

Personal assistance in a Scandinavian context: similarities, differences and developmental traits

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Personal assistance (PA) has been characterized as a melting pot consisting of, on the one hand, a social rights discourse with its basis among disabled people, and, on the other hand, a consumer directed market discourse increasingly putting its stamp on welfare policy in the Western world. In the realm of welfare politics, these discourses are, in many ways, opposites, but have found common ground in the demand for a more individual and consumer friendly provision of services. Within a shared welfare state model, the application of PA has developed divergently in the Scandinavian countries and relates to the two discourses in different ways. In this article, PA in Denmark, Norway and Sweden is presented and similarities and differences are discussed and analysed. Questions raised include: How can the differences between the countries be understood? What dilemmas within welfare policy do they illustrate? How do the different discourses put their marks on the different PA-models in the Scandinavian countries? How do the PA programmes seem to develop further and what kind of PA will the Scandinavian countries end up with in the future?

Keywords: personal assistance; Scandinavia; policy; cash for care

Introduction

In brief personal assistance (PA) implies that disabled people employ their own assistants as an alternative to receiving assistance from the established services. While it still constitutes a modest share of the total welfare services for disabled people, the extent of personal assistance (PA) during the last 25 years has grown remarkably. Starting from experiments in isolated countries, it has become an integral part of the welfare services in nations like the USA, Canada and most of the countries within the EU (Van Hauwermeiren and Decruynare 2009; Ungerson and Yeandle 2007). So far PA has been most commonly accepted as an alternative for disabled people, but in several countries the principle has also been extended to services for a wider range of users, e.g. people with learning difficulties and older people (Glasby and Littlechild 2009; Ungerson and Yeandle 2007). In the UK PA is a main ingredient in ‘personal budgets’, which is rolled out as a main commitment to greater personalisation of welfare services. PA can here be combined with other public, private or voluntary services. The government has announced that the key principles of individual budgets should be open for everyone

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eligible for publicly funded adult social care support (Glasby and Littlechild 2009; Wilberforce et al 2011).

The rationale behind PA is to strengthen the users' influence and control over their services, and in turn over their lives. However, the justifications for the rationale differ. PA has been characterized as a melting pot consisting of a social rights discourse with its basis among disabled people on the one hand and a consumer directed market discourse increasingly putting its stamp on the welfare policy in the Western world on the other (Pearson 2000; Glasby and Littlechild 2009). In many ways the trends are welfare political opposites, but have found common ground in the demand for a more individual and consumer friendly provision of services.

PA is established as a service in all the Scandinavian countries. However, within a common welfare state model the arrangement has grown and developed differently and relates to the two discourses in different ways. In the article PA in the Scandinavian countries Denmark, Norway and Sweden is presented and similarities and differences are discussed and analysed. Questions raised are: How can the differences between the countries be understood? What welfare political dilemmas do they illustrate, and how do the different discourses put their marks on the PA-models in the Scandinavian countries? How will the arrangements develop and what kind of PA do the Scandinavian countries seem to end up with in the future?

PA: a welfare political mixture

During the last few decades, the welfare states in the Western world have increasingly developed towards individualization and consumer control. The welfare state is criticized for standardization and for being bureaucratic and rigid. The welfare professions are criticized for their strong position of power at the expense of the users' autonomy. Development in the welfare sector has been greatly influenced by market-based models under the label New Public Management (NPM). In many countries, including within Scandinavia, NPM has been the ideological basis for a 'modernization' of public services. Central components of NPM include privatization, subcontracting, freedom of choice for the user and the conceptualization of service users as consumers (Klausen and Ståhlberg 1998; Peters 2001). A significant aspect of the market ideology is that welfare contributions are increasingly being offered as direct payments, allowing the users to buy services of their choosing rather than being tied to the established public services (Glendinning and Kemp 2006; Ungerson and Yeandle 2007).

The market models represent innovations in the welfare services initiated from above, from the state authorities. At the same time, different bottom-up initiatives arise when user groups demand the right to have more influence on their own situations. They regard themselves as oppressed and marginalized in society and demand as their democratic right the opportunity to influence measures and services which concern them (Braye 2000). In the name of 'empowerment', user groups are critical of what they perceive as incapacitating and authoritarian service providers, as well as an oppressive and disempowering society. These trends are prevalent among different user groups but have probably been most noticeable among disabled persons and people with mental health problems (Beresford 2002, 2005; Barnes, Mercer, and Shakespeare 1999; Bonfils 2008, Oliver and Barnes 1998).

Though they in many ways are political opposites, the social rights discourse and the market discourse have found common ground in their demands for a more individual and consumer friendly provision of services. In this area, arguments from both the discourses

are mixed together among both the users and the authorities. In fact, among advocates for the social rights discourse, there has been concern regarding the weakening of demarcation between the two discourses (Barnes and Mercer 2006). They emphasize that from their point of view control over the services is just part of a greater project aimed at disabled people obtaining full rights to participate as citizens. Still, the two discourses have a shared attitude regarding how the welfare services should be organized, and behind their differing approaches there are also concurring views. In their opposition against clientification and disempowerment both discourses share the belief that the clients are best suited to assess their own problems and needs. A common trait is the strong emphasis on freedom of choice for the individual. Glasby and Littlechild (2009, 80) characterize the alliance in this way: 'While these groups are often uneasy bedfellows in the long term, they tend to create a momentum for change in the short term when their interests and ideas begin to coalesce'.

PA is the most distinct example of the fusion of the two discourses. PA is the child of the Independent Living (IL) movement that originated among physically impaired students in the USA in the late 1960s (DeJong 1983). The IL ideology has since spread and created a pivotal basis for powerful and active movements among disabled people in a number of countries, and has been able to apply considerable pressure in the political arena. IL challenges the traditional 'rehabilitation paradigm' in public services in which disability is presented as the result of a deficit in the individual, which needs to be altered. In contrast, IL promotes a paradigm based on rights, independence and self-determination. The allocation of PA is seen as a decisive means to realize disabled people's rights as citizens (Spandler 2004). However, a consumer profile is also a distinct aspect of the IL ideology. Consumer sovereignty and the freedom to choose are fundamental principles. PA should be seen as an individual right for persons who prefer the arrangement and should preferably be organized as direct payments in order to liberate the users from the dependence of the existing services (Askheim 2005).

PA in the Scandinavian Countries

In literature the 'Scandinavian welfare state model' is a well-established term, characterized by extensive public responsibility for the welfare of the inhabitants, universalism and redistribution (Esping-Andersen 1990; Kuhnle 2001). However, within a common model, the Scandinavian countries have developed individual models for PA with considerable differences. Clear dissimilarities emerge in central areas such as the extension of the arrangement, the strength of the actual right to get PA, the organization and implementation of PA, the degree of free choice for the users and how the user groups are defined. In the following part the differences and peculiarities will be described more in detail.

Sweden: from consumerism to re-regulation

The IL movement has had a decisive influence on PA in Sweden. The beginning of PA can be dated to 1983 when the IL cooperative STIL (The Stockholm Cooperative for IL) was established. STIL was the first European initiative where disabled people organized and employed their own personal assistants. Some years later a similar cooperative was established in Gothenburg (The Gothenburg cooperative for Independent living). At the same time a few disability organizations started up their own assistance projects with

similar goals. For some of these projects PA replaced municipal home-based services (Hugemark and Wahlström 2002).

The development of PA must be seen as a part of broader tendencies in Sweden dating back to the 1960s when a social perspective on disability gained strength, influenced by a strong and active disability movement. The disability movement and the IL ideology had a decisive influence on a comprehensive public committee project, starting in 1989, to prepare a new reform in the disability area (referred to as ‘the handicap reform’). In their final report the committee proposed a new Act concerning support and services for disabled people. The proposal was unanimously accepted by the Swedish parliament, and the ‘Act concerning support and service for persons with certain functional impairments’ [Lag om stöd och service till vissa funktionshindrade (LSS)] was passed and effected from 1 January 1994 (Bengtsson and Gynnerstedt 2003). The target group for the Act was persons with extensive impairments. The Act defined, and extended strong individual rights to, 10 separate contributions and arrangements. Of these PA was the one to achieve the most attention and has been characterized as the symbol of ‘handicap’ reform. The municipalities, i.e. the local authorities, were given the responsibility to implement this reform.

As a supplement to LSS the government proposed an additional Act: the ‘Act concerning assistance and compensation’ (Lag om assistansersättning [LASS]). Here it was stated that the Swedish Social Insurance Agency (Försäkringskassan) would have the responsibility to cover the costs for PA for persons with the most extensive needs. PA was initially established as a municipal service, with the exception that, for persons with a need of assistance exceeding 20 hours each week, the national authorities should cover all the costs. However, the relevant paragraph was changed in 1997, subsequently requiring the municipalities to always cover the costs up to 20 hours each week, while the national authorities cover the additional costs.

According to the Acts above, three more closely defined groups should have individual rights to PA: (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 durable physical or mental disabilities that are evidently not caused by normal ageing (Proposition 1992/1993, 159). No conditions were placed on the person’s abilities to manage such an arrangement. The decision further implied that PA could either be organized by the municipality or as direct payments to the user. He/she could then either retain the responsibility for employing the relevant assistance (hiring and managing the employment oneself) or could hand it over to a cooperative, a private company or another organization.

In 2010 more than 16,000 people received PA under LASS (Försäkringskassan 2011). LSS provided PA to about 3500 persons (Socialstyrelsen 2011). The majority of users (60%) belonged to group 3. About 38% belonged to group 1, while group 2 was rather small. On the other hand, users from group 2 received the highest number of hours of assistance per week. On average the LASS users had 113 hours of assistance each week.

The largest proportion of Swedish users has the municipality as the employer of their assistance providers, but the number is rapidly decreasing. In 2010 44% of LASS users utilized the municipality to employ assistance services (Försäkringskassan 2011). The most notable increase is in the use of what is called ‘other service organizations’, in which private companies are included. Such organizations had the employment responsibility for 42% of the users. The share of the cooperatives as employers was about 10% and the share employed by oneself only 2.5%.

The construction of PA has been heavily debated since it was implemented in LSS/LASS in 1994. Much attention has been connected to the costs of the reform which have far exceeded the calculations of the national authorities. In the bill preparing LASS the government estimated that the reform would include 7000 persons and that 40 hours each week would be the average amount of assistance per person. The costs for the state were estimated at 2,850,000,000 Swedish crowns (SEK) per year¹ (Socialstyrelsen 1997). However, in just the second year it had already become 900,000,000 SEK more expensive than estimated. In 2010 the total costs were 21,800,000,000 SEK of which the state was responsible for 80% (Försäkringskassan 2011).

In 1995 a committee was formed with the goals of better organizing the development of the programme and improving control of costs (SOU 1995:126). In the subsequent years various initiatives have been taken with the same intentions. Some changes have also been implemented (Bengtsson 2004). In 1996 it was stated that what was defined as 'basic daily needs' for the individual should be at least 20 hours each week before LASS assistance was granted. 'Basic daily needs' were defined as 'help to manage hygiene, to dress and undress, to have meals and to communicate with others'. In 1997 the costs of PA were standardized, which meant that the costs should be covered by the same hourly rate for all the users (in 2011 the rate was 267 SEK/hour (Försäkringskassan 2011)). However, the costs have continued to increase. On average the costs have grown between 8% and 14% each year in fixed costs (SOU 2008:77).

Along with the above, a number of other problems have arisen, as the Swedish programme has been developed. One problem has been to interpret and adapt the criteria for who should be included in the different categories that have the right to get PA. The most controversial category is persons with psychiatric diagnosis. Another critical criterion to develop is how much assistance a person can have from his/her relatives. Furthermore, the authorities have required stronger control of the arrangement of services. Reports have shown considerable variation in the quality of assistance among the employers; direct payments were given in different ways and some companies were suspected of using the money for purposes other than that for which it was intended (SOU 2012:6).

In 2005 a parliamentary committee proposed a more thorough and active public inspection of the programme (SOU 2005:100). The national authorities also wanted to be better positioned to control the spending of money to secure appropriate use of resources. The committee proposed that more specific criteria should be developed to define the quality of PA and that these criteria should then constitute the guidelines for inspection of the PA arrangement. Since 2011 employer organizations must receive permission from The National Board of Health and Welfare (Socialstyrelsen), and any individual who wants to retain the employment responsibility themselves must announce it to the same group. In 2011 LASS was suspended and incorporated into a new act, the Social Insurance Act, but the distribution of the costs between the municipalities and the state is the same.

Summarizing the Swedish model, it appears to be a pure fusion of the market discourse and the social rights discourse. The arrangement started out as a bottom-up initiative. The disability movement inspired by the IL ideology was the initiator and has, since the start of the reform, had a strong influence on the development of PA. In the progress towards the enactment of LSS and LASS strong alliances were built between the disability movement and some politicians. The concrete design of PA came about as a result of a report from a public committee over which the disability movement had a strong influence. In the published laws PA ended up with a strong consumerist profile.

There were strong individual rights for the users and no further responsibilities put upon them in terms of being able to manage the service. The arrangement is mainly organized as direct payments. Private companies and other organizations, as well as cooperatives and the municipalities, offer PA, and the users are free to allocate the responsibility of who should be the employer of their service providers.

The tendency in Sweden now is towards efforts to reregulate the arrangement, in order to put an end to disadvantages resulting from the extensive amount of freedom built into the model. The main reason for this is that PA has become too costly. The national authorities are undertaking efforts to control the arrangement in a more active way, in order to secure good quality services and to ensure that the resources are spent in legitimate ways. Special measures are being taken to prevent cheating and errors in the process. For example, it will be harder to obtain permission to start private firms or organizations providing PA. The process of investigation will also be more detailed and feature improved means to evaluate and control implementation (SOU 2012:6; Proposition 2012/2013:1).

Denmark: from strict paternalism to growing consumerism

The first initiatives with PA were taken in Denmark's second biggest city, Aarhus, as early as the mid-1970s. A group of young disabled citizens refused to be institutionalized, and after a dialogue with social counsellors and civil servants, they were 'allowed' by the municipality to hire their own assistance, thus permitting them to continue to live in their own private homes. The agreement has been characterized as 'more or less accidental' (Lenger 2011). It was neither 'official policy' nor a political agreement. Neither was there any clear ideology behind the claims. It was primarily a way of meeting the demands and the needs of a specific group of young disabled people. The municipality of Aarhus unofficially and informally agreed to allow such arrangements. Each person's individual budget corresponded to the municipal costs of him/her residing in an institution – the logic being that the individual budget for hiring assistance should not exceed the cost of the established service alternative. The amount corresponded to a maximum of 80 hours of PA a week (Jensen and Evans 2005). PA in this period was referred to as the 'helping arrangement'.

From the time of the establishment of the arrangement, until the end of the 1980s, a great number of young disabled people moved to Aarhus in order to obtain PA, thus avoiding institutionalization in their municipality of origin. Hence, the first PA arrangement in Denmark came to be known as the 'Aarhus-Arrangement', many years before it was part of the official judicial portfolio. To this day, the municipality of Aarhus is still home to three times more PA users than Copenhagen – a city which is four times the size of Aarhus.

PA as an unofficial arrangement continued until 1987, when the Danish Ministry of Social Affairs recognized it by working out national guidelines and making it an official option; thus legitimizing this specific interpretation of a certain section in the Social Security Act. As a consequence, the municipalities were obliged to include the arrangement in their spectrum of social services. In 1998 PA was included in the new Social Services Act as an independent section.

The target group for the arrangement in Denmark was strictly defined. The individuals had to be able to: (1) act as employers in their own name, carrying all legal responsibilities themselves, managing the assistants directly and (2) maintain a certain 'activity level'. To get PA the persons should have an activity level making it necessary to

render special support (Socialministeriet 2003). In the Ministry of Social Affairs' guidelines to the arrangement it was emphasized that the target group was much more restricted than for other benefits for disabled people (Socialministeriet 2003). It was up to the local authorities to interpret the legal framework and to evaluate whether or not an individual was eligible; whether the person maintained a 'sufficient' level of activity and was able to function as an employer for his/her assistants. Practice among the municipalities differed greatly. Many municipalities had very few or no users and were reluctant to implement PA. It was even sometimes the case that there were varying procedures within a single municipality. By the end of 1999 there were less than 650 persons with PA in Denmark.²

In the years to come there was a growing criticism of these restrictions of the arrangement (Jensen and Evans 2005; Sandø, Andersen, and Jensen 2007). PA was often characterized as an arrangement for 'the elite' among disabled people, especially when compared to how the programme was organized in Norway and Sweden. Persons who were not eligible because of their low 'level of activity' were seen by the critics as those who often would need PA most of all. Still, disabled peoples' organizations (DPOs) continued to a certain extent, to praise PA the way it was. They feared that too much focus on changes would have the potential to pose a threat to the principles of user control of the arrangement. However, the DPOs gradually began to change their approach – from a defensive policy of maintaining the Act, to wanting to adopt important principles derived from how it was organized in Norway and Sweden. More people should be eligible, not just an elite of people with physical mobility impairments.

Also, the Ministry of Social Affairs was prepared to make reforms in this area, arguing that the principles behind PA constituted an important feature in the development of the welfare state. In 2006 the Ministry commissioned a report on experiences from Norway and Sweden related to the Danish context, with a clear intent to start a reform process (Sandø, Andersen, and Jensen 2007). The report was made public in April 2007, and, from January 2009, a revision of the PA-Act stepped into force. The official name is now 'Citizen-led Personal Assistance'. The aforementioned barriers to eligibility were removed. There is no longer any declaration of an obligatory 'activity level', and PA can now be used if it is seen as the most suitable solution for the individual. The user retains the responsibility for the management of his/her own arrangement, but third sector cooperatives and private enterprises are now allowed to function as the employer of the assistance. It is up to the user to select the employer. The municipalities cannot be an employer, but they can choose to take care of the wage payments for persons who choose to be employers themselves. However, the user can also choose to ask a private firm to take care of the payment of the salaries.

In 2008 the cooperative 'The national organization for citizen controlled personal assistance' [Landsorganisationen for borgerstyret personlig assistanse (LOBPA)] was established, inspired by the Norwegian cooperative on personal assistance (ULOBA). Several private enterprises have also ventured into the PA-market. Many of them have limited connections to the disability field – including concepts such as IL and the history of PA. The majority of PA users continue to act as formal employers and managers for themselves. However, most of the 'new users' (since 2009), prefer to hire their assistants through private enterprises or LOBPA (Socialstyrelsen and Deloitte 2012).

Still, many municipalities in Denmark have limited experience with PA. In 2010 there were about 1400 PA users.³ The biggest user groups are people with muscular dystrophy, cerebral palsy and tetra- and paraplegics. The average number of hours of assistance each week is assessed to be about 100 per user (Socialstyrelsen and Deloitte 2012).

Summing up PA in Denmark, the arrangement has in many ways gone through an opposite movement compared to the development in Sweden. From a rather strict and paternalistic position, PA has moved towards a more market-based model. Also, in Denmark PA started up as a bottom-up initiative, but with no clear ideology among the initiators and without formal connections to the IL movement or the established disability organizations. It was a pragmatic solution to meet the demands of a limited group of physically impaired people who refused to be institutionalized. When PA was integrated into the Social Service Act, strict requirements had to be met before persons were admitted to PA, and the dimensions of the arrangement were very limited. However, in the last few years the arrangement has changed radically. The requirement that the users must maintain a certain activity level has been abandoned. It is still the case that the user must have the capacity to manage his/her assistants in order to be admitted to the programme, but they can, at their discretion, hand over the employment responsibility to a cooperative or private company. Alone among the three Scandinavian countries compared here, in Denmark the municipalities do not employ assistants on behalf of the PA users, although they do sometimes take care of the payments of the salaries.

Norway: extension of the target group and pressure for stronger rights

The first organized efforts with PA in Norway started in 1990 when the Ministry of Social Affairs gave a grant to an experimental project initiated by the national association of persons with physical impairments (Norges Handikapforbund 1994). An important result of the project was the establishment of the IL-inspired cooperative ULOBA in 1991.

PA became a part of public policy when the programme was launched as one of the areas of priority in the government's plan of action for the disabled 1994–1997. Financial contributions from the state were granted to municipalities wanting to try out the arrangement. In 2000 PA was included in the Social Services Act, described as an 'alternative organisation of practical and personal help for people with comprehensive disabilities with a need of assistance in their daily life, both inside and outside their homes' [Ot.prp. (White Paper) nr. 8 (1999–2000), 1]. PA might be combined with other municipal welfare services such as, for instance, home help and home-based nursing services. Although the Act generally emphasizes that the caseworkers are to consult the users and attach importance to their preferences, in the end the municipality has the final word about which services are the most appropriate.

The authorization of PA in the Social Services Act gave the municipalities an obligation to include PA in their repertoire of services in the same way as other services regulated in the Act. However, that did not mean that every individual who wanted PA received the right to have it. People in need of help have a right to assistance and services depending on their needs, but it is the municipality which has the final word deciding what services are most suitable even if it is emphasized that the user must be consulted and great importance must be given to the user's opinion before a decision is made. If the users disagree they can complain to the County Governor.

The decisive criterion to get PA in Norway has been, from the start, the user's ability to act as manager for her/his assistants. Before a person was granted PA they had to go through an assessment in which representatives for the municipality considered if the users' competence was sufficient and if PA would be the most appropriate service to cover their needs. To emphasize the importance of managing the assistance, the official term for the arrangement is 'user controlled personal assistance'. One consequence of this

emphasis was that, until 2006, the main rule was that the user had to be over the age of 18 to get the arrangement.

However, since 2006, PA has been extended to persons who are not able to act as managers of the arrangement on their own (Helse- og omsorgsdepartementet 2005). With this change in regulations, a person other than the user can be the manager instead of, or jointly with, the user. The government especially mentioned adults with intellectual disabilities and families with disabled children as groups that could benefit from having their services organized as PA.

Almost 2900 persons received PA in Norway in 2011 (Gabrielsen, Otnes, and Sundby 2012). It remains the case that the large majority (80%) of PA recipients are persons with mobility impairments (Johansen et al. 2010). However, as a result of the extension of the target group, the portion of PA recipients with other impairments has increased. The share of persons with sensory impairments had increased from 13% in 2002 to 23% in 2010. The portion of persons with intellectual impairments had increased from 4% to 12%, and the percentage of persons with acquired brain injuries increased from 14% to 19%. Also the age composition of the group had changed as a consequence of the extension of the user group. Although the average age of the users was relatively stable (46 in 2002 and 45 in 2010), the share of children under the age of 18 had increased from 2% in 2002 to 8% in 2010.

Most of the Norwegian users utilize the municipality as their employer (Johansen et al. 2010). However, increasingly, the cooperative ULOBA has been preferred over the municipalities as the employer. From 2002 to 2010, the proportion of users that chose ULOBA went up, from 26% to 33%, while the share that chose the municipalities declined, from 65% to 54%. In the same time period, the number of users choosing to retain the employment responsibility themselves was stable, about 10%. So far private enterprises constitute a very modest share of the employers and are mainly operating in the big towns.

Before the arrangement was authorized in the Social Services Act, organizations of the disabled in Norway [The national association of persons with physical impairments (Norges Handikapforbund), ULOBA] argued strongly that PA should be an individual right, as it was in Sweden, to secure equal treatment and freedom from dependency on the municipal judgements. The debate has been intensified as the years have passed. In 2007 the Ministry of Health and Care issued a Green Paper proposing that PA should be authorized as an individual right for disabled persons in need of extensive services (Helse- og omsorgsdepartementet 2007). However, in their later proposal for a common Act about municipal health and care services (Helse- og omsorgsdepartementet 2010), the ministry, mainly for economical and administrative reasons, chose not to support the proposal of PA as an individual right. Instead the ministry recommended a special duty for the municipalities to have PA among their services. This meant a continuation of existing practice, but it was suggested that the duty should be specified in a special paragraph in the new Act.

However, the ministry's proposal met resistance from both within the government parties and from the opposition. When the proposition for the new Act was discussed in parliament, the government was required to examine further the economical and administrative consequences of authorizing PA as an individual right for persons with extensive needs (Helse- og omsorgsdepartementet 2011). The ministry gave the Health Directorate the task of examining the criteria for whom PA should be a possible right and what services should be included, but made it clear that an eventual extension of rights should be done within the same economic frames as today. In its report, the Health

Directorate (Helsedirektoratet 2011) concluded that an authorization of PA would imply increased public costs, since it is more costly to give services as PA than to just provide the ordinary services. It referred to studies showing that persons with extensive needs who are given PA receive more hours than those having their assistance organized in other ways. The report subsequently concluded that some limitations must be placed on who should have the right to PA. The Ministry of Health and Care, based on this report, in spring 2013 issued a Green Paper with proposals to statutory provisions (Helse- og omsorgsdepartementet 2013). PA was there authorized as an individual right for persons with a need of assistance exceeding 32 hours each week. Persons with a need of between 25 and 32 hours each week got the right to PA if PA was not figured to be considerably more expensive than other services. PA was strictly limited to practical and personal help, which meant that home-based health services and respite care were excluded from what was defined as PA. The strong limitations of who should get PA as a right in the proposal were met with strong criticism from the organizations of disabled. What will be the result is so far not clear, also because there was a change of government in autumn 2013 when the centre-left wing government was replaced with a conservative government.

Summing up, PA also started as a bottom-up initiative in Norway. Both the national association of persons with physical impairments (Norges Handikapforbund) and especially the cooperative ULOBA have been important drivers behind the arrangement. At the same time the implementation has taken place in alliance with the state authorities from the very beginning, when the Ministry of Social Affairs granted money to the first experiments with PA. However, the alliance between the disability movement and the authorities cracked when PA was included in the Social Service Act. Both parties wanted an enactment of PA, but the disability movement wanted PA authorized as an individual right modelled after the Swedish solution. Conversely, an examination of the Swedish experience with PA provided the Norwegian authorities with important economic motivations to consider alternative solutions. Recent developments in Norway, though, indicate a movement towards the Swedish model. The target group has been extended to include users who are unable to operate as managers of the arrangement on their own, and private companies are cautiously moving into the arena. It is likely that PA be authorized as an individual right, but only for parts of the user group and with considerable limitations.

PA in Scandinavia: different solutions to similar dilemmas

Comparing the development of PA in the three Scandinavian countries we find both similarities and differences. If we take closer looks at who were the initiators of PA, what were the ideological justifications for the arrangement and what were the strategies to implement the reforms, we find [Table 1](#).

In all three countries, the PA arrangement originated from bottom-up initiatives, and ended up as official policy and part of the public welfare system. However, while the disability movements were initiators in Sweden and Norway, the arrangement in Denmark was mainly instigated from outside the established disability organizations as a local initiative without connections to the organizations or the IL movement.

The process leading to the enactment of PA also follows different lines. In Sweden, the enactment followed the recommendations from a broad public committee, while in Norway it took place after a period during which PA had been given priority in the government's plan of action for the disabled. In Denmark the authorization of PA was more a pragmatic official recognition of what had become an established practice. In

Table 1. Initiators, ideological justifications and strategies to implement personal assistance in the Scandinavian countries.

	Initiators	Ideology	Implementation
Sweden	Disability movement	Independent living	Public committee  authorization in new separate laws
Norway	Disability movement	Independent living	Statutory action plan  integration in the Social Services Act
Denmark	Disabled persons in one of the municipalities	Pragmatism	Local arrangement  Integration in the Social Security Act (Later the Social Services Act)

many ways the processes seem to follow typical national implementation tracks. Comparisons of Scandinavian strategies for equality for disabled people conclude that statutory instruments are a typical Swedish strategy, while Norway is characterized as ‘the country of action plans’. In Denmark the main strategy seems to be pragmatic solutions based on a continuous dialogue between the disability organizations and the authorities, what has been characterized as the ‘way of good will’ (Nordiska Nämnden for Handikappfrågor 1997; Brattström 1998). However, the decision to implement PA in a separate Act in Sweden represents a deviation from the Scandinavian tradition of integrating decisions related to disabled people into the existing general laws, and must be seen as a result of the strong influence the disability movement exerted in Sweden.

The PA arrangement was modelled, and has developed differently, in the three countries. In all the countries we can find the mixture of the social rights discourse and the market discourse, but in different ways. The market discourse is most clearly expressed in the Swedish model, while PA in Norway and Denmark has been more strongly regulated, and has more paternalistic traits. In previous comparison of PA in the Nordic countries the Swedish model has been characterized as ‘a liberal mass model’, the Danish one as a ‘pure elite model’ and the Norwegian one as a ‘mixed model’ (Askheim 2002, 9). The addition to the existing Social Service Acts gave much more limited rights to the users in Norway and Denmark than in the new rights-based Swedish Act. Especially in Denmark, the strict criteria to get PA limited the user group, but also in Norway there were strict requirements for the user’s ability to act as manager for his/her assistants as a criterion to get PA. At the same time, PA in Norway also had traits from the Swedish model. PA was established as a municipal arrangement and, simultaneously, opened up for user controlled cooperatives to have the employment responsibility.

One consequence of the differences between the models is that the number of persons receiving PA varies considerably between the countries. While 1.78 persons per 1000 inhabitants in 2005 had PA, the numbers in Norway and Denmark were 0.24 and 0.27 persons, respectively (Edelbalk and Svensson 2005). Also the target group has been much broader in Sweden than in the other countries, since no conditions were placed on the person’s ability to manage his/her own arrangement there. As shown above, in 2010 almost 40% of the users were classified as having learning disabilities, autism or conditions similar to autism. In Norway and especially in Denmark the requirements for

the users' ability to act as managers have been much stricter with a more homogenous target group as the result.

There are different reasons for the differences. In Sweden and Norway, the IL ideology had a much stronger position than in Denmark. It was especially strong in Sweden, and STIL was an important source of inspiration for the Norwegian experiments that began in 1990. In Sweden the influence from IL was one of the main reasons why PA there ended up with the consumerist profile with strong individual rights for the users and an extensive unregulated market of employers. All in all the disability movement had a stronger position in Sweden than in the other two countries and achieved a decisive influence on the policy leading to the Acts in 1994.

At the same time the market ideology in welfare probably had a stronger impact in Sweden than in the other Scandinavian countries (SOU 2001:79). Market models had a breakthrough after the accession of the right wing government in 1991 as it proclaimed 'the freedom of choice within the welfare system' (SOU 2001:79, 164). When the social democrats returned to power in 1994 there was no considerable change in this area. This was precisely the period when LSS and LASS were enacted. There was, in other words, a stronger basis in Sweden than in the two other countries for an alliance between the IL ideology advocates and proponents for a more market-based welfare policy. As a consequence the NPM concept got a stronger foothold there.

A third reason for the design of the Swedish model is probably that the decisions leading to LSS/LASS were taken in a period of recession (Barron, Michailakis, and Söder 2000). Across the party boundaries, there was a strong commitment among the politicians to secure a decent life for people with comprehensive disabilities. Giving extensive rights to disabled people and handing over the main financial responsibility to the state could therefore also be seen as a strategy for 'protecting' vulnerable groups against financial cutbacks in the municipalities.

In Norway the pressure for individual rights among the users was not taken into account by the state authorities. The model there was designed with a more paternalistic profile and with stronger control from the municipal authorities. The IL movement was not so firmly established in Norway as in Sweden, and a strong emphasis on disabled people's rights was put on the agenda much later. It was not until 1999 that a public commission got the mission to elucidate whether disabled people's rights were sufficiently taken care of and to suggest strategies and measures to promote equality and participation in the Norwegian society. The report from the commission was published in 2001 (NOU 2001:22). When the question about legislating PA in Norway came on the agenda the state authorities had also witnessed the economic consequences of the rights-based Swedish Acts and were scared by what they saw (Sosial- og helsedepartementet 1999). In addition, the argument that the fundamental principle of the Norwegian care policy was that the municipalities should have the main responsibility for the services for their inhabitants resulted in the integration of PA into the Social Services Act.

In Denmark the IL movement was scarcely visible when the first PA arrangements were established. For many years the users were also proponents of a strict enforcement of who should get PA (Askheim 2001). It is only in recent years that the disability movement has pressured for a softening up of the model and an extension of the user group. From that time, the inspiration from IL and the Norwegian and Swedish experiences has become much stronger. However, the users' scepticism of the municipalities is preserved. Municipal employment responsibility is still not an option.

Towards a Scandinavian model?

Following the development of PA in the Scandinavian countries we can see that the initiators in the three countries have been influenced by each other. The IL-inspired cooperatives in Sweden were important sources of motivation for the first experiments with PA in Norway. In the last few years the cooperative models in Sweden and Norway have been influential to the development of the Danish model. The struggle for stronger individual rights in Norway has been directly affected by the Swedish experiences. However, while the national authorities have been inspired by each other, they have also looked at the experiences in the neighbouring countries in order to avoid similar problems and pitfalls. The increase in public expenditures in Sweden has scared especially the Norwegian authorities and must be seen as an important reason for choosing a more paternalistic profile and showing stronger scepticism to a rights-based model like the Swedish one.

The development of PA in all the three countries has in the main been realized in alliance between disabled people and the political authorities. Disabled people are looked upon as 'worthy needy' in welfare policy and have mainly sympathy and goodwill among the politicians. However, there now seems to be a tendency, especially in Sweden and Norway, for this alliance to crack over time. In both countries the state authorities want stronger regulations of PA than the users do. In Sweden the users mobilize against the state authorities' efforts to more strongly regulate the arrangement. In Norway the users want stronger deregulation than the authorities seem willing to implement. The users seem to be attempting to strategically combine the traditional generosity of the Scandinavian welfare state model with the individual focus of the more liberal welfare states.

What we are seeing now is that tensions between the social rights discourse and the market-based discourse are brought out more distinctly in the implementation of PA in the Scandinavian countries. At a more fundamental level, the development of the PA programmes illuminates basic tensions within the Scandinavian welfare state. The traditional strong public management and collective solutions are challenged by market-based models and demands for individual rights among the users.

The development of PA seems to indicate a move towards a stronger convergence of the arrangement between the Scandinavian countries. In Sweden where PA has been characterized by strong deregulation, efforts are made to reregulate the arrangement. In Norway and Denmark the tendency is the opposite: from a more paternalistic model, the tendency is deregulation and a more consumerist profile. Apparently we are approaching a more common 'Scandinavian model of PA'. How this eventually will materialize, and how it will seek to reconcile the social rights discourse and the market discourse is too early to tell. However, the development should be followed closely to watch whether PA will maintain its position as a tool for liberation and self-determination for disabled people.

Notes

1. One euro is about 9.25 SEK.
2. Information from 'Amternes specialkonsulentordninger for bevægelseshandicap' 22 February 2000.
3. <http://www.sm.dk/noegltal/sociale-oraader/handicap/voksne/Sider/Start.aspx>.

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