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**The Norwegian system of supporting
people with disabilities in independent
living, including assistant services**

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Foreword

The report is part of the project “Independent living of disabled students and graduates of higher education institutions”, which has been financed by the European Economic Area and Norwegian Financial Mechanisms Programme.

In accordance with the Consortium Agreement between the University of Warsaw and the Inland Norway University of Applied Sciences, this report explains “The Norwegian system of support for people with disabilities in pursuit of independent life, including the system of assistants for people with disabilities”. The report is the first of two. The other will discuss more specifically “The Norwegian personal assistance services for people with disabilities in the work environment”.

This report intends to provide a solid overview of the support system and discuss current developments in the area. The data are based on studies of official documents and previous research on the topic.

November 2019

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Abstract

User-controlled personal assistance (UPA) is an arrangement for disabled people with extensive needs for assistance. With its background in the so-called independent-living ideology based on rights, self-determination and consumer control, the main intention with UPA is to make services more flexible and to provide people with opportunities to live an independent life. This report gives an account of and discusses UPA in the Norwegian welfare context, its legal foundation, its organization and coordination with other welfare services, and how the arrangement is implemented in the municipalities. Further, this report describes the user group and the assistants in more detail, along with their experiences with UPA. This report concludes that UPA in most ways must be considered a success, mainly because it fulfils the goals of greater independence and participation from the users. However, UPA also appears to have inherent tensions. The different goals within the arrangement give rise to tensions, and these have become more pronounced as the arrangement has become more established. A major tension is between the ideological goal of seeing UPA as a tool for liberation, expressed in goals such as independence, participation and user control, on the one hand, and the authorities' wish and need both to control the costs of welfare services and to secure quality in the services and equality between different user groups, on the other.

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Disability policy in the Norwegian welfare state

Since the late 1960s, an increased awareness of the rights and resources of disabled people has influenced the Norwegian welfare policy (Guldvik & Askheim in review). The stated aim of this welfare policy is that disabled people are seen as full citizens with the right to the same standard of living as others and that any division between disabled people and others should be avoided. The principle of normalization means that there should be no unnecessary divisions between disabled people and others in terms of medical care, social treatment, education, employment or welfare. This policy represented a break with the medical interpretation that had previously characterized the understanding of disability.

The so-called relational definition of disability as an interaction between the individual and society should be the norm for social policy. “A disabled person is one who because of chronic illness, injury or defect or because of social deviance is seriously impaired in his/her practical life and the community surrounding him/her. Among other things, this will concern education, choice of occupation and physical and cultural activities.” (St. meld. nr. 88 (1966–67), p. 10).

The normalization principle has been followed up with a stronger focus on social and organizational integration. Organizational integration concerns the principle that society’s ordinary welfare services should have full responsibility for all inhabitants. The necessary specialized measures should be included in ordinary services and not categorized as separate specific measures. Social integration should allow disabled people to live as though they are not disabled and to live and work in their environment in the same way as non-disabled people. As a consequence, assistance and care services are a municipal responsibility that apply to all inhabitants (Romøren 2018).

In 2007, Norway signed the UN Convention on the Rights of Persons with Disabilities, which was ratified in 2013.

From the start, user participation in Norway related mainly to participation by representation on a system level in bodies such as user councils. User participation at the individual level emerged for the first time in policy documents in the mid-1990s and has thereafter become increasingly important (Guldvik & Askheim in review). The governmental “Action Plan for Disabled People” (1994–1997) reported that, to avoid offering services that do not fulfil individuals’ needs, people who depend on public services must have a say in the type of measures offered to them and their delivery. It proposed that disabled people should be

regarded both as consumers of services and as citizens with democratic rights. As a result of the increasing preoccupation of individual user participation, stronger user control of the services became a focus. A concrete result was that “user-controlled personal assistance” (UPA) as a pilot scheme became a prioritized issue in the action plan.

User-controlled personal assistance (UPA): Background and legal foundation

UPA is a true child of the so-called independent living ideology, which originated in the USA in the 1970s (DeJong 1983). Independent living represents a resistance against what this approach calls the “rehabilitation paradigm”, in which a disability is presented as a problem with root causes in the individual. Consequently, it is the individual who must be changed. Disabled persons are expected to enter a client role through which they obediently take orders from the welfare professionals. In opposition to this the independent living concept proposed a new paradigm based on rights, self-determination and consumer control. In this perspective, disability is defined as the result of societal exclusion, discrimination and marginalization. Since its modest start, variants of the concept of personal assistance have spread from the USA to Canada and most European countries (Van Hauwermeiren & Decruynare 2009; Ungerson & Yeandle 2007).

The first attempt at UPA in Norway started as a pilot project directed by the Norwegian Disability Association in 1991–1994 (Norges Handikapforbund 1994). The arrangement was tried out for a few people in Oslo and Bergen. One result of this project was the establishment of the user-controlled co-operative Uloba, which has since become an important driving force in the development of UPA.

The government’s Action Plan for Disabled People (1994–1997) included a separate section about “User-controlled home services—personal assistance”, which covered user participation and freedom of choice at the individual level. It stated that few experiences with user-controlled home services existed in Norway at that time and referred to the other Nordic countries where personal assistance was a legal right for people with severe disabilities. UPA was noted as a prioritized issue in the action plan but was still defined as a pilot scheme. However, municipalities that wanted to establish UPA received earmarked grants from the

state. The experiences from these pilots provided the background for determining how UPA should be organized in the future (St. meld. nr. 34 (1996–97)).

In 2000, UPA was legislated in the Social Services Act as a service that municipalities are obliged to offer as part of their repertoire of services (Ot.prp. nr. 8 1999–2000; Innst. O. nr. 22 (1999–2000)). UPA was defined as a kind of “practical aid or assistance” in the following statement. “The social services shall include practical assistance and training, *including user controlled assistance*, to those with a particular need of help because of illness, disability, age or for other reasons” (Social Services Act § 4-2 a, italics added for emphasis). Services for which medical competence is regarded as necessary should normally not be included in UPA.

From the start, the intention of UPA related mainly to disabled people with extensive need for assistance and the concept that they should have the opportunities for active participation in society. One main intention was to make the services more flexible and provide users with more opportunities to live an independent life. A major principle was that the arrangement should be controlled by the user as the manager of his/her assistants. Being able to take on the role as manager was essential to being allocated UPA. The management role includes the recruitment of assistants and assigning their tasks according to the number of hours the user had been allocated and the times the assistants should assist.

The integration of UPA in the Social Services Act means that the allocation of UPA follows the ordinary rules for help and services as outlined in the Social Services Act. The allocation of services is based on a discretionary estimation of the user’s needs, both in terms of whether the user qualifies for the services and the extent of the services (Kjønstad & Syse 1997). The bill’s text emphasized that UPA is not a new service but provides an alternative way of organizing practical assistance and aid, and that the allocation should be considered in the same way and within the same judicial frames as other services outlined in the Social Services Act. It also emphasized that services outside the user’s home should be included if the goal to enable an active social life should be fulfilled. However, at the same time, the act noted that times and activities spent in organized areas not covered by the Social Services Act should not be included in UPA. This meant that UPA should normally not be allocated to times where the user is at work or school. Instead, the municipalities were encouraged to co-ordinate UPA with other services.

Because the decisions are based on municipality discretion, it is possible that the law may be interpreted differently by different municipalities. To avoid arbitrariness, users have the right

to complain to the county governor if they consider a decision to be unreasonable or illegal. They may complain about decisions if they were not granted UPA and, if granted UPA, the extent of the arrangement made.

In 2005, the target group for UPA was extended to people who are unable to take on the management role and user control by themselves and who needed help to do this (Circular I-15/2005). The user's parents or guardians or other people who had received authorization from the user could represent the user as a manager.

After a change in the distribution of responsibility for welfare services and how the services should be organized in Norway, in 2011, the responsibility for UPA was transferred to the Health and Care Services Act. This act includes a distinction between "personal assistance" and "user-controlled personal assistance" (i.e., UPA). Personal assistance is described as a common designation for the practical assistance and training provided by the services; in addition to practical assistance in the user's home, personal assistance should also include assistance to help the user participate in leisure time activities (Prop. 91 L (2010–2011)). It was also noted that the term "personal assistance" was selected to emphasize the importance of user participation and user control of the service. In addition to "personal assistance", the Ministry of Health and Care Services also proposed that the municipalities should have a special obligation to have a service designed as "user-controlled assistance" (UPA). In an additional paragraph to the general decision about personal assistance, UPA was described as a continuation of the existing right and that it should be formulated as a separate paragraph in the act. "The municipality is obliged to offer personal assistance (practical assistance and training) as user controlled assistance" (Prop. 1S (2011-2012)).

Both the earlier Social Services Act and the Health and Care Services Act are based on a municipal discretionary estimation of whether the user qualifies for UPA and the extent of the services. The user organizations claimed that users should have a stronger individual right to have UPA. In the 2015 Patient and User Rights Act, people with a long-standing and high need for personal assistance under the Health and Care Services Act were given the right to have such services organized as UPA (Prop. 86 L 2013-2014). A major need was defined as a service requirement of at least 32 hours per week. However, it was noted that users with service needs of at least 25 hours per week should also have the right for services to be organized as UPA, unless the municipality could document that such an organization would result in significantly increased costs for the municipality. Long-standing need was defined as

one beyond 2 years. The right was restricted to persons under the age of 67 years. The present government later announced that the age limit would be removed for those who currently have UPA but would be applied to new applicants.

The law repeated that a prerequisite to obtain UPA was that the person was capable of acting as the manager of the arrangement. In practice, this means having the responsibility for the daily operations of the service, including the organization and content of the arrangement, according to the person's needs. Important elements of the management task are the ability to define one's personal needs, to take part in the recruitment and employment of assistants, to guide the assistants in their learning how the aid should be performed, and to set up and control work plans. To improve the potential for people with disabilities to take on the management role, the government funded training measures. In 2018, the Directorate of Health published a user handbook for user-controlled personal assistance as a tool for both new and established managers of the arrangement.

The law repeated that health services are not included in the right to UPA but, at the same time, it opened the possibility of allowing certain simple health services to be part of UPA where it was seen as proper and the user wanted them (Circular I-9/2015). What people ordinarily do themselves could be left up to the assistants provided that it could be justified.

Table 1: Institutionalization of UPA in Norway

1991–1994: Limited attempts in Oslo and Bergen initiated by the Norwegian Disability Association.
1994–1997: UPA noted as a prioritized issue in the government's Action Plan for Disabled People, and earmarked grants were given to municipalities that wanted to test the arrangement.
2000: Legislated in the Social Services Act.
2005: Extension of the target group to people who could not take care of the management role on their own.
2011: Legal basis transferred to the Health and Care Services Act.
2015: Individual right to UPA for people with long-standing and high need for assistance legislated in the Patient and User Rights Act.

Although UPA was legislated as a right for parts of the user group, UPA may still be granted within the intention of the Health and Care Services Act if the municipality decides that the user qualifies for UPA and the extent the service should have. A review of the policy development showed that beneath the ideological goals of participation, activity,

independence and equality, the state policy has been characterized by considerable ambiguity, contradictions and unclear signals about the content of the arrangement, who should be included in the target group and the weighting of the ability to control the arrangement (Askheim et al 2014). This review noted tension between arguments emphasizing the liberating and participating potential of UPA for disabled people and those emphasizing the costs of the arrangement. Also noted were concerns about securing proper services for the municipality's inhabitants and the need to avoid inequalities between different user groups. The legislation of rights did not change this, and the implementation of right is subject to interpretation. The unclear signals from the state in the next turn have led to different interpretations of how UPA should be organized and implemented. The municipalities must manoeuvre between the different signals contained within the state policy documents.

Organization of employment responsibility

UPA contains a strict division between the management responsibility and the employment responsibility. The management responsibility relates to the responsibility borne by the user or the person who takes care of the management of assistants(s) on behalf of the user. It includes the recruitment of assistants, deciding their tasks within the number of hours the user has been allocated, scheduling the assistants and the daily management of the arrangement. The employment responsibility includes the responsibility for formulating the contracts for assistants, payment (including pension payment), and ensuring that the laws and regulations are followed.

Three possible models have been applied for the employment organization of UPA: the municipality, the individual user or a co-operative of users, or a company. It is the municipality which has the responsibility for deciding the employment model to be used for UPA. However, the state guidelines say that the municipality should also consult users about the choice of employment model.

At the beginning, ULOBA was the only company that organized UPA. However, as the scope of the arrangement has increased, more organizations have entered the field, especially since 2010, when new companies that provide employment responsibility for the assistants have joined the market. Rambøll (2012) identified 10 companies plus ULOBA and the co-operative JAG, which was established specifically for people with intellectual impairment. A recent

study by Uloba reported that the number of providers had increased to more than 30 (Uloba 2018). The companies often have different profiles regarding their target group(s) and how they present themselves. Most of them are commercial companies.

In 2010, for 54 per cent of users, the municipality was the employer of their assistants, about one-third used Uloba and 11 per cent had individual responsibility (Johansen et al 2010). Compared with 2002 (Guldvik 2003), more users had chosen to leave the employment responsibility to Uloba (an increase of 7 percentage points) and fewer to the municipality (a reduction of 11 percentage points).

Guldvik and Andersen (2013) estimated that, at that time, about one-third of the assistants (about 3000 people) were employed by private companies and about 70 per cent by ULOBA and the remainder were spread among other companies. Their study showed a large variation between municipalities in the organization of the employment responsibility. In some municipalities, only the municipality was the employer, whereas in others, the municipality and the individual user were the employers; in others, the municipality and Uloba or other companies were the employers. In the latter cases, users could choose freely between the different employers that satisfied the criteria the municipality had set for the employers.

More recent studies indicate that an increasing proportion of users choose a co-operative or private company as the employer of their assistants. In 2017, 43 per cent of users had left the employment responsibility to a co-operative or a company (Ervik et al 2017). It is interesting to note that such a consumer-oriented model has won forward in the Norwegian welfare state model, In the same way as in the other Scandinavian countries, strong public responsibility for welfare services is considered a primary hallmark (Kuhnle 2001). Unlike other welfare services, for which there is strong opposition from left-wing parties to allow commercial companies to compete with municipal services, this has not been the situation for UPA in Norway.

Who are UPA users?

UPA was received by 3206 people in 2016 (Ervik et al 2017), an increase of about 25 per cent from 2010. UPA is still a very modest arrangement. In 2014, only 1.4 per cent of the recipients of municipal care services had UPA (Mørk et al 2018). For municipal home-based services, the number of recipients of UPA was 3.67 per cent of the total number of recipients (Agenda Kaupang 2018).

In 2016, the average number of hours each week for UPA was 37.5 (Ervik et al 2017), up from 30.2 in 2010. The distribution of hours varied widely among users. Johansen et al (2010) reported that in 2010, 43 per cent of users received fewer than 15 hours, 36 per cent had 16–38 hours, and 21 per cent had more than 38 hours each week. The number of users with the lowest number of hours increased by 11 per cent from 2002 to 2010, and the share with the highest number increased slightly (2 per cent). By contrast, for users in the middle group, their share had decreased by 15 per cent. The figures from 2016 show that the number of users with the highest number of hours increased after 2010 (Ervik et al 2017). In 2010, 44 people had UPA for 168 hours each week (24 hours a day), and this number increased to 79 in 2016.

The number of assistants employed by the individual users varied depending on the extent of UPA. Johansen et al (2010) reported that the average number of assistants was three (range 1–15) in 2010.

The main users of UPA are people with physical impairments. Eight out of 10 users reported mobility impairments in 2010 (Johansen et al 2010), and four out of 10 had more than one impairment. The number with sensory impairments, acquired brain damage or learning disabilities/cognitive impairment has increased since 2010. Statistics from 2017 show that, as a consequence of the extension of the target group, the percentage of users with cognitive impairments had increased to 28 per cent (Ervik et al 2017).

In 2010, one-fifth of users were not managing their assistance on their own, and most had their parents or guardians as their managers. In other words, there is now a more varied and complex user group who have UPA than when the arrangement started in the early 1990s.

The average age of users is mid 40s (Johansen et al 2010), although the age range has been expanding with time. After the extension of the target group in 2005, more children and young people received UPA and accounted for 8 per cent of all users in 2013 (Askheim et al 2014). The share of older users also has increased. The strongest growth from 2010 to 2016

was in people older than 67 years (Ervik et al 2017), most likely because they started UPA at an earlier age and continued with it, and not because they started receiving it at an older age.

A larger proportion of UPA users have higher education at university or university college level than disabled people in general. In 2010, Johansen et al (2010) reported that 38 per cent of UPA users had completed studies at university or university college level, compared with 23 per cent of disabled persons in general.

In 2010, Johansen et al (2010) noted that 20 per cent of users reported having paid work, although few of them worked full time. The majority received social security contributions as their main income. In the 2002 study (Guldvik 2003), only 5 per cent specified that paid work was their main income source, and 10 per cent reported a combination of paid work and social security insurance. More recently, Econ (2010), reported that 25 per cent of UPA users said they had ordinary paid work, and about half of them were working full time. Two-thirds of those who were in ordinary paid work reported that they would not have been working without UPA, and the other informants said they would have worked fewer hours.

The main activities for the other UPA users in the study by Johansen et al (2010) were education/studies (13 per cent), daily activities such as housework, listening to radio/watching television, reading, spending time with children and family (48 per cent) and organized activities such as in organizations, physical training or work training (19 per cent).

What tasks do users receive assistance for?

UPA is intended to help users in their daily life, both inside and outside the home. Two studies from 2001 and 2010 (Guldvik 2001; Johansen et al 2010) provide an overview of the services that are included in UPA.

Table 2: Services provided by personal assistants, expressed as a percentage

	2002	2010
Housework, cooking	87	91
Errands	80	86
Transportation	62	71
Casual work (car, pets, garden)	62	70
Leisure time activities (sport, courses, etc.)	72	68
Personal care morning and evening	58	58
Holidays	49	54
Organizational work	21	25
Work/education	10	22
Childcare		14
N	378	759

Table 2 shows that the use of most kinds of services has increased from 2002 to 2010 except for personal care, which did not change, and leisure time activities, which decreased slightly. These findings suggest that more users seem to make use of the assistants for a variety of tasks. The increase is clearest in the area of work/education, with plus 12 percentage points. The percentage of users employing assistants for transportation and casual work also increased. Johansen et al (2010) provide more details about how users make use of their assistants during a week.

- Eight out of 10 users use assistants for housework and cooking.
- Seven out of 10 use assistants for errands.
- Five out of 10 use assistants for transportation and personal care.
- Three to four out of 10 use assistants for various chores and leisure time activities.
- About one of 10 use assistants for work and education.
- Fewer than one of 10 use assistants for childcare (7 per cent), organizational work (4 per cent) and holidays (3 per cent).

Services can be classified as *compensatory* or *developing* (Åstrøm 1998). The primary aim of compensatory services is to compensate for activities users are unable to do on their own, such as house cleaning. The primary aim of developing services is to provide the individual user the same preconditions to live an independent life as non-disabled people, for instance

taking part in leisure time activities outside the home. As shown in table 2, tasks such as personal care, housework, daily errands and casual work help to compensate for users' inability to perform these tasks on their own. The other services enable users to live an independent life in the same way as non-disabled people. Studies indicate that assistants are primarily employed to perform compensatory tasks, especially housework and daily errands, but that strong elements of developmental services, such as transport and leisure time activities, are also represented.

UPA is not meant to provide assistance at work or school. For assistance at work and at school there are as mentioned other available services, and the municipalities are encouraged to co-ordinate UPA with these.¹ However, the circular that describes UPA as a right in more detail gives a somewhat contradictory message (Circular I-9/2015). For example, the introduction explicitly stresses that UPA provides users with better opportunities for taking part in work life and studies and to live an active and independent life. However, this document also states that UPA is not normally granted for the time at work or school and that, in such cases, it is expedient to co-ordinate UPA with other services.

However, Rambøll (2012) noted that UPA can influence users' participation in education and work life. Together with other practical adaptations and assistance at work, the UPA arrangement can act as an important pillar. For many people with disability, UPA mainly has an indirect effect by making the situation at home, in family life and leisure time easier, thereby increasing the user's capacity and strength to participate in work and/or education.

In many ways, it seems that UPA has a more direct effect on participation in work life for the users' families than for the users themselves (Rambøll 2012). The UPA arrangement frees up time for the users' family carers. For some close relatives, the UPA arrangement seems to be crucial to their being able to undertake paid work. This is especially true for parents with children younger than 18 years with UPA and for spouses of those with comprehensive needs for assistance. A study of parents of children with UPA (Jenhaug & Askheim 2018) found that all of the parents said that it would not be possible for them to work as they did without the UPA arrangement. For other relatives, the UPA arrangement has an indirect effect by decreasing their responsibility for care and housework. Relatives living with the user, as a parent or spouse/partner, report that the arrangement allows them to live like "an ordinary

¹ Assistance services for participation in work and studies will be described in a separate report.

family”. An important aspect is that they can be confident that the user will receive the necessary assistance at the times they have agreed, and this allows them to stay at work.

UPA and other services: Extent, combinations and variations

In the guidelines from 2000, the Ministry of Health and Social affairs noted that UPA is a part of the complete services repertoire that municipalities can offer to their inhabitants and may be combined with other services if the user sees this as an expedient solution. An increasing number of people with disability have UPA as their only service: almost 60 per cent had only UPA in 2010, an increase from 33 per cent in 2002 (Johansen et al 2010). This increase is interpreted as reflecting a greater understanding and experience of both users and municipalities about UPA and that they because of this “dare” more (Johansen et al 2010; Rambøll 2012).

Many users also had other municipal services besides UPA; in 2010, 40 per cent used additional services (Johansen et al 2010). However, for most of them, the other services constituted only a minor part of the total support services received. In 2010, the average total use of municipal services for UPA users was 37 hours each week, 33 hours of which (89 per cent) were granted as UPA. Most of the other services were medical services performed by the home care service; other services such as home help and personal support are now increasingly included in UPA.

It is logical that medical home care services are considered to be outside UPA because these should be performed by people with medical competence. The share of users who have medical home care services in addition to UPA ranges from 30 to 45 per cent in different studies, with an average scope of 12 hours each week (Johansen et al 2010; Gabrielsen & Otnes 2011). Some municipalities still include some health services in UPA (Rambøll 2012). As mentioned above, the Ministry of Health and Care Services noted that there may be good reasons for including simple health services in the UPA arrangement if the municipality finds it proper and expedient (Prop 86L (2013–2014, Circular I-9/2015)). As the Ministry sees it, one guideline could be that what people ordinary do themselves also could be done by an assistant. .

The paragraph about municipal implementation (pp. 20-23) also shows that user organizations fear that moving the legal foundation for UPA from the Social Services Act to the Health and

Care Services Act in 2011 shifted the focus from goals, such as participation and activity, to caretaking of health and care, and that this is reflected in the municipal implementation of UPA (Uloba 2018). In that case, more health services will be integrated in UPA while others are increasingly left out.

User satisfaction

UPA scores very high on user satisfaction. In a study from 2010, 77 per cent of UPA users stated that they were very satisfied with the arrangement (Johansen et al 2010). Including those who answered “fairly satisfied” increased this to 99 per cent. High user satisfaction was confirmed in interviews reported by Ervik et al (2017). The users stressed that the arrangement was very important for them and allowed them to live a freer and more independent life.

In the study by Johansen et al (2010), users were asked to differentiate between aspects of the UPA service and to judge their degree of satisfaction. They differentiated between *relational aspects* (choosing their own assistants, fewer people to relate to, good relationships with assistants); *flexibility in the arrangement* (flexibility related to what tasks the assistants perform and at what times) and *the opportunity for independence* (user control, having an active life, increased equality and quality of life). The results showed mainly that the users were satisfied with most aspects of UPA. The key factors that contributed to high satisfaction were the combination of having good relationships with assistants, flexibility and the opportunity for independence.

Johansen et al (2010) present three different user profiles according to what the users find are the most important aspects of UPA: 1) *ideologues*, who emphasize that they are the experts on their own life and that flexibility of assistance should therefore be maximal; 2) *traditionalists*, who emphasize that “the good life” should be designed in co-operation between users and their assistants; and 3) *rehabilitants*, who primarily seek safety so that services are performed safely by qualified staff. The ideologues formed the largest group (62 per cent); 30 per cent were characterized as traditionalists and 8 per cent as rehabilitants.

Even if the great majority of UPA users are very satisfied and experience few problems, some do experience difficulties and challenges with the arrangement. Some complaints relate to the extent of UPA. In 2010, about 18 per cent were dissatisfied with their total extent of

municipal services (UPA and others) (Johansen et al 2010). However, 82 per cent were satisfied (39 per cent very satisfied, 43 per cent fairly satisfied). Almost half of the users were very satisfied with the composition of their services (UPA and other services); 86 per cent were either very satisfied or fairly satisfied, and only 14 per cent were dissatisfied with the composition. In Ervik et al (2017), some of the interviewed users complained that they received fewer hours than they felt they needed and that this limited their opportunity to live an active life and to participate in society. The 2018 Uloba report gave a similar impression: 24 per cent of those interviewed were not satisfied with the municipal decisions (Uloba 2018). Johansen et al (2010) identified the recruitment of assistants as the greatest problem for users. More than 20 per cent had experienced major problems recruiting assistants and 43 per cent had experienced some problems. However, these figures are somewhat lower than those reported in Guldvik (2003), where 31 per cent and 45 per cent, respectively, were reported. Recruitment problems seemed to be greater when a municipality was the employer than when assistants were employed by a co-operative or the individual user.

Most users (87 per cent) found they could influence the process of recruiting their assistants (Johansen et al 2010). More than half (53 per cent) chose their assistants themselves, 19 per cent made the decision in consultation with relatives or a guardian and 14 per cent made the decision with the employer (municipality/company). Thirteen per cent answered that they did not participate in the employment process because the decision was made by their relatives and/or employer. Thirty per cent of the assistants were recruited from the user's former network, with the majority being recruited by people outside this network. These figures were mainly related to where the municipalities had the responsibility for employment. In Uloba, the principle is that users employ their assistants.

About one in four users described problems related to the administration and control of the arrangement, but only 4 per cent defined the problem as major, and 68 per cent said they had not experienced such problems. The problems seemed to be greater when the municipality had the responsibility for employment. Some of this challenge is related to the special relationship that often arises between users and their assistants, which can become very close. An assistant may be used in many private settings, and users must often accept having this person play such a role in their private life. However, the tendency seems to be that the management role becomes more professionalized over time. While 27 per cent of users saw the relationship with their assistants primarily as a working relationship in 2003, this percentage increased to 35 per cent in 2010 (Johansen et al 2010). Two-thirds of users

described the relationship “primarily as a working relationship” or “more like a working relationship than a friendship”. Only 4 per cent characterized the relationship primarily as a friendship relationship.

Fifteen per cent identified some problems with the planning of the assistants’ tasks, but only 1 per cent rated the problem as major, and 83 per cent said they had no problems with implementation. Nineteen per cent mentioned that their assistants tended to be dominating and took control of the arrangement, but only 1 per cent said this was a major problem and 78 per cent said it was not a problem.

17 per cent of the users were dissatisfied with the guidance the municipalities gave them when they experienced problems and 25 per cent were dissatisfied with the training they received from the municipalities (Johansen et al 2010).

Summary

To summarize the data described above, UPA users constitute only a small percentage of users of municipal welfare services, and slightly more than 3200 people use UPA. The scope of service varies, and the average use is 37.5 hours each week. Most users have social security contributions as their main income, but about one of five have paid work, mostly as part-time work. Although UPA started mainly as a service for people with extensive physical impairments, the target group has become more varied after being extended to those who are not capable of managing the assistance on their own. Disabled children and people with cognitive impairments are also included in the target group. The assistants essentially perform “compensatory services”, that is, services to compensate for tasks the users are unable to do on their own, but they also include “developing services” or services that aim to provide users the same opportunity to live an independent life as non-disabled people. These activities include transportation and leisure time activities. Increasingly, users have UPA as their only service, but many still have medical services performed by the home care services in addition to UPA. Assistance at work is not included in UPA, but the arrangement can indirectly affect the users’ opportunities to participate in education and work. UPA scores very high on user satisfaction, in particular with respect to opportunities for independence, flexibility of the arrangement and the relational aspects of the arrangement.

Municipal implementation of UPA

The implementation of UPA is a municipal responsibility. As noted, since 2011 UPA has been statutory in the Health and Care Services Act. The act is based on a municipal discretionary estimation to determine whether the user qualifies for UPA and the extent the service eventually should have. This basic condition is fundamental in the regulation of the arrangement also after UPA was granted as an individual right for people with “long-standing and high need for personal assistance”, estimated to at least 32 hours per week.

The guidelines from the Ministry of Health and Care Services stated that UPA is not a new service but is an alternative way of organizing practical assistance and that the allocation should be considered in the same way and within the same judicial frames as other services. However, in practice, many users who had other services before they received UPA now have an extension of their services compared with what they had before. Johansen et al (2010) showed that the service scope was extended for more than 60 per cent of users, for which there might be different reasons. One seems to be that age is important and that younger people receive more help than older people. Another possible explanation is the strong emphasis on the UPA goal of contributing to an active life. UPA differs from other municipal services because it emphasizes the provision of help both within and outside the home, which offers a broader spectrum of services than ordinary municipal services. An underlying premise is that users should be capable of living a life similar to that lived by people of their own age who are not disabled. In this way, young people are more likely to be granted extensive assistance to enable them to live an active life. For older people, the attitude is that a more passive life is more common.

Nevertheless, there seems to be a decreasing tendency to treat UPA users differently from users of other municipal services. Even if about 60 per cent of UPA users reported that they had received an extension of their services in 2010, the number was significantly lower than the 90 per cent reported for 2002 (Johansen et al 2010). In 2010, 21 per cent said the scope of their services was the same as before they received UPA, whereas the corresponding percentage was 6 per cent in 2002. In 2010, 17 per cent reported that their scope had decreased, whereas the corresponding percentage was 4 per cent in 2002. In 2010, 46 per cent

of users expressed insecurity about whether they would retain their scope of UPA, whereas the corresponding figure was less than one-third in 2002. In the 2018 Uloba report, 9 per cent of interviewees said that the scope of their assistance had been reduced in the previous 3 years (Uloba 2018).

A review of studies of the municipal implementation of UPA shows that about 15 per cent of the municipalities did not include UPA in their repertoire of services (Askheim 2013). These were mainly small municipalities (with fewer than 10 000 inhabitants). The review concluded that among the municipalities that offer UPA, there is considerable variation in the criteria they use for offering UPA: who is granted service, the extent of UPA and the criteria their decisions are based on. Even though UPA is regulated in the same act, there are differences between “liberal” and “restrictive” municipalities. This variation is manifested as considerable differences in how actively the municipalities inform potential users and market the arrangement. There are also differences in the way municipalities weight the different aspects of UPA. Some placed weight on the ideological aspects of the arrangement (independence, autonomy, user control), whereas others were more concerned with the more practical aspects (service for people in need of practical assistance). Some municipalities saw the arrangement as being particularly well suited for younger people. Rambøll (2012) showed that, in one municipality, there was agreement that UPA would not be granted to people needing fewer than 20 hours of assistance each week.

A 2014 study with a focus on the implementation of UPA indicated that a common tendency was for municipalities to clarify and restrict what should be included in the UPA arrangement (Askheim et al 2014). The clarification could be seen as an attempt to interpret the policy signals from the state but may also reflect the municipalities’ experiences with the arrangement over time and their need to have more control over the arrangement.

Consequently, the municipalities defined distinct criteria for determining who should qualify for the arrangement and what kind of aid should be included. Using these criteria allowed the municipalities to develop clearer guidelines for determining the number of hours. Despite the differences between liberal and restrictive municipalities, a common trait was that they increasingly emphasized the capability to manage the arrangement as a decisive criterion. The tendency to tighten the criteria was also expressed as clearer limits for what should be included in the term “practical aid” and what kind of services should be seen as a municipal responsibility. For areas where the limits between the municipal and private responsibility seemed unclear, many municipalities felt that their practice was too liberal. The study

concluded that variants of UPA are implemented in the municipalities which in different degrees are concerned to accommodate the users' desire to have control over the arrangement.

From the perspective of user organizations, moving the legal foundation for UPA from the Social Services Act to the Health and Care Services Act has shifted the focus from goals such as participation and activity to caretaking of health and care. This movement is reflected in municipal practice (Uloba 2018). As a consequence, assistance for activities outside the home has become less of a focus of UPA.

The studies mentioned above were completed before UPA was made an individual right for people with "long-standing and high need for personal assistance" in 2015. Ervik et al (2017) indicated that this right has not had any significant influence on the number of UPA recipients, given that the number of UPA recipients increased only modestly between 2010 and 2016. In contrast, the average number of hours each week granted for UPA increased considerably from 30.2 hours in 2010 to 37.5 hours in 2016. However, these figures do not reflect whether this change affected the number of people needing fewer than 32 hours per week. Ervik et al (2017) concluded that there is greater variation in municipal practice than originally intended by legislating rights to UPA for some potential users. The municipalities were unclear about what should be included in the rights, which in turn led to different municipal practices.

Consequently, Andersen and Askheim (2019) have warned that a possible negative side effect of the rights as designed is that the legislation will be used by some municipalities to limit UPA and that people with less need will be in a weaker position to be granted UPA. This warning seems to be confirmed because the Health and Social Services Ombudsman report showed that some municipalities tend to stipulate the users' needs in a way that makes them fall outside the minimum criteria for being included in the rights legislation and these people are then offered other kinds of practical assistance (Uloba 2018).

The tendency to tighten the scope of UPA may reflect a municipal fear that the costs of UPA will be too high. In a 2018 study of the municipalities, the growth in municipal expenses to fund UPA from 2014 to 2016 was estimated as 22 per cent (Agenda Kaupang 2018).

Mitt Liv (2010) reported that 41 per cent of municipalities characterized UPA as an expensive service, in contrast to 32 per cent who disagreed. When the target group for UPA was extended in 2005, the Norwegian Association of Local and Regional Authorities also expressed worries about the economic consequences of the extension; the organization

repeated and reinforced these worries when UPA became an individual right for some potential users in 2015 (Uloba 2018). However, the municipal expenditure for UPA constitutes only 4.5 per cent of their expenditures for home-based services.

The tightening of the criteria to grant UPA may also reflect the desire of the municipalities to offer more equal treatment for different user groups when the aid is meted out. Some municipalities consider the UPA arrangement as unfair because some users receive assistance for some activities and others do not, or they have to pay for the aid themselves. Furthermore, some municipalities believe that some UPA users rather should receive other services. In the report from Agenda Kaupang (2018), the municipalities noted that they did not change their practice after UPA became an individual right for some users. However, they admitted that it was challenging when the state guidelines gave conflicting signals, for example, where the guidelines note the user's right to control his/her services at the same time as emphasizing that the scope of services should be the same as if UPA had been granted as an ordinary municipal service.

Summary

In summary, despite the wide variations in the implementation practice between municipalities, the main picture seems to be that the municipalities are concerned about restricting and clarifying what UPA should include. They fear that municipal costs will increase to an unacceptable level and that other user groups may be treated less generously than UPA users, leading to unfairness. The criteria for what should be included in the term "practical assistance" are restricted, and the weight put on the user's capability to take care of the management responsibility is increasing. It appears that UPA is increasingly being treated more like other municipal services. This tendency shows that municipalities are making efforts to tackle the inherent tensions in the UPA arrangement between goals such as independence, participation and user control, and the authorities' wishes and needs both to control the costs to welfare services and to secure quality in the services and equality between different user groups.

Complaints to the county governor

As noted, the decisions about the provision of UPA in accordance with the Health and Care Services Act are made according to municipal discretionary estimation about whether the users qualify for UPA and the extent the service should have. Users who are dissatisfied with the decisions and believe these to be unreasonable or illegal have the right to complain to the county governor.

The municipalities give three main reasons for rejecting applications (Agenda Kaupang 2018). First, they may find the user's need for help to be too small to be organized efficiently as UPA. An aspect of this argumentation is that these users mainly need services that can be performed quickly and that it is impossible to recruit assistants for such short visits. Second, the user may not be regarded as capable of acting as the manager of his/her assistants. Third, the user's health condition may be considered to be sufficiently weak that it is not seen as appropriate to organize UPA.

In a study of the complaints made in 2001–2003, Begg (2006) found a clear increase in the number of complaints involving rejection of the request for UPA and the number of hours granted, with this latter complaint increasing the most. There were more complaints related to UPA than to the more established municipal services such as home help. Comparing the number of recipients of home help, only 1 per cent complained to the county governor in 2001–2003, whereas 8 per cent of UPA applicants complained. From 2003 to 2013, the number of complaints about UPA did not change much and was slightly lower than in 2001–2003 (on average 5.4 per cent of the number of UPA applicants) (Askheim et al 2014).

There was a stronger tendency for the number of complaints to increase after UPA became an individual right for people with extensive and lasting needs in 2015. From 2014 to 2015, the number of complaints increased 34 per cent, and this high level of complaints continued in 2016 (Ervik et al 2017). This percentage is significantly higher for UPA than for other health and care services.

In Begg's (2006) study, from 2001 to 2003, about 60 per cent of the municipal decisions were confirmed, and this number increased to 68 per cent in 2012–2013 (Askheim 2013). It seems that the county governors were careful not to overrule the municipal decisions. Still, the number of decisions that were changed after a complaint increased during the period, but the studies also showed large differences between different county governor offices. A more recent study indicates that a higher percentage of decisions are changed after a complaint. For

example, although 30 per cent of complaints were accepted completely or partly in 2013, this percentage increased to 45 per cent in 2015 and 40 per cent of complaints were accepted or sent back to the municipalities for reconsideration in 2016 (Helsetilsynet 2017).

In Norway, there is a system of Health and Social Services Ombudsmen in the counties who work to safeguard users' needs and interests, and to enforce the rule of law in relation to the authorities. From 2013 to 2016, this service registered an increase of more than 70 per cent in the number of inquiries about UPA (Uloba 2018).

Personal assistants

Data from 2010 show that UPA users had, on average, slightly more than three assistants, (Johansen et al 2010), which means that nearly 10 000 assistants are employed at present. In 2001, the vast majority of assistants (85 per cent) were women (Guldvik 2001). There is no up-to-date information about the distribution of men and women working as personal assistants. However, this percentage is similar to that in the care sector in general (NOU 2012:15). The average age of assistants in 2001 was 39 years, and 56 per cent were aged 18–30 years. About 40 per cent had an educational background in health and care.

Personal assistance is mainly part-time work. A 2013 study showed that only 14 per cent of assistants worked full time, 34 per cent worked 14–29 hours a week and 53 per cent worked less than 14 hours each week (Guldvik & Andersen 2013). Comparison with 2001 data indicates that the percentage of assistants with short-term appointments has increased. Guldvik & Andersen (2013) suggested that this might be because many users are interested in maximal flexibility in their UPA arrangement.

Most assistants combine the job as personal assistant with other activities. Guldvik (2001) reported that 30 per cent combined assistant work with other kinds of health and care work, 20 per cent combined it with other paid work and 10 per cent with housework; 15 per cent combined assistance work with studies and 30 per cent did not specify whether they combined assistance work with other activities. A more recent study of assistants employed by Uloba showed that 20–30 per cent of assistants combined assistant work with studies and a corresponding percentage with other paid work (Guldvik & Andersen 2013).

Most personal assistants are paid as unskilled care workers (Guldvik & Andersen 2013). Seniority is added when their payment is calculated and, in a few cases, qualifications are

considered. The payment level is about the same in municipalities and co-operatives/companies.

Guldvik (2001) reported a high turnover among assistants. The average time of employment was 1 year and 7 months, and 45 per cent had been employed by their current user for less than 1 year, and about the same percentage had been employed for 1–3 years. Only a small percentage had been employed by their present user for more than for 3 years.

In response to the question whether they imagined they would work as a personal assistant for the next 2–3 years, 25 per cent said that they had plans to leave their job, and 40 per cent answered “do not know”. These figures are considerably higher than for other groups of municipal health and care workers.

The Norwegian Working Environment Act, which relates to working environment, working hours and employment protection, states that permanent employment should be the normal employment condition, but that temporary employment could be agreed when the job characteristics warrant it, and the work is separate from what is usually performed in the organization. Guldvik (2001) reported that 53 per cent of assistants answered that they were employed permanently, 15 per cent had been employed temporarily for more than 6 months and 8 per cent for less than 6 months. Guldvik and Andersen (2013) showed that the municipalities operate with different work agreements. Many municipalities make use of permanent employment, but many are also sceptical about giving assistants permanent employment because of the obligation to ensure other compatible work in the municipality if the present employment ends. Some municipalities therefore make use of “assignment agreements”. Those working on “assignment agreements” are not considered employees according to the Working Environment Act, but have an agreement to perform some defined work tasks. In 2009, almost 1000 personal assistants were reported to be working on assignment agreements (Guldvik & Andersen 2013).

Although co-operatives such as Uloba say that their assistants are permanently employed (Guldvik & Andersen 2013), this does not mean that they have what is traditionally thought of as permanent employment. Assistants are formally employed at the co-operative/company, but in reality, they are employed by their manager (i.e., the UPA user). If the arrangement ends, the assistant loses his/her job. The co-operative/company will help the assistant apply for a new job, but it is the individual user who decides who is to be employed. The conclusion

is that, in practice, many assistants do not have permanent employment according to the traditional meaning.

An issue that has attracted increasing attention is the growing proportion of assistants from an ethnic background other than Norwegian. This is especially true in the large municipalities, as well as in co-operatives and companies. Guldvik & Andersen (2013) reported that in one municipality investigated, 36 per cent of the employed municipal assistants had a non-Norwegian ethnic background. Among co-operatives and private companies, the percentage ranged from 9 to 54 per cent.

How do assistants experience their work situation?

Personal assistance is a profession with distinctive features. Assistants work closely with one person and spend much time with this individual over a long time and in varied situations. Because of the user's need for assistance, the assistant is often involved in the user's private life. The work can seem to be lonely because assistants are not part of a larger group of colleagues. However, in a study of assistants, Guldvik (2001) found that they were mainly satisfied with their work. Four out of five assistants answered that they were content or very content with their work situation, and they mainly considered the co-operation between them and their managers positively. The circumstances they were least satisfied with were that they wanted an extended position (15 per cent), they lacked security in their employment (20 per cent) and they received wages that were too low (31 per cent).

A recent master's thesis highlighted assistants' experience of loneliness and isolation as employees (Enger & Skurdal 2019). Although the scope of this study was limited to interviews with a few assistants, they complained about feeling lonely in their daily work and about the lack of a network of colleagues. They missed having a common location where the assistants could meet. Most of them knew little about what the other assistants were doing when they were at work. Because of a lack of transparency in their work situation, they felt they could more easily be exposed to exploitation.

The distinctive work of the personal assistant brings about tensions. In many ways, the traditional power relationship between the service user and the service provider are interchanged. Assistants may perceive that the emphasis placed on user control compromises their autonomy and professional responsibility, and the user's wish for flexibility might be at

the expense of the employee's opportunity for self-determination and responsibility for his/her work situation. Guldvik (2001) reported that 15 per cent of assistants noted such problems. However, this may also relate to the assistants' experience that some users perform their role as manager in a rather vague way. Three out of four assistants in Guldvik's study stated that the user had the main responsibility or a partial responsibility for deciding the tasks that should be done; at the same time, one out of five assistants perceived the user to be passive when decisions were needed about which tasks should be undertaken. Mostuen (2010) noted that assistants found that trying to identify what the user really wanted was a challenge, while at the same time, they were concerned that they should not take more initiative than agreed with the user. They emphasized the large differences between users and that not all are ready to take on the management role. In practice, the decision process is characterized by negotiations in which the assistants feel they must balance being too active and directive in the process required to identify the user's wishes. Assistants perceived the handling of this dilemma as complex.

Another issue is connected with the close relationship that often develops between assistants and users. Some of the assistants in Guldvik's study (2001) felt that users involved them too much in their private life and in issues that were not related to the assistant's role. Others felt ignored when with the user's friends and acquaintances or felt uncomfortable in situations involving the user's family. Such tensions may also reflect difficulties in distinguishing the role as a service provider/assistant from that as a friend. In Guldvik's study, 45 per cent considered the relationship with the user as mainly a working relationship, while 43 per cent described it as a combination of a working relationship and a friendship. As noted, later studies of users have reported an increasing tendency for the relationship to be perceived as a work relationship over time (Johansen et al 2010). Although 27 per cent of users answered that the relationship was mainly a working relationship in 2002, this percentage had increased to 38 per cent in 2010.

Falch (2010) described personal assistance as a profession characterized by "emotional work". This means that the relationships with other people are close and personal, and that the service provider elicits an emotional state in another person, at the same time as he/she must control his/her own emotions. The assistants in Falch's study found the emotional work they performed as part of their assistance work to be the greatest challenge. They felt they were closely involved as individuals and were expected to provide service to a manager who was

dependent on their help. The work was seen as meaningful but at the same time, it could be exhausting. The absence of colleagues added to the stress.

Because of these tensions, assistants emphasized the importance of receiving supervision and guidance in their job about how their role should be performed. In Guldvik's study (2001), 40 per cent specified that they did not receive any supervision or guidance. Johansen et al (2010) reported that the situation later seemed to have improved, but 25 per cent of the users still were dissatisfied with the guidance and training the municipalities gave to their assistants. The users connected to Uloba were more satisfied than those who had the municipality as the employer of the assistants.

The recent study by Enger and Skurdal (2019) indicated that assistants still perceive a lack of supervision and guidance. The assistants complained of having few possibilities to take courses and receive guidance and that this reinforced their feelings of isolation. The lack of training and guidance from the municipalities was also highlighted in the 2018 study of municipalities (Agenda Kaupang 2018). The responsibility to follow up assistants as employees is too often left to the users as managers of their UPA.

Summary

In summary, personal assistance appears to be a part-time job populated mainly by women. Many assistants combine assistance work with other work, studies or other activities. Most of the assistants are paid as unskilled care workers, and turnover is high. About half of the assistants are permanently employed, but many municipalities are reluctant to give them permanent employment. If the present employment of an assistant should end, municipalities are obliged to provide other compatible work. Most assistants are mainly satisfied with their job, but they also experience tensions and dilemmas from working so closely with users and often being involved in a user's private life. Some assistants experience loneliness and isolation in their work. They also miss better opportunities to participate in courses and receive supervision and guidance.

UPA: Success, but with inherent tensions

Especially because of the very positive feedback from users, UPA must be characterized as a success. The arrangement seems to fulfil the goals of greater independence and participation for users. However, UPA increasingly appears to be an arrangement with inherent tensions. That is, there are tensions between the different goals within the arrangement, and these tensions has become more pronounced as the arrangement becomes more established. A major tension is between the ideological goal of seeing UPA as a tool for liberation expressed in goals such as independence, participation and user control on the one hand, and the authorities' wish and need to control the costs of welfare services and to secure quality in the services and equality between different user groups on the other. Some concrete expressions of the tensions are reflected in questions such as, "What should be the criteria to get UPA and how should the content be defined?", "What kind of assistance should be included and what should be the limits for the service?", "What should be the legal foundation for the arrangement?", and "How should the demand to manage the arrangement be interpreted and who should decide the employment responsibility?"

Ambivalence and conflicting signals characterize the official state policy and have resulted in different interpretations of what UPA should involve and how these are translated to municipal practices. More pragmatic versions are now gaining ground, and UPA is increasingly measured using the same standards as other municipal welfare services and as user control is realized.

These tensions have been acknowledged by the government. In September 2019, the government appointed a broad public commission to consider and provide suggestions about how UPA can better fulfil its intentions (Regjeringen.no 20.09.2019). The background is the apparent gap between the judicial regulations and expectations about what is possible within the actual framework for the arrangement. The government states that there seems to be a gap in the degree to which different actors perceive and experience how the municipalities meet the judicial claims and intentions of the UPA arrangement.

More concretely, the commission has as mandate to consider and suggest how UPA can better fulfil the goals of equality, equal opportunity regardless of place of residence, participation in society for disabled people, good working conditions for assistants and the sustainability of the arrangement. UPA should be defined as a tool for fostering equality and not as a health service. The commission shall look more closely at how UPA can be organized to secure

participation by people with disabilities in work, studies and leisure time activities. As part of this, the commission shall consider relevant and adjoining assistance arrangements in other arenas such as work life and education.

It is explicitly noted that at least one of the commission's suggestions should be implemented within the existing budget frames of the public sector.

The commission shall further consider and provide suggestions about how the arrangement should be designed to secure real user control while avoiding conflict with the responsibility of the public authorities. The commission shall discuss and identify which user groups should be included in UPA.

Finally, the commission has been asked to examine the basic tensions associated with UPA, as described in this report. Whether and how the commission will solve the dilemmas and clarify the considerations and suggestions will become evident only with time. The report from the commission is to be delivered on 1 October 2020.

References

- Agenda Kaupang (2018): *Notat om BPA*. [Note about UPA] Oslo: Kaupang.
- Andersen, J. & Askheim, O.P. (2019): «Behov for å tenke nytt?» [Time to think new?]. *Dagsavisen* 23.09.
- Askheim, O.P. (2013): *Brukerstyrt personlig assistanse – Kunnskapsstatus*. [User-controlled personal assistance – status of knowledge] Forskningsrapport nr. 157, Høgskolen i Lillehammer.
- Askheim, O.P.; Andersen, J.; Guldvik, I.; Jenhaug, L. & Begg, I.S. (2014): *Brukerstyrt personlig assistanse – statlig policy, kommunal implementering og klagesaker*. [User-controlled personal assistance – state policy, municipal implementation and complaints]. Forskningsrapport nr. 162, Høgskolen i Lillehammer.
- Begg, I.S. (2006): *Nytter det å klage? Fylkesmannens behandling av klager vedrørende brukerstyrt personlig assistanse*. [Is it of use to complain? The county governor's treatment of complaints about user-controlled personal assistance]. Forskningsrapport nr. 127, Høgskolen i Lillehammer.
- DeJong, G. (1983): "Defining and Implementing the Independent Living Concept". I N.M. Crewe and I. K. Zola (eds.): *Independent Living for Physically Disabled People*. Jossey-Bass Publishers, San Fransisco.
- Econ Pöyry (2010): *Borger-/brukerstyrt personlig assistanse i et samfunnsøkonomisk perspektiv*. [User-controlled personal assistance in an economical perspective] ECON-rapport 2010-026, Oslo: Econ Pöyry.
- Enger, P.I. & Skurdal, G. (2019): «Glemmer vi assistentene?» [Do we forget the assistants?] *Klassekampen* 12.09.
- Ervik, R.; Kjerstad, E.; Skogedal Lindén, T. & Rubecksen, K. (2017): *Rettighetsfesting av BPA – store forventninger, betinget suksess*. [Securing rights to UPA – big expectations – contingent success]. Rapport nr. 2, UniResearch Rokkansenteret, Bergen.
- Falch, W. (2010): *Står til tjeneste. Emosjonelt arbeid i tjenestemøtet*. [Ready to service. Emotional work in the meeting with the services]. Karlstad University Studies 2010:23, Karlstad.
- Gabrielsen, B. & Otnes, B. (2011): *Brukerstyrt personlig assistanse (BPA). Statistikk om mottakerne på grunnlag av IPLOS-data for 2009*. [User-controlled assistance – statistics]. Oslo-Kongsvinger: Statistisk Sentralbyrå.
- Guldvik, I. (2001): *Mellom brukerstyring og medbestemmelse – Å jobbe som personlig assistent*. [Between user control and participation – working as personal assistant]. ØF-rapport nr. 4, Lillehammer: Østlandsforskning.

Guldvik, I. (2003): *Selvstyrt og velstyrt? Brukernes erfaringer med brukerstyrt personlig assistanse*. [Users experiences with user-controlled personal assistance]. ØF-rapport 03/2003. Østlandsforskning: Lillehammer.

Guldvik, I. & Andersen, J. (2013): *BPA – trekk ved kommunal saksbehandling, arbeidsgivernes tilrettelegging og assistentenes arbeidsbetingelser*. [UPA – traits with the municipal implementation and the assistants' working conditions]. Forskningsrapport nr. 156. Høgskolen i Lillehammer.

Guldvik, I. & Askheim, O.P. (in review): "Constructing User Participation for Disabled People – The Norwegian Context". In review for publication in *Scandinavian Journal of Disability Research*.

Helsetilsynet (2017): *Statistikk* [Statistics] 03.04.2017.

Innst. [Recommendation] O. nr. 22 (1999-2000): *Innstilling fra sosialkomiteen om lov om endring i lov av 13. desember 1991 nr. 81 om sosiale tjenester mv. (brukerstyrt personlig assistanse)*. [Recommendation from the Parliamentary social committee] Sosialkomiteen i Stortinget 2. desember 1999.

Jenhaug, L. & Askheim, O.P. (2018): "Empowering Parents as Co-producers: Personal Assistance for Families with Disabled Children". *Scandinavian Journal of Disability Research*, 20(1), pp. 266–276. DOI: <https://doi.org/10.16993/sjdr.57>

Johansen, V.; Askheim, O.P.; Andersen, J. & Guldvik, I. (2010): *Stabilitet og endring – Utviklingen av brukerstyrt personlig assistanse*. [Stability and change – The development of user-controlled personal assistance]. Forskningsrapport nr. 143, Høgskolen i Lillehammer.

Kjønstad, Asbjørn og Syse, Aslak (1997): *Velferdsrett* [Welfare law]. Ad Notam Gyldendal.

Kuhnle, S. (2001): «Velferdsstatens idegrunnlag i perspektiv», [The ideological foundation of the welfare state in perspective] in Kuhnle, S.; Hatland, A. & Romøren, T.I. (eds.): *Den norske velferdsstaten*. [The Norwegian welfare state] Oslo: Gyldendal Akademisk.

Mitt Liv (2010): *Kommunestyrt personlig assistanse? En rapport om variasjoner i kommunenes håndtering av ordningen med Brukerstyrt Personlig Assistanse – BPA*. [Municipal controlled personal assistance? A report about the municipal handling of user-controlled personal assistance – UPA]. Oslo.

Mostuen, B. (2010): *Det er jo du som må bestemme... En kvalitativ undersøkelse om personlige assistenters arbeid for å fremme selvstendighet*. [It is you who must decide. A qualitative study of the assistants work to promote independence]. Masteroppgave. Oslo: Høgskolen i Oslo.

Mørk, E.; Beyrer, S.; Haugstveit, F.V.; Sundby, B. & Karlsen, H.K. (2018): *Kommunale helse- og omsorgstjenester* [Municipal health and care services 2017]. Oslo: Statistics Norway.

Norges Handikapforbund (1994): *Brukerstyrt personlig assistanse. Erfaringer fra et forsøksprosjekt*, [User-controlled personal assistance. Experiences from a pilot project]. Oslo.

- NOU 2012:15: *Politikk for likestilling* [Policy for equality] Official Norwegian Report.
- Ot. prp. nr. 8 (1999-2000): *Om lov om endring i lov 13. desember 1991 nr. 81 om sosiale tjenester mv. (brukerstyrt personlig assistanse)*. [About change in the law 13. December 1981 about social services (user-controlled personal assistance)]. Sosial- og helsedepartementet.
- Prop. [Proposal] 91 L (2010–2011): *Lov om kommunale helse- og omsorgstjenester m.m. (helse- og omsorgstjenesteloven)*. [Law about Health and Care Services]. Oslo: Helse- og omsorgsdepartementet
- Prop. [Proposal] 1S (2011-2012) *Proposisjon til Stortinget* [Proposition to Parliament] Oslo: Helse- og omsorgsdepartementet.
- Prop. [Proposal] 86L (2013-2014): *Endringer i pasient- og brukerrettighetsloven (rett til brukerstyrt personlig assistanse)*. [Changes in the Patient and User Rights Act (right to user-controlled personal assistance)] Oslo: Helse- og omsorgsdepartementet.
- Rambøll (2012): *Kunnskap om behov for og tildeling av brukerstyrt personlig assistanse*. [Knowledge about the need for and the allocation of user-controlled personal assistance]. Oslo: Rambøll.
- Regjeringens handlingsplan for funksjonshemmede 1994-1997 [The Government's action plan for disabled 1994-1997]
- Regjeringen.no (2019): *BPA-ordningen skal gjennomgås og forbedres*. [UPA shall be investigated and improved] 20.09.
- Romøren, T.I. (2018): "Funksjonshemmede" [Disabled], In Hatland, A., Kuhnle, S. & Romøren, T.I. (eds.): *Den norske velferdsstaten* [The Norwegian welfare state]. Oslo: Gyldendal.
- Rundskriv [Circular] I-15/2005: *Brukerstyrt personlig assistanse (BPA) – utvidelse av målgruppen* [User-controlled personal assistance – UPA – extension of the target group]. Helse- og omsorgsdepartementet.
- Rundskriv [Circular] I-15/2015: *Rettighetsfesting av brukerstyrt personlig assistanse (BPA)* [Securing of rights for user-controlled personal assistance]. Oslo: Helse- og omsorgsdepartementet.
- St. meld. [White paper] nr. 88. (1966-67) *Om utviklingen av omsorgen for funksjonshemmede* [The development of care services for disabled people].
- St. meld. [White paper] nr. 34 (1996-97): *Resultater og erfaringer fra regjeringens handlingsplaner for funksjonshemmede og veien videre* [Results and experiences from the Government's action plans for disabled and the way forward]. Sosial- og helsedepartementet.
- Uloba (2018): *Mitt liv – mitt ansvar* [My life – my responsibility]. Uloba.
- Ungerson, C. & Yeandle, S. (eds.) (2007): *Cash for Care in Developed Welfare States*. Hampshire: Palgrave MacMillan.

Van Hauwermeiren, J. & Decruynare, E. (2009): *Direct Payments in the Care. Current Situation in 8 European Countries*. Gentbrugge: Expert Centre Independent Living.

Åström, K. (1998): «Funktionshindrade mellan SoL och LSS» [Disabled between SoL and LSS.]. In Bengtsson, H. (ed.): *Politik, lag och praktik. Implementeringen av 1994 års handikappreform*. [Policy, law and practice. The implementation of the handicap reform of 1994]. Lund: Studentlitteratur.



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In accordance with the Consortium Agreement between the University of Warsaw and the Inland Norway University of Applied Sciences, this report explains “The Norwegian system of support for people with disabilities in pursuit of independent life, including the system of assistants for people with disabilities”. The report is the first of two. The other will discuss more specifically “The Norwegian personal assistance services for people with disabilities in the work environment”.

This report intends to provide a solid overview of the support system and discuss current developments in the area. The data are based on studies of official documents and previous research on the topic.