assistance (PA) is a response to the requirement of independent lives for people who need practical help in everyday life. In particular, many disabled people use this service.

The PA scheme was established with a focus on the needs and desires of the user, and user control is seen as its central value. This creates tensions and possibly contradictions between user control and assistants' working conditions. During the development of the PA scheme, disabled peoples' organizations were advocates for transferring more power to the users. Few, however, considered the implications of the developing scheme for those working as personal assistants. This lack of focus on the rights of the care worker is related to the historical roots of care work and the gendered labour market. These conditions have contributed to the imposition of a weak societal position for care workers, even in Scandinavia. Within the PA scheme this is reflected in the recruitment of part-time workers, mostly women, who are given potentially unsecure working conditions with temporary contracts and unpredictable wages.

---

\*Corresponding author. Email: [Ingrid.guldvik@hil.no](mailto:Ingrid.guldvik@hil.no)

Studies in the Scandinavian countries have shown that personal assistants can obtain rich experiences from their work (e.g. Gough 1994; Guldvik 2001; Christensen 2010). Many of them report that they receive great satisfaction from the opportunity to combine the assistance work with other activities on a flexible basis, and some are also very happy with their relationship with the user (Hugemark and Wahlström 2002; Larsson & Larsson 2004; Andersen et al. 2006). Our article does not deny such findings, but it has a different focus. Our focus is on the structural risks (and therefore not necessarily real risks) of the PA scheme for those who work as personal assistants. We intentionally take the perspective of the employees in order to explore the potential risks for care workers under a welfare scheme geared towards empowering users.

Empirical studies in both Scandinavia and internationally point to recruitment of assistants as a vulnerable aspect of the PA scheme (Glendinning et al. 2000; Larsson & Larsson 2004; Johansen et al. 2010). We do not know to what extent the recruitment problems are related to the working conditions for personal assistants. However, empirical studies clearly point to tensions and challenges for those who work in these positions (e.g. Guldvik 2003; Larsson & Larsson 2004; Christensen 2010, 2012; Egard 2011).

This brings up two questions: what may happen to the working conditions for the assistants when user control becomes an overarching guiding principle? How is it possible to avoid the potential subordination of workers that is built into the PA scheme?

In this article we will highlight three concepts of importance for the employees, all related to implications of user control and user power, and to current general working life discussions. These three concepts are flexibility, professionalization and co-determination, here between the service user and the assistants. However, transformed by the PA scheme – oriented towards user control – these concepts may turn into inverted forms, and consequently, we will focus on the following concepts: (1) other-oriented flexibility as a way of outlining the flexibility of the situation based on the priorities of the service user and not necessarily those of the assistant, (2) deprofessionalization of the services in order to meet the individual service user's specific requirements and needs while ignoring generally accepted qualifications that give the professional control over the services and (3) de-co-determination, which refers to the avoidance of dialogues, between the service user and the provider, about the work content and/or organization. While professionalising workers, giving them flexible working conditions and influencing them through co-determination are generally seen as ways of strengthening employees, this is not necessarily so within the PA scheme. It is therefore important to investigate these trends, particularly within a Scandinavian context where employees' rights are relatively strong.

The body of this article is divided into four sections. The three first sections each present one of the three theoretical dimensions related to user-controlled services described above: other-oriented flexibility, deprofessionalization and de-co-determination. Each part also contains a discussion of the respective dimension on the basis of empirical studies. The fourth part is a concluding discussion in which we suggest that solidarity, in terms of mutual respect and recognition, might serve as a principal framework for an organizational structure that will offer a sustainable balance between user control and assistant co-determination.

## **2. Other-oriented flexibility**

Since the 1990s, 'flexibility' has been one of the most central concepts in discussions of organizational changes in paid work and working life in post-industrialized society (Negt

1984; Senneth 1998; Rønning 2002; Olberg 2007; Nielsen et al. 2010). A central part of this discussion concerns how this flexibility balances between the needs of a changing labour market and its various types of employers and the security of the workers, including the risk of ‘flexploitation’ (Olberg 2007, 9) if the imbalance is on the employer side. While the wider discussion of this balance is comprehensive and complex (see e.g. Wilthagen and Tros 2004), we confine our discussion here to concrete implications of increasing flexibility for the users of PA. We will use the terms ‘quantitative’ and ‘qualitative’ flexibility from this literature (see Goudswaard and de Nanteuil 2000) to point out implications of the user’s option of organising her or his allocated PA time in ways best supporting the relevant and changing demands in daily life of the use, and the content and adjustments of the work demanded, respectively.

Our discussion of implications of user flexibility, from the perspective of the care worker, should be seen in light of two issues. One is that PA work belongs to a welfare scheme that is often viewed as being at the forefront of modern social services and this scheme has increased in all Scandinavian countries. This implies that the PA work in focus here takes place within Scandinavian working life context with high regulation standards, including expectations of rights and duties for both employers and employees (Olberg 2007).

Another issue concerns the importance of bringing in a gender dimension into the discussion of organizational issues relevant to PA work. Scandinavian women’s entry to the labour market during the 1970s had a significant impact on the development of ‘flextime’ (Senneth 1998), making it possible for women to combine part-time work with their responsibilities as mothers and wives towards their families (though simultaneously developing potential dilemmas), and for the labour market to cover demands for a greater labour force.

Further, the concrete way PA work has been organized historically was inspired by housework organization as described in the body of housework literature (see e.g. Sellerberg 1973; Danielsen 2002). Also included in the housework literature is the issue, very central to this context, of combining subordination with personal and emotional aspects in the relationship between employer and employee (Christensen 2012). This is related to the more general possibility of developing ‘other-orientation’ towards the user and the user’s needs in this type of home-based personal care work (Christensen 1998a).

In the following part, we apply, from this theoretical background, a gendered flexibility perspective on PA, in order to highlight some central organizational aspects of PA work. Using this gendered flexibility perspective, we discuss why the PA scheme in general has flexibility as its most important principle of organization and what implications this has for the personal assistants.

### ***2.1 Quantitative flexibility – assistance time***

A very important part of the history of PA was, as mentioned earlier, the criticism of traditional services, and not least institutions, because of their hindrance of individual planning of daily life. In contrast, therefore, this self-controlled planning – including planning of when the assistance needed should be provided – was central to the organization of PA. Data from a Norwegian study illustrate the deeply rooted character of flexible assistance time. The study shows that the number of hours allocated per week decreased from an average of 36 hours/week in 2002 to 33 hours/week in 2010 (Johansen et al. 2010, 13). However, the change in the minimum-maximum hours/week from 1–175 to 1–265 reveals that the reduction of hours is accompanied by a larger variation in hours.

If these figures are then related to the average number of assistants each user has, 3.0 in 2002 and 3.1 in 2010 (Johansen et al. 2010, 32), we see that a full-time job is, on average, 'shared' by three assistants. Broken down to minimum-maximum numbers, these figures again reveal large variations, between 1–17 in 2002 and 1–15 in 2010. While a user can employ up to 15 personal assistants, the majority of users in Norway in 2010 had 4 or fewer assistants, according to the same survey. Though the figures from the other Scandinavian countries may vary a bit, this is of less importance here. Rather, the point is that the PA scheme is organized in a way that promotes the use of several part-time workers. The following may be among the reasons for this organization: in case of sickness one of the other workers can cover the hours, the relationship can be too personal of an experience to have the same person coming in every day, and different care workers might have different competences of interest to the user (e.g. driving, cooking and organising). In other words, PA work is typical part-time work, with flexibility in time directed by the needs of the user.

The latest Norwegian survey about just personal assistants revealed that two out of three had an agreement about varying working hours (Guldvik 2001). This indicates a way of organising welfare services in strong contrast to the fixed and inflexible hours of traditional social services. Looking at the situation of personal assistants, according to the flexibility perspective, this new power of controlling the working time can be explored further: for example, if the user wants to have three care workers instead of two, s/he is free to reduce the worker's hours. In general, this user flexibility structurally means insecurity for the care worker. For example, it might be difficult to get another job that fits hours fixed for four evening hours one day a week and four day hours another day. This 'flexible' part-time work thereby requires of the workers that they are not dependent on a secure and permanent wage and that they can work flexible hours. In other words, they are required to be untraditional employees. We assume this is an important reason why this work attracts students, housewives, migrants and those traditional workers who want a small extra income from a second job (Guldvik 2001; Christensen 2012).

It is then the case that these groups of workers accept weak, in this case insecure, working conditions and are either satisfied with the situation, or are in a period of transition that makes their influence on the working hours less important to them because they are aiming at a future (generally higher) position in the labour market (Guldvik 2003; Christensen 2010). Examined broadly, the imposition of flexible work hours for the personal assistant maintains its status as a gendered, part-time role and obstructs the option of making PA jobs into full-time work. Or, as expressed in a Danish study: 'To be flexible sounds like a positive personal quality, but it is a burden when the irregular working time makes the income insecure' (Munk-Madsen 2007, 30).

## ***2.2 Qualitative flexibility – assistance work***

While traditional services like home care are increasingly predefined and exclude the option of getting help for tasks not mentioned in the contract, the range of tasks remains flexible in the PA scheme (see e.g. Christensen 2006). After the user has been allocated a certain amount of hours on the basis of her/his needs, the user fully controls what will be done with these hours. An additional important difference is that while traditional home care services can only take place in the home, the PA scheme allows users to be accompanied by assistants for a variety of activities outside the home, e.g. on holidays, journeys, conferences, seminars and the like. Depending on the specific impairments of the user, the assistance granted can consist of help with ordinary everyday life tasks, or it

can require specific knowledge and/or skills, e.g. how to manage a breath-support machine, which can require instruction by hospital nurses. Thus the issue is one of user flexibility: that the user's control of the content of assistance directs the assistance work.

However, while the Scandinavian literature into the flexible time requirements mentioned above is more unambiguous, this seems to be not fully the case regarding the discussion here about flexible assistance. While there is research that takes as its starting point the practice of referring to personal assistants as the arms and legs of the disabled persons (Munk-Madsen 2006a, 2006b), there is also research that concerns itself more with variations in this work, towards disabled people (Larsson & Larsson 2004). In addition, there is research that more systematically presents different profiles of personal assistants (Guldvik 2003) or assistance strategies (Christensen 2010). Two similar profiles/strategies are called 'the pragma profile'/'the pragmatic strategy', encompassing individuals, e.g. students, who pragmatically choose this work temporarily while preparing for another (better) position later, and 'the huma profile'/'continuing carer biography', typically referring to those workers who are a bit older, have been working in other parts of the care sector and have developed an identity as carers during their lives (Guldvik 2003; Christensen 2010). While the pragmatic assistants do the assistant work in accordance with the independent living ideology (in terms of providing 'assistance') the humanistic ones carry out 'help', as opposed by the independent living ideology (see Oliver 1993). In other words, the historically developed gendered care work is not welcomed by the PA scheme except for the other-orientation if this is combined with user control (other-oriented flexibility), flexible assistance directed and controlled by the user, in a formally non-pyramidal but still powerful way (cf. Senneth 1998). Although those personal assistants with a pragmatic strategy may be better situated than those with a humanistic profile in a career perspective – as they are gaining more capital for future work (Christensen 2010) – their practice of flexible assistance still contributes to maintaining PA as unqualified work directed by welfare users' flexibility demands. This leads to the next discussion about PA and professionalism.

### 3. Deprofessionalization

One method of characterizing a profession is to focus on the two key criteria of formal education and acquisition of specific skills (Parsons 1951). However, there are no clear criteria that distinguish professions from other occupations. Some claim that professionalism over time will extend to all occupations, and that one can talk about different degrees of professionalism (Fauske 2008). An example of this is the professionalization of home-helpers through education, specific skill requirements and formalization of work in the Nordic countries during the 1980s and 1990s (Christensen 1998b; Thorsen 2000).

Working as a personal assistant is typical non-professional, unskilled work characterized by relatively low wages, low status, minimal benefits and a high worker turnover rate. The ways the assistants are recruited underline the classification as non-professional work because there are few entry requirements in terms of qualifications. The user is free to hire the assistant s/he prefers independent of the assistants' formal education, skills, experiences and seniority, which are standard criteria for recruitment. In the case of PA, the users' requirements, needs and desires are the decisive criteria.

The fact that the majority of personal assistants are women, 85% in Norway (Guldvik 2001) and similarly high figures in Denmark and Sweden, is a third reason that makes gender a significant issue. Whilst the recruitment of assistants has few requirements of formal qualifications, the job is also characterized by the way in which it is stereotyped as

being typically female. Rasmussen (2004, 521) claims that care work is gendered because women and men are constructed as 'appropriate' gendered care workers by the different expectations the workers have of themselves, as well as by what is expected of them. From the user's point of view, a female care worker might be seen as a helper while a male care worker would be seen as a person of authority.

Furthermore, Rasmussen (2004, 508) describes gendering of the greedy organization where the care workers are empowered by improving their autonomy and opportunity for action on the one hand and also by intensifying their workload and increasing their subjection on the other. However, when the care workers expressed their concerns about the intensification of work and lack of time to provide high-quality care, this argument was not recognized because they were seen as 'women' who were not able to limit the tasks in an appropriate way; they were seen as non-professional. Deprofessionalization is therefore reinforced by society's gendering of care work. In our context the subordination of personal assistants depends on the construction of the work as both non-professional and gendered, and the close connection between the two dimensions.

The independent living ideology prescribes deprofessionalization of the PA work as an instrument to reach freedom and independence for disabled people (Oliver 1993). The character of this work leads to at least two challenges for the PA-model and for the assistants. First, there are few opportunities for further qualification built into the PA model. Second, the lack of entry requirements and specific skills means that the experiences gained from assistance work will be of limited value for further advancement in working life. These structural factors will perpetuate PA as a non-professional occupation with low status. In the long term, this might be negative for the recruitment and retention of assistants to the PA model, and hence, this might become a problem for the users.

On the basis of these general dimensions we will now highlight the two key criteria (education and skills) for professionalization in relation to PA work.

### ***3.1 Education for assistants***

Professions are characterized by formal education. Care work is mainly carried out by different kinds of professions such as nurses, social workers, physiotherapists, occupational therapists, etc. No research regarding assistants' backgrounds has been carried out in Scandinavia during the last few years. However from early 2000 we know that 30% of assistants in Sweden and 20% of assistants in Norway had education at the university level (Guldvik 2001, Larsson 2004). This relatively high number of assistants with higher education is due to the fact that many assistants are students. Nevertheless, most are not studying health and welfare professions. Of the Norwegian assistants 40% had formal training in health and social care, mostly from the upper secondary school level. If we combine this group with those who had related previous work experiences, the number of assistants in Norway with a background in the health and social care sector reaches 60% (Guldvik 2001). Also, in Sweden the majority of the assistants had a similar background (Larsson 2004). From this point of view, a majority of the assistants are professionalized to some degree, even if this is not a requirement for the job. However, these qualifications are not reflected in the salary the workers receive.

The users, and especially those who are active in the independent living movement, prefer assistants without training and experiences from social care work. The assistants, on the other hand, believe that the acquisition of formal qualifications would attract more people to this work, and also help retain those assistants already employed in it

(Glendinning et al. 2000, 209). Assistants express a need for more formal, transferable skills not least because the work includes considerable elements of more skilled, health-related care, as well as social and domestic tasks (Glendinning et al. 2000, 209).

### **3.2 Skills and developing competence**

What kind of skills do the assistants need? Each user is unique and needs to train her/his assistants in specific tasks, such as the use of advanced technologies for lifting, breathing, etc. Service work requires that the customers should be treated on the basis of their specific wishes and needs. Even so, some aspects of the work are challenging in all kinds of service work, including assistance work. Competence on relational aspects is important in service work in general. In PA work this is of more crucial importance because the relationship is so close and in many ways intimate. Most assistants find the relational aspects among the most challenging factors of their work (Guldvik 2001; Larsson 2004; Falch 2010; Egard 2011; Christensen 2012).

The assistants take on different roles in relation to the users. Some assistants state that the relationship is a kind of friendship, others say it is a working relationship and some see it as a combination of the two. This ambiguity may make it problematic to delineate when one is or is not at work. A Swedish study describes the relationship in this manner: 'There is a risk for too much closeness and no limits between work and leisure time. There are difficulties in combining the different roles as for example friend/curator/mother or daughter. This creates a feeling of inadequacy among assistants' (Larsson & Larsson 2004, 198). The assistant often gets emotionally involved with the user, and after working time they might help the users with tasks that are not part of the assistant (paid) job (Egard 2011). This situation is described as a duality where PA is carried out in a tension between the home and the working sphere (Hugemark and Wahlström 2002). From this point of view the assistance work may promote features from 'the greedy organisation' where gendering of care work presupposes that female assistants should extend the work beyond the agreed hours. These expectations may come from both the users and assistants involved.

The close relationships between the two parties may also cause emotional challenges. Falch (2010) describes three different forms of relations between users and assistants. The first is a subject symmetric relation where the two interact as friends. The second is an object symmetric relation, which is an instrumental relation where the two treat each other like objects. These symmetric relations give positive energy and meaning for the assistants because there is a kind of agreement about the kind of relationship. The third is described as an asymmetric subject-object relation, where the user acts as an active subject and the assistant is treated like an object, or like a 'robot' (Falch 2010, 124–125). This relation creates irritation, anger, frustration and emotional dissonance among the assistants. There are few systems for debriefing for the assistants in such situations.

The assistants have, to a limited degree, access to systematic guidance and training in their job. In Norway, many of the assistants are trained by the user (44%), while some are trained by other assistants (27%). This training is connected to the user's needs: how to perform the services, use of technical aids, etc. One in four assistants has not had any training at all (Andersen et al. 2006). Some providers of PA services (cooperatives, private companies) occasionally offer short courses for users and assistants. However, this is not systematically implemented for all assistants (Andersen et al. 2006). Personal assistants frequently find that their opportunities to acquire training and qualifications are

greatly reduced while working for a private individual, compared with working for a residential home or care agency (Glendinning et al. 2000, 207).

Training and guidance are important activities of working life in general and of social work in particular. Taking the challenging working conditions for assistants into consideration, it is surprising that personal assistants do not have access to systematic follow-up from the municipalities, providers of the services or other actors.

#### **4. De-co-determination**

Co-determination and influence are central concepts in the field of disability research, and in particular in research into PA based on a user perspective (see e.g. Askheim and Guldvik 1999; Larsson 2008; Egard 2011). These are also important concepts or norms when seen from an employee perspective. In this perspective, the concepts emphasize potential options for employees for practising democracy at the workplace, including participating in decisions about their work situation in different ways.

In the Nordic countries, special regulations on co-determination and influence in working life for employees have existed since the 1970s. In Sweden, for example, there is a regulation in the act on influence in working life (Medbestämmandelagen [MBL], 1976, 58). MBL includes regulation of employee-influence, rules about collective agreements, union and negotiation rights and conciliation. The rules are aimed at strengthening the employee's position at the workplace (Olshed 2008). Among other things, the employer is required to give information and to negotiate. The rules are institutionalized through an agreement between the parties (Simonson 1989). The situation is the same in Denmark and Norway (LBK nr 1072 af 07/09/2010 and LOV 2005-06-17 nr 62, respectively). The regulations imply that the employees have responsibility for delivering the activity/work, and can thereby participate in influencing it.

In the 1970s and 1980s, the idea of influencing labour on a collective basis was put on the agenda, not least because of the introduction of legislation (Allvin et al. 2007). At this time there was a general interest in employees' health and influence/control. However, the sympathy for co-determination and influence in working life for employees has to be seen in the light of the changes in working life over the last 30 years. Working life has come under pressure from private market forces, globalization, a partly regulated labour market, new information technology, new employment conditions and changed requirements to employees and their working tasks (Allvin et al. 2007). These changes are important for the discussion of PA.

Several studies from the 2000s have investigated assistants' working conditions from different perspectives regarding co-determination and influence, even if this has not always been an explicit aim (Ahlström and Klinkert 2000; Guldvik 2001; Larsson and Larsson 2004; Larsson 2004, 2005; Munk-Madsen 2006a, 2007; Christensen 2010). The content related to co-determination and influence can be about the assistants' rights or options regarding, among other things, discussion of their working conditions, possibilities of influencing breaks, the hours of work, participation in staff meetings and meeting fellow workers during working hours. It is also about receiving information from the employer on how the work is carried out and plans for the future.

In the following, the discussion on co-determination and influence will be based on two conditions of PA work which we will call 'the blurred frameworks for assistance' and 'blurred employment types'.

#### **4.1 Blurred frameworks for assistance**

In comparison with many other occupational groups, the work of assistants is difficult to grasp and not clearly worded in official documents. The main part of this framework for assistance is about supporting the user's general needs. The assistant is providing help to the person who, due to impairments, needs help for personal hygiene, meals, dressing, undressing, communicating with others, social life, etc. The most clear dividing line between this work and other similar kinds of work in the care sector is that the PA scheme emphasizes the user's right to decide about the work content in different ways (e.g. Edebalk and Svensson 2005; Hugemark and Wahlström 2002; Larsson 2008).

In Sweden there is a norm suggesting that the personal assistant should carry out the tasks together with the user and not on her/his own (Prop. 1992/93: 159, 176). Neither should personal assistants replace staff from other sectors like school, health, daily activities, etc. However, it is known from practice that assistants sometimes replace staff and sometimes do shopping on their own (see e.g. Larsson and Larsson 2004; Larsson 2005).

In the early 1990s when the PA scheme was still under development, Gough (1994) described the assistance work as being informal and of a general human character. The study by Hugemark and Wahlström (2002) showed that the assistants, on one hand, experienced their work as independent, varied and with the possibility of being able to influence it. On the other hand, they were unsure about their role towards the user. Larsson (2004) shows that some assistants do not experience their work as traditional work, but rather as something enjoyable they do for and with a companion in her/his home. These may be some explanations for why the role of the assistant sometimes is unclear.

Calleman (2008b) has pointed out that PA tasks are often weakly described, including how the work has to be carried out. This is the case even in the general labour legislation, as this does not regulate the working tasks that are going to be performed. Calleman (2008b) mentions that if there is no agreement on anything else than that someone is going to work as an assistant, it means that s/he shall only carry out the working tasks the employer or manager decides on. This is even more complex when other parties are involved in managing the assistance. The question here is how much influence and co-determination does this give the assistants?

In the magazine 'I like my job', about working as a personal assistant (Information-sprojektet om yrket personlig assistent 2009, 3), there is an example illustrating user control: Carina, who has been working for 10 years as a personal assistant for Anna, says that:

As an assistant it's ok to take a step back and let somebody else shine. I do not have any expectations about what is going to happen when I am working. In my working time it's Anna's needs that are the most important.

Taking this as the starting point, there is not much room for the assistant to practice co-determination if s/he would like to do that.

#### **4.2 Blurred employment types**

The PA scheme includes several different 'new' employment types stressing customer choice and flexibility. Some of these can be characterized as weak and unpredictable for the employees. A study by Larsson and Larsson (2004) presents different employment

types, e.g. hourly paid work, permanent hourly paid work and temporary employment (as long as the agreement lasts), and a study by Guldvik (2001) focuses on temporary employment of more than six months and less than six months. The question is: what implications do the employment types have for the assistants' co-determination and influence on their work?

There is not much knowledge available today about personal assistants' influence on their employment type based on their wishes and professional requirements. For example: do they have any influence over the quality of their employment? The quality of employment might be affected by the predictability of the employment situation: having a concrete schedule or set time of notice and length of work time. It may also depend on being utilized for the number of hours they need to work, in order to receive the necessary level of income. According to Larsson and Larsson (2004) those assistants who were unsatisfied with their employment were unsatisfied with being employed only for six months or less with receiving fewer hours of work than they wanted. Although work is not a human right, the degree of user control in relation to the employment of the assistants creates a risk of ignoring the right assistants have not to be discriminated against (Calleman 2008b). Discrimination laws in the Scandinavian countries are intended to prevent that certain groups of people are discriminated against in working life, for example, due to gender, age and/or ethnicity. When users may freely choose the person to be employed as an assistant, there may be a risk that this choice will conflict with provisions of anti-discrimination legislation.

Another area in which knowledge is limited is the degree to which the type of employment can impact the assistants' options for influence and co-determination. Some assistants experienced that they were forced to do whatever the user or the family of the user wanted them to do, in order to avoid being dismissed. Several assistants mentioned that the users could get rid of them without giving any explanation, and sometimes it was just about insignificant things (Larsson and Larsson 2004). Calleman (2008a) also finds that the demand of a fair reason for being dismissed is neglected within major parts of the market of assistants. If this is the case, it may be challenging for assistants to practice any co-determination and influence; they might be afraid of being dismissed.

## **5. Concluding discussions**

This article has focused on working conditions and potential challenges for personal assistants, who are working within a welfare scheme which has user control as its basic principle. In our final discussion, we will discuss possibilities for avoiding the structural risk of exploitation of personal assistants, as well as strategies for surmounting obstacles to developing qualifications for a broader labour market.

Over the last few decades working life has changed significantly, and one of the central elements discussed in the literature in regard to these changes is the increasing demand of a flexible workforce. The type of work personal assistants provide is directed by PA users' demand for flexible help and therefore represents a current case of flexible work. In other words, the flexibility is structurally distributed asymmetrically between the user and the worker. Our analysis shows that the characteristics of the PA scheme, such as asymmetrical distribution of power and imbalance in the roles of the parties, do not fit into the Scandinavia's high working life standards. An equal power balance could contribute to more stable working relationships, and also make the prospect of working as a personal assistant more attractive both to those already employed as such, and to those considering work in this area.

However, based on our investigations, we find that the assistants have a very limited influence on the tasks they perform, as it is significantly important for disabled people to act as managers of their help. Nevertheless, the PA scheme could still benefit from a greater specification of which tasks are and are not covered by the assistants' services. That is, there is a need for some kind of regulation, or parties contractually agreeing on principles for the content of the service. When it comes to the number of working hours, our analysis shows that co-determination between the user and the PA should clearly be stronger as it is crucial in regard to the assistants' income level. Otherwise, the workers are forced to do several jobs, creating a stressful, unsecure and deviant working life situation which limits their economic independence. We also find that more predictable employment types for the assistants, as in other parts of the Scandinavian labour market, would strengthen the scheme. People employed in many other occupations – whether semi-professionalized or less – are seldom hired on an hourly basis or for a period of less than six months. These types of working conditions are 'non-Scandinavian', and care workers choosing PA work should not be subjected to them.

Personal assistants are a large occupational group in Scandinavia. According to the National Board of Health and Welfare there were 50,000–60,000 people working in the profession in Sweden (Socialstyrelsen 2007), approximately 5000 in Denmark (Deloitte 2012) and 7000–8000 in Norway (Johansen et al. 2010), with even more today. There are thus many employees affected by the circumstances described above. The conditions for these jobs are essentially an issue for employers and the trade unions, although this may vary slightly in countries described in this study. Improved conditions for assistants concerning their employment can be achieved through new agreements between the parties in the labour market and further through changes in legislation that will strengthen job security for the assistants.

Finally, our analysis indicates that there should be an institutionalized process of qualification, to bring about a degree of professionalization, as this would add value to temporary work in this sector. However, this does not mean that the open entry to this work should change. By avoiding any specific qualifications, the work will continue to attract diverse groups of workers; and their different backgrounds and knowledge are worth maintaining in the social service sector.

Nevertheless, our discussion points out that there is a need for professionalization of the work in order to establish stable recruitment and retention of assistants. Formal education for personal assistants has been on the agenda in both the UK and Sweden (Glendinning et al. 2000; Hugemark 2006). Formal education could be planned and carried out in cooperation between educational institutions and user organizations. Transferable and personalized training could be accommodated within the training programmes, based on the 'social model of disability' which defines disability as social oppression (Campbell and Oliver 1996). Through user cooperation, one could avoid the more formal caring elements of conventional professional training that disabled people have found disempowering (Glendinning et al. 2000, 209). Such training might promote the status and career opportunities for the assistants as well as reduce turnover and enhance the continuity of assistance for the users in need of this.

Formal education and systematic competence building could also be important elements of an institutionalization of more collective arrangements between assistants on the one hand and municipalities, providers and users on the other. This would require institutional norms and values for PA work that would promote solidarity, in terms of a sense of interdependence and common concern between the parties. Additionally, solidarity means that the parties are willing to give up something for the sake of the

other (Østerberg 2003, 32). In this context, solidarity would be a symmetrical relationship between users and assistants. If there is a sense of interdependence and common concern, the users might give up some of their control of the number of working hours to secure assistants' income level, while on the other hand the assistants might hand over the control of the task performance to the users to secure the users' management role. More symmetrical power relations are an advantage for both parties in these relationships in the long run.

The Scandinavian tradition of tripartite cooperation in working life may be an inspiration for sustainable development of the PA scheme. A third party (the other two being the assistants and the user as manager) could be a moderator and facilitator between the possible conflicting interests of the user and the assistant. This third party could be drawn from, for example, representatives from trade unions, employers and public authorities at the local level. This suggestion would enhance solidarity through emphasising equality, mutual respect and recognition between assistants and users in order to create sustainable working conditions for the assistants and confidentiality towards and respect for the user.

## References

- Ahlström, G., and P. Klinkert. 2000. *Den svåra balansgången – personliga assistenters möjlighet att tillämpa de etiska värdegrunderna i LSS* [The Difficult Balancing Act – Personal Assistants' Option to Apply the Ethical Value System in the LSS]. Örebro: FoU-enheten, Psykiatri och rehabilitering, Örebro läns landsting.
- Allvin, M., G. Aronsson, T. Hagström, G. Johansson, and U. Lundberg. 2007. *Gränslöst arbete – socialpsykologiska perspektiv på det nya arbetslivet* [Boundless Work – Social-Psychological Perspective on the New Working Life]. Malmö: Liber.
- Andersen, J., O.P. Askheim, I. S. Begg, and I. Guldvik. 2006. Brukerstyrt personlig assistanse [User Controlled Personal Assistance]. *Kunnskap og praksis* [Knowledge and Practice]. Göteborg: Gyldendal Akademisk.
- Askheim, O. P., and I. Guldvik. 1999. *Fra lydighet til lederskap. Om brukerstyrt personlig assistanse* [From Obedience to Leadership. On User Controlled Personal Assistance]. Oslo: Tano Aschehoug.
- Calleman, C. 2008a. "En motsättning mellan två principer om likabehandling? Om rätten att välja personlig assistent [A Contradiction between Two Principles on Equal Treatment? The Right to Choose Personal Assistant]." *Socialvetenskaplig tidskrift nr 3–4*: 295–314.
- Calleman, C. 2008b. En flexibel arbetsrätt inom personlig assistans? [A Flexible Working Act within Personal Assistance?]. *Svenska Juristtidning 93* (5–6): 484–498.
- Campbell, J., and M. Oliver. 1996. *Disability Politics: Understanding Our Past, Changing Our Future*. London: Routledge.
- Christensen, K. 1998a. "Andre-orientering og omsorgsarbejde [Other-Orientation and Care Work]." *Tidsskrift for Velferdsforskning nr 2*: 82–97.
- Christensen, K. 1998b. *Omsorg og arbejde. En sociologisk studie af ændringer i den hjemmebaserede omsorg* [Care and Work. A Sociological Study of Changes in Home-Based Care]. Bergen: Universitetet i Bergen.
- Christensen, K. 2006. "Sosiologisk aldring [Sociological Ageing]." In *Tverrfaglig geriatri. En innføring* [Interdisciplinary Geriatrics. An Introduction], edited by M. Bondevik and H. A. Nygaard, 29–40. Bergen: Fagbokforlaget.
- Christensen, K. 2010. "Caring about Independent Lives." *Disability & Society 25* (2): 241–252. doi:10.1080/09687590903537562.
- Christensen, K. 2012. "Towards Sustainable Hybrid Relationships in Cash-for-Care Systems." *Disability & Society 27* (3): 399–412. doi:10.1080/09687599.2012.654990.
- Danielsen, H. 2002. *Husmorhistorier: norske husmødre om menn, barn og arbeid* [Norwegian Housewives: Norwegian Housewives about Men, Children and Work]. Oslo: Spartacus.
- Deloitte. 2012. *Borgerstyrt personlig assistanse. Afsluttende evalueringsrapport* [Citizen Controlled Personal Assistance. Final Evaluation Report]. København: Socialstyrelsen.

- Edebalk, P.-G., and M. Svensson. 2005. *Kundval för äldre och funktionshindrade i Norden* [Customer Choice for Elderly and Disabled People in the Nordic Countries]. Köpenhamn: Nordiska Ministerrådet.
- Egard, H. 2011. *Personlig assistans i praktiken: beredskap, initiativ och vänskaplighet* [Personal Assistance in Practice: Contingency, Initiative and Friendliness]. Lund: Lunds universitet.
- Falch, W. 2010. *Står til tjeneste: Emosjonelt arbeid i tjenestemøtet* [At Your Service: Emotional Work in the Service Meeting]. Karlstad: Karlstad University Studies.
- Fauske, H. 2008. "Profesjonsforskningens faser og stridsspørsmål [The Phases and Contradictory Questions of Research on Professions]." In *Profesjonsstudier*, edited by A. Molander and L. I. Terum, 29–53. Oslo: Universitetsforlaget.
- Glendinning, C., S. Halliwell, S. Jacobs, K. Rummery, and J. Tyrer. 2000. "New Kinds of Care, New Kinds of Relationships: How Purchasing Services Affects Relationships in Giving and Receiving Personal Assistance." *Health & Social Care in the Community*, 8 (3): 201. doi:10.1046/j.1365-2524.2000.00242.x.
- Goudswaard, A., and M. de Nanteuil. 2000. Flexibility and Working Conditions. *A Qualitative and Comparative Study in Seven EU Member States*. European Foundation for the Improvement of Living and Working Conditions. Luxembourg: Office for Official Publications of the European Communities.
- Gough, R. 1994. "Personlig assistans – en social bemästringsstrategi. En undersökning av hur pionjärerna för Independent Living rörelsen i Sverige organiserar sin personliga assistans [Personal Assistance – A Social Coping Strategy]." Akademisk avhandling. Tromsø: Samhällsvetenskapliga fakulteten.
- Guldvik, I. 2001. *Mellom brukerstyring og medbestemmelse: Å jobbe som personlig assistent*. [Between User Control and Co-Determination: Working as Personal Assistant]. ØF-rapport. Lillehammer: Østlandsforskning.
- Guldvik, I. 2003. "Personal Assistants: Ideals of Social Care Work and Consequences for the Norwegian Personal Assistance Scheme." *Scandinavian Journal of Disability Research* 5 (2): 122–139. doi:10.1080/15017410309512618.
- Hugemark, A. 2006. "Åter i stöpsleven: Personlig assistans mellan marknad och reglering [In the Melting Pot Again: Personal Assistance between Market and Regulation]." *Socialvetenskaplig tidskrift* nr 4: 313–330.
- Hugemark, A., and K. Wahlström. 2002. *Personlig assistans i olika former: mål, resurser och organisatoriska gränser* [Personal Assistance in Various Forms: Aims, Resources and Organisational Limits]. Stockholm: Forsknings- och utvecklingsenheten Socialtjänstförvaltningen.
- Informationsprojektet om yrket personlig assistent. (2009). *Jag gillar mitt jobb. Om yrket personlig assistent* (I Love My Work. On Personal Assistance). Föreningen JAG (Jämlikhet, Assistans och Gemenskap) och IFA (Intressegruppen för assistansberättigade).
- Johansen, V., O. P. Askheim, J. Andersen, and I. Guldvik. 2010. Stabilitet og endring - Utviklingen av brukerstyrt personlig assistanse [Stability and Change. The Development of User-Controlled Personal Assistance]. Lillehammer: Høgskolen i Lillehammer.
- Larsson, M. 2004. "Personlig assistent – kompis, startmotor eller någons armar och ben? [Personal Assistant – Companion, Starter or Somebody's Arms and Legs?]." In *Personlig assistans och medborgarskap*, edited by K. Gynnerstedt, 123–145. Lund: Studentlitteratur.
- Larsson, M. 2005. Personlig assistans – på brukarens, assistentens eller bådas villkor? [Personal Assistance – On the User's, the Assistant's or Both's Conditions?]. FoU-Skåne. Kommunförbundet Skåne. Skriftserie 2005:1. Lund: Lunds ljuskopieringsbyrå.
- Larsson, M. 2008. "Att förverkliga rättigheter genom personlig assistans." [Realization of Rights through Personal Assistance]. Lund Dissertations in Social Work. Lund: Socialhögskolan Akademisk avhandling.
- Larsson, M., and S. Larsson. 2004. Att vara ett mänskligt hjälpmedel. *En studie om att arbeta som personlig assistent* [To Be a Human Tool. A Study on the Personal Assistance Work]. Malmö: Harecpress.
- LBK nr 1072 af 07/09/2010, Arbejdsmiljøloven § 6, changed the act from 1977. [Denmark].
- LOV 2005/06/17 nr 62: Lov om arbejdsmiljø, arbeidstid og stillingsvern mv., changed the act from 1977. [Norway].
- MBL. 1976 Lag (1976:580) om medbestämmande i arbetslivet. [Sweden].
- Munk-Madsen, E. 2006a. "Verdens bedste hjælperordning? [The World's Best Support Arrangement?]." *Tidsskrift for arbejdsliv* [Journal for Working Life] 1: 11–31.

- Munk-Madsen, E. 2006b. "Brugerens arme og ben [Arms and Legs of the User]." *Social kritik* [Social Critic] 105: 58–71.
- Munk-Madsen, E. 2007. *Handicaphjælperes arbejdsmiljø – en hjælperundersøgelse* [Handicap-Helpers' Work Environment – A Helper-Investigation]. Roskilde: FOA, Fag og Arbejde.
- Negt, O. 1984. *Lebendige Arbeid, enteignete Zeit. Politische und kulturelle Dimensionen des Kampfes um die Arbeitszeit* [Living Work, Expropriated Time. Political and Cultural Dimensions of Struggles for Working Time]. Frankfurt am Main: Campus Verlag.
- Nielsen, L. D., K. A. Nielsen, E. Munk-Madsen, and K. Hartmann-Petersen. 2010. *Fleksibilitet, flygtighed og frirum – en kritisk diagnose af det senmoderne arbejdsliv* [Flexibility, Transitoriness and Possibilities – A Critical Diagnosis of the Late Modern Working Life]. Roskilde: Roskilde Universitetsforlag.
- Olberg, D. 2007. *Flexicurity – nordiske arbejdslivsmodeller i nye kontekster?* [Flexicurity – Nordic Working Life Models in New Contexts?]. Fafo-paper 2007/24. Oslo: Fafo (Institute for Labour and Social Research).
- Oliver, M. 1993. *The Politics of Disablement*. Hampshire: Macmillan.
- Olshed, M. 2008. *Arbetsrätt*. [Labour Rights]. Malmö högskola. Malmö: Printex.
- Østerberg, D., 2003. *Sociologiens nøkkebegreper* [The Key Concepts of Sociology]. Oslo: Cappelen Akademisk forlag.
- Parsons, T. 1951. *The Social System*. London: Routledge & Kegan Paul.
- Prop. 1992/93. 159 Stöd och service till vissa funktionshindrade [Support and Service to Certain Disabled People].
- Rasmussen, B. 2004. "Between Endless Needs and Limited Resources: The Gendered Construction of a Greedy Organization." *Gender, Work & Organization* 11 (5): 506–525. doi:[10.1111/j.1468-0432.2004.00245.x](https://doi.org/10.1111/j.1468-0432.2004.00245.x).
- Rønning, E. 2002. "Jakten på den moderne arbeider [Hunting the Modern Worker]." *Samfunns-speilet*, 4–5.
- Sellerberg, A. M. 1973. *Kvinnorna på den svenska arbetsmarknaden under 1900-talet. En sociologisk analys av kvinnornas underordnade position i arbetslivet* [Women in the Swedish Labour Market. A Sociological Analysis of Women's Subordinated Position in Working Life]. Lund: CWK Gleerup Bokförlag AB.
- Senneth, R. 1998. *The Corrosion of Character: The Personal Consequences of Work in the New Capitalism*. New York: W. W. Norton & Company.
- Simonson, B. 1989. *Arbetarmakt och näringspolitik: LO och inflytandefrågorna 1961–1982*. [Workers' Power and Business Policy]. Stockholm: Allmänna Förlaget.
- Socialstyrelsen. 2007. *Personlig assistans som yrke* [Personal Assistance as Profession]. Stockholm: Socialstyrelsen
- Thorsen, K. 2000. "Eldreomsorg, kvaliteter og lokal kontekst [Care for Elderly People, Quality and Local Context]." *Tidsskrift for velferdsforskning* 3 (4): 203–218.
- Wilthagen, T., and F. Tros. 2004. "The Concept of 'Flexicurity': A New Approach to Regulating Employment and Labour Markets." *European Review of Labour and Research* 10: 166–186.