

Personal Assistance in Sweden and Norway: From Difference to Convergence?

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ABSTRACT *Within the same welfare state model, Norway and Sweden have established very different models for personal assistance. Sweden has developed a model with a strong consumerist profile with extensive rights and choices for users. In Norway, state control of the arrangement has been stronger. Users' rights have been weaker and decisions are left to the discretion of the professionals in the welfare services. Recent political signals in both countries indicate that the models might converge in the future. In Sweden, authorities are worried that users' rights have become too extensive. Efforts have been made to restrict users' rights and to make public control stronger. In Norway, the target group for the arrangement has been extended and stronger individual rights to obtain personal assistance are proposed. The article will clarify the tendencies in the two countries and discuss the consequences – for the arrangement and for the users' control over their assistance.*

KEYWORDS: Personal assistance, different models, user control

Introduction

In personal assistance different discourses are unified. Pearson (2000) has characterised personal assistance as a mix between a social justice discourse and a liberalist market discourse. Radical trends among disabled people seeing themselves as suppressed and discriminated against are merged with market-based trends characterised by consumerism and the freedom to choose as fundamental principles. As a consequence, personal assistance is applauded both by the left and the right in the political landscape. However, actors may have very different agendas for supporting the arrangement, as personal assistance is filled with tensions. Different ways of organising personal assistance arrangements can therefore be seen as efforts to unite the different trends in various ways.

Within the same welfare state model, the neighbouring countries Norway and Sweden have established very different models for personal assistance. Sweden has developed a model with a strong consumerist profile with extensive

rights and choices for the users. The arrangement is primarily organised as direct payments, at least for the users with extensive need for assistance. Private companies as well as municipalities and user controlled cooperatives offer personal assistance. In Norway, in contrast, state control of the arrangement has been much stronger. Users' rights have been weaker and decisions are left to the discretion of the professionals in the welfare services. The arrangement is presented as an alternative way of organising public social services. As a rule, users should be able to act as manager for his/her assistants to obtain the service. However, recent political signals in both countries indicate that the models might converge in the future. In Sweden, the authorities are worried that the users' rights have become too extensive. Efforts have been made to restrict users' rights and to make public control stronger. In Norway, the target group for the arrangement was recently extended and stronger individual rights to obtain personal assistance have been proposed.

This article will clarify the different tendencies in the two countries and discuss the consequences of the arrangement and of the users' control over their assistance. As a background for the discussion, it is necessary first to describe in some detail the different models of personal assistance in the two countries before the new reforms.

Personal Assistance in Norway and Sweden

Strong Individual Rights in Special Acts versus Integration in the Ordinary Social Services Act

The history of personal assistance in Sweden goes back to 1986 when the user controlled cooperative STIL (The Stockholm Cooperative for Independent Living) was established. Cooperatives in other cities followed in the years to come. In 1994, two particular acts were passed where personal assistance was established as an individual right for persons who qualified for the service (*Lag om stöd och service til vissa funktionshindrade* (LSS) – “The act concerning support and service to certain groups of disabled people”; and *Lag om assistansersättning* (LASS) – “The act concerning assistance and compensation”).

The primary aim of both acts was to secure persons with extensive impairments better opportunities to live independent lives. Three groups of disabled people obtained individual rights to personal assistance: (1) persons with learning disabilities, people with autism or conditions similar to autism; (2) persons with considerable intellectual disabilities/learning disabilities as a result of a brain injury in adult age (acquired brain injury); and (3) persons with other major and permanent disabilities which cause considerable difficulties in their daily life and as a consequence of this have a considerable need for supporting services and where the disability is not caused by the normal process of ageing (Socialstyrelsen 1997). Persons belonging to either of these categories got an absolute right to personal assistance. No conditions were placed on the users' abilities to manage the service.

In Norway, personal assistance was enacted later. In 2000, the arrangement was included in the Social Services Act. Personal assistance at that time had a

10-year history in the country as the first experiments started in the early 1990s, initiated by the national association of persons with physical disabilities (Norges Handikapforbund 1994). In the commentaries to the Social Services Act personal assistance was described as “an alternative organisation of practical and personal help for people with comprehensive disabilities with need of assistance in their day to day life, both within and outside their own homes” (Ot. prp. no. 8 1999–2000:1). Even if the Social Services Act generally emphasises that the services are to consult the user and attach importance to his/her preference, in the end the municipality has the final word about which services are the most appropriate for the users. In this way, the rights of the users are considerably weaker than in the Swedish acts. Personal assistance is not limited to certain categories of disabled people in Norway. Until 2005, the decisive criterion for being entitled to the arrangement was the user’s ability to act as manager for his/her assistants. Before a person is granted the service the user is assessed by representatives for the municipality, who should evaluate whether the user is sufficiently competent as manager of his/her assistant and whether personal assistance is seen as the most appropriate service to cover his/her needs for care and help. As a consequence, very few persons with intellectual impairments were granted personal assistance.

Different Financial Solutions

The main reason for the authorisation of personal assistance in two different acts in Sweden is a separation of the financial responsibility for the arrangement. LSS services are a municipal responsibility, while LASS was originally established as a solution to relieve the municipalities of the costs of users with extensive needs for assistance. Placing the responsibility for these users on the national level, the intention was to ensure that personal assistance should not be dependent on municipal financial priorities. From the start, municipalities were responsible for financing assistance for users with a need for assistance up to 20 hours each week, while the arrangement was fully financed by the national authorities for users with more extensive needs. However, in 1997 this principle was changed, and national authorities now pay for assistance exceeding 20 hours a week.

In Norway, personal assistance is exclusively a municipal responsibility. However, to stimulate the municipalities to implement the arrangement, national authorities offer support for a period of three years to cover additional costs for the municipalities when the arrangement is introduced to a new user. However, the amount is rather low: 100,000 Norwegian Kroner (approximately € 12,500) the first year, and NOK 50,000 the next two years.

The Prevalence of Personal Assistance

The different principles for organising personal assistance influence the prevalence of the arrangement. There are more than 10 times as many users in Sweden as in Norway (16,000¹ and 1500, respectively; see Andersen,

Askheim, Begg & Guldvik 2006, SOU 2005:100). Compared to the total number of inhabitants in the two countries 1.78 per 1000 inhabitants have personal assistance in Sweden, while the corresponding number for Norway is 0.24 (Edebalk & Svensson 2005). The diversity of impairments is also much wider in Sweden. While 35% of the Swedish users are classified as belonging to category 1 (persons with learning disabilities, people with autism or conditions similar to autism), only 4% of the Norwegian users are classified as persons with intellectual impairments (Guldvik 2003, SOU 2005:100). The majority of the Swedish users also receive considerably more hours of personal assistance than the Norwegian users do. LASS users, who constitute 75% of the Swedish users, receive on average 97 hours of assistance each week, while the Norwegian users receive 36 hours each week (Guldvik 2003, SOU 2005:100).

Employers' Responsibility

In both Sweden and Norway, either the municipality, a user-led cooperative, or the user him- or herself can assume employers' responsibilities for personal assistance. In Sweden, private companies can also employ personal assistants, while Norway has not opened up for private, commercial actors. The number of persons who prefer to assume employers' responsibilities is very small in both countries. The municipality is the main employer (Guldvik 2003, SOU 2005:100). Still, both in Sweden and Norway the position of the municipalities has been weakened, as cooperatives, and in Sweden especially private companies, have strengthened their position. The share of the users who left employers' responsibilities to private companies increased from 14 to 23% in the period 1994–2004 (SOU 2005:100). The cooperatives' share in Sweden remained relatively stable in the same period and in 2004 recruited 12% of the users. In Norway, there is only one user cooperative, and in 2002 it recruited about 25% of the users (Guldvik 2003). Studies from both countries indicate that users regard user control as better in the cooperatives than when the municipalities are the employer (Guldvik 2003, Larsson & Larsson 1998). In Sweden, private companies also score higher on user control. It seems like it is more difficult for the municipalities to hand over the responsibility and control to the users (Andersen *et al.* 2006).

Direct Payments or Alternative Service?

In Sweden, personal assistance is primarily carried out as direct payments. LASS users receive personal assistance exclusively as direct payment, while personal assistance according to LSS can be delivered both as a service and as direct payments. As mentioned, 75% of the users are offered personal assistance authorised through LASS and these are the users in need of the most comprehensive assistance. The arrangement's primary character as a cash allowance is reinforced as the users can freely choose employer for their assistants. The character of direct payments was further reinforced when the costs of personal assistance became standardised in 1997

(Riksförsäkringsverket 1999). The costs are covered by the same hourly rate for all the users.

In Norway, personal assistance has primarily been defined as an alternative organisation of services, and it is emphasised that the arrangement should be seen in combination with other municipal services. The guidelines of the Social Services Act state that the municipality has the right to choose the employer in each case. Finally, the municipality is responsible for making provisions for the basic training of the assistants, irrespective of who is the employer.

Different Solutions – Remaining Dilemmas

Comparing the different solutions of personal assistance in the two countries, the first impression is that the Swedish model seems to fulfil the goals of user control and empowerment better than the Norwegian version does. More users are granted personal assistance in Sweden and most of them receive more hours of assistance than do the Norwegian users. More hours give better opportunities to utilise the flexibility of the arrangement. The possibility of adjusting the assistance to personal needs will improve and user control will be easier. Studies of Norwegian users indicate that users with the most hours of personal assistance are more satisfied and have the best control of the arrangement (Guldvik 2003). Further, the consumerist profile of the Swedish arrangement is consistent with how disabled activists and organisations of disabled people want personal assistance organised (Oliver & Barnes 1998, Barnes, Mercer and Shakespeare 1999). The users have strongly advocated that personal assistance be given as an individual right for persons who prefer the arrangement and that it should be organised as direct payments in order to liberate them from dependence of the service.

However, in practice it is an open question as to whether the Swedish model always attends to user control in the best way. A more precise description would probably be that the different solutions in the two countries in different ways illustrate dilemmas and tensions of the personal assistance arrangements. One dilemma is the strength of the ideological profile of personal assistance. When great importance is attached to users' rights to control the arrangement, the users' ability to act as employers is fundamental. At the same time this will restrict the target group for personal assistance. On the other hand, more pragmatic solutions would include a wider group of users, and one consequence might easily be that the ideological basis of personal assistance will fade and be eroded. One important consequence for personal assistance in Sweden seems to be that pragmatic solutions are gaining ground, especially in cases where the municipality is the employer (Lewin 1998, Socialstyrelsen 1997). As a consequence, the difference between the models and the traditional home based services has been reduced (Larsson & Larsson 1998). The user organisations see such a tendency as a serious threat to the arrangement (Bengtsson 1998).

On the other hand, one consequence of the Norwegian requirement of users to be able to act as a manager for the assistants has been that several

groups are excluded from an arrangement that seems to give much better opportunities than ordinary services for the users to gain influence and autonomy. A Norwegian study of personal assistance among people with intellectual disabilities shows that personal assistance offered much better opportunities for user influence than the ordinary services (Askheim 2001a). It offered better opportunities for flexibility, predictability and individual solutions. The capability to act as manager for the assistants, being a condition to qualify for personal assistance, could accordingly lead to the arrangement becoming a solution for the “élite” among disabled people, while other disabled persons are left with the routines of the ordinary services.

The Swedish arrangement has been criticised for being based on the idea that the user is always a competent and rational actor. The user is seen as having the qualifications and competence to choose the best solutions for her/his needs. This conception of the assistance users as always competent and well informed is criticised as illusory. The critics are especially concerned that the special needs of weaker groups among the disabled are ignored and made invisible (Caruso 1999, Sundran 1994). In other words, the question is whether there is a discrepancy between the basic assumptions of the model requiring user competence, and the competence that users actually possess. From such a position it would be relevant to ask whether the Swedish arrangement favours disabled people who are able to successfully present their interests, to exert a “rebellious influence” (Barron *et al.* 2000, Lewin 1998). Since personal assistance is authorised as an individual right, one consequence is that the disabled person has to be active to get the service (LSS §8). Consequently, public reports have raised the question of whether persons who are not able to speak for themselves or do not receive assistance from their relatives receive less satisfactory public support than they ought to (Riksförsäkringsverket 2002:8).

If so, the question is whether some users are denied the qualified help they need (Askheim 2001b). Some users might need treatment or rehabilitation rather than personal assistance. Critics are worried that some users might become passive and lose functional skills because they are not granted the services they need, or that demands are not made of them from the assistants in fear of undermining the users’ right to self-determination. If users do not express wishes for leading a different or more active life, the assistants might find it difficult to intervene even when they wish to do so. Because there is such a multitude of users who are granted the arrangement, the question has been asked whether “more paternalism to strengthen the individual’s autonomy” is needed in some cases (Lewin 1998:226). A public report concludes that 40% of the users who have been granted personal assistance according to LASS have difficulties in managing their assistance (Riksrevisionen 2004). Therefore, more limitations of the target group are suggested, so that only persons who can act as managers should have the right to personal assistance. However, the suggestion was met with strong resistance from organisations recruiting people with intellectual impairments, and the Government quickly withdrew the proposal.

Public control of personal assistance is more extensive in the Norwegian model than in the Swedish one. The principle that the user always is seen as competent and in a position of knowing what is the best for him/her is not absolute. As mentioned before, the professionals in the municipality have to make an assessment of the users' competence in managing the arrangement before personal assistance is granted. In this way, the Norwegian model appears much more paternalistic than the Swedish one.

However, paternalism is an ambiguous concept. Christensen & Nilssen (2006) make a distinction between "weak and strong paternalism". Weak paternalism deals with restrictions in the right to self-determination for people who for different reasons are not able to present reflection or judgements in making voluntary and deliberate choices. It deals with collective obligations of the welfare state to citizens who are not capable of living an autonomous life, for instance people with limited cognitive abilities. From such a position the power which is exercised is seen as individualised care, since it contributes to prevent hardship, or is a contribution to improve the individual's ability to make autonomous choices. The authors emphasise that this kind of paternalism requires empathy and the involvement in the user's situation and a strong ethical consciousness from professionals. If not, weak paternalism could easily distort into guardianship. On the other hand, the way Christensen & Nilssen define strong paternalism, restrictions are not set up because the individuals are unable to make autonomous decisions, but to prevent choices which are seen as unacceptable.

The paternalism in the Norwegian personal assistance model can be classified as weak paternalism. The public control can be explained as a means to make sure that the interests of weaker groups among the disabled do not become invisible and are ignored in the name of user involvement, as critics maintain is a consequence of the Swedish arrangement. Since access to personal assistance is so closely linked to the users' ability to act as a manager of the service, the paternalism in the Norwegian system could be explained as a way of ensuring that users are actually able to manage it. Stronger public control could further be seen as a way to secure good quality of assistance.

However, the classification of personal assistance into different kinds of paternalism should not be taken too far. Strong paternalism can be obscured by a rhetorical support of weak paternalism. For instance, lack of ability to act as manager for the assistant can be overcome by training and practice. Many of the Norwegian personal assistance users criticise municipalities for not taking their responsibility as employers seriously by not training the users in the role as managers of their assistants (Andersen *et al.* 2006). In this way, one consequence of the municipalities' right to take the final decision with regards to personal assistance being the most suitable solution for the individual user could be that some users who qualify for the arrangement are excluded.

Towards Convergence?

Within the same welfare state model, personal assistance in Norway and Sweden has developed very differently. However, recent observations in both

countries indicate that the arrangements will converge in the time to come. In Sweden, efforts are made by the authorities to limit the arrangement and make public control stronger. In Norway, the development takes the opposite direction. The tendency there is an extension of the arrangement and stronger individual rights for the users.

In 2004, a parliamentary committee was set up in Sweden to give a broad overview of personal assistance. Among other things, the commission was mandated to discuss the formal requirements for assuming employers' responsibility for personal assistance, and to discuss ways to implement stronger public control. One reason involved reports showing considerable variation in quality among employers. Further, direct payments were made in different ways, and some companies were suspected of using the money for other purposes than for which it was intended. As a consequence, the committee in its first report proposed a more thorough and active public inspection (SOU 2005:100). Also, the national authorities, financing personal assistance, should be placed in a better position to control the spending of the money to secure appropriate use of resources. The committee proposed that more specific criteria should be developed to define what good personal assistance is. These criteria should then constitute the guidelines for inspection of the personal assistance arrangement.

The committee stated that in future reports proposals would be presented to restrict or stabilise the costs for personal assistance and improve cost control. A main reason for the eagerness to restrict personal assistance in Sweden is that public costs have been much higher than expected. Just one year after LASS had been passed in 1994, the expected costs were increased by 900 million SEK (€ 130 million), and the expenses have continued to escalate (Socialstyrelsen 1997). In the period 1994–2004, costs increased by an average of 15% each year. At the end of the period, the expenses were 12.7 billion SEK (€ 1.9 billion) (SOU 2005:100). The parliamentary committee was thus just one of many efforts by the government to gain better control of the public expenses, which by far have exceeded the official expectations.

In Norway, the target group for personal assistance was, late in 2005, extended to persons who are not able to act as managers of the arrangement on their own (Helse- og omsorgsdepartementet 2005). Another person than the user can now be the manager instead of or jointly with the user. The person can be one of the user's parents, his/her guardian or an administrative assistant appointed by the user. The government especially mentions adults with intellectual disabilities and families with children with impairments as groups that could profit from having their services organised as personal assistance. In 2007, the Ministry of Health and Care issued a Green Paper proposing that personal assistance should be authorised as an individual right for disabled people in need of extensive services (Helse- og omsorgsdepartementet 2007). More exactly, the right should come into force when the need for services extends to 20 hours a week. The ministry further proposes that the users have the right to decide who should take on employers' responsibilities for the assistant. As mentioned above, this has so far been the responsibility of the municipality. The new proposal represents a

transition of personal assistance to a direct payments model. The municipalities are to grant the users a certain number of hours calculated on the basis on fixed hourly rates. Users may spend the money on more expensive assistance if they want to, but will then have fewer hours at his/her disposal. Or they can administer the arrangement themselves and get more hours at their disposal. The ministry explicitly emphasises that one consequence of the proposal will probably be that more employers will be interested in entering the personal assistance market.

The consequences of the changes in the two countries are still uncertain. The proposals in Sweden to strengthen control and inspection have received support from the users. Since 1995, user organisations (*Interesseföreningen för Assistansberättigade IfA*) have set up procedures for the approval of employers. The intention has been to assist the users in selecting serious employers, who offer assistance of good quality. However, suggestions to reduce the costs by narrowing down the arrangement will probably be met with strong resistance. The national authorities have also earlier made efforts to reduce costs, which were met by strong resistance from the users, and the authorities have been forced to retreat (Askheim 2001b).

At first glance the implication of the extension of the Norwegian arrangement seems to indicate a democratisation. More people will get personal assistance and the rights for at least some of the user groups will be stronger. However, whether this will be the only consequence will depend on different circumstances.

Firstly, the consequences of the extension will probably depend on how the reform is supported financially. As mentioned above, the national authorities at present contribute for a period of three years to cover the municipalities' additional costs when the arrangement is introduced to a new user. Otherwise, personal assistance is exclusively financed by the municipal budgets. According to the new proposals, the national transfers in the future will not be linked to the individual user, but will be directed towards more general information and guidance about the arrangement. At the same time, nine out of 10 users have received increased hours of service after they were granted personal assistance, compared to other services. Many of them have attained considerable increases (Guldvik 2003). The main reason for this is the low number of persons in each municipality who are granted personal assistance. The municipalities appear to use different criteria when allocating resources to personal assistance compared to other services. However, if personal assistance becomes more common and more people claim the service, a more modest number of hours to each user could easily be the result. Due to scarce municipal resources and need for help from other groups, the municipalities will probably become more restrictive when personal assistance is allocated and thus adapt to the level of other services. In the city of Trondheim, the third biggest municipality in Norway, the authorities quickly indicated that there would be fewer resources available to personal assistance as a the consequence of the extension of the service (*Handikappnytt* 2006).

A consequence of fewer resources to personal assistance might therefore easily be that the users get less assistance and that their needs are not met.

A further consequence is that the users' opportunities for self-determination will be weakened. As mentioned above, the average number of hours of personal assistance is much lower in Norway than in Sweden. At the same time, users who are allocated the most hours experience the best opportunity for user influence. If the hours allocated to personal assistance are further reduced, assistants will only have time to carry out duties that are strictly necessary like personal care and practical tasks in the house. The user's influence will then be further reduced. The opportunities for active participation and social integration in society will be considerably reduced.

If the intention is to protect the personal assistance users against municipal financial priorities, a divided financial responsibility between the state and the municipalities, like in Sweden, will probably be necessary also in Norway. However, in the Green Paper from 2007 the Government makes it clear that the financial model of personal assistance will not be changed. A divided solution, i.e. partly national, partly local funding, will change the principles of responsibility between the different administrative levels as they were established in Norway in the 1980s. There has been a wide political consensus about these principles (Hagen & Sørensen 1997). They imply that the administrative level with the authority and responsibility for making decisions should also assume responsibility for financing the costs of the decision. In addition, there is no doubt that the very high state costs for personal assistance in Sweden have also influenced the Norwegian authorities to modesty.

The proposal to extend the individual right to personal assistance can in a similar way undoubtedly have unexpected consequences. The rights are limited to persons with extensive need for assistance (minimum 20 hours a week). An extension can make the day-to-day situation more secure and predictable for these persons. However, the consequences for persons with less extensive needs are uncertain. About 25% of the Norwegian users today have less than 15 hours of personal assistance per week (Guldvik 2003). An unforeseen consequence of the reform may be that the municipalities claim that the users must be in need of at least 20 hours each week to get the service. In other words, the extension of rights to users who need most assistance could easily turn into a limitation of eligibility. For users in need of less assistance the result can be diminished chances of getting their services organised as personal assistance.

The consequences of extended rights combined with organising personal assistance as direct payments are also unclear. As mentioned above, such a model receives wide support from disabled activists and organisations of disabled. However, critics point out that the dangers and risks connected to such a model have also been neglected from the organisations of disabled (Glasby & Littlechild 2002). They are criticised for not considering seriously the special needs and problems of persons with learning disabilities. Also, there seems to be a growing concern in Sweden that the special needs of the weaker groups among disabled people are ignored and made invisible as a consequence of their personal assistance model. Similar worries might appear in Norway as the target group for personal assistance is extended and as

persons with extensive needs are given an individual right the arrangement within a direct payments model.

Old Dilemmas in New Costumes

The different models for personal assistance in Norway and Sweden illustrate fundamental dilemmas with personal assistance as a welfare service. Important dilemmas refer to whether personal assistance should be an arrangement for a limited group, and maintain a strong ideological profile, or whether the user group should be extended, at the risk of more pragmatic solutions at the cost of weak user groups. Additionally, user control seems to depend on how the financial situation of the arrangement will develop. Few hours of personal assistance will limit the assistance to strictly necessary tasks and diminish the user's opportunities for activity and participation in society. On the other hand, different treatment of personal assistance users compared to other people dependent on public services could quickly result in a strong increase in other public expenses. Thus, assistance users might gain a privileged position compared to other needy groups. In turn, this might lead to a conflict of interests between different groups, who are all dependent on services from the welfare state. It is interesting to note that the result of Swedish and Norwegian efforts to solve the dilemmas may be a closer convergence between the models in the two countries. Sweden is approaching the Norwegian model while Norway is moving towards the Swedish solution. It may well be that this convergence will not solve the dilemmas, but that they will reappear in new clothing.

Note

¹ 12,000 of the Swedish users are granted personal assistance according to LASS and scarcely 4000 according to LSS.

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